IMPACT: EVALUATION OF THE SOCIAL SERVICES AND WELL-BEING (WALES) ACT

Literature Review – Technical Report

for Welsh Government

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INTRODUCTION

This document is a review of the literature to inform the evaluation of the *Social Services and Well-being (Wales) Act 2014* (hereafter referred to as 'the Act'). The Welsh Government (WG) 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 Act is positioned as an ambitious framework to enable transformational policy change, organisational and system level change, and practice change for those who need care and support and carers. These changes in turn are expected to be reflected in the tangible experiences of care and support by individuals, families and communities, in changes in the workforce and organisations, and over time, in the attainment of wellbeing outcomes, and sustainable social services.

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
- Voice and control
- Co-production
- Multi-agency working

There is also a focus on the financial and economic considerations of the implementation of the Act and this area forms the sixth evaluation study theme. This approach is complimented with a focus on the following 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.

Each of the six evaluation study themes have a set of research questions shown in Table 1 below. The literature reviews position the Act evaluation in the wider academic and policy literature in order to build upon the current knowledge base and debates pertaining to each of the study themes.

Table 1: Study theme research questions

Theme	Study Research Questions
Well-being	*How has well-being and quality of life (QoL) been defined for the purposes of the legislation by Welsh Government (WG) and stakeholders (organisations and partners)?* *How have WG and stakeholders implemented measurement of QoL and well-being for those covered by the legislation?* *How the definitions of well-being and QoL from the first two questions above map to definitions reported in the literature and best practice for measurement and meaningful changes?* *What gaps are there in understanding of and appropriate definitions of QoL and well-being?* *What gaps are there in measurement of QoL and well-being to enable the impact of the legislation?*
Voice and control	*What does 'voice and control' mean for people?* *To what extent has there been a change in the relationship between individuals, their families and carers, and the professional care workforce which includes care managers and social workers?* *What has moved in the culture of the workforce in the light of the Act?* *How do people recognise impact, and how do they know that people have been positively impacted upon?* *To what extent has the balance of power between the individual and the professional shifted?* *What resources are required in order for greater control to be exerted by individuals?* *How have local authorities and regional partnerships responded to this new agenda?*
Prevention and early intervention	*How is the prevention and early intervention agenda of the* Act *being interpreted and what frameworks are being used in practice?* *How are the key stakeholder implementing and evaluating prevention and early intervention agendas?* *What are the early results and impacts of this work?* *What improvements might be made to better realise the prevention and early intervention ambitions of the Act, including the frameworks in use?* *What research methods could be used to quantify the changes that result from the preventative and early intervention work (including what did not happen)?*

Theme	Study Research Questions
Co-production	*What good or bad changes have come about as a result of attempts at co-production?* *Which of these changes are most significant?* *What was it like before, what is it like now and what brought about the changes?*
Multi-agency working	*Has implementation of the Act promoted sustainable integrated care and support?* *What are the critical success factors for multi-agency working?* *Which critical success factor are most important and have most impact?* *When, how and for whom were multiagency networks implemented?* *What resources are required for multi-agency working to achieve the outcomes expected?* *How have cross boundary governance arrangements supported people and agencies to work together?*
Finance and economic	*Estimate of the costs and benefits of implementing the Act to derive an indicator of the return on investment.*

METHODOLOGICAL APPROACH

The overall literature review comprises of six discrete reviews: well-being, voice and control, prevention and early intervention, co-production, multi-agency, and financial and economic reviews. Each is authored by members of the respective theme study team. The well-being literature review used systematic mapping to source/identify relevant literature and this method is discussed in section 2.1 below. For the other themes, the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis – Moher et al, 2009) approach has informed the action plan/steps for the literature search and review. This process is shown in the flow table below.

Table 2: Literature review flow table

SEARCH TERMS

Population Intervention, Control/Comparison and Outcome Tool (PICO tool) to identify initial search terms
↓
Circulated to team for refinement
↓
Search terms, inclusion/exclusion, and online databases agreed
↓

DATABASE SEARCH STRATEGY

Evaluation team identified any seminal or key articles or authors
↓
Search terms sent to Welsh Government library
↓ ↓
Brief screen and remove irrelevant Papers ↓
Large number of citations – refer to leads to refine and amend terms, inclusion/exclusion ↓
Save search results
↓
List of papers for screening sent to theme leads
↓

ASSESSING FOR INCLUSION/EXCLUSION

Evaluation theme lead and/or advisor scans titles and abstracts ↓
Duplicates removed ↓
Include/Uncertain ↓
Exclude ↓
Full text articles assessed for eligibility ↓
Include ↓
Exclude ↓
Number of studies included in review
(n=30-50 papers) ↓

LITERATURE REVIEW

SEARCH TERMS

Combinations of search terms agreed and refined by individual leads and advisors were entered into online databases, for example, Scopus, ASSIA, CINHAL, and Social Care Online.

Voice and control

"What matters" conversations AND Policy OR legislation OR policy implementation AND independence OR control OR voice

Shared decision-making OR person centred care planning OR person centred assessment OR person centred decision making AND policy OR legislation OR policy legislation AND social care practice

Prevention

"Prevention" AND "social care and support"

"Role of the third sector in prevention and social care"

"Community development in social care" OR "Community development in social services"

Co-production

Co-produc* OR coproduc* AND policy

Co-produc* OR coproduc* AND legislation

Co-produc* OR coproduc* AND policy AND public AND legislation

Multi-agency

Multiagency OR partnership OR Collaboration [TI] AND "public sector" [AB] AND "success factors" [AB]

Integration [TI] OR "Multi sector working" [TI] OR "joint working" [TI AND "Public sector"[AB] AND "success factors" OR outcomes [AB]

Financial and economic

"Cost benefit analysis" OR financial OR economic OR valuing OR valuation OR quantifying OR "attribution of benefits" OR "distributional impacts" OR resource OR "economic evaluation" OR evaluation AND well-being AND voice and control OR voice OR control OR advocacy OR co-production OR "health and social care integration" OR multiagency OR prevent* AND social care OR health AND policy OR legislation OR programme

Other criteria

Theme leads and advisors defined inclusion/limiter criteria of which there were some variation (e.g. date range, age of participant). However, core criteria applied across all themes included:

- English Language
- Peer reviewed
- UK, developed countries
- Peer reviewed, scholarly journals, grey literature

Abstracts identified from the search were read and articles identified as potentially relevant were saved for screening/reading. A snowball search was conducted using the reference lists from papers returned from the search to source additional relevant literature. To ensure the number of papers included in the review was manageable, theme leads and advisors agreed 30-50 papers, per theme were to be included in the review.

The total approximate number of papers included within each of the themes was:

- Voice and Control = 52
- Prevention = 50
- Co-production = 52
- Multi-agency = 48
- Financial and Economic = 16

WELL-BEING: SYSTEMATIC MAPPING

As the last relatively comprehensive review of policy-focused well-being research was published eight years ago (Dolan and Metcalfe, 2012) and the focus on well-being is a relatively recent policy trend in the UK, the lead authors of the Well-being theme review made the decision to update this review through producing a systematic map of relevant literature published in the intervening years. A systematic map is a database of academic, grey, and policy literature published on a specified topic and coded by categories of subject area, methodology, population of interest or study, theoretical approach, and so on. The purpose is to produce an easily searchable 'map' of the salient literature, that can be filtered according to interest, in order to provide a concise overview of knowledge and gaps in the field. Unlike a systematic review, to which the method is closely related in approach, the systematic map does not provide insight as to the quality of the literature. This methodology of approaching the literature as a rapid method ensured that key papers would be collected whilst also capturing lesser known publications on targeted areas of interest for the Act evaluation. This acknowledges that where the literature may be sparse and hence, all contributions to the field are of high value.

To produce the map, keyword and Boolean searches of all the key accessible social science and social care databases were conducted using words and phrases of relevance to the subject of well-being in social care. The exact nature of the searches varied according to the search requirements of each database, however the below is a typical example of the Boolean searches used alongside single word searches such as 'well-being' and 'happiness':

Social Care Online (searched through OVID – Social Policy and Practice to enable more complex Boolean searches)

(('well-being' or 'well-being' or 'life satisfaction' or 'happiness' or 'quality of life') and ('measure' or 'scale' or 'rating' or 'population') and ('subjective' or 'objective' or 'eudemonic') and ('social care' or 'social work' or 'welfare' or 'social services'))

2011 onwards. Results: 45 total. 6 after filtering

Synonyms and related concepts to well-being were included due to the interchangeable use of the terms 'life satisfaction', 'happiness', and 'quality of life' throughout much of the literature (this problematic emergent issue is discussed further below). To capture that literature that was policy-relevant, rather than focused on individual circumstance (as reflects much of the literature in this area), the terms 'measure' or 'scale' or 'rating' or 'population' were included. To discover those papers which were concerned with the theoretical underpinnings of well-being approaches, the searches included the common conceptual terms of 'subjective' and 'objective' or, also sometimes used, 'eudemonic' (sometimes spelled 'eudaimonic'). Finally, social care related terms were specified to avoid the vast store of physical health-related literature that dominates the subject of well-being. To complement this, notable authors in the field were also searched by name, including the following: Susan Galloway, Sara Pinto, Andrew E Clark, Paul Dolan, Robert Metcalfe, David Bell, Richard Easterlin, Diane Coyle, Paul Frijters, David Blanchflower, Richard Layard, Andrew Oswald, Luis Salvador Carulla, Ramona Lucas, and Teresa Peasgood.

The above Boolean search results were collated with single term searches. After removing duplicates, results were manually filtered by abstract or summary alone, applying the following criteria:

- References must discuss well-being/happiness/QoL/life satisfaction in a conceptual manner, relevant either to whole country populations OR to the following broad populations/subject categories relevant to social care research: children, older people, disability, adulthood, welfare and social service provision
- Should not discuss specific interventions unless the reference also appears to contain original contributions to the above

This final filtering resulted in 478 references remaining in the systematic map. After coding and filtering, it became clear that the published field of research into this area remains patchy in its salience to specific social care priorities and relevant populations. The gaps are revealed in Table 3 which represents the number of papers available cross-referenced by conceptual and subject focus (note that this table has been edited for brevity to remove codes where less than two papers were returned within a code).The researchers manually selected a range of key literature from this list to cover in this literature review.

The well-being literature review was based on the systematic map. The papers were included in the review if they related to the focus of this review - that is:

- The definition of the term ‘well-being’ and other terms that are related, substituted or overlap;
- The population of the UK (which meant that where relevant we included papers that were European in origin if they were relevant);
- Measuring well-being;
- Determinants of well-being;
- Research into well-being for children, young people, adults and older people;
- Research into well-being for people receiving care and support;
- Research into well-being for carers of people who receive care and support;
- Well-being in UK and Welsh policy.

Of the 478 references identified through systematic mapping, 55 have been included in this review.

Table 3: Mapping the well-being literature

	Primary Focus						
Subject Areas	Economic Well-being	Economics	Happiness	Life Satisfaction	Quality of Life	Subjective Well-being	Well-being
Affective/emotional wellbeing						2	3
Behavioural economics	3	2	2				4
Capabilites approach					1	1	4
Children			1	2	2	16	15
Community well-being					1		10
Cognitve impairment					2		1
Environmental approach						1	1
Environmental/ecological approach			1	1		5	2
Governance			2				2
Health Policy research					1		3
Housing			9			2	
Income and wellbeing				2		10	9
Measurement					1	1	
Mental Wellbeing			1				5
Mental/Psychological Wellbeing	1		3	1	2	5	11
Midlife /U shape			1	1		1	2
Older people		1		1	3	5	8
Overall wellbeing, including physical	1	1	22	3	7	38	39
Physical Impairment	1						
Population level analysis				1		2	2
Public policy		1	9		1	8	13
Retirement						1	1
Sustainability and well-being	1		1		1		4
Work and employment			1	1			3
Young people							3

WELL-BEING

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

WHAT IS WELL-BEING AND HOW IS IT MEASURED?

Well-being is central to the purpose of the Act yet differences still persist in the definition of well-being and its relationship with life satisfaction, mental health, comfort, quality of life (QoL) and happiness. The terms are often used interchangeably even in the same report, article or journal paper. With this issue in mind in 2014 Salvador-Carulla et al. (2014) and Pinto et al. (2017) published literature reviews undertaken to identify the different concepts and constructs of well-being and those emerging from the differing perspective of social scientists, economists and health scientists. The differences were unpicked and presented in the journal articles, but with a focus on health related well-being emerging from Salvador-Carulla et al.

The authors suggest that whilst there is overlap between the concepts (Pinto et al.) considerable differences exist on the definition of well-being and its relationship with QoL, happiness and functioning in the health context. From a dimensional perspective, Salvador-Carulla et al. suggest that health related well-being could be regarded as an overarching construct, where well-being embeds the concept of "ill-being" in the same manner as "health" incorporates the concept of "disease".

Pinto et al. also introduced the concept of comfort alongside the other terms we have identified. They suggest that comfort is the broader holistic concept whilst well-being is mainly related to psycho-spiritual dimensions. Pinto et al. also suggest comfort is a concept that is inherently linked to the practice of nursing care and sits in a health context. It is characterised by the satisfaction of one's needs, by the person feeling strong, safe, supported and cared for, so the concept of comfort, they state is particularly used within the nursing profession. Given the focus of the Act on people who receive care and support, it might be a term that pertinent alongside and overlapping with well-being but the literature on comfort is sparse and absent from 2000 and for this reason we excluded it from our narrative.

Given the complexity of the constructs of happiness, life satisfaction, QoL and the interrelationship with well-being constructs, the evaluation of well-being is inevitably complex. Salvador-Carulla et al. propose that to address this a synset[1] of the different terms used by the different disciplines that would facilitate transfer across the sectors, but as yet this has not happened. Pinto et al. urge caution in the correct use and framing of the concepts in research.

In 2012 Henderson and Knight published a paper discussing the hedonic and eudemonic perspectives of well-being in reference to philosophy and psychology. Whilst this paper does not

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[1] A set of one or more synonyms that are interchangeable in some context without changing the truth value of the proposition in which they are embedded.

unpick the differing terms used to describe well-being it is helpful in taking the reader to the heart of the constructs.

The hedonic perspective states that increasing an individual's pleasurable experiences, and decreasing painful ones, maximises well-being. This approach can be traced back to philosophers such as Aristippus, Epicurus, Bentham, Locke, and Hobbes. These philosophers likened well-being to the positive emotional state that accompanies the satisfaction of desire, such as experiencing pleasure, enjoyment and carefreeness. The hedonic approach takes a 'subjectivist' view, in that the individual is perceived to be in the best position to determine their own level of well-being.

The eudemonic perspective, on the other hand, contrasts with the hedonic perspective, through advocating living a virtuous life to achieve well-being. Eudemonia was developed as a construct by Aristotle, who believed that acting virtuously through living a life committed to the values of justice, kindness and honesty and working to reach meaningful goals would demonstrate a good life. Aristotle's eudemonic approach takes an 'objectivist', view, as well-being is considered from an outside perspective, where others are able to ascertain if an individual is living a 'virtuous' life.

The Welsh Government definition of well-being, as outlined in the Well-being Statement (Welsh Government, 2014) is strongly eudemonic – assessing well-being as it does through a set of criteria based on health, contribution to society, access to rights etc. It works against the hedonic perspective in that it does not include the criteria of people's own views of their happiness or enjoyment (except through 'personal well-being outcomes', more on which below). The approach taken to measurement thus far coheres with this perspective, seeking to measure well-being through key performance indicator (KPI) statistics on housing, employment, etc. (i.e. determinants of well-being) rather than through surveying happiness and self-satisfaction alone. This moves the Welsh Government definition away from subjective well-being (SWB) and into the realm of what might be more accurately described as 'living standards'. However, the Act also focuses on the production and assessment of 'personal well-being outcomes' – which employs the language of SWB and suggests directly that individuals are the best judges of their own well-being. This is then contradicted by introducing the rule that personal well-being outcomes should be designed to map onto the National Outcomes Framework (NOF) (Welsh Government, 2016) categories, leading to a disconnect between who is actually judging what produces the well-being of individuals – the Welsh Government or the individuals themselves and how the results of the measures should be interpreted.

A basis of subjective well-being is provided by Van der Deijl (2017), who suggests that well-being can be defined as how good a life is for the person living it. The first key principle is subject-dependence, which encapsulates both hedonism and desire-satisfaction and refers to the notion that the things that an individual perceives as good in their life depend on their own personality and views, including their attitudes, values and desires. The second is the epistemic limitation, which is the notion that people's beliefs about their own values, desires, views and happiness can be misguided sources of information. This makes the inclusion of both objective and subjective measures important to accurately reflect the potential and actual impact of public policy on the well-being of individuals. Dolan and Metcalfe (2012) advise that it is important for the different accounts of well-being (objectivist, subjectivist) to not be conflated with each other, however it seems that there is a risk of this conflation in the personalisation of the NOF outcomes as apparently synonymous and mutually implicated. They also caution that *'Our choice of account of well-being[sic] could clearly have important implications for who we think of as doing well or badly in life'* (2012: 412), which particularly matters when we evaluate policy catering for the most marginalised and vulnerable groups in society.

A further conceptual (yet practical) refinement of well-being is proposed by Atkinson (2013) who described a 'components approach' to well-being. The components approach is the current dominant discourse for well-being and involves defining well-being through breaking it down into a series of components or independent elements. The components approach can include either hedonic subjective components of well-being, objective eudemonic components, or both. This approach also perceives well-being as individualised and as a commodity or entity for the individual to strive towards. Consequently, policies based on the components approach seek to drive interventions that enable people to attain these components to enhance their well-being. For example, the UK Office of National Statistics (ONS) uses a set of components to measure well-being, based on surveys; i.e. relationships, health, activities of work/leisure and balance, location, personal finance, education and skills, contextual domains of governance, economy and natural environment in addition to life satisfaction.

The components approach is arguably the model currently being actioned within Wales: the Act and its associated Well-being Statement (Welsh Government, 2014) and NOF (Welsh Government, 2016) apply a set of domains and subsets of criteria to achieve acceptable living standards and opportunities to pursue positive actions in support of individual well-being. Success in these domains rests on a personal level of comfort and satisfaction with these living standards and opportunities; however, as might be anticipated in broad national policy, the exact definition of what those standards should be is opaque. For example, in the domain of 'Suitability of Living Accommodation', the criteria to be attained is "I live in a home that best supports me to achieve my well-being" (Welsh Government, 2014: 2) without reference to what the expectations for high-quality accommodation should be for various populations and levels of need (i.e. for one person that suitable accommodation might be a room in a shared house, while for another it might be their own two bedroom flat).

Atkinson (2013) argues that this model is inadequate and that a relational approach is a more reflective model to develop. She suggests that well-being is a fluid, complex, abstract, term that is difficult to define and interpret for policy purposes and advocates moving from the components approach to a relational and situated approach and account of well-being. In this account, well-being is viewed as dependent on resources (people, services, places) and is amenable to change. While the components view is less flexible and views well-being as the end goal, the relational approach sees well-being as more of a process that leads to various goals. Rather than aiming to improve well-being for the individual through policy interventions, instead the focus would be on enhancing the *"social, material and spatially situated relationships"* that affect and effect collective well-being. The provision of community 'hwbs' in Wales, funded as part of the 'Communities First' policy was an example of an attempted national relational approach. When Communities First was discontinued, a 2017 report on the lessons learned from this approach highlighted the value added by such centres and recounted significant concerns raised by Local Authorities about the future of these community assets (National Assembly for Wales Commission, 2017). Many have, in fact, been retained through other funding streams since the closure of Communities First. A further examination of the impact and potential future of such centres would be valuable as part of our evaluation.

Taylor (2011) proposed a relational view of well-being and welfare as mutually constitutive and used psychosocial analyses to explore well-being. Taylor describes how welfare and well-being are inter-related: welfare could be argued to provide the conditions in which well-being can be exercised and well-being could be viewed as a process rather than an outcome. Well-being is viewed by Taylor as a dynamic concept in that it changes with the interplay between different social, economic, political and cultural factors. Taylor proposes that well-being changes according to different contexts. Taylor also argues that these contextual factors can be split into those with a 'close' or 'distant' relationship with the process of well-being. Close relationships refer to those that are 'denser' or have a deeper importance and emotional connection for people, such as family, friendship, care and community. Distant relationships refer to those that are more 'detached' in involve public services and goods. This approach may be helpful for determining public policy and supporting people's relationships with well-being.

To make some attempt to overcome the problem of defining well-being for this literature review, as far as is possible, great care has been taken to establish what the authors, stakeholders and participants actually mean when they use the term 'well-being' and we included papers in this review where we are confident that well-being, subjective well-being, and life satisfaction are the focus where it has been clearly stated that this is intended as a measure of well-being rather than health related well-being or QoL.

WELL-BEING AND THE RELATIONSHIP TO CAPABILITY

The capability approach conceives of well-being as the freedom people have to enjoy valuable activities and states. Amartya Sen has powerfully articulated the features, scope, advantages, and considerations of the capability approach in relation to well-being (Alkire, 2015). The construct is described in this quote from Sen's book, The Ideas of Justice:

"In contrast with the utility-based or resource-based lines of thinking, individual advantage is judged in the capability approach by a person's capability to do things he or she has reason to value. A person's advantage in terms of opportunities is judged to be lower than that of another if she has less capability – less real opportunity – to achieve those things that she has reason to value. The focus here is on the freedom that a person actually has to do this or be that – things that he or she may value doing or being. Obviously the things we value most are particularly important for us to be able to achieve. But the idea of freedom also respects our being free to determine what we want, what we value and ultimately what we decide to choose" (Sen, 2009: 232)

The aspect of freedom articulated within the Capability Approach provide a strong challenge to the components approach, where those components are selected and described by central government; the consequence being that choice surrounding what constitutes well-being as an individual is removed, and that high well-being is defined by the meeting of living standards, rather than by a person's lived, subjective experience of their own well-being. The Well-being Statement and NOF reach beyond this limitation by locating attainment as, at least partially determined by an individual's own satisfaction with the domains outlined, however the boundaries placed around personal well-being outcomes (which must map onto the NOF) remove the agency to think outside of the given categories and 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 perceptions, is questionable.

Sen's Capability Approach is endorsed by other researchers. Pillai, in 2013, published an epistemic enquiry of SWB. Traditionally nations focused on GDP as a measure of how well a country was performing. Pillai (2013) notes that that well-being was becoming the way used to determine how well a country performs. Monetary and non-monetary determinants (income, education, physical health, psychic health, security, environment etc.), are frequently used in mainstream economics to yield a measure of well-being. Pillai reviews the roots of well-being which centred on hedonia (seeking pleasure and avoiding pain) and eudemonia (seeking to be virtuous and lead a good life) and proposes that well-being, be focused on the importance of people as agents in their own well-being. This complements Sen's Capabilities Approach in that it focuses on individuals receiving the 'social primary goods' that they need or want and avoiding too much interference from others while having 'positive freedoms' such as access to education and employment. These latter 'freedoms' are incorporated within the Well-being Statement, however the degree to which 'social primary goods' are accommodated is questionable.

However, similarly to others, Pillai also notes that well-being is a complex term, and can be separated into subjective and objective types, and subjective well-being can also be separated further into cognitive (life satisfaction and domain satisfaction) and affective well-being (emotional experiences).

Muffels and Headey (2013) conducted an empirical test of Sen's capability approach (CA) using multivariate analysis of German and British panel data. They suggest that the CA for defining and understanding well-being can be defined as "*the freedom of choice to achieve the things in life which one has reason to value most for his or her personal life*". The authors examine the impact of these capabilities and choices on well-being and whether the approach can explain long term patterns of well-being and the impact on subjective and objective well-being in Britain and Germany. Subjective well-being was explored using life satisfaction as an indicator, and income and employment security were used to measure objective well-being. Three measures of well-being were constructed: life satisfaction for subjective well-being and relative income and employment security for objective well-being. The findings strongly supported Sen's capabilities framework and provided evidence on the way capabilities, choices and constraints matter for objective and subjective well-being. Capabilities pertaining to human capital, trust, altruism and risk taking, and choices to family, work-leisure, lifestyle and social behaviour show to strongly affect long-term changes in subjective and objective well-being though in a different way largely depending on the type of well-being measure used.

Given the emerging interest in UK Government's use of subjective well-being as an alternative to Gross Domestic Product (GDP) for monitoring national progress, informing and appraising public policy, in 2012 Dolan and Metcalfe published recommendations for measures to use by Government. In this review Dolan and Metcalfe reprise the three main concepts of SWB literature: evaluation (life satisfaction), experience (momentary mood) and eudemonia (purpose). Dolan and Metcalfe propose that policy-makers should seek to measure all three, at least for the purposes of evaluation and monitoring impact of policy. Nonetheless Dolan and Metcalfe acknowledge that there are some major challenges to the use of SWB measures and in this paper suggest that two related and well-rehearsed issues are the effects of expectations and adaptation on ratings of SWB i.e. the degree to which well-being can be allowed to vary according to expectations and adaptation are vexing moral problems. Dolan and Metcalfe provide some concrete recommendations about precisely what questions should be asked in large-scale surveys, provided below in Table 4 (below) taken from the paper, but importantly draw attention to the need to capture rating of SWB by those "*least inclined*" to take part in surveys.

A very recent publication on the topic of well-being, its measurement and its role in decision making was from Peasgood et al. (2019). It reports a qualitative study of the views of health and social care decision makers on the role of well-being in resource allocation decisions in the UK. The research explored the opinions of UK decision-makers on the relevance of well-being and SWB (which was defined as good and bad feelings or overall evaluations of life, such as life satisfaction) for resource allocation decisions within health and social care. The authors identified a range of opinions about the role of well-being and a broadly held view that there was a need for improved consideration of broader quality of life outcomes and identified considerable caution in relation to the use of SWB.

The review of the literature warns us that the 'well-being landscape' is wide ranging, subject to considerable mixed, overlapping and unclear use of the term 'well-being' (indeed the spelling of well-being is not consistent, 'wellbeing' often being used) 'subjective well-being', 'quality of life' and 'health-related quality of life' both amongst health care researchers, health and care decision-makers and at a policy level. Peasgood et al. note that at the measurement level clearer theoretical and empirical differences between these concepts emerge, yet without the explicit link to specific measures the terms could be referring to the same or quite different things.

Henderson and Knight (2102) describe how both hedonic and eudemonic approaches have been adapted for use in creating, often opposing, scales or questionnaires to determine well-being. For example, the hedonic perspective was central to creating a SWB questionnaire, in which positive emotional experiences (i.e. hedonic) result in increased well-being scores. Whereas theories and constructs that equate well-being with personal growth and life meaning are firmly embedded within the eudemonic, not hedonic perspective. However, recent research has suggested that the two perspectives are not in opposition to one another as, for instance, reaching a life goal (eudemonia) leads to pleasure (hedonia).

Table 4: Recommended measures of SWB (Dolan and Metcalfe, 2012)

	Monitoring progress	Informing policy design	Policy appraisal
Evaluation measures	Life satisfaction on a 0–10 scale, where 0 is not satisfied at all, and 10 is completely satisfied e.g. 1. Overall, how satisfied are you with your life nowadays?	Life satisfaction plus domain satisfactions (0–10) e.g. How satisfied are you with: your personal relationships; your physical health; your mental wellbeing; your work situation; your financial situation; the area where you live; the time you have to do things you like doing; the wellbeing of your children (if you have any)?	Life satisfaction plus domain satisfactions Then 'sub-domains' e.g. different aspects of the area where you live Plus satisfaction with services, such as GP, hospital or local Council
Experience measures	Affect over a short period from 0 to 10, where 0 is not at all and 10 is completely e.g. 2. Overall, how happy did you feel yesterday? 3. Overall, how worried did you feel yesterday?	Happiness yesterday plus other adjectives of affect on the same scale as the monitoring question e.g. Overall, how much energy did you have yesterday? Overall, how relaxed did you feel yesterday? Overall, how much stress did you feel yesterday? Overall, how much anger did you feel yesterday?	Happiness and worry Then detailed account of affect associated with particular activities Plus 'intrusive thoughts' e.g. money worries in the financial domain over specified time
'Eudemonic' measures	'Worthwhileness' of thing in life on a 0–10 scale, where 0 is not at all worthwhile and 10 is completely worthwhile 4. Overall, how worthwhile are the things that you do in your life?		Overall worthwhileness of things life Then worthwhileness (purpose and meaning) associated with specific activities

Henderson and Knight (2012) assert that integrating both the eudemonic and hedonic perspectives of well-being are key to progressing with research in well-being and creating measures that truly capture what well-being is. Using both perspectives is referred to as the "flourishing" model of well-being. The first scale created to measure flourishing was the Orientation to Happiness Scale (Peterson et al., 2005), in which respondents rate both hedonic and eudemonic components of well-being. The results revealed that strong ratings of either were predictive of well-being, but those that rated both as high had the highest levels of well-being. However, Henderson and Knight (2012) believe that well-being isn't about having the fullest life, but about the correct balance for the individual, and that this needs to be explored thoroughly in research. Thus Henderson and Knight propose that well-being measures should integrate both hedonic and eudemonic components of well-being in context, in order to validate their utility to everyday life and consequently help to create practical guidelines to help people.

Dronvalli and Thompson (2015) conducted a systematic review of measurement tools to assess the effectiveness of community-based interventions intended to impact on health and well-being. In total 123 journal articles were reviewed that included 27 different measurement tools. Each of these tools were reviewed for their validity, reliability, length, responsiveness, global health or well-being assessment, ability to use in cross-cultural settings, cost, use of subjective measures, and clarity. Scores were given for each of these domains, and a composite score was then created for each measurement tool. Overall five out of the 27 tools were rated as excellent for measuring the impact of community-based health and well-being interventions. The five 'best' tools were deemed to be QOLS (Quality of life scale), PWI (Personal Well-being Index), CWI (Community Well-being Index), WHOQOL- BREF (World Health organisation's Quality of Life Index, short version) and WHOQOL (standard version). Of these five, QOLS and the two WHOQOL instruments specifically measure QoL, rather than well-being.

In relation to the review described above and the high performance of the WHOQOL instruments it is interesting to note that Salvador-Carulla et al. suggest that the World Health Organisation (WHO) framework for the conceptualisation of health related well-being using the international classification of Functioning Disability and Health is a first attempt to create a standard language for well-being in the context of health and related problems (WHO, 2001).

Van der Deijl (2017) argues that this is due to the fact there is little agreement on the nature of well-being. However, he suggests that there is agreement on two principles surrounding how to measure well-being, and that this is sufficient to create an objective means of evaluating the quality of different types of well-being measures, to discover which ones are more valuable and informative. The first key principle is subject-dependence, which encapsulates both hedonism and desire-satisfaction, and refers to the notion that the things that an individual perceives as good in their life depend on their own personality and views, including their attitudes, values and desires. The second is the epistemic limitation, which is the notion that people's beliefs about their own values, desires, views and happiness can be mis-guided sources of information. Van der Deijl believes that these principles can help to determine the utility of a well-being measure, and that a closer relationship between philosophical and empirical approaches can be helpful in successfully measuring well-being. Unfortunately, the paper does not go so far as to suggest the 'best' instruments for use in practice.

Kassenboehmer and Schmidt (2011) explored the utility of measures of welfare and well-being beyond GDP and other hard economic indicators in Germany in a study undertaken in 2011. They investigated the extent to which several non-monetary measures could provide information about welfare that goes beyond the usual economic indicators such as GDP to fully understand the welfare or well-being of citizens. These non-monetary measures included job security, crime levels, education, health, leisure, environmental factors and sustainability. Social data from surveys in Germany were used. Results revealed that in Germany the hard-economic indicators, in particular GDP and the unemployment rate, were strongly related to levels of well-being. The authors suggested that GDP continues to influence well-being, and can therefore still be regarded as a robust measure of well-being. Results also showed that other non-monetary measures explored, including air pollution, health and job security, had a low impact on well-being scores individually, and tended to correlate with each other and with the hard-economic indicators. The authors conclude that at the moment, it seems that it is possible to rely on hard indicators to understand well-being and welfare.

Stutzer and Frey (2012) discussed developments in the economics of happiness (also interchangeably called SWB by authors). At that point they report that research had measured happiness or SWB using survey questions that involved one or more evaluative questions about life satisfaction. The authors proposed that affective well-being should and can be measured through asking individuals to reflect on real or imagined life events and experiences. Participants' answers to both these questionnaire types are then viewed as a proxy for their individual welfare and well-being. The assumption is made by the authors that people would like to reach different well-being goals to improve their lives.

Fabian (2018) propose a theory of SWB - the well-being production function theory. This theory enables the creation of a framework in which to understand well-being that can influence welfare economics and public policy. The idea is that SWB must be understood as an outcome and a process, and that SWB is defined as "a function of hedonia, eudemonia and despair". These dimensions of SWB are interconnected, "affective signals" from hedonia guide the needs of the eudemonia domain, which in turn results in the "meaning, seriousness and identity" of the despair domain. If people are looking for higher levels of SWB, they are influenced in this endeavour by their capabilities (e.g. income, health and education). However, this framework suggests that people can experience improvements in life satisfaction over time, but this is not what is seen in the life satisfaction survey data of developed countries. The author suggests that this is due to a problem with scale norming in life satisfaction surveys. In conclusion, the thesis has demonstrated that measuring and analysing SWB is complex, and is unlikely to happen using quick and easy metrics, although this is what is needed to explore SWB in order to inform policies and welfare economics. The future relationship between SWB and public policy is described as lying with the domains of behavioural policy. This includes policies for schools, prisons, workplaces etc. so that these institutions can better support well-being and basic needs.

Notwithstanding the issues described above, the UK Office for National Statistics (ONS) introduced questions on what is classified as 'personal well-being' into the Annual Population Survey (APS) in April 2011. The four questions on personal well-being have remained unchanged in the APS since they were first introduced. The questions are:

1. *Overall, how satisfied are you with your life nowadays?*
2. *Overall, to what extent do you feel that the things you do in your life are worthwhile?*
3. *Overall, how happy did you feel yesterday?*
4. *Overall, how anxious did you feel yesterday?*

The scales run from 0 to 10, where nought is 'not at all' and 10 is 'completely'.

These four measures were first collected in England, Scotland and Wales at local level in April 2011 while in Northern Ireland in April 2012. The first year from which we have a full UK baseline at local level is the year ending March 2013. Data are reported as weighted mean averages and as changes from baseline (2013). While the ONS measures include SWB, Selwyn et al. (2017) note that the question selection and design is centred on state concerns rather than focusing on what might be important to people in their own lives. In another section of the ONS APS to make the point, they give the example of a question about obesity, within a medicalised model of a healthy relationship with the body, but do not ask about body image or the impact of media in this area; factors which are likely to prominently feature in people's personal narratives of body image and health.

Measurement of well-being it seems is fraught with complications. It is clear that measurement of something related to well-being, but embedded in different theories and constructs can be accomplished, but whether what is measured matches the intent of Welsh Government policy is not certain. Examination of this will form the next steps in this research programme.

DETERMINANTS AND DOMAINS OF WELL-BEING

Economists have developed a strong interest in happiness as an alternative to Gross Domestic Product (GDP) as a measure of a country's performance. In 2012, Stutzer and Frey published a review of the development of the research of the economics of happiness as the construct of SWB. The authors suggest four factors are important in determining SWB: (1) income; (2) employment; (3) social capital and (4) health, and discuss them as determinants of well-being.

- Income: studies have shown that an individuals' income is related to their SWB, but emerging research suggests that this relationship does not hold for the relationship between a nation's income per capita and average SWB. A lack of longitudinal data for many countries has meant that this is still a contentious issue for economists.
- Employment is considered as related to SWB, but it has been extended to include different types of employment.
- Social capital refers to non-economic determinants of well-being, and is increasing viewed as important. Personal relationships and their quality are perceived as social capital.
- Health is viewed as important to SWB, but the casual effects of health on SWB are difficult as people that have always been healthy may not rate health as that important to SWB.

A systematic review by Azizan and Mahmud of the determinants of SWB was published in 2018. The review concluded that the influential determinants of SWB were heath, personality traits and socio-economic circumstances including financial, income and employment status. However, the review also suggests that the context of a research study that has different socio-demographic status of respondents also influences the effect of personality traits. Unemployment and lower income also results in lower level of SWB and health conditions also significantly associated with SWB of individuals, those with poor health having low SWB. The findings also suggest that a high commitment to religion has increases SWB of individuals.

D'Acci (2011) explores the different ways of measuring national performance comparing using well-being, with GDP per capita. D'Acci proposes using GDP as a proxy for well-being is not straightforward in developed countries, as there is a demonstrable gap between income and well-being; once a certain level of income is reached, an increase in income does not lead to a proportionate increase in well-being. D'Acci suggests that monetary measures of economic resources that are not included in GDP take into account some of the economic factors that affect well-being, such as household size and the amount of disposable income available to each household member and amount of leisure time measured through number of hours worked and holiday pay. Social indicators are also measurable non-economic outcomes. In the paper D'Acci reminds us that the OECD uses four domains to explore social indicators, self-sufficiency, equity, health, and social cohesion. Self-sufficiency is the ability to earn a good living, as measured by years of education, school performance and the education of family members. Equity refers to the distribution of household income, and health is measured through illness and life expectancy. Social cohesion, on the other hand, refers to a sense of feeling like part of a community, and is measured through levels of crime and volunteering rates.

Stutzer and Frey describe the four factors that have emerged as determinants of happiness or SWB in economics literature: (1) income; (2) employment; (3) social capital; and (4) health. Firstly, income is generally captured in GDP in economics research, and is typically found to be strongly related to SWB and is true of individuals regardless of their own wages or whether they live in a rich or poor country. The issue of using these determinants, the authors suggest is that SWB has not been found to grow over time in line with increasing wages and that recent research has suggested that the relationship between income and happiness depends on social comparison, i.e. whether an individuals' income compares favourably to those around them or not, and whether their income is sufficient to achieve their goals. Employment can refer to job satisfaction and autonomy as well as unemployment rates. Social capital refers to the quantity and quality of social relationships and amount of socialising in general. High levels of SWB are associated with good quality relationships and greater socialising. Finally, the authors emphasises that the relationship between health and SWB has been established by a wealth of research studies and the importance of mental health to happiness has also been highlighted in recent research.

The determinants of well-being appear to be more aligned in the research literature and are useful to measure alongside well-being itself, in order to understand key influencers and drivers of well-being. Health per se and mental health is clearly an important driver of well-being but the determinants of well-being for people receiving care and support have not been the specific focus of research, but can largely be inferred from the research reported on what is likely to matter to this population.

WELL-BEING FOR PEOPLE WHO NEED CARE AND SUPPORT

The research discussed thus far largely describes well-being in terms of national populations. The Act evaluation, however, looks at a specific subset of the population: those who need care and support through public services. This population is generally divided into four groups with broadly generalizable areas of need around supporting their well-being (though there is also great diversity within their members). Those groups are children, young people, adults, and older people, however the literature tends to cluster around 'children' (into which category young people are grouped), and 'older people', with adults in need of care and support receiving little attention in the literature. Therefore, in this section we refer to that literature which specifically examines what well-being might mean for children and young people, and to older adults, with reference to their broad characteristics and common circumstances.

Research has shown that baseline well-being for different groups in UK society varies by age. Bowling (2010) investigated whether older and younger adults differed in their reported levels of well-being and why, using data from a national survey of adults in the United Kingdom (n=1,049) aged 16 and above. Results revealed that most participants (78%) rated their well-being overall as high. Self-reported physical health, mental health symptoms and social support were strongly associated with well-being scores across all age groups. However, there were some age-related differences in that older people (65 years and above) were more likely to define well-being as being able to continue doing the things they had always done. Other factors such as total income and gender effected participants' responses. For example, women were more likely to report depression and anxiety than men. Bowling concluded by stating that understanding what influences well-being across different age groups is vital when policies are created. In this review the study team have a further task to consider: the influences on well-being for society's most vulnerable groups who are in need of care and support through public services.

Well-being in Children and Young People

Ben-Arieh and Frønes (2011) discuss the need for a taxonomy of child well-being indicators. The authors argue that with a rise in the amount of research focused on child indicators of well-being, a common unifying taxonomy or classification system of these indicators is needed. In previous research, childhood indicators of well-being have been used to measure objective and SWB, and differ if the study explores individual level data or cross-country data. Some of these indicators have been used to develop dimensions or indexes that subdivide indicators in separate aspects. For example, education could be an indicator that is subdivided into aspects that could include parental level of education, for example. The fact that these indicators are so complex, the authors argue, demonstrates that a classification system is needed to elicit a common 'language' used by everyone.

The authors state that there are three types of indicators for children's well-being. The first is input indicators and includes protective factors, risk factors, interventions and investments. Secondly, indicators of children's status refer to the economic, social, physical, legal and emotional factors that affect children's freedom to make choices and achieve goals. Finally, outcome indicators include the results of interventions, and help to connect desired outcomes with goals and consequences. The authors conclude that well-being indicators are complex, and that their discussion helps to demonstrate how important it is to develop a framework in which to understand them.

Domínguez-Serrano, del Moral-Espín, and Gálvez Muñoz (2019) explore children's views of their own well-being to create a framework that comprises a capabilities approach (CA) with a social provisioning approach. The CA provides a framework for evaluating the well-being of individuals through its main idea that well-being is achieved through "the expansion of people's capabilities, defined as what each person is able to do and be". The approach also advocates policies that can help people to have these capabilities. In order to understand specifically how children view well-being and their capabilities, a survey was conducted under the UNICEF Child-Friendly Cities programme, and involved participants from 10 cities (n=309) aged between 8 and 17 years. Children were asked to rate how important different capabilities were to children and adults. Children rated physical and mental life and health and education and training capabilities as the most important to themselves and to adults. However, for adults they also rated co-responsibility and care-work as high as well as economic and material well-being, but did not think they were relevant for children. In conclusion, the authors affirm that the results of the study reveal that children differ in terms of the capabilities they believe affect their own well-being and those of adults'. Evidently it is important to involve children in the creation of a framework to explore children's capabilities and well-being.

A focus on children and young people is distinctive due to their specific needs and social position, and necessary, as these factors have substantial consequences for the ways in which their SWB is measured. Children and young people, especially those who have been involved in high-risk behaviours or who suffer from mental health difficulties, as is often the case with children in care (Long et al., 2017; Vincent & Jopling, 2018), are sometimes not considered to possess a full capacity to reflect on and make judgements regarding their experiences. As a consequence, measures of SWB outcomes are often produced using the judgements of others surrounding them – professionals, family, and carers. Furthermore, the instrument design, recording, and interpretation of their views and experiences is usually conducted by adults and thus, necessarily, by someone holding an adult's perspective, rather than a child's. This matters as research suggests a disparity between what adults believe are important to children's well-being while in care, and their own views (Selwyn & Briheim-Crookall, 2017)

There are key domains which are agreed to be vital for the well-being of all children across the available evidence; the most prominent example being education. Hart and Brando (2018) use a capability approach to discuss how children's well-being, agency and participatory rights can be developed in schools. Sen's Capability Approach (CA) described above refers to the idea that the freedom and opportunities that children have to make choices about their lives and aspiring to future goals is vital for their well-being. The authors state that instead of focusing on the outcomes of education, this study focuses on the processes and policies that can be put in place in school for children to enact these capabilities, reach their goals, and, hence, enhance their well-being. This concept has a number of policy implications, which the authors highlight. First, quality assurance procedures for education would need to involve assessing for the opportunities that children are presented with that allow them to develop critical agency (the capacity to act or to do something themselves to achieve an end goal) and the fulfilment of participatory rights (ability to speak freely). This is the idea that assessing traditional education outcomes, such as pupil attendance, exam scores and the number of students attending university, is not sufficient. A CA would also involve assessments of students' participation and their empowerment, and how well opportunities are distributed amongst students of different genders, backgrounds etc. Secondly, the CA also suggests that education policies could be changed to promote schemes that develop moral reasoning and critical thinking as well as academic achievement. The authors conclude that the study has helped to initiate discussion about the potential roles of schools to enhance children's well-being through a capability approach.

Bradshaw, Keung, Rees and Goswami (2011) compare children's SWB across different countries. The study investigated the results of a survey on SWB that was completed by children in England (micro level) and children in other European countries (macro level) and included demographic data. The survey assessed three domains of SWB: (1) personal well-being; (2) relational well-being; and (3) well-being at school. The results of the study in England revealed that girls have higher school well-being and boys have higher personal and family well-being. Personal well-being was also shown to improve with age. At macro level, the results revealed that personal well-being was associated with housing circumstances, and relational well-being was associated with but that school well-being was not associated with any demographic variables. These results demonstrate that at the macro level indicators of deprivation (such as poor housing conditions) are associated with young people's well-being. At micro level, there are associations between age, gender and well-being. Although it must be noted that age and gender data are only available for the European study.

McLellan and Steward (2015) investigate school-age children's well-being using a new survey that aimed to identify some of the factors that shape children's self-reports of well-being. The study involved a survey that asked children to rate statements about 'how I feel about myself and my school', such as 'I feel happy'. These statements were chosen based on previous theories and research, and evaluative as well as affective and eudemonic well-being statements were included. Demographic data was also obtained, and altogether 5170 children completed the survey from 20 primary and 20 secondary schools across England. Half of the schools were taking part in a Creative Partnerships programme that aimed to nurture children's creative skills and capacity to learn. The authors found the statements could be combined into four factors that were called: (1) interpersonal; (2) life satisfaction; (3) competence and (4) negative emotion. Results revealed that there were differences in terms of gender and age, with older children having lower levels of life satisfaction, and girls experiencing more negative emotions than boys. There were also age x gender interactions, in which primary school girls had higher levels of life satisfaction than boys, but this situation reversed in secondary schools. The Creative Partnerships programme was also shown to have no effect on children's self-reports of their well-being. The authors conclude that the survey appears to be robust, but that further studies are needed to explore the test-retest reliability of the instrument.

What is well-being to children in care?

A range of attempts to define and measure well-being for children in care internationally have been developed in recognition of the fact that their childhoods face consistently distinct challenges to their well-being to their peers not in care. The UNICEF (2009) 15 indicators are some of the best known and prominently applied around the world but these do not account for SWB, resting instead on adult-produced notions of well-being and protection.

Social care professionals use measures of well-being to supporting care planning and measure a child's response to interventions (Ryder, Edwards, & Clements, 2017). One of the most commonly used measures is the Strengths and Difficulties Questionnaire (commonly abbreviated to 'SDQ') to measure well-being, however this tool – whilst having strong evidence to back its widespread use – is designed to identify emotional and behavioural problems, rather than to produce oversight over a child's personal well-being. Ryder et al. note the view of professionals that well-being is a holistic concept that extends beyond physical and mental health and they call for a more expansive definition of well-being developed with children and young people, which Selwyn et al. (2017) were already developing at the time of publication. Practitioners report that they apply their own expertise and experience in their own assessment of holistic well-being, however in order to ensure consistent excellent practice a set of clear guidelines as to the specific components of well-being for children in care, led by children themselves, would provide a standard by which to measure the quality of care provision and its outcomes. Selwyn et al. have now produced this as a component of the 'Bright Spots' research design.

To co-produce the Bright Spots online survey, Selwyn et al. (2017) ran 18 focus groups with 140 children and young people to establish what they felt were important factors in their personal well-being. They discovered that while this group shared some common well-being factors to the wider child population, like relationships, there were also some factors which were unique to care-experienced childhoods. After thematic analysis, the focus group findings were categorised into four broad domains that the participants felt were central to their well-being as care-experienced children and young people: relationships; rights; resilience building; and recovery. Under these four domains were specific areas of concern, many of which reveal features and needs distinct to childhoods in care.

> *Relationships*: a wider range of important relationships were highlighted as important to care-experienced children than might be expected for non-care-experienced peers. While birth parents, siblings, friends, and teachers featured here, the participants also identified the importance of good relationships with carers and social workers – those additional and, potentially, more transient relationships experienced by children cared for by professionals as

well as family. This resonates with other research suggesting that relationships are the most important for well-being after children have entered care as relational difficulties can continue into foster placements. King (2017) found that 65% of children in foster care feared rejection from their foster carer, while 47% displayed a rejection or confusion surrounding appropriate relational roles, treating their foster carer as the child and themselves as the parent. Poor quality relationships with peers and adults are correlated with poor well-being for both children in and out of foster care, however children in foster care are more likely to have difficulties with social relationships. Once relationships were adjusted for, poor relationships was a better predictor of SWB than foster care experience (Long et al., 2017).

Rights: Alongside being free from bullying, discrimination and abuse, care-experienced children also raised that they needed to have an age appropriate account of personal history, which is often disrupted for children in care due to the number of changes they experience and the lack of continuity in their lives. They also valued being able to express opinions about their care and wished to feel included in social work decision-making.

Resilience building: Frequently without a stable environment or parental figures, children with care experience were focused on mitigating their vulnerability through strong support in building resilience. They raised a sense of being loved as important to their well-being, as well as having a key trusted adult and carer support for learning.

Recovery: This domain is particularly distinct for care-experienced children and young people. With more frequent exposure to traumatic events, and far greater incidence of mental health problems than the broader child population, it is not surprising that they prioritised their recovery from such experiences in their overall well-being. They identified several key factors to this, including appropriate access to support services and being given the same opportunities as peers. They also wanted to see their lives getting better after their difficult early years, which for most children would not necessitate such concern.

The identification of these issues by Selwyn et al.'s participants suggest substantial refinement to broader policy around children's SWB for children receiving care and support. The author's note that when the pilot survey was delivered, *respondents "were as satisfied with life as children in the UK general population but expressed more unhappiness"* (2017: 77). This suggests that while the material, 'objective' domains of their life were generally not lacking compared to their non-care-experienced peers, and their SWB relied on more than good living standards to be fulfilled. This disparity produces a powerful argument to include measures of SWB co-produced with care-experienced children and young people, least it be assumed that better living housing, education, or protection is sufficient to improve well-being in this group. Finally, a further notable finding from this research was that children as young as six were able to contribute meaningful ideas around their SWB, suggesting a challenge to the notion that younger children always require an adult to speak for them around well-being issues.

Within Wales, the School Health Research Network (SHRN) in Wales, led by the DECIPHer Research Centre at Cardiff University, applies the Short Warwick-Edinburgh Mental Wellbeing Scale

(SWEMWBS; Haveret al., 2015) in survey form to measure the well-being of secondary-school aged children. The survey links SWB to other health-related behaviours, such as smoking, drug use, and sexual behaviour, as well as family, community, and relational characteristics. As the survey incorporates questions regarding family and home life, including whether or not a child is in care, the researchers have been able to compare the well-being of children in care to that of the broader child population. The researchers reported significantly lower subjective well-being in children in foster care than their peers, and a higher incidence of risky health-related behaviours, such as drug use and smoking. However, while substance misuse was associated with care status and poor SWB, interestingly their statistical analysis showed that the quality of a child's personal relationships provided a stronger correlation with SWB than care status (Long et al., 2017). This finding promotes the importance of personal relationships to SWB for children both in and out of care, and suggests that the NOF could be increased in its relevance by virtue of increased focus on such relationships.

While the Welsh Government have established dual-stream guidelines for promoting the well-being of all children, with specific standards set for children and young people in need of care and support through the Act, it should be noted that some argue that targeting well-being policy in this way is a flawed approach. Eckersley (2011) argues that young people more broadly increasingly have problems with obesity and mental health due to cultural changes. Eckersley asserts that these difficulties are not limited to those with low socio-economic backgrounds, but are faced by young people as a whole. He argues that changes need to be made to deal with this widespread problem, such as changing from policies that focus on the marginalised, to broader all-encompassing policies that work for all youth. Eckersley concludes by recommending that changes are made across sectors, including research, health, education, business and politics.

Older people

Well-being is generally reported to increase from mid-life onwards into older age (Charles and Carstensen, 2010; Steptoe et al., 2015). However, critique of the well-established well-being 'U-shape' (where reported well-being decreases from childhood to middle age, and then steeply increases again into older adulthood) suggests that cultural and cohort trends accounting for historical events and an increase in living standards over the past fifty years in the Westernised world could be the reason behind this observation, rather than age itself being the key factor (Steptoe et al., 2015; Ulloa et al., 2013). In spite of this possibility, socio-economic, community, physical and mental health, and familial factors have all been observed to contribute to ongoing well-being inequalities in later life, even where the U-shape of well-being is found (Frijters and Beatton, 2012), and these factors are of particular concern for older adults needing social care and support.

Socio-economic inequalities in older life are significant factors in the degree to which older adults may access public social care services. The role these inequalities play in SWB have been addressed within studies seeking to interrogate the evidence for a gradual increase into older adulthood. Fancourt and Steptoe's 2018 study of over 55s in England found that engagement in cultural and community-based activities, such as education, arts or music classes and church or religious groups, has a positive effect on well-being in older age. However, such engagement is observed in less than a quarter of the older adult population, and is weighted towards those of higher socio-economic status. These findings echo those of Simone and Haas (2013), who found that high frailty and low social leisure engagement was associated with reduced SWB for over 50s in the USA, and Ku et al. (2016), who found that both physical and social activities contributed to higher well-being in Taiwanese adults over 70.

It should be noted, however, that generalising the impact of social activity across all older age groups may be misleading: Litwin and Stoeckel (2013) analysed the second wave of the Survey of Health, Ageing and Retirement in Europe, incorporating over 14,000 older adults, and found that positive effects of social engagement on well-being were significantly stronger in the 'younger-old' (age 60-79) than in the over 80s. This raises the possibility that stronger social relationships are not the only answer to positive well-being in later life. A further complication was observed by Siedlecki et al. (2014) when they measured the role of social support in the life satisfaction of USA adults aged between 18-95. Their research found that the impact of social support on life satisfaction was reduced to insignificance across all age groups once individual personality traits, including extraversion and emotional stability, were accounted for. This suggests that SWB measures that account for individual priorities and goals are important to capture in national measures.

Jivraj and Nazroo (2014) ran a comparative study of England and the USA applied measures of life satisfaction and QoL for the over 50s. They found that the presence of disability, chronic conditions, and low household wealth are strongly associated with poorer life satisfaction and Qol. Their findings also suggest that the more generous welfare state delivered in England to an extent counteract the further effect of educational inequality observed in the USA. This latter finding provides evidence for the positive effects that public policy may have on SWB in older adults. In a Southern European comparative study, Moreno and Vicente-Virseda (2016) found evidence that effective social care and state provided welfare is able to provide as the same or greater well-being benefits of close familial support for over 65s seen within multi-generational households.

While socio-economic inequalities produce an impact on care and support needs, another substantial effect is produced by health and physical well-being. While social well-being and associated mental health needs are the core focus of this review, physical health is a significant factor in reported SWB, and there are key areas of research here that are valuable for the purposes of the evaluation. Care and support for adults with dementia is a key area of concern for current policy and practice across the UK, and a systematic review focusing on this group's well-being reinforces the above findings for all older adults: relationships and social engagement hold the strongest correlations with high well-being, while low-well-being of carers – another relational factor – had a strong negative impact on an individual's own well-being (Martyr et al., 2015).

Functional impairment and disability among older adults is another key policy and practice focus in Wales at present, and the needs of this group in terms of living standards are acknowledged within the Well-Being Statement and NOF in relation to the needs for a suitable home that supports well-being, and support to do the activities an individual wishes to do. Research offers some support for this approach: a systematic review of 19 studies by Trecartin and Cummings (2018) found a consistent relationship between appropriate home environments with positive well-being for adults with functional impairments across their included studies. However, the focus of the studies they included was highly variable and while the authors conclude that there is strong evidence to suggest that a focus on home quality is important to the well-being of this older adult group, they also highlight significant knowledge gaps and recommend that further research on the subject of well-being and home environment is required.

Finally, with reference to well-being measurement, Vanhoutte (2014) cautions that our understanding of contributing factors to well-being in older age is curtailed by the application of measures that overly conform to either the hedonic or eudemonic approach, with little multi-dimensional measurement designed to capture both elements of well-being harmoniously.

THE PLACE OF WELL-BEING IN UK POLICY

Well-being made the media headlines in 2010 when UK Prime Minister David Cameron announced that a new well-being measure, developed by the UK Office for National Statistics (ONS), would be used to better understand the state of the nation. GDP had long been established as the standard measure of welfare and well-being until research by Richard Easterlin revealed that well-being was not rising in line with GDP (Easterlin, 1974). Cameron's Government suggested that a measure of the country's well-being would be a better reflection of how people are doing than economic measures like GDP. As mentioned in section 1.3, questions on life satisfaction, worthwhileness and happiness are integrated into annual, population-wide surveys across each of the UK's nations.

For social care services, specific frameworks emerged in Scotland, England and Northern Ireland, as well as Wales. The English Adult and Social Care Outcomes Framework (ASCOF) (2019) incorporates quality of life outcomes under the domains 'control', 'personal care', 'accommodation', 'safety', 'social participation', 'occupation' and 'dignity'. These are contextualised alongside other services domains such as prevention. Scotland's National Health and Well-being Outcomes Framework (2014) offered nine distinct outcome measures on themes such as independence, safeguarding and consideration of personal circumstances. Northern Ireland's own Social Work Strategy for Improving and Safeguarding Social Well-being (2012) also incorporates well-being outcomes relating to service use within an emphasis on person-centred practice. However, measurement of these outcomes, as with the NOF, exclude the SWB indicators of the broader annual population surveys, and do not aggregate the extent that individual service users feel they are meeting their personal well-being goals.

Using income and GDP to measure the welfare and well-being of individuals is increasingly recognised as being insufficient. Layard makes a powerful case for measurement of SWB in an article in Science in 2010:

> *"...for many key areas of public policy, such measurements (that money that the beneficiary has shown he or she would be willing to pay for a change of state) make no sense because little individual choice is involved—think, for example, of physical health, mental health, responsible parents, family stability, (un)employment, and community life. In these areas, we can get much better measures of the benefits of a policy change through direct measures of subjective well-*

> *being. It is therefore time to begin developing an alternative system of cost-benefit analysis in which the units are units of subjective well-being". (Layard 2010: 535)*

Forgeard et al. (2011) also discuss measuring well-being for public policy, because, they state governments had discovered that there were *"distressingly large gaps"* between GDP and citizens' reported of levels of well-being. Forgeard et al. additionally report that governments are also using different objective and subjective indicators to measure well-being. Subjective indicators include happiness, positive emotion, engagement, meaning and purpose, life satisfaction and achievement and competence using surveys and questionnaires. Happiness is measured through simply asking people to rate how happy they are, but, they suggest, these surveys lack construct validity, as it is unclear what criteria different people use when assessing their own happiness. Life satisfaction is the most common measure of well-being and uses surveys to determine how satisfied people are with their lives.

Kenny also reviewed the results of SWB surveys and their potential implication on policy making in 2011. SWB polls are an alternative measure of well-being and happiness to measures that focus solely on income and GDP or preference-based measures. One of the strengths of SWB polls is perceived as the fact they do not force a specific view of happiness on to respondents. SWB surveys vary in their construction, and can ask respondents to rate their level of satisfaction or happiness, however there is strong agreement between different SWB survey data. Results of SWB surveys suggest that happiness is associated with employment, higher self-esteem, and more friends. However, it also seems that happiness can be viewed as a personality trait, as a twin study by Lykken and Tellgren (1996) found that 80% of the reported answers to a life satisfaction poll were heritable, rather than associated with social and economic factors. In addition, a cross country study of 41 countries that varied greatly in their levels of development and GDP, found that 87% of the variation in responses to a life satisfaction survey were associated with within-country factors rather than across country (Vitterso et al., 2002). Other cross-country studies have supported this by showing that income, health, human rights and social factors have little influence on SWB (e.g. Dorn et al., 2005). This suggests that SWB polls do not cover all the issues that are important to people's happiness. In terms of policy, the authors suggest that policies could tax or discourage the pursuit of positional goods, as SWB polls show this does not make people happy. Instead policies could encourage time spent with family of holidays. In conclusion, Kenny asserts that SWB polls do not capture everything, and policy makers should be careful in how they use data from these polls to inform new policies.

In 2013, Bache and Reardon reviewed the rise of well-being in British politics and the use of measures other than wealth to determine progress in society. The authors used John Kingdon's (2011) multiple streams approach to explain the shift in importance of well-being. Three streams are discussed, the policy stream, the political stream and the problem stream, which refers to the existence of a crisis or high-profile event that propels change. They describe how well-being has affected the policy stream, and the political stream has also made a huge leap forward regarding the importance of well-being, but that advances have not been made within the problem stream. This has meant that well-being has reached the government agenda, but has not reached the decision agenda. A clearer alliance between all three streams is needed for well-being to become *"an idea whose time has come"*. The authors conclude by asserting that while the multiple streams approach is useful, it does not allow for the inclusion of influences beyond the UK system that have an effect, such as policies at EU or international level. The question of whether the 'time' has indeed come for well-being is one that can be usefully applied to the political background of the Act. An examination of whether the 'problem stream' has been sufficiently progressed in the seven years since Bache and Reardon's review will support the understanding of how decision-making within Wales is bringing well-being to bear on social care practice and the individual experiences of those in need of care and support.

DISCUSSION

The decision to measure the success of the nation using well-being in addition to measuring economic growth using GDP was a step change in thinking about the ultimate goal of government and policy focus for the UK Cameron government when it came into power in 2010. The importance of well-being has also become embedded in the policy of Welsh Government with the Act and the Well-being of Future Generations (Wales) Act 2015, well-being, becoming the embodiment of the goal of policy to influence well-being.

The NOF captures most of the contributory factors within an individual's well-being, and in this sense it is a strong tool for measuring how well Welsh policy and practice is doing in creating the conditions for a good standard of living and the promotion of rights for vulnerable people. However, given the literature assessed within this review, the measurement strategy for the NOF fails to get to the heart of what it means to apply the term 'well-being', due to the subjective components of the concept covered here that are not necessarily derived from living standards, resource, or rights. If the intention of the Act is to increase the well-being of people in need of care and support, and carers needing support, then measurement of its success needs to ask people how they feel about their well-being. The NOF itself has one of its criteria, embedded amidst a long list of living standards, "I am happy and do the things that make me happy". This statement sits as a reasonable proxy for subjective well-being within the NOF, though its location as simply one of many criteria is conceptually at odds with the literature.

Within this, the understanding of subjective well-being is granted equal or greater import than the measurement of living standards. Yet, beyond the National Survey for Wales which captures a particular sub-sample of the population, we are not actually asking people in need of care and support, and carers in need of support, whether or not they are happy. By focusing on living standards in well-being measurement, we are neglecting subjective well-being and, according to the conceptual literature covered here, we simply cannot know whether or not the SSWB Act is increasing the well-being of the citizens it applies to. Based on the literature reviewed here, we argue that the statement regarding personal happiness within the NOF should be given greater prominence within both the framework itself and within the measurement strategy. A national strategy for collecting and collating data on whether or not the people covered by the SSWB Act actually *feel* a sense of well-being should be proposed and piloted, with a focus on efficiency to minimise the administrative burden on social services departments. We propose that this data can and should be collected as part of statutory assessment by social workers to inform the measurement and evaluation of the SSWB Act going forward.

Comprehensive measurement of SWB in the UK was initiated in 2010 via an UK national survey undertaken by the ONS and is ongoing. This also feeds through to the NOF in Wales enabling observation of a sample of the Welsh population who respond to the survey and answer the four well-being questions. This is not focussed on people receiving care and support or the people who care for them but they should be represented in the sample. However, given the variation in both the constructs of well-being and the theoretical underpinning it is far from certain whether the ONS data collection is really measuring what Welsh Government intend to measure or need to measure in order to assess the impact of policy on well-being. At the personal level and for people who receive care and support it is far from clear whether their well-being is the same construct as that of the general population. We just don't know what research tells us as the literature is sparse and/or not pertinent to this setting. However we can make informed speculation that the capability approach accesses what is important to people receiving care and support.

Paying attention to Atkinson's proposal (Atkinson 2013) that rather than aiming to improve well-being for the individual through policy interventions, policies that support mandatory provision and delivery of support services for specific and broader populations might also support the Act objectives.

KEY MESSAGES

There are a number of key messages to emerge from the review undertaken:

- The philosophy of well-being underpinning the Act needs further development to ensure coherence and support further development of the national agenda for well-being; this will enable evaluation of the impact of the Act (and potentially support evaluation of the Wellbeing of Future Generations Act).
- Identification of and appropriate measurement of SWB should be integrated into the evaluation of the Act and also into ongoing measurement;
- Given the gaps in the literature for people who receive care and support and carers who need support, further focus is required to better understand how SWB needs may vary across the life course of people in need of care and support;
- The Group Capability Approach may be a fruitful avenue to pursue for evaluating the impact of the Act;
- Children and older people in need of care and support may require more complex living standard aims than are currently offered by the Well-being Statement and NOF.

The immediate next steps in the research being undertaken to evaluate the Act includes analysis of interviews being undertaken with people in receipt of care and support to understand what well-being means to them. The literature review will aid our analysis and understanding of the interviews and subsequently inform our recommendations about measurement of well-being for people who receive care and support.

PREVENTION AND EARLY INTERVENTION

Fiona Verity, Simon Read and Jonathan Richards

INTRODUCTION

The wording of Section 15 of *The Social Services and Well-Being (Wales) Act 2014* is the starting point of this section of the literature review, which is focused on prevention and early intervention. The Act requires and encourages the implementation of a range of preventative approaches. It advises that:

> *'…a local authority must provide or arrange for the provision of a range and level of services which it considers will achieve the purposes in subsection (2) in its area. (2) The purposes are — (a) contributing towards preventing or delaying the development of people's needs for care and support; (b) reducing the needs for care and support of people who have such needs; (c) promoting the upbringing of children by their families, where that is consistent with the well-being of children; minimising the effect on disabled people of their disabilities; (e) contributing towards preventing people from suffering abuse or neglect; (f) reducing the need for — (i) proceedings for care or supervision orders under the Children Act 1989, (ii) criminal proceedings against children, (iii) any family or other proceedings in relation to children which might lead to them being placed in local authority care, or (iv) proceedings under the inherent jurisdiction of the High Court in relation to children; (g) encouraging children not to commit criminal offences; (h) avoiding the need for children to be placed in secure accommodation; (i) enabling people to live their lives as independently as possible.'*
>
> *(Social Services & Well-Being (Wales) Act, 2014: Part 2, Section 15)*

This is the way that the Act defines preventative approaches most clearly. Key verbs are that this preventative work is to 'contribute to', 'reduce', 'delay', 'promote', 'minimise', 'encourage', 'avoid' and to 'enable'. Preventative interventions, as named in the Act, include the promotion of social enterprises, 'co-operative organisations or arrangements', co-production in the development of preventative services, and promotion of the 'the availability in its area of care and support and preventative services from third sector organisations'. Provision of culturally and linguistically appropriate clear and accessible information, assessment and advice is also required.

The development of these interventions in diverse localities and for diverse population groups is to be informed by population needs assessment and planning processes, co-production and collaborative and multi-sector working. There is an implicit link between the design and delivery of preventative services and approaches and the other themes canvassed in other sub sections of this literature review, in particular with co-production and multiagency working.

In addition to understanding the early results and impacts of the preventative work, implemented as part of the requirements of the Act, the evaluation focus is to explore the prevention and early intervention frameworks in use, how these concepts are being interpreted and the manner in which preventative interventions are being implemented and evaluated. This section explores literature which highlights the key research questions associated with this evaluation theme. The literature included incorporates a diverse range of documents including research reports, education / training frameworks, philosophical perspectives, guidance or strategy documents, and journal articles. This review is organised into the following 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;
- Prevention approaches in social care.

It concludes with a summary of some of the key lessons emerging from the literature review.

CONCEPTS AND DEFINITIONS

Against this backdrop, our reading of the papers, our selection of those to review in detail and this literature review have been informed by Gough (2013) and Miller and Whitehead (2015). The latter paper provides worked examples from six local authorities in the West Midlands to demonstrate the theoretical approaches of the former. Gough (2013) notes the important contribution of what he calls the 'onion model' of Dahlgren and Whitehead that has underpinned many approaches to prevention since the early 1990s, especially in public health. Gough (2013:1) comments that the spheres of society, economy and environment 'are inextricably and increasingly linked and interdependent and must be addressed together to plan for a sustainable future'. There are a range of frameworks and approaches within each sphere. He cites Coote's general definition that 'prevention' may occur:

- *"upstream (prevent harm before it occurs)",*
- *"midstream (mitigate the effects of harm that has already happened)" and*
- *"downstream (cope with the consequences of harm, stop them getting worse)"* (2013:3)

The concepts of Dahlgren and Whitehead's onion model can be observed in the Act, in the domains of individuals, families and carers, communities, the workforce and organisations.

The upstream, midstream and downstream metaphor is central in the 'public health prevention parable', which unpacks and signals the complexities of prevention and early intervention, in this case of ill-health, and the trade-offs in decisions between allocating scarce resources to prevention of the 'causes of the causes', or upstream work, and decisions to respond to immediate needs and 'changing the effects of the causes' or downstream work (NCC for Determinants of Health, 2014: 2). The NCC for Determinants of Health recount this parable as follows:

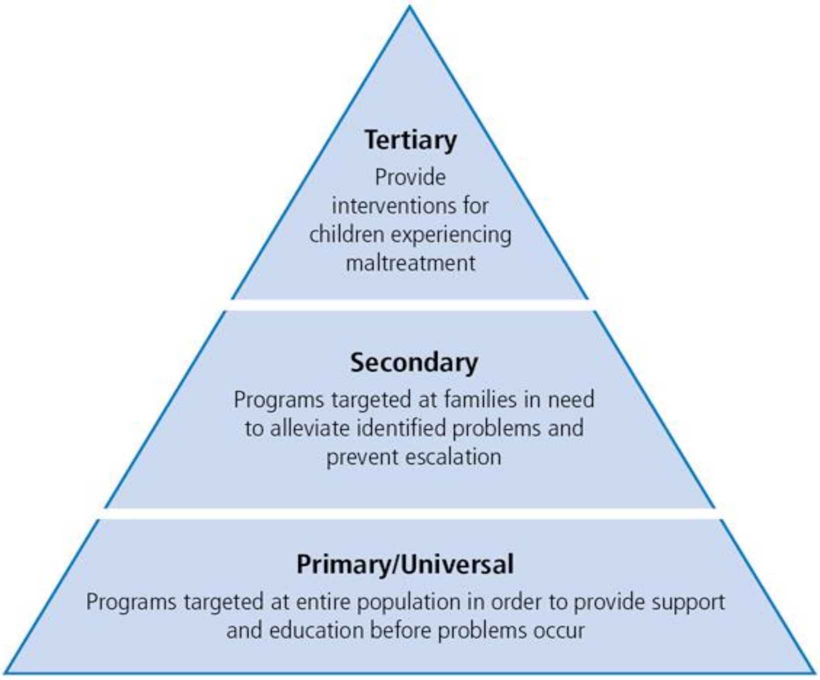
> *In the classic public health parable credited to medical sociologist, Irving Zola, a witness sees a man caught in a river current. The witness saves the man, only to be drawn to the rescue of more drowning people. After many have been rescued, the witness walks upstream to investigate why so many people have fallen into the river. The story illustrates the tension between public health's protection mandates to respond to emergencies (help people caught*

> *in the current), and its prevention and promotion mandates (stop people from falling into the river)* (2014: 1)

Upstream work or interventions can include reforming of '…the fundamental social and economic structures that distribute wealth, power, opportunities, and decision-making' (NCC for Determinants of Health, 2014: 2).

A three tiered approach to prevention is evident in the social care literature reviewed. Here there is a borrowing from public health discourses joined with a distinctive social care lexicon. An example is the public health model of child welfare services, depicted in the following figure from the Australian Institute of Family Studies. This model delineates prevention at a tertiary level, secondary level and primary/universal level. Prevention at each level will require the provision of various types of programs aimed at different audiences. In this model, at the tertiary level, prevention is to 'provide interventions for children experiencing maltreatment'. At the secondary level, prevention can be programs for 'families in need to alleviate identified problems and prevent escalation', and at the primary and universal level, prevention is the delivery of programs 'targeted at entire populations in order to support and educate before things become problems'. Each program type is preventative but intervening at different points of the metaphorical stream; intervening to reach a universal or wider population (early intervention) and intervening to help those who are immediately impacted and in need, and therefore prevent things from escalating.

Figure 1: Public Health model of child welfare services



Source: Adapted from Bromfield & Holzer, 2008; Child Family Community Australia, 2014

This distinction between levels or types of prevention in social care is common. Some examples are given below. Curry (2006) cites Wistow's work who depicts three levels of prevention in the context of support for older people. These levels are:

- *to prevent or delay ill health or disability consequent upon ageing*
- *to promote/improve quality of life of older people, their independence and inclusion in social and community life*
- *to create healthy and supportive environments.* (Curry, 2006:6)

Each of the above objectives –'to prevent or delay', 'promote or improve' and to create and support' lend themselves to certain sorts of interventions or services, as noted by the Australian Institute of Family Studies in their child welfare services model.

A similar emphasis is articulated by Stagner and Lansing (2009), who define prevention in the context of 'childhood maltreatment'. Stagner and Lansing's definition foregrounds action to address both social and environmental factors and individual behaviour and beliefs. As they write, prevention is needed to stop problems occurring in the first place which otherwise may be more costly to address in the future. From their perspective, effective prevention is thus predicated on sound knowledge about causal factors, or why things happen as they do. Stagner and Lansing's conceptualisation introduces considerations of temporality and past and future horizons, where investing in prevention and early intervention is both a backward focused endeavour to understand how the present came to be, and a commitment to an unknown future time and place:

> *…prevention can be conceptualized as investing in future outcomes by influencing current behaviour or conditions. Expenditures made now, if they change conditions or behaviour, may stave off future problems that cost more than the prevention efforts, even when future costs are discounted. (Stagner and Lansing, 2009: 20)*

Warin et al, (2015) in their research on obesity prevention for young people in 'socio-economically disadvantaged communities' reflect on practices of temporality in prevention. They suggest that a prevention agenda based on an imagined future too far away from the everyday realities and necessities of people's lives can create dilemmas and challenges in being effective in preventative work. They caution about a '…spatio-temporal disjuncture between 'the future' in public health obesity initiatives and the embodied reality of eating' (2015:309). They propose instead that it is a much 'shorter future horizon' that should inform prevention agendas, in order to base such interventions in people's needs and realities; '*the immediacy of poverty, contingencies and survival that mark people's day to day lives'* (2015; 309). Whilst Warin et al (2015) are writing about community-based obesity prevention, their questions about which temporal horizon informs the preventative ambition has wider relevance.

Whilst there is, broadly speaking, commonality in a delineation of prevention spheres / levels, there is nonetheless much contestation in how prevention is defined. This contestation is framed in various ways. Allen and Glasby (2010:33) comment that in *'…spite of a stated commitment to prevention, there is a lack of clarity about what it means or how to do it in practice'*. Kerslake (2011:3) observes 'loose terminology' surrounding prevention in social care. Curry (2006) in an overview of literature in this area writes there is 'no agreed definition', 'no consensus' and 'haziness around boundaries' when it comes to prevention in social care. Likewise, a recent Think Local Act Personal report highlighted how practitioners from different settings are 'often not sure they are talking about the same thing, let alone working to the same goals' (2016: 7). Prevention may be described as mitigation, coping, minimising, early stage disease detection, reducing events, stopping events, changing conditions, identifying at-risk populations, amelioration or containment of a problem, avoiding further harm and preventing the emergence of a problem.

Some of these descriptors are to be found in The Act, as noted earlier. In social care, prevention might be about preventing social isolation, reducing carer fatigue and supporting carers, rehabilitation, re-ablement '...to maximise independence and quality of life in older age' (Allen and Glasby, 2010:31), prevention of child abuse and neglect, reducing homelessness, preventing unnecessary hospital admissions, promoting well-being and quality of life, building stronger communities, reducing need for formal social care services and so on. It is also the case that preventative interventions can meet multiple goals.

Marczak et al (2019) report findings from an exploratory study of the implementation of the statutory duty to support prevention under *The Care Act 2014*. Through document analysis and semi structured interviews in 6 local authorities in England, the researchers explored conceptualisations of prevention, how and why the local authority commissioned certain preventative services and links to evidence and evaluation (Marczak, et al, 2019:210). They found conceptual differences across the study sites in respect to what is meant by prevention in social care, and that this ambiguity flows into decision making and practice. Furthermore, as they write, '[T]he under conceptualisation of prevention and its contested nature posits serious challenges to the development of necessary evaluations and requires further study' (Marczak, et al, 2019:213).

To add to this picture of contestation and complexity, Gough (2013: 1) cautions us that '[p]revention is almost entirely seen as a good thing', indicating that it can be approached in an uncritical manner. He further notes; 'Behind ideas often lurk different organised interests' (2013: 5). This definitional slipperiness and uncritical appraisal calls for attention to how prevention is conceptualised, and by whom, the link between concepts and what is done in the name of prevention, e.g. the sort of interventions or approaches that are implemented, where the change will be (i.e. individual/family, community or structural). These points raise some fundamental questions. Should scarce resource be invested in a preventative agenda about immediate and short-term individual needs and stopping things from escalating, or in creating future worlds which enable social, cultural and material capital and enhance capabilities? Does it have to be an either/or and how are decisions best made about where to place limited resources.

One of the longstanding debates in the prevention literature, in both social care / health and in environmental sustainably (see for example climate change debates), is how to re-orient the investment and intervention focus from a response to crises to prevention. Allen and Glasby explore this dilemma in their work on prevention in the context of services for older people. They write:

> *At present resources are concentrated on a small number of older people in crisis, and there is too little investment in prevention. It is hoped that by inverting the triangle services can invest in prevention for a larger number of older people, reducing future crises. Attractive though these models are intuitively, they remain largely aspirational, with insufficient evidence to*

> *back up some of the claims and little sign of the long-term political/financial support that might be needed to make such changes. (2010: 28)*

Gough (2013) shares this assessment. Despite a discourse of a three tiered model of prevention, he suggests the practice focus since the 1970s (he examined practices in health, early years interventions and crime prevention), tended to be concentrated on secondary and tertiary prevention rather than upstream or primary prevention. For example, he notes an absence of structurally focused interventions to address the 'causes of the causes' (e.g. poverty prevention). That said, more recently there has been an upturn in primary, community-centred approaches to prevention looking to address local issues through sustainable initiatives, community businesses, hubs and social enterprises (Abrams et al, 2019; Bedford and Harper, 2018; Hull et al, 2018).

In summary, these definitional and conceptual matters have relevance for the analysis of the implementation of the preventative agenda required under the Act in Wales. Prevention can be implemented as an individualised intervention, and examples include provision of support, services or approaches that stop or delay more intensive service use and that support empowerment and well-being, independence, and resilience. It can also have an 'upstream' orientation and aim to address the underlying structural factors that impact on social care needs and the provision of formal and informal care and support. The delivery of preventative interventions can also vary from being grafted into existing health and care systems and developed outside of them (Allen and Glasbury, 2010).

WHAT IS DRIVING THE PREVENTATIVE FOCUS?

Curry (2006: 1) writes that prevention has become 'increasingly prominent in health and social care policy rhetoric in recent years'. Yet prevention is not a new initiative in social care and social work (Dunk-West and Verity, 2018; Smith and Barnes, 2013). Dunk-West and Verity (2018) show this in their historical examination of the life and work of 3 early social work pioneers; Jane Addams (1860–1935) reformer and community development activist, and co-founder of Hull House, a community development and educational initiative, was awarded the Nobel Peace prize; across the Atlantic, Alice Salomon (1872–1948) German was a social services reformer and social work educator who wrote a PhD about 'The Causes of Unequal Payment for Men's and Women's Work'; and Clare Britton Winnicott (1906–1984) casework social worker and psychoanalyst worked closely with Donald Winnicott in child welfare practice and research. Each of these innovative social workers were concerned with both individual health and well-being, and with change in wider contextual and social conditions. Their work embodied a holistic approach to preventative work, across all levels of the metaphorical stream. Clare Winnicott, who practiced social work in Merthyr Tydfil in the late 1930s, writes:

> *We could easily get bogged down in the detail of the family dynamics of the individual, and lose sight of the structure. I feel so strongly that the two things have to go together. We have to be altering the structure to meet the individual, and helping the individual within the structure. I think you can't ever take your hand off either of these things. It's tremendously*

> *important and it always has been to me, to see the context in which I'm working. (Cohen, 2013: 19)*

Prevention in social care and social work, as is the case in health, was also to the fore in the 1970s (Gough, 2013; Clark, 2019). Clark (2019:20) in tracing the developments towards a preventative agenda at this time notes it was, in part, '…catalysed by the financial pressures the health service was experiencing'. It is outside the scope of this review to canvas these historical developments more fully, except to note the historical continuities and lessons.

The contemporary 21st Century shift to prevention is driven by several factors, with echoes of previous policy discourses; cost saving imperatives, measures to reduce demands on tertiary and secondary health and social care, ideological or values- based approaches both in the direction of fostering individual responsibilities and to support social reform and change in the interests of social justice and reduction of inequalities, and 'bottom up' community agendas emerging from interests outside of the state (Marczak et al, 2019). There are however, contested views on which of these aims and objectives are most important. Some experts like Kerslake argue the 'primary goal of any prevention strategy has to be the reduction of future demand' (2011:14). This starting point has implications for the types of interventions that are in the planning and decision-making frame and where funds are invested (Marczak et al, 2019).

Curry (2006) notes the financial imperative running through prevention discourses in social and health policy. Within such discourses there is an assumption that shifting to prevention can lead to reductions in financial expenditure in the face of demands and 'unsustainable spending'; in other words, as Curry writes, that prevention is a means to prevent more costly interventions at some future point in time (2006:6). She gives the examples of reduced hospitalisations because of falls prevention programmes. The Office of the Deputy Prime Minister (2006), cited by Curry (2006: 6), provide an example which fuses the aim of cost saving with better quality of life. They define prevention in terms of the provision of services that reduce or delay expenditure on 'more costly intensive services' and '…that promote the quality of life of older people and their engagement with the community'. Similarly, several reports highlight the emphasis on community-centred approaches as a means of cost-saving, often alongside other outcomes such as improved user experience and greater efficiency (Bown et al, 2017; Centre for Enterprise and Economic Development, 2017; Department for Communities and Local Government, 2009).

While the economic, cost-saving discourse is prominent, numerous authors also highlight the role that commissioning bodies play in determining which prevention initiatives are progressed (Cooperatives UK, 2017; Bedford & Harper, 2018; Department of Health, 2010; Local Government Association, 2017; Marczak et al, 2019). Kerslake (2011) argues the need to develop commissioning models suited to decisions about investment in prevention in social care, and which link more closely funding decision-making and allocations, outputs and outcomes. He writes: 'if demand is to be reduced it has to be through interventions integrated at the point of delivery, be targeted and evidence based, tackle performance where that is an issue and change the basis on which the funding of prevention is made' (2011:4). He identifies some key components of a methodology to make decisions about investment in prevention. These are: having a framework which sets out different types of preventative interventions; identifying the evidence base for the interventions selected; a 'local commissioning framework that is interdisciplinary, interagency and interdepartmental'; and the methods to assess the 'value of prevention by its cost against the outcomes it achieves' (2011: 15-16).

Knapp et al (2013) in their work on cost benefit analysis and prevention in social care, establish that a policy and programmatic turn to prevention has potential for economic savings. They explore the cost effectiveness case for prevention in social care through modelling of possible costs and benefits associated with three types of community capital building interventions: time banks, befriending and community navigators. They explored cost effectiveness of these interventions to compare '…the resources expended with the outcomes achieved' (2013:315). For each intervention type, drawing on an evidence base (literature and expert opinion) they established both the costs for a period of a year and assumed benefits, to which they assigned a monetary value. For example, for time banks they assigned an economic value to the following potential outcomes: 'value of service hours created'; increased probability of a time bank participant returning to paid or unpaid work, and 'reduction in benefit claims'. They also calculated well-being improvements through using a health utility parameter and 'Value of one quality adjusted life year'. On the cost side of the ledger they established the costs of running a time bank for a year. Through this simulation of costs and benefits they established that for each intervention type there were '…net economic benefits in quite short time periods' (2013:327). They further make the case for the development of such cost benefit modelling frameworks for preventative and community capital building interventions in social care. These issues are explored more comprehensively in the review on economic and financial matters pertaining to The Act.

The view that prevention in social care is to save money is disputed by those who argue the opposite: that prevention needs investment and should not be considered as the cheaper alternative. A report by Cooperatives UK (2017) saw cooperative approaches to prevention and well-being seen as an 'untapped cost saving resource, with too little recognition of the fact that integrating volunteers with professional services can involve costs and burdens, as well as boosts to overall effectiveness' (2017; 4). Miller and Whitehead also write that developing preventative interventions cannot be 'rushed'. In the introduction to their report entitled 'Inside out and upside down: Community based approaches to social care prevention in a time of austerity' they comment:

> *In adult social care an investigation regarding the deployment of such models in local authorities discovered that they are being developed, but raised concerns of the "dangers of top-down solutions, of such approaches being misconstrued as 'cuts' and of trying to rush a process that many felt needed to be small-scale, bottom-up and led by communities themselves.* (2015:1)

The energy and resources of communities, in taking matters into their own hands in the face of austerity, closure of local services or unmet needs is another driver for prevention (Foot and Hopkins, 2010; Wales Cooperative Centre, 2011). This community action has resulted in the development of local projects and social enterprises. McClean et al (2019) performed a systematic review of community businesses for health and social care, stating both positive health and well-being outcomes and the need for further longitudinal evidence. Similarly, Munoz et al's (2014) study on community-led social enterprises developed a five stage process supporting their development. Within this, deeply engaging with communities and catalyzing their potential is regarded as a central feature, identifying needs specific to local contexts (2014; 8). Hull, Davies and Swersky (2016) paint this picture of a dynamic 'bottom up' growth in preventative interventions in England in their report on *The Community Business Market in 2016*. In tracking the steady growth in this sector in England, they state:

> *A key area of growth for the community business market has been in sectors where valued local assets or services come under threat; and*
>
> *…we see many examples of communities coming together, galvanising support and succeeding where a purely commercial or charitable model would not. (2016:5)*

Finally, there is a perspective that prevention is a human right; to have realised the social and economic prerequisites for support, care and social justice (Smith, 2018). For example, this perspective informs the values base of social work.

STATE OF EVIDENCE FOR PREVENTION IN SOCIAL CARE

In this section, there is an examination some of the debates on the state of evidence about prevention in social care. There is a thread running through the literature reviewed that the scientific evidence base about prevention in social care is limited; that there is a need for more empirical evidence about effective and cost effective preventative interventions; and more compelling evidence about the impact of prevention and for whom (Curry, 2006; Stagner and Lansing, 2009; Emerson, Hatton, & Robertson, 2011; Knapp, et al, 2012; Gough, 2013; Miller and Whitehead, 2015; Allen and Miller, 2013; Marczak et al, 2019). Curry (2006:1) argues there is 'a paucity of long-term quantitative studies' that track the implementation of various levels of preventative programmes in social care, a viewpoint echoed by McLean et al (2019) in calling for longitudinal research into community business approaches, and Marczak et al (2019) in their exploratory study of prevention in social care, as used in six local authorities in England. The limited research evidence base can make it harder to argue the positive value of certain types of preventative services and approaches, a point made by Miller and Whitehead (2015: 1). It can also unintendedly funnel prevention investment in areas where there is a recognised evidence base, at the expense of more long term and upstream approaches (Marczak et al, 2019), as well as limit understanding on the conditions under which certain approaches work best. Knapp, et al, (2012) illustrate how this evidence can be obtained, as shown in the earlier discussion of their simulation of cost benefits for community capital programmes.

Yet this narrative about the lack of evidence masks some of the complexities in this area. Stagner and Lansing (2009) unpack some of the dilemmas in what can be seen as an 'evidence deficit'. Assessing prevention requires a long-term perspective and consistent interventions over time. This is due to the long term impact of prevention in dynamic social contexts. The social conditions and behaviours that preventative social care seek to change and modify are complex and not static; they are shaped by contextual factors (social, economic, cultural, health, demographic factors and policy and practice contexts).

Furthermore, an additional complexity is the definitional contestation noted above; the evidence base and the methods for establishing and interpreting the evidence about prevention, hinge on what is meant by prevention, and what the investment in prevention is seeking to change, reduce or stop (Kerslake, 2011). The goal of the preventative intervention will have implications for how it is funded, evaluated and against what criteria (Kerslake, 2011). It can be hard to compare across evaluations. Curry (2006: 1) notes: 'a small number of research papers have included quantified cost effectiveness information but this is often only for small scale studies and not comparable with other evaluations'. Similarly, Kerslake (2011:4) writes 'much of what has been described as prevention has also either not used the evidence available to design preventative approaches or has not delivered replicable results'.

Allen and Miller (2013) in work on prevention services, social care and older people suggest:

> *The type, approach and depth of evidence gathering vary considerably between LAs and interventions and this makes it difficult to combine this information meaningfully with formal research studies. Having a similar approach to setting and reviewing outcomes would enable collation and comparison of evidence. (2013: 1)*

Shapiro and colleagues (2013), from the perspective of prevention in youth health and well-being, argue there is a scientific evidence base about preventative interventions, but one of the dilemmas is how to best get that evidence into practice at the time, and in a way it can inform intervention choice, design and the allocation of funds. It is also the case that there is evidence available about preventative social care from lived experience and practitioner wisdom, and that this is valued differently to research evidence generated from empirical studies or through systematic evidence reviews. A fundamental point for any discussion about the evidence for and about prevention, and one made by many authors is that it is difficult to measure and evidence what did not take place because it was prevented (Allen and Glasby, 2010: 33), As Allen and Miller (2013: 2) write, there are challenges to gather evidence 'about what would have happened without the intervention'. These dilemmas are part of the conceptual puzzles to unravel in the work of establishing a robust evidence base in preventative social care.

Notwithstanding the above dilemmas, there are contemporary examples of evaluations and research contributing to the evidence base about prevention in social care. Miller and Whitehead (2015: 5) report on Community Team Plus (Stoke-on-Trent) who have developed a preventive programme and a parallel evaluation process. As they write, this evaluation framework developed by the Community Team Plus initiative '…has three tiers – Individual Outcomes & Economics, Demand, Capacity & Capability, and Strategic Impact Measures (i.e. how does the model compare with the other teams and what would be the costs and benefits of extending it wider' (2015:4). As well, there is a growing body of evidence about the community business market, which includes social care initiatives such as community hubs and social enterprises providing care support for community members (see for example work commissioned by Power to Change). We discuss some of the findings about community businesses in a later section of this review on prevention.

There are also propositions about how to better use existing routinely collected data to understand the effectiveness and impact of preventive interventions. Emerson et al (2011:16) suggest there is a way to build this evidence base by '…estimating some of these costs and benefits using information from a combination of undertaking new systematic reviews and re-analysis of evaluation data that are or could be made accessible'. Shapiro at al's (2013) work is instructive here. They conducted a community-randomized trial of a programme called Communities That Care (CTC), a "prevention service delivery system" that combines the use of evidence and stakeholder consensus for prevention planning" (2013:2). They were interested in knowing if this model for the diffusion and uptake of scientific knowledge of prevention interventions, made a difference to what happened in practice. The community-randomized controlled trial of CTCs showed that at 1.5 years into the programme, leaders within the CTC communities were using scientific evidence more than leaders from control groups, although this usage varied across the CTC communities. Of interest is the value of such a deliberate mechanism -in this case CTCs-to support the translation of scientific evidence about effective preventative interventions into practice use.

PREVENTION APPROACHES IN SOCIAL CARE

The range of preventative approaches outlined in *The Social Services and Well-Being (Wales) Act 2014* mirror types of tertiary and secondary approaches we read in the literature on prevention in social care. Smith (2018) writes that preventative approaches and practices might include 'person-centred and community-led social care'. Local conditions, needs and policy contexts and decision making practices and funding constraints shape these initiatives (Richards, Vascott, Blandon & Manger, 2018a, 2018b, 2018c; Miller and Whitehead, 2015; Marczak et al, 2019). Emerson et al (201: 2) writing about prevention and social care for adults with learning disabilities, convey how the prevention approach will vary depending on the needs that have been identified and what change or support can help. They delineate further levels of prevention within the three-tiered framework raised earlier; universal strategies, selective strategies and indicated strategies

There are a range of preventative initiatives or social care interventions designed with the purpose to support and be responsive to individual needs. These include re-enablement programmes, services that provide information, advice and assistance, technology-based interventions, falls prevention, and what is described as 'self-directed support' (Allen and Miller, 2013; SCIE, 2019). These are underpinned by different theories, for instance ideas about how to maintain independence, promote empowerment, social connectedness and reduce isolation.

The focus on diverse community development and community-based approaches is highlighted by Miller and Whitehead (2015:6) in their analysis of 6 case studies of prevention in social care. They report that the initiatives they reviewed could be divided into three types or mechanisms:

> *…in-house specialist community development services which work alongside general care management teams; changing the overall care management model to incorporate community-based approaches; facilitating third sector organisations to develop and co-ordinate the new approach through commissioning or partnership arrangements.* (2015: 6)

The approaches in use are based in various theoretical perspectives about change and levels of change, the determinants of conditions to be prevented, approaches for meeting needs and engagement. Many contemporary initiatives draw on ‘strengths perspectives’, and relationship-based approaches, for example social work and community development approaches like Assets Based Community Development (ABCD), and it is common to read theoretical ideas about social capital informing preventative interventions (e.g. Public Health England, 2015; Foot & Hopkins, 2010; Kern & Holman, 2017). Principles of ‘voice and control’ and ‘co-production’ also inform prevention in social care, as is noted elsewhere in this literature review.

There are many contemporary examples of these community based preventative interventions. One example is the growth in social businesses meeting social goals; this is a distinctive area of preventative social care. Richards et al (2018c) undertook research in England on what works in community business. They define community businesses as follows:

> *Community businesses are usually established by local communities in order to meet a local need, whether that is to revive local assets, protect the services that local people rely on, or address local needs. (2018c: 3)*

Commissioned by the organisation ‘Power to Change’ Richards et al focused on community businesses in the sectors of ‘community hubs, health and well-being, and sports and leisure’ (2018c: 1). Using the methods of desk-based review, an online survey responded to by 126 community businesses and in-depth case studies with 15 community businesses, they explored what made these community businesses work, and how they managed in the face of barriers.

Their desk top review identified examples where community businesses had contributed to positive developments within communities and importantly, the range of initiatives that falls under this heading. They write these businesses include, ‘social enterprises, community interest companies, community benefit societies, social co-operatives and charitable trusts’ (2018c:13). The research evidence showed that community businesses did well when they had financial self-sustainability, strong engagement with volunteers and community roots, the right skill set amongst staff and local people involved in the community business. It was also related to the strength of the links between the community businesses with others (2018c:2). For instance, in their report on case studies on community hubs, the research team emphasises the importance of close links between what a community hub does and the local need it is trying to serve.

> *A common enabler of success reported by community hubs is the importance of maintaining a focus on the specific needs of the community it serves. Community hubs report that to achieve this, ensuring regular engagement with the local community is key. Many community hubs also report that this engagement is also the key source of gathering of information regarding the demand for services. (Richards et al, 2018b:7)*

Several studies and reports similarly highlight the need for social enterprises or community businesses to react to their specific local contexts (Think Local Act Personal, 2016; 2017; Public Health England, 2015; Munoz et al, 2015; Institute for Voluntary Action Research, 2018). SCIE (2019) in a briefing paper on promising models for community based social care in the Northern Ireland context, highlight the possibilities and potential for these models to meet local needs in the context of care systems under pressure. They couch this potential in financial terms and cost savings, capacity for older people to stay in their own homes and reduced visits to GPs and hospitals. One of the models they describe is called CLARE (Creative Local Action, Responses and Engagement). CLARE features an integrated set of practices to support the older person in their local community and family context. These practices include community social workers working from a strength's perspective and co-productively with the older person, Community Champion volunteers, and close links with health providers and other community services. Evaluation data from 2017 '…reported 67 per cent of its clients said they felt increased feelings of positivity' (2019:5).

The authors also suggest that there needs to be change in commissioning processes to realise these potential gains and support the scaling up of these sorts of prevention and early intervention approaches. These changes include more evaluation tools to measure the process, impact and outcomes of this work, mechanisms to support the cross fertilisation of good ideas and practices and clear expectations from commissioners. On the latter point they write: 'Commissioners should pay care and support providers on the basis that they improve resilience, independence, self-care and social connections' (2019:15).

KEY THEMES

In summary, there are common and key themes or messages which emerge from this review of literature:

- Prevention is inextricably linked to co-production, voice and control and multiagency working.
- Definitions of prevention in social care are contested, and concepts can be loosely applied. There are a range of preventative social care services and approaches that span levels of prevention (primary, secondary, and tertiary prevention), and focus areas (individual - community -structural). Some writers argue that there is less attention to upstream prevention in social care.
- Across these levels of prevention there will be interventions of a longer term, future orientation (e.g. upstream community and structural approaches) as well as those concentrated on shorter term approaches closer to the immediate social care needs of people, families and communities. There is an argument for both approaches to operate concurrently.
- Prevention can be implemented for many reasons. These include a belief in the right to and power of prevention based in social justice principles and/or a view that prevention is a way to save money and stop the demand for and use of more expensive services, such as tertiary health care. These agendas do not have to be mutually exclusive.
- 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.
- The scientific evidence base for prevention in social care is 'underdeveloped', and where there is evidence it can be underused in practice. Gathering evidence is complicated because

of the innate purpose of prevention (i.e. to stop something), long term tail, matters to do with meaningful comparisons across interventions and localities, and lack of quality studies.

- There are a range of sources of evidence for the effectiveness, and impact of preventative social care (lived experience, practitioner wisdom, and scientific evidence).
- 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.

CO-PRODUCTION

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

DEFINING CO-PRODUCTION – A SLIPPERY FISH

The literature selected for this section of the co-production theme allows us to track the definition of co-production across a number of different areas in which co-productive approaches have been applied. It is important to recognise that these definitions themselves are to some extent contested, and so what counts as co-production is by no means a matter of simple consensus. This reflects the fact that this is both a relatively young field of academic inquiry, and a tangled one: co-production has been approached from a wide range of academic disciplines, and put into practice within diverse public service settings. These settings themselves often sit at the intersection between quite different areas of policy influence, professional expertise, and public involvement.

Across the sources covered in this literature review, there is significant variation in ways which reflect these factors. Some sources discuss projects which would not count as co-production from other points of view (so even if the project in question is successful, this may not mean that it is accurately described as successful *co-production*). Some may refer to projects which clearly count as co-production *in principle*, but are not necessarily 'panning out' in co-productive ways. And some cover projects which are *not* 'officially' labelled as co-production, but in fact can be argued to be successful examples of it in action.

Towards a working definition

For the purposes of this literature review, we frame the definition of co-production in line with how it is presented within the Social Services and Well-being (Wales) Act 2014. This legislation places a duty on Health Boards and Local Authorities to promote the well-being of citizens and communities. The Codes of Practice (cf. pages 48 to 80) for Part 2 of the Act explain that 'essential to fulfilling this duty will be an approach which is based on co-production principles'. This approach is defined as one which:

- 'Recognises people as assets, and as having a positive contribution to make to the design and operation of services.
- Supports and empowers people to get involved with the design and operation of services.
- Empowers people to take responsibility for, and contribute to, their own well-being.
- Ensures practitioners work in partnership with people to achieve personal outcomes at an individual and service level.
- Involves people in designing outcomes for services'

The Codes also say: 'People must be involved in the design and delivery of services'. The Act thus effectively treats each of these features as a necessary condition for an approach or practice to count as 'co-production'. It then specifies a series of goals and requirements, which can be taken as means by which to achieve those conditions:

- ‘Local authorities must ensure that providers from whom they commission or procure services encourage and enable the involvement of all people in designing the shape of services and how they will operate to deliver personal outcomes, and that providers involve people in evaluation and review’.

And:

- ‘Part of the duty to promote (well-being) means putting robust arrangements in place for encouraging the involvement of people. This means focusing on outcomes, rather than processes and outputs, in order that organisations and arrangements are designed with, and led, by people who need care and support, and carers who need support. This means at an individual, organisational and strategic level’.

And:

- ‘The principles and practices of co-production are intended to build the local core economy of people exchanging their skills, interests and time. They will help to shift the emphasis towards support which is created through the shared interests and common commitment of people with an investment in it. Social enterprises, co-operatives, user led services and third sector organisations lend themselves well to applying co-production principles because they are often democratic, membership organisations’.

And:

- ‘Local authorities should assess and ensure that services meet people’s personal outcomes and, where possible, provide added value. Social enterprises, cooperative organisations, co-operative arrangements, user led services and the third sector often conduct activities which are deemed to add value to society; for example, through the employment of local people in delivering the service’.

And: ‘Local authorities must:

- Put in place transparent arrangements where people are equal partners in designing and operating services.
- Ensure these arrangements comprise of local and regional panels of commissioners, citizens and providers, working together to shape services that meet the needs of people who need care and support.
- Report on what they are doing to support co-production in the Director’s Annual Report’.

This presents an account of co-production that qualifies and in some senses goes beyond the influential brief definition given by the New Economics Foundation (Harris and Boyle 2009):

> *‘Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and neighbours’.*

As stated in a review of co-production for Welsh Government (Bovaird and Loeffler 2014), if such a definition is taken literally, then there is virtually no co-production anywhere, since ‘equal and reciprocal’ relationships are rare. The review also questions the focus on ‘co-delivery’ and suggests that the concept needs to include the co-commissioning of services; the co-design of services; the co-delivery of services and the co-assessment of services in monitoring and evaluation. As a result of the authors propose an alternative, less categorical and more inclusive definition of co-production where it is framed as a matter of degree:

'Public services, professionals and citizens making better use of each other's assets, resources and contributions to achieve better outcomes or improved efficiency' (Bovaird and Loeffler 2012: 1121).

Taking this as a working definition, we now consider some of the key challenges in creating the right organisational environment for co-production.

CREATING THE RIGHT ORGANISATIONAL ENVIRONMENT FOR CO-PRODUCTION

This richer and more inclusive definition of co-production may warm the heart, but even with the bar placed less high there are significant concerns about the feasibility of making co-production a meaningful reality, due to many interdependent and multi-faceted factors in public service planning and delivery (Sicilia et al 2016). These authors point out that the cycle of public services is often not covered by a single organisation, rather:

> *'…intersecting organisations located at different institutional levels are responsible for the provision of public services. In this context, decisions regarding the service (planning, design, delivery and evaluation) might be shared between organisations intertwined vertically and/or horizontally' (Sicilia et al 2016: 10)*

Within complex adaptive systems, such as public services, a lot of worthwhile and fruitful 'co-production' effort in one part, can easily be thwarted by conflicting processes within other parts of the system (McMillan 2008). With this in mind, a range of authors identify key themes and issues to be explored and addressed. We summarise these here as a series of separate, but sometimes overlapping, challenges.

The challenge of co-production to traditional approaches to planning and evaluation

Eoyang and Oakden (2016) discuss the definition of co-production across evaluation practice. They suggest that a synergy between complexity theory and evaluation practice may help to improve on traditional models of evaluation. They identify that a challenge with traditional evaluation practice is that 'traditional evaluation designs assume a high level of predictability and control' and that the problem with this is that 'complex programs or contexts challenge this basic assumption (of predictability).' (Eoyang and Oakden, 2016: 1). The authors suggest that an adaptive approach to evaluation is needed to successfully evaluate complex programmes or contexts and recommend Adaptive Actions as a process to improve evaluation performance over time. They explore the synergy that they have identified between complexity theory and evaluation practice, using the theoretical approach of human system dynamics and a case study of a complex program of social change. They develop theoretical foundations for a new approach to evaluations in complex environments.

Statutory organisations in Wales have for many years applied approaches to planning and evaluation that are built on methods such as Prince 2 and Results Based Accountability. Whilst such methods have their place, it is increasingly recognised that in complex adaptive system, such as social care and health services and community development, such methods are not fit for purpose (Auspos and Cabaj 2014). What is required is something much more sophisticated.

The challenge of building trust in co-production

Having defined co-production, there is a need to move beyond 'apple pie' rhetoric, towards making it a reality in practice. This requires an understanding of the conditions required for it to be put into practice – such as a certain degree of 'trust' between parties. Whilst acknowledging notable success in building trust between statutory organisations and the public, the overall track record paints a more prevailing picture that is somewhat counter to this, as demonstrated in the rise of user-led organisations that feel they have to collectively *challenge*, rather than *trust* statutory organisations (Beresford 2013).

Fledderus et al (2014) explore the theoretical foundations for the prevalent idea that co-production of public services fosters trust with public services clients. They suggest that there is 'insufficient research' to prove the assumption that co-production of public services fosters trust with service users. Their article provides theoretical insights into the relationship between co-production and trust. Claiming that 'co-production relates to identification-based trust,' they go on to identify the important theoretical mechanisms that link the two concepts – 'increasing self-efficacy and the creation of trust networks' (Fledderus et al 2014: 430). The authors suggest that 'a third step is to move towards a more contingent perspective,' in order to further build the connection between trust and co-production and identify the conditions needed in service development to building this relationship between the two concepts of trust and co-production.

One approach to building trust through the development of interdependent well-being in health and social care services is the development of relationship-centred care and 'enriched environments' of care and support (Nolan et al 2006). Within such environments, service users, family carers and practitioners all achieve a sense of security, continuity, belonging, purpose, achievement and significance.

The challenge of creating meaningful dialogue in co-production

However defined, trust rests on a certain quality of communication and dialogue between the participants concerned – another factor treated as a necessary condition for co-production to be successfully enacted. It must be grounded in 'relational and responsive' rather than excessively bureaucratic and procedural approaches to planning and performance (Patterson et al 2011) and 'human-centred' approaches to learning and development (Lowe and Plimmer 2019).

This requires a clear and consistent understanding and use of dialogue, which goes beyond just talking together, to become a caring, relationship-building and values-driven activity (Higham et al 2015). An example of values-driven and dialogic co-production can be seen the application of the *Index for Inclusion* in schools development, which centres on the fundamental question 'How can we live well together?' (Booth and Ainslow 2016). Escobar (2011) discusses the importance of defining the term 'dialogue' in the context of public engagement. He suggests that the term dialogue has become synonymous with so many different meanings (such as conversation, consultation, participation, dissemination, etc.) that 'there is a risk that it may end up meaning nothing at all'. Escobar (2011: 6) aims to 'introduce a summarised, communication-focussed view of various approaches to public dialogue and deliberation,' in an effort to bring together ideas and conceptualisations of public dialogue and use in them in meaningful public engagement.

There is increasing recognition of the central role of dialogue in the development of highly effective organisations that promote 'collective genius' (Hill at al 2014). Research in psychology, linguistics and neuroscience now encourages the view that human intelligence is distinctively collective and that language has evolved to enable collective thinking. We do not only use language to interact, we use it to 'interthink' (Littleton & Mercer, 2013). Contrary to popular beliefs about lone geniuses, it is increasingly accepted that many of the major achievements of humankind have resulted from effective collaboration and communication in small groups. Yet poor communication in workplace teams is common (Edwards 2012, Andrews et al 2015).

The Wales School for Social Care Research has been supporting statutory and third sector organisations in applying practical techniques to encourage dialogue-learning and development (Andrews et al 2020), including the use of techniques such as Community of Enquiry (Lipman 2003) and Most Significant Change (Davies and Dart 2005).

The challenge of seeing people as equals and sharing power in co-production

Co-production also involves assumptions about 'what counts and knowledge and whose knowledge counts?' (Hodgson and Canvin 2005) and brings into question where power lies in decision-making. This demands the scrutiny and challenge of prevailing discourses such as how society perceives older people, who are 'are not generally recognised as co-creators of knowledge, learning and development but as passive recipients of care, or objects of research' (Andrews et al 2020). Likewise, the voice of children is often missing in child safeguarding decision making and recording (Wilkins et al 2016).

Disempowering discourses of people supported by social care services (including children and adults) are reinforced by how 'expert' knowledge is reinforced through educational institutions – and particularly, through how research happens. In contrast to valuing and including everyone's knowledge through 'interthink', Hall and Tandon (2017: 3) discuss the concept of 'epistemicide', which they define as 'the killing of other knowledge systems'. They contend that 'higher education institutions today are working with a very small part of the extensive and diverse knowledge systems in the world' and attempt to illustrate how 'Western knowledge has been engaged in 'epistemicide' (Hall and Tandon 2017: 1). The authors discuss ways to deal with this, through community-based participatory research, which they suggest is 'about the rendering visible of the excluded knowledges of our remarkable planet'. They discuss 'theoretical dimensions of knowledge democracy,' (Hall and Tandon, 2017: 2) and the ways in which the evolution of community-based participatory research can help deal with the epistemicide they identify.

The challenge of avoiding 'stand-alone' co-production

There is a recurring focus on the relationship between co-production and 'neighbouring' concepts such as collaboration, and consultation – and the importance of the boundaries between these.

Sancino and Jacklin-Jarvis (2016) offer a critical analysis of the concepts of co-production and inter-organisational collaboration, with specific reference to public services. They offer 'emergent conceptualisations of the relationships between them' and use case-studies to illustrate these relationships between the two concepts. They attempt to 'assert the importance of both distinguishing between co-production and inter-organisational collaboration and more clearly articulating the relationships between the two' (Sancino and Jacklin-Jarvis 2016: 14).

Further relationships between co-production and other concepts are discussed in Tuurnas et al (2014), where they outline the relationship between network management and co-production with complexity sciences. They argue that these approaches have not previously been connected in existing research literature, and that 'this conceptual framework offers new insights for analysing the challenges of co-production in complex network settings in the local public services'. The authors present a case study of a 'multi-professional service network producing social and health care services for youth,' in Finland (Tuurnas et al 2014: 4). The clients in this case study needed support from multiple services simultaneously. Findings indicate 'that the outcomes of the service process are not only dependent on the client's needs, but rather on organizational and professional interests' (Tuurnas et al 2014: 10). They suggest that their research 'gives new insights for the discussion on co-production,' particularly in relation to the improvement and delivery of public services.

One approach to service developments in Wales that brings together the concepts of co-production and professional and interagency collaboration is embodied in place-based initiatives such as the Raglan Project in Monmouthshire (a local authority home care service) and the Buurtzorg community nursing pilots. Relationships, trust and the freedom to self-organise are central to such initiatives. This enables them to engage in co-production in a way that is much more difficult for large regional transformation initiatives.

The challenge of engaging hearts and minds in co-production

The relationship between processes of co-production and their outcomes is significant. Whilst the term co-production can itself sound quite mechanistic and process focused, Huss (2018: 78) analyses the ways in which art mechanisms can be used to help *'co-produce knowledge between service users, social workers and policy makers'*, in ways that are deeply human and engage both the heart and the mind. Their case study focused on images of a group of marginalised Bedouin women in Israel. They suggest that 'the arts can enable a space to reflect, to give concrete shape and to discuss and explore new meanings of an issue, for both 'sides' of the interaction together'. The article refers to implications of conceptualising the relationship between social work and the arts and humanities as a way to enhance social workers' skills'. On this subject, Andrews and Beer (2019) outline the powerful role of an arts-based approach to the involvement of a person with dementia in co-production.

The challenge of understanding the outcomes of co-production

Whilst clearly a heart-warming concept, it is important that we do not assume that co-production is inherently beneficial, or that everything that emerges from co-production is constructive by definition, or in a uniform way. As one of the founding fathers of co-production points out, it requires the coming together of people with diverse and sometimes conflicting priorities, which can be 'painful' (Cahn 2000)

There may be risks in assuming that co-production can by itself solve existing problems to do with how such organisations function, given the inevitable complexity of the factors in play in any practice setting. Puustinen et al (2012: 2) critique the conceptualisation of co-production as a purely positive 'silver bullet' for governments and public services and suggest that 'that with co-production comes something unintended and unexpected that should be examined closely'. They use a complexity lens to focus on dilemmas introduced by co-production across politics, ethics, economics, culture and managerial practice.

It is therefore very important to understand the impact of co-production on people and services across Wales. As would be expected, there are lines of debate on what kinds of evidence are most appropriate to the understanding and evaluation of co-productive projects. Voorberg et al (2015: 1346) conducted a systematic review of co-creation and co-production with citizens in public innovation. Their review analysed '(a) the objectives of co-creation and co-production, (b) its influential factors and (c) the outcomes of co-creation and co-production processes'. Findings identified that 'most studies focus on the identification of influential factors, while hardly any attention is paid to the outcomes,' and suggest that further studies should focus on outcomes, and that more quantitative research would be welcome in this field, as it is broadly dominated by qualitative, case study research. Whether or not this reflects any assumption that quantitative data is by its nature better fitted to the assessment of outcomes (which will be disputed by others), the point remains that the amount of quantitative work in this area is comparatively small.

Within Wales, the IMPACT study is planning to gain further insight into the outcomes of co-production using Most Significant Change methodology which encourages the identification of both positive and negative changes including unintended outcomes.

FIVE DOMAINS OF STUDY

Having identified some of the underlying complex themes and challenges regarding the conception and definition of co-production, the following section explores them at the five levels that have been selected as a framework for the IMPACT evaluation study.

Individual

Co-production at an individual level should be the most straight forwarded and is consistent with the approach to assessment, care and support planning under the Act, which promotes voice and control and building on people's strengths. However, these priorities are often regarded as running against the grain of those embedded in managerialist and resource-driven approaches to practice (Parry-Jones and Soulsby 2001), the influences of which over the past three decades will not be easily overcome (Miller and Barrie 2016). Miller and Barrie (2016) refer to the Exchange Model of Assessment (Smale et al 1993) which represents the importance of negotiating different perspectives, with particular emphasis on including the perspective of those using services to agree outcomes and actions. This model of assessment has been found to be extremely helpful in highlighting the importance working with the individual to identify outcomes important to them and bring together the views of all those involved. Social Care Wales are currently taking this work forward through their 'collaborative communication' training programme and their person outcomes focused practice work programme (Social Care Wales).

Whilst power sharing with individuals is a key feature of co-production, this is likely to be compromised within social care services that have safeguarding duties and responsibilities, and a history of risk aversion, in part due to the consequences when things go wrong (Munroe 2011). In dementia care, Clarke et al (2011) refer to 'contested territories' of everyday life (e.g. going out). They suggest that decision making in relation to these territories is all too often driven by professionals or families, without due regard to the views of the person with dementia. This makes genuine co-production challenging. This issue is common in other service areas including learning disability, mental health and child protection.

In this vein, Beresford identifies barriers and obstructions to co-production for certain groups and individuals in his report for Shaping Our Lives in 2013. He suggests that 'some groups face many more barriers than others getting involved and this reinforces the difficulties that they may face and excludes their important perspectives from consideration'). Within his report he explores why 'some groups tend to be left out in this way and how they may be fully and equally included in the future,' (Beresford, 2013: 7) and suggests that some groups, particularly from minorities, 'often experience generally inferior access to and support from services'. Beresford (2013: 7) also suggests that these same groups 'are likely to have inferior opportunities to get involved in schemes to strengthen their voice'. As part of the research for this report, researchers worked with four local user controlled organisations, collecting qualitative data via interviews and group discussions, on how best to support those excluded from co-producing services and re-assert their voice in this dynamic.

Budge et al (2018) use participatory methods to explore participants' experiences of The Bridge Collective (a peer-led mental health organisation), and its democratic processes. Using thematic analysis to identify the ways in which the democratic processes of The Bridge Collective 'both nurtured and challenged participants' wellbeing,' (Budge et al, 2018). The authors identified three main themes– negotiating relationships, feeling the responsibility of involvement, and sharing power. Their findings 'identify the value of democratic processes in enabling meaningful social support and empowerment', and also identify the challenges of inclusion and workload management in participatory democracy.

Family and Carers

This section reviews the literature identified in the co-production theme relevant to family and carers. This may refer to the ways in which – for example – family carers are actively incorporated into co-productive practices and projects. It may also cover how the relationships between family members, or caregivers and care-receivers, affect how care-receivers themselves, or less-visible family members such as children, might be involved in those projects. Andrews et al (2009) conducted research with the All Together Now initiative in Swansea, South Wales, on using a collaborative and relationship-centred approach to improving assessment and care management with older people. They suggested that ‘the need for more holistic and inclusive approaches to assessment and care management for older people is widely promoted but difficult to achieve’. The All Together Now initiative attempts to promote improved practice in assessment and care-management ‘by actively involving all stakeholders, older people and family carers, and practitioners and service providers from across the statutory and third sectors’. This paper describes how a relationship-centred approach combined with co-productive input from stakeholders was used to develop the goals for the All Together Now initiative, as well as outlining the proposed evaluation model.

Percy-Smith and Dalrymple (2018: 220) used an innovative research concept known as the ‘river of experience’ to analyse co-production approaches for children on the edge of care. Their research highlights the ‘gap between assumptions and practices of child and family services and the realities and needs of children and families’. The paper formulates questions in order to challenge statutory services on these disjunctions. They ask ‘why, in spite of serial involvement of professionals, do children still end up in the care system’. Finally, the paper argues ‘for a different approach to responding to families facing difficulties involving human centred, holistic family support and a more reflexive and relational approach to professional practice’.

Bradley (2014) provides an outline and description of existing literature on co-production within mental health care in the UK. Bradley debates ‘the cultural and ideological shift required for staff, service users and family members to undertake co-produced care and outlines challenges ahead with respect to service redesign and new roles in practice’. He concluded that ‘informal carers (family and friends) are recognised as a fundamental resource for mental health service provision, as well as a rich source of expertise through experience, yet their views are rarely solicited by mental health professionals or taken into account during decision making’ (Bradley 2014: 233).

Cree et al (2015) explored carer’s experiences of involvement in the care planning process for people with severe mental illness. Despite formal recognition and involvement of carers in mental health services, and identifying a desire to be involved, results highlighted that many carers felt a lack of involvement in the care planning process. Furthermore, they felt a lack of recognition and appreciation of their role from health professionals. Barriers preventing involvement included structural (timing and location of meetings), cultural (relating to power imbalances within the system), and specific barriers relating to confidentiality.

Whilst the involvement of carers and families in co-production is vitally important, for it to qualify *as* co-production this must not be done in such a way as to undermine the agency of the people they support. This has been a particular issue in disabled children’s’ services, where over-protective parenting practice can result in long-term harm (Sanders 2006). This issue brings us back to the importance of the Exchange Model of Assessment (Smale et al 1993) at an individual level.

Community

This section focuses on literature discusses co-production alongside aspects of community. Here, a key theme is the co-existence of various kinds of organisations and influences on how co-production takes place – from the statutory, to the commercial, to the voluntary. Doran and Buffel (2018) discuss the development of age-friendly initiatives, and the extent to which older people can be involved in co-producing these initiatives. The Translating Research into Action project worked with a number of older co-researchers, to analyse whether they felt their neighbourhood was age-friendly and found that 'physical and social issues were found to be contingent on each other and mutually reinforcing, and should therefore not be considered in isolation'. However, findings 'highlighted physical environmental issues as a major concern; transport was a dominant overarching theme'. Their article demonstrates the issues facing older people being involved in co-producing age friendly initiatives.

Kleinhans (2017) writes about how Dutch community enterprises work in the context of co-production and austerity measures. Suggesting that 'entrepreneurial forms of active citizenship are considered as a new form of public management to fill gaps left by spending cuts and to continue neighbourhood regeneration' (Kleinhans 2017: 1500). Community enterprises have been set up to provide services and benefits to those in deprived areas. The article reveals a mixture of supportive responses, as well as resistance, from local governments. They suggest that 'within a positive policy discourse on co-production, institutional responses often encompass forms of 'counter-production' that hold CEs in full uncertainty about crucial conditions for their business' (Kleinhans 2017: 1500).

Within Wales, a number of small community-based organisations have come together under the banner of 'Small is Beautiful'. These organisations feel that the move towards regional commissioning is squeezing them out in favour of larger third sector organisations. They are calling for more voice, recognition of them as expert, not amateur, and supportive approaches to performance that allow for a contextual understanding of what good looks like.

Meerkerk et al (2018) explore similar themes in their article on the durability of community enterprises. They examine the interplay of four conditions in the durability of community enterprises – 'social capital, entrepreneurial community leadership, supportive relationships with institutional key players and a strong business model' (Meerkerk et al 2018: 653). Their main conclusion 'is that the presence of social capital, strong entrepreneurial leadership and a strong business model is the most important configuration leading to a durable CE' (Meerkerk et al 2018: 651).

Milsom (2018) explores the development of a new direction in the Cymru Older People's Alliance. This new direction is an attempt to adapt to the adverse impact of austerity on older people's engagement in Wales. They found that 'co-production, increased citizen engagement and promoting well-being are important new concepts in Welsh legislation' but that there needs to be supporting infrastructure that 'enables older people to represent their own interests'

Workforce

This section of the literature review focuses on articles surrounding the workforce and co-production. Here, crucial questions emerge surrounding the internal cultures and orientations of different professions, the readiness with which they might work with others, the ways their involvement in co-production might vary from one context to another, and the relationship between the imperatives of co-production and their established, perhaps habitual ways of working.

Andrews et al (2015) presented a report, published by the Joseph Rowntree Foundation, on developing evidence-enriched practice in health and social care with older people. The report summarised the lessons learned from 'an appreciative and collaborative approach to using a range of evidence in service and workforce development to promote a better life for older people, carers and the staff who support them,' (Andrews et al, 2015: 4). They conducted research with participants at six project sites in Wales and Scotland, looking at how they 'combined research from A Better Life and local, contextual evidence to make improvements in service and workforce development,' (Andrews et al, 2015: 4). They outlined 'the key elements that support and inhibit the use of evidence in service and workforce development' and looked at the well-being and learning outcomes of the project, as well as outlining the project costs and resources needed to sustain projects of a similar nature.

Gale et al (2018: 205) analysed co-production in the epidemiological clinic, exploring the tensions in community based, client-facing risk work. Focussing on the tensions inherent in policy narratives regarding public health risk, and co-production, they looked at co-produced data developed with health trainers in a deprived post-industrial region of England and used a decentred analysis to analyse this data. This was informed by theories of risk work developed by Habermas, to 'explore the extent to which elite narratives of public health risk are resisted, absorbed, or bracketed off by client-facing health workers'). They argued that 'co-production —albeit in a highly constrained form—is possible while delivering public health interventions'. However, they temper this finding by noting that in a community where health is negatively affected by wider social problems, and where lower status healthcare workers are in client facing roles, 'workers must find their own ways to negotiate and attempt to reconcile this context with the risk-framed practices they are required to carry out' (Gale et al 2018: 216).

Gunasekara et al (2017) explore the question 'what makes an excellent mental health doctor?' by integrating the experiences of service users with critical reflections of psychiatrists. The experiences and expectations of psychiatrists were explored in interviews with 22 service users. Findings were then contextualised in formal consultations with psychiatrists. They note that 'psychiatrists share service users' aspiration of equitable partnership' but that 'competing demands and 'professional boundaries' constrain engagement' (Gunasekara et al 2017: 1760). They found that 'consistent delivery of the person-centred, recovery-oriented care promoted by policy and sought by service users will require substantial revision of the structure and priorities of mental health services'. Again, the tensions between policy imperatives and workforce resources and constraints is apparent in this paper.

Schlappa and Imani (2012) presented a conference paper attempting to 'initiate a debate about the utility of the concept of co-production in developing a better understanding of contemporary challenges to leadership and management in the provision of public services'. They posited that 'leadership must be shared to some extent for co-production to take effect,' (Schlappa and Imani, 2012: 2) and also suggested that 'to develop models of leadership which reflect the nature of the co-production process, institutional concepts based on hybridity and blurred boundaries' are likely to provide a useful starting point.

Workforce challenges/enablers

Nandram and Koster (2014) describe the case of the Buurtzorg Nederland as a good practice example of integrated care, focussing in particular on the organizational aspects of its innovation. The authors used a case study of 38 interviews with staff, founder, co-founders, coaches, nurses, clients and a trainer and analysis of internal company reports. The authors suggest an integrated approach as the main explanation of the good practice at Buurtzorg rather than a focus on one single concept such as management structure, information and communication technology, community-based care or a patient focus. Buurtzorg's success lies in its over-riding focus on organizing care around the needs of the individual and its emphasis on putting the client at the centre.

O'Leary et al (2012) recognise that in all professional relationships, there are power imbalances and the potential for discrimination and exploitation; hence the concept of advocating professional boundaries. Focusing on social work relationships the authors acknowledge that historically, professional boundaries created in this profession have been influenced by other professions, most notably medicine. Integral to these traditional models are professional boundaries that separate the professional from the client and concentrate on what the boundary is, rather than why it is needed and how it is created. Consequently, professional boundaries within social work have become increasingly incongruent with developments in the profession's unique theoretical and value base. O'Leary et al (2012) examines professional boundaries and presents an alternative conceptualisation of boundaries in social work relationships; a model which emphasises connection rather than separation, advocating a process that encourages mutuality.

Care organisations

This section of the literature review focuses on papers concerned with care organisations and co-production. Allen et al (2018) focus on the tensions apparent in co-producing social care evaluations. They note that 'funding for care service research is increasingly subject to the satisfaction of two requirements: public involvement and adoption of validated outcome tools'. Their paper seeks to identify competing paradigms within these funding requirements, and 'reveals significant challenges faced by researchers who seek to satisfy them'. They explore the extent to which research studies can 'conduct high-quality public involvement and genuine co-production of knowledge, whilst attempting to produce quantifiable outcome scores'. Findings contribute to the debate on how to include diverse perspectives in research, and they also highlight 'constructive attempts by academic and co-researchers to make the combination of approaches work in the field'. Their conclusions 'foreground the importance of broader awareness of how tensions and power imbalances related to this combination of approaches play out in social policy research practice'.

Baines (2018) conducted a systematic review and critical interpretive synthesis on patient and public involvement in design, administration and evaluation of feedback tools in psychiatry. They sought to identify through this review the extent to which patient and public involvement (PPI) was present in the development, delivery and evaluation of PPI tools in psychiatry. They concluded that 'The majority of patient feedback tools are designed, administered and evaluated from the professional perspective only'. They identified a number of assumptions present in existing evaluation tools, including 'professional and patient agendas are synonymous; psychometric validation is indicative of patient acceptability; and psychiatric patients do not have the capacity or desire to be involved'. They suggest that 'Future patient feedback tools in any healthcare setting should be co-produced from the outset to ensure they are valued by all those involved'.

Bovaird and Loeffler (2012) explored the ways in which service users and communities contribute to outcomes and public value. They suggest that though there has been recent clamour and drive towards co-production in improving publicly valued outcomes, 'citizens are only willing to co-produce in a relatively narrow range of activities that are genuinely important to them and are keen that their co-production effort is not wasted by public agencies' (Bovaird and Loeffler 2012: 1136). They suggest that 'while offering potential significant improvements in outcomes, and cost savings, co-production is not resource-free'.

Freeman et al (2016) outlines research on working towards co-production in rehabilitation and recovery services. The paper presents an outline of a service provider, service user and carer group, set up to develop strategies for service user and carer co-production. They use a reflective narrative account to present the process of the formation of the group, as well as the development of a working model to shift towards more co-produced services. This model outlines three stages for services to work through in order to achieve meaningful and sustainable co-produced services. The article helps us to understand the benefits and challenges of using co-production in rehabilitation and recovery services.

Ellis (2017) looks at the ways in which universities can co-produce histories of mental health and learning disability with charities dealing with those issues. They note that 'a growth in the interest in public history and in the history of mental healthcare has offered new opportunities for those in the humanities to engage new audiences and to challenge perceptions about care in the past' (Ellis 2017: 92). They analyse the AHRC funded Heritage and Stigma project at the University of Huddersfield, which supports mental health and learning disability charities in 'the exploration and dissemination of their own histories'. The paper purports to provide 'evidence of an inclusive, co-productive model of design and highlights the positive contribution to communicating mental health made by those based in the humanities.'

Ford (2015) also examines co-production in a mental health setting, by examining the experiences of those patients who are compulsorily detained. They used a thematic analysis literature review alongside a lived-experience commentary of patients' experiences. The paper identifies three key themes – 'people's views on the justification of their compulsory detention; the power imbalance between patients and staff; and the lack of information or choice' (Ford 2015: 127). They explore in their discussion section 'the potential of co-production between people who access services, their supporters, and professionals to improve treatment for people who may need compulsory detention'. The paper 'contributes to the discussion on how services for people in crisis can be improved and raises important questions about current service provision and the legislation that underpins it'.

Harlock (2014) explores issues around performance management in the third sector, drawing on interviews with six adult social care commissioners across six different Local Authorities in England. The paper 'examines how social value – as a key dimension to outcomes-based commissioning – is being assessed and applied in commissioning processes with the third sector' (Harlock 2014: 1). The paper found that 'difficulties in quantifying and measuring social value posed considerable challenges to its implementation'. They also identified safeguarding pressures associated with vulnerable service users, alongside financial accountability imperatives, had a significant impact on commissioners evidence requirements. The paper concludes by arguing that 'the challenge of measuring and demonstrating social value is likely to fall to the third sector'.

Maurits et al (2018) conducted a survey investigating the attractiveness of people-centred and integrated Dutch home care. This survey was distributed to nurses to gauge their opinions on the attractiveness of this practice framework. They found that 'most home-care nurses (70% to 97%) and 36% to 76% of the hospital nurses regard the different aspects of people-centred, integrated home care as attractive' (Maurits et al 2018: 1). Home care nurses specifically found attractive the idea of 'promoting the patient's self-reliance and having a network in the community,' whereas hospital nurses were 'mainly attracted to health-related prevention and taking control in complex situations'. Their paper concludes that 'most home-care nurses and a minority of hospital nurses feel attracted to people-centred, integrated home care, irrespective of their educational level'.

McCarry et al (2018) discuss the potential for using co-production in developing violence against women services in Wales. The article draws on focus groups and interviews with fifty-three service users and thirty-one purposively selected service providers on this issue. They suggest that 'there are clear shared priorities and some tensions between service user and provider perspectives on appropriate services,' and argue that though there is a 'long history of intermediate co-production in VAW services,' there is now a need for 'co-production at the strategic level' in relation to violence against women services in Wales (McCarry et al 2018). They argue that strategic co-production would 'provide an arena for resolving tensions, setting standards and developing funding criteria to enable coproduced VAW policy and build resistance to funding cuts'.

Patterson et al (2011) discuss organisational culture change in relation to acute hospital care for older people. They note that staff assumptions and beliefs are central to understanding their patterns of behaviour. They further note that 'there is little evidence to underpin suppositions underlying the importance of culture for health care delivery and the dynamics of culture change programmes'. They also critique the fact that 'there are very few robust studies of cultural change initiatives and produced a nascent toolkit which they suggest 'provides a potentially useful way of empowering practitioners not only to better understand, but also to begin to change, the 'clinical micro-system'. They concluded that what is needed, in addition to the toolkit, is 'is an approach to culture change that translates our key findings from the complexities of a final report into a form that speaks to practitioners in a language that they can relate to and thereby see the potential of applying to their own situation'.

Pearson et al (2017) discuss the impact of the Scottish personalisation agenda in social care policy. The Social Care (Self-directed Support) Act 2013 (SDS act) 'marked a major shift in how social care is delivered and organized for both users and professionals across the country'. This shift emerged through the 'personalisation agenda' and self-directed support in social care. The article explores the reasons that 'SDS has yet to produce radical transformative change'. Their article highlights the challenges in promoting co-productive practice through policy initiatives, and they suggest that 'this has been compromised through SDS implementation'. They also argue that SDS has not brought about transformative change because it has 'been caught up in a policy overload and ultimately overshadowed by new legislation for health and social care integration'. Finally, they argue that 'the timing of SDS in a period of acute austerity in social care has resulted in disabled people being offered limited choice rather than increased opportunities for independent living'. This links back to some of the observations in previous literature on the restrictions to providing truly co-productive services in times of austerity.

Pilgrim (2018) explored co-production in involuntary psychiatric settings. They sought to explore whether the policy concept of co-production could be feasible in involuntary psychiatric settings. They listed the assumptions of co-production and used these 'as a basis for an immanent critique to test the feasibility described in the purpose of the paper'. This paper used a critical realist standpoint to explore these concepts and conduct analysis. They conclude that 'a distinction is made between the co-production of knowledge about mental health services and the actual co-production of those services. It is concluded that the former has emerged but the latter is not feasible, given the limitations on citizenship imposed by psychiatric detention'. They suggest that 'mental health legislation pre-empts confidence in the co-production of mental health services'. Again, the tension here between policy imperatives encouraging co-production, and the feasibility of implementing such policy drivers in a specific care setting, are apparent.

Thom and Burnside (2018) explore how co-production could be utilised in treating prisoners with mental health issues in New Zealand. They explore how co-production has been 'conceptualized and used in criminal justice systems internationally' and offer 'an experiential account of our first steps into co-production both in service delivery and research'. They conclude by 'proposing a way forward to expand partnerships between those who have experience-based expertise and researchers within the criminal justice context, offering a small- and large-scale project as potential examples of what co-production may look like in this space' (Thom and Burnside 2018: 1258).

Vaeggemose et al (2017: 122) explored the co-production of community mental health services in Denmark and highlight the tension apparent in public services and civil society discourses and imperatives. They suggest that 'these challenges are typically encountered by provider organisations and their staff who must convert policies and strategies into practice'. They aimed to investigate 'how provider organisations and their staff navigate between the two logics'. They conducted critical case studies of two municipalities using the Community Families programme, 'which aim to support the social network of mental health users by offering regular contact with selected private families/individuals' (Vaeggemose et al 2017: 122). Their findings 'confirm the central role played by staff and identify a close interplay between public services and civil society logics as essential for the organisation of co-production'. They suggest that if organised in the right way, 'co-production can succeed even in a mental health setting associated with social stigma and in a welfare state dominated by public services'.

Wharne (2015) explores the potential and restrictions on co-productive practice within enforced psychiatric treatment. Using a hermeneutic phenomenological approach, they collected qualitative data from two sources: a social worker and a psychosis patient. In their findings, both individuals 'report that their choices are limited by mental health law' and both experience themselves as passive. Wharne observed that the patient 'rejects society and withdraws to avoid stress; while the Social Worker just follows legal guidelines. Interaction in mental healthcare is experienced as lacking trust, involving threat, but sometimes negotiation is possible' (Wharne 2015: 256). They state that 'Psychosis is not experienced as a separate illness process and control is exercised over the person rather than that illness'.

CROSS-CUTTING ISSUES AND THEMES

Across the literature reviewed in this section, there are a number of emergent and recurring themes, and salient points of debate. Here, we summarise these by way of two main headings:

A. Organisational strategy
B. Participation

Under each heading, we identify (1) key issues to tackle; (2) key changes required, and (3) key aspects of learning which may facilitate such changes. We have provided indicative references for each item.

A. Organisational strategy

Key issues to tackle

- Possible incompatibilities between the requirements of co-production, and dominant managerial approaches (Parry-Jones and Soulsby 2001, Keinhans 2017)
- Understanding what makes co-productive enterprises and projects sustainable (Denbighshire Voluntary Services Council (DVSC) 2018; Meerkerk 2018)
- The navigation of power-sharing in particularly sensitive services, e.g. those where safeguarding duties are paramount. (Munroe 2011; Clarke et al 2011)
- Tensions between
  - policy imperatives and organisational/workplace constraints (Gunasakera et al 2017; Pearson et al 2017; Pilgrim 2018; Thom and 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)
  - service-centred and wider social imperatives (Vaeggemose et al 2017)

- Gauging the savings and costs involved in transition to co-production, and the value added (Bovaird and Loeffler 2012; Harlock 2014)

Key changes required

- Cultural shifts in order to allow for genuine co-production at each stage of a process (Bradley 2015; Patterson et al 2011)
- Adaptation to the ongoing legacies of spending cuts affecting relevant services (Keinhans 2017; Pearson et al 2017; Milson 2018)
- New forms of public management conducive to co-production (Keinhans 2017)
- Revision of priorities of some 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)

Key aspects of learning to facilitate change

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

B. Participation

Key issues to tackle

- Uneven barriers to participation (structural, cultural, relating to specific areas of practice) faced by 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 people supported by a service (Sanders 2006; Smale et al 1993)
- Barriers to participation posed by factors beyond a service's control, e.g. transport infrastructure (Doran and Buffel 2018)
- Risks around overlooking some forms of organisation, e.g. smaller ones (DVSC 2018)

Key changes required

- Finding workable holistic and inclusive approaches which genuinely accommodate all parties – e.g. service-users and service providers (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 the full range of groups (Milson 2018)

- Finding ways of working with or around risk-/deficit- based practices (Gale at al 2018)
- Reform of potentially exclusionary aspects of organisations’ established working cultures to (Andrews et al 2015)

Key aspects of learning to facilitate change

- Promoting democratic processes in negotiating relationships (Budge et al 2018)
- Recognition of the role of collaborative, connection-focused, relationship-centred and person-centred approaches (Andrew et al 2009; Andrews et al 2015; O’Leary 2012; Nandram and Koster 2014; Maurits et al 2018)
- Appreciation of the role of social capital (Meerkerk 2018)
- Addressing the different roles and impacts of co-produced services for different groups (Ford 2015)
- New/adapted forms of assessment (Miller and Barrie 2016; Andrews 2009)

POLICY AND GOVERNANCE

This final section of the literature review explores the literature on co-production that relates to policy and governance. As we have seen, co-production is an increasingly prominent policy imperative in the UK and Europe. Yet this itself points to pressing questions about whether, why and how governance regimes and practices are adapting to the particular nature of co-production as a process – and the effect this may have on associated practices and conceptions of appropriate outcomes. These papers explore the interplay between policy, governance and co-production further. At the close of this section, we relate key themes and issues emerging here back to the Welsh context.

Askheim et al (2016) conducted a historical discourses analysis of national documents in Norway, analysing the user participation perspective across three different groups: older people, disabled people and people with mental health problems. Their analysis points to ‘a democracy/social rights discourse, based on the idea of social citizenship, as a common and historically stable discourse for all three user groups and relates this to the specific characteristics of Norwegian welfare policies’. They discovered a ‘contrasting consumer discourse, stressing users’ consumer role and related to the impact of New Public Management reforms, is only evident in the case of older people and from the 1990s’ (Askheim et al 2016: 1). They also found that ‘A co-production/co-partnering discourse, stressing user/professional-partnership, is evident in the current policies directed at older people and those with mental health problems.’ Finally, they found that the consumer and co-production discourses were ‘marginal in the case of disabled people’.

Bianchi et al (2017) explore how a dynamic performance management (DPM) framework can assist policy makers in dealing with (what they term) ‘wicked problems’ in policy. They suggest that an outcome based approach to solving ‘wicked policy problems’ ‘has to balance three very contrasting objectives of stakeholders in the policy making process – improving service quality, improving quality of life outcomes and improving conformity to the principles of public governance’ and that a DPM approach can help balance these competing demands. They highlight the use of DPM for policy makers through a case study of a 'highly successful co-production intervention to help young people with multiple disadvantages in Surrey, UK'. They argue that 'implications of DPM are that policy development needs to accept the important roles of emergent strategy and learning mechanisms, rather than attempting 'blueprint' strategic planning and control mechanisms'. They also suggest that 'undertaking simulations with the model and recalibrating it through time, as experience builds up, may allow learning in relation to overcoming barriers to achieving outcomes in the system'.

The nature of citizen engagement forms a key part of how co-production policy takes shape in practice. Bovaird et al (2014) explored the co-production behaviours of citizens, using a large sample survey in five European countries to further understand this issue and highlight that 'there has been little quantitative empirical research on citizen co-production behaviours' and sought to address this gap with this research. Their article examines what they identify as 'an especially significant finding from this research – the major gulf between current levels of collective co-production and individual co-production'. Their article 'explores the drivers of these large differences and examines what the social policy implications would be if, given the potential benefits, the government wishes to encourage greater collective co-production'.

Duner et al (2019) analyse the processes and practices of 'individualised eldercare' in Sweden, 'focusing on preconditions for older peoples' choice and control'. Data was collected using qualitative interviews with home care service users, staff and participant observations of meetings between staff and older people. They noted that 'three approaches to enable older people choice and control over their home care services were revealed: test and revise, services elaborated in close collaboration between users, care managers and home care staff; choices in the moment, users could choose services at each occasion; and quality improvement through competition, competing providers develop attractive services' (Duner et al 2019: 129). They suggest that their findings could help to guide policy makers in 'in combining the strengths of these approaches to enable older people in need of support to become co-producers in designing, managing, as well as consuming, care and services'.

Flinders and Wood (2018) used an ethnographic study to examine different notions and conceptualisations of co-production. They seek to emphasise 'the underlying politics of co-production in the sense of who defines co-production, especially in relation to initial decisions concerning which specific policy areas are deemed suitable for co-designing, co-creating, or co-delivering with services users or local communities' (Flinders and Wood 2018: 279). They argue that 'the rejection of co-production by government may inflame political resentment and reconfirm negative pre-existing attitudes about "the establishment". Their study 'contributes to existing work by analysing what happens when co-productive structures are terminated or when public protests demand the reinstitutionalisation of those relationships'.

Lowe and Plimmer (2019) produced a report for Collaborate for Social Change, seeking to explore the practical implications of a 'complexity-informed approach' in funding, commissioning and managing. Their report explores the key elements of this approach, which they state are 'working in a way that is human, prioritises learning and takes a systems approach'. This is termed a HLS (human, learning, systems) approach. They argue that working with a HLS approach as distinct advantages, stating ‘for people accessing support, it can result in better experiences, better outcomes and them being better equipped for life’ and that ‘For organisations and systems, it has potential to increase collaboration, enable innovation, build employee motivation, and deliver cost savings’.

Miller and Barrie (2016) produced a report based on findings from the ‘Meaningful and Measurable’ project. This project was ‘was a collaborative action inquiry project which involved seven multi-sectoral organisations in Scotland, and one local authority in Wales’ (Miller and Barrie 2016: 52). They conclude that what is described in the report is ‘significant culture change, which is known to require sustained focus’. They state that ‘the main focus of this project was the backstage work going on in organisations, and how this can hinder or support a focus on what matters to people, in generating information for decision-making’.

Voorberg et al (2018) analyse the impact that government financial incentives have on stimulating co-production. They note that ‘Western governments are increasingly trying to stimulate citizens to coproduce public services by, among other strategies, offering them financial incentives’. To test this analysis, they ‘designed a set of experiments that offered subjects a financial incentive to assist municipalities in helping refugees integrate’ (Voorberg et al 2018: 1). They conducted these experiments with university students and a generalised adult sample. They conclude that ‘results suggest that small financial rewards have no effect: they neither increase nor decrease people’s willingness to coproduce. When the offered amount is increased substantially, willingness to coproduce increases only marginally. Hence, financial incentives are not a very cost-efficient instrument to stimulate coproduction’.

Vrangbaek et al (2018) sought to explore policy lessons in Denmark from ‘co-production between local governments and voluntary community associations (VCOs) to promote activities for health and wellbeing among older adults’. They used survey data from voluntary organisations to explore this dynamic. Their survey ‘addressed 13 issues and potential problems within four categories – ‘’members and volunteers’, ’economics, ’media and the public’ and ’’politics and the local government’. Their findings present ‘a relatively positive picture of the potentials in municipal-VCO collaboration’ (Vrangbaek et al 2018: 1255). However, they also found that ‘a sizeable number of VCOs point to problems and obstacles particular in regards to recruitment of members and economics’. They finally conclude that ‘municipalities must pay close attention to the issues and conditions for VCOs in order to succeed with their policy initiatives in this area’.

Weaver (2018) explores how ‘User Voice Prison Councils in England have contributed to shifts in aspects of prison governance and practice’. They attempt to reveal how co-production works from the inside of User Voice Prison Councils, using qualitative interviews with Prison Council participants. They state that ‘User Voice and prison staff revealed that the development of such “bottom–up” participatory governance practices require and restore interpersonal trust, the mechanisms of which are interactions underpinned by a distinct manner of relating and the establishment of a network of relations oriented to the common good’ (Weaver 2018: 249). They conclude that ‘revealing the “how” of co-production, from the “inside”, the argument advanced here is that while the effects of co-production may be more ameliorative than transformative, such collaborative and dialogic approaches can enable differently situated people to forge new norms of interactions and forms of democratic participation to achieve collective goals'.

These studies link in significant ways to the framing of co-production in the Social Services and Well-Being (Wales) Act 2014. Its pluralistic specification of the key features of co-production are explicitly in line with the 'co-production/co-partnership discourse identified in the Norwegian context by Askheim et al (2016). Similarly, the dynamic performance management framework (Bianchi et al 2017) is an attempt to capture and balance competing demands which are echoed in the requirements of the Act: the successful involvement of people in the design and delivery of services, together with the provision of added value as an outcome, and the devising of improved arrangements for service organisation. The focus by Bovaird et al (2014) on the gulf between different scales of co-production carries implications for the commitment in the act that co-production be promoted different kinds of enterprises and projects relevant to the provision of care and support. The evidence from Sweden presented by Duner et al (2019) is of direct relevance to the practical challenges posed by the aim of genuine involvement of specific groups (older people, in the case of that study) in the design and management of services. There are warnings in the work of Flinders and Wood (2018) concerning the risks of co-production being promised but not realised, which accentuate the importance of co-production being seen to happen in concrete, visible ways (in the words of the Act, 'to meet people's personal outcomes, and provide added value') within local communities.

Lowe and Plummer's (2019) stress on the importance of prioritising learning, and their wider HLS approach, hold clear significance in light of the Act's requirement that local authorities ensure that commissioners, citizens and providers work together to shape effective services. This point is also echoed in Miller and Barrie's (2016) findings about the importance of focusing on what matters to people, in generating the appropriate forms of culture-change needed for meaningful co-production to emerge, in the conclusions reached in Denmark by Vrangbaek et al (2019) about the need for close attention to the circumstances of community organisations, and in Weaver's (2018) conclusions about the development of 'bottom-up' participation in prison governance and practice. There are immediate tensions involved in governments aiming to stimulate co-productive projects, when these by definition will need to have ground-level input from the outset – and importantly in light of the Act's aim of 'building the local economy of people exchanging their skills, interests and time', Voorberg et al (2018) find that financial incentives are not an efficient stimulus.

The findings of these studies reinforce the conclusion that co-production is a simple idea, but a complex process. It is complex because each context of co-production will have its own distinctive aims, stakeholders and purposes which have a material impact on the challenges faced and how they are negotiated; because the process of co-production itself is dynamic and creative; and because of the sheer array of factors and variables – from the environmental, through the organisational, to the individual – which affect how any particular instance of co-production will unfold. Policy in Wales has been bold in putting co-production at the front of the reform of social services. The Act adopts an appropriately broad and multi-dimensional definition of co-production and its requirements. This is of significant potential advantage in addressing the different emergent themes. Where service transformations take place, these will be – in the words of one recent study – 'multi-layered, messy, fluid and emergent' (Dougall et al 2018). These features will be pivotal to any full and accurate gauging of the effectiveness of policy innovations promoting co-production. Rather than being measurable via a single metric or yardstick, the processes and outcomes of co-production associated with the Act will require duly nuanced, adaptable, contextual and multi-dimensional means of evaluation, able to do justice to the detail of what Weaver refers to as the 'how' of co-production.

SUMMARY

Using the findings from literature included within this review, a number of important factors which can enable co-production are presented in Table 5.

Table 5: Factors for co-production

Knowledge, understanding and planning	Recognising and responding to challenges	Fostering a supportive and enabling culture and environment
Thinking wide-to gain a clear understanding of the potential for co-production across the design, delivery and evaluation of public services	Recognising and grappling with the challenges for co-production within the complex multi-level governance of public services	Developing a culture and way of thinking in professionals and organisations that truly values the worth and knowledge individuals and communities
Ensuring clarity on the distinction between co-production as such, and related ways of working such as collaboration	Recognising and addressing the tension between the discourses of individual rights/consumerism and mutuality/compromise	Providing supportive environments and embedded systems that enable co-production, which come at cost
Importance of combining different kinds of evidence in evaluating co-productive projects	Challenging existing approaches to planning and performance that call for predictability and control and thus allowing for emergence	Developing a common language and meaningful relationships through caring dialogue and deliberation, which creates trust
	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	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

MULTI-AGENCY WORKING

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

WHAT ARE THE CHARACTERISTIC SUCCESS FACTORS OF MULTI-AGENCY WORKING IN PUBLIC AND NON-PUBLIC SECTOR SERVICES?

In this chapter we offer an understanding of the many definitions of the terms used in the Act to describe how we work together, that is multi-agency working, 'cooperation', 'integration of care', 'partnership', 'joint arrangements'. 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. 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

THEME DEFINITION

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 (Kings 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. 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).

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.

The term 'multi-agency' in the literature is often used interchangeably with inter-agency (between agencies) and partnership working. For example, Cheminais (2009: 4) refers to it as 'multiagency partnership working' where practitioners from multiple agencies agree to work together jointly, not necessarily concurrently, but sometimes sequentially depending on the shared aims and outcomes. The act of agreeing to work together between agencies requires certain shared decisions, mechanisms and processes at multiple levels of the organisation to be put into place, e.g. sharing information, planning tasks, allocating responsibilities and coordinating services (see Table 6). Sometimes it requires a neutral space (or 'brokering white space') which facilitates and enables people to undertake this work (Warner & Gould, 2009; Alter & Hage, 1993). 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).

The term 'integration of care' in the Act gets us to consider both terms of integration and integrated care. We draw on Nuffield (2011) who cites Kodner & Spreeuwenberg (2002) and Leutz (1999) when defining the terms.

> '*Integrated care is an organising principle for individual care [& support] delivery that aims to improve individual care [& support] and experience through improved coordination. Integration is the combined set of methods, processes and models that seek to bring this about'.* Adapted from Nuffield Trust (2011: 7), it too includes coordination as a feature of integrated care.

Integrated care is an outcome of the act of integration (WHO, 2016; Kings Fund, 2019). The steps that need to be taken to make integrated care happen have been documented by the Kings Fund (2013) and are included in Table 6. However, we should be mindful that the literature on 'integrated care' mainly originates in health (disease) and health service delivery, whereas the term used by the Act advocates that 'integration of care' is a broader term, suggesting an adaptation of the WHO people centred approach to care is required as follows:

> Integrated care '*consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health [and support] systems that are organized around the comprehensive needs of people [rather than individual diseases], and respects social preferences. People-centred* care *also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health [and wellbeing] of people in their communities and their crucial role in shaping health [and wellbeing] policy and health [and support] services'* (adapted from WHO, 2018).

Having produced some definitions, the question remains. Where does multiagency working fit in the continuum from parallel working to integration (Leutz, 1999, 2005; Boon et al, 2004) and what are their success factors? As we can see, the act of coordinating services (coordination) is a feature of integration and multiagency working (Table 6), whilst cooperation (linkages) appears to be a precursor of coordination (Figure 2) and requires the minimum of communication and information exchange in order to enable people to work together across agencies (van Raak et al., 2003). To achieve cooperation the act of collaboration is required between different organisations (Kings Fund, 2019). This is the early stage of working together with a shared vision. Huxham and Vangen (2005: 4) defined collaboration as '*any situation in which people are working across organizational boundaries towards some positive end.'* It requires active management with two key concepts 'collaborative advantage' (successful collaboration) and 'collaborative inertia' (slow progress or death of the relationship).

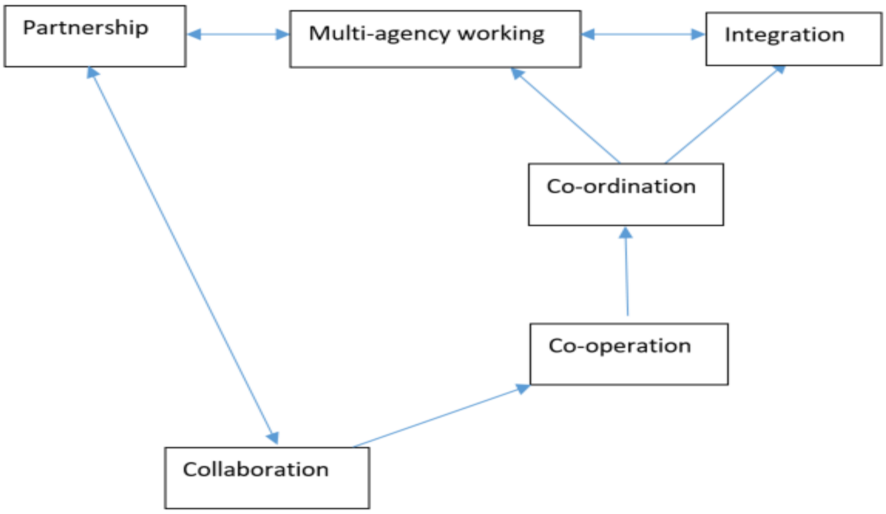


Figure 2: Types of working together and their relationship with one another

Operational coordination has been described in the past as **sequential** client flow (treated by one agency, service terminated and the person is referred to the next service).

Reciprocal client flow is where the person is treated simultaneously by more than one agency and **collective** client flow where the person is treated simultaneously by staff from several agencies who develop goals or plans together and systematically share tasks (Alter & Hage, 1993). Certainly, in recent years the act of coordinating services is encouraged to use a people centred approach, creating effective relationships, networks, aligning processes across health and social care. This ensures that the principles of people centred care i.e. equity in access, quality, responsiveness and participation, efficiency and resilience are promoted (WHO, 2016).

What is apparent from this array of definitions is that they have a number of shared characteristics and success factors. The forty-eight (n=48) peer reviewed papers identified from the search strategy have been analysed to develop Table 6 which compares the success factors and characteristics of coordination, integration, multiagency working and partnership. It is no wonder that the terms are often used interchangeably and can sometimes lead to concept confusion. These terms are used to work with individuals, carers, families and communities. Therefore clarity is needed to build equal relationships with common language and purpose, culture (trust, honesty, reciprocity), managing expectations, permissions and processes; although it is acknowledged that this can be resource (including time) intensive (Kings Fund, 2019; Leichsenring et al., 2016). What holds back multi-agency working across health and social care are its cultural and structural differences between the systems, expectations (are sometimes unrealistic, especially time) and there is no effective way of measuring how well services are working together (Kings Fund, 2019). For example, Lai Meng and Cameron (2019) comment that there are still over 70 terms and phrases and 175 definitions and concepts of integrated care. This leads to individuals and organisations being less clear about integration and integrated care 'across space, time and context', which in turn means stakeholders will influence policy transfer in different ways and eventually who benefits and loses in that process.

Table 6: Working success factors and characteristics (further explanation for these can be found in the following domains)

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
Working together jointly (Dickinson and Neal, 2011) as a shared desirable outcome (Montoya et al, 2015); formal information sharing agreements and working arrangements, access to statutory sector databases by third sector (Abendstern et al, 2016)	Sharing realistic aims (Christensen et al, 2018)	Working together jointly strategically and operationally- timely planning, comprehensive and co-productive with individuals and families (Bhaumik et al , 2011)	Partnership boards/ Community advisory boards (Citrin et al, 2018)
Joint planning- shared responsibilities, information sharing protocols (Hansson et al. 2010; Dickinson and Neal 2011)	Shared Information, tasks and responsibilities (Barber and Wallace, 2012; O'Halloran, 2016); sharing information technology (Oskman & Hujala, 2017; Citrin et al, 2018)	Information sharing between each other, acknowledging individual knowledge and expertise (Tong et al, 2018)	Sharing information (Abendstern et al, 2016)
Delivery of coordinated services, Sequential or reciprocal or collective types (Alter & Hage, 1993; Prammer, 2012)	Responsive and informal interactions (Christensen et al, 2018; Barber and Wallace, 2012)	Coordination of service provision (Bhaumik et al, 2011)	Pooled budgets (Rozansky et al. 2017)
Co-ordination of service provision, coordinated person centred planning (Hansson et al. 2010;Bhaumik et al , 2011)	Information and knowledge sharing (Christensen et al, 2018; Barber and Wallace, 2012; Citrin et al, 2018)	Joint visiting or assessment (Fernandez et al, 2018)	Equal partnerships between agencies (Abendstern et al, 2016)
People centred care and services proportional to level of need (Abendstern et al, 2016)	Joint visiting and/or shared assessment/care plans- (Barber and	Formal strategic assurance/arrangements (Tong et al, 2018)	Formal information sharing arrangements- reshaped over time (Karlsson et al. 2017),

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
	Wallace, 2012; O'Halloran, 2016; Oskman & Hujala, 2017)		
Alignment and harmonizing of processes (Dickinson and Neal, 2011)	Formal strategic arrangements- structural and functional differences between organisations inhibit integration in practice(Christensen et al, 2018)	Limited understanding of the processes by which trust is built up and maintained between and within social enterprises (Lyon, 2013).	Recognition of all partners (Abendstern et al, 2016)
Create networks (Hansson et al. 2010; Montoya et al, 2015)	People centred care (Nicolaisen, 2016); citizen initiated care (Turnhout et al, 2016); person-centred care and preventative self- care(Beacon, 2015)	Working with individual or family (Bhaumik et al , 2011)	Equal status built through understanding each other's roles and earning respect to overcome suspicions (Abendstern et al, 2016)
Recognising non-statutory workers as equal partners (Dickinson and Neal, 2011) with distinct and necessary roles and functions (Abendstern et al, 2016)	Exchange/share of Standardized information with support of appropriate information governance- 'concrete collaboration models' (Oskman & Hujala, 2017) .	Specific needs – including individual, population (general and specific) to each agency; shared understanding of need across agencies (Choca, et al, 2004; Bhaumik et al , 2011)	Timely contract arrangements (Prammer, 2012)
Altering commissioning arrangement e.g. single point of access (Dickinson and Neal, 2011);	Continuous monitoring of outcomes – both individual, population and systemic (Bhaumik et al , 2011; Oskman & Hujala, 2017)	Training & support – for individuals, community and workforce to understand (Tong et al, 2018) the prevention agenda (Choca, et al, 2004)	Knowing who to contact when there is staff changes especially when high staff turnover. (Abendstern et al. 2016)
Building relationships –having the ability to adapt (Hansson et al. 2010); maintaining integrity of partners, not diverting resources from core business, simple structures, co-	Ability to adapt (Oskman & Hujala, 2017; Citrin et al, 2018)	Non-traditional partners – inclusivity provides opportunity for greater knowledge and resources for the individual and population. (Choca, et al, 2004)	Informal interactions, intense communication, knowledge sharing and general socialisation (Christensen et al, 2018)

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
location of partners, joint governance (Dickinson and Neal, 2011)			
Identifying a niche role in the wider network (Dickinson and Neal, 2011); avoiding duplication with statutory services (Abendstern et al, 2016);	Joint coordinators/named coordinators to coordinate planning and support (Bhaumik et al , 2011; Hebert, 2015)	Data – comprehensive management data; data sharing; good quality (Choca, et al, 2004)	
History of cooperation used to establish coordination (Hansson et al, 2010).	History of local and personal informal cooperation (Barber and Wallace, 2012) and co-production (Oskman & Hujala, 2017).	Shared desired outcome (Bhaumik et al, 2011)	
Harmonizing and avoiding short term contracts (Abendstern et al, 2016)	Shared responsibilities- identifying high needs (Oskman & Hujala, 2017	Integrated referral system (Bhaumik et al, 2011)	
Streamlining administration (Prammer, 2012)	Clear roles and routines(Barber and Wallace, 2012; O'Halloran, 2016)	Clear Care pathways linked to referral systems (Bhaumik et al , 2011)	
Exact rules for work processes (Dickinson and Neal, 2011; Montoya et al, 2015)	Team coaching (O'Halloran, 2016)	Monitoring individual and systemic outcomes (Bhaumik et al , 2011)	
Competencies – implementing exacting rules about work processes. (Prammer, 2012)	Learning needs – core training leads to confidence for safe delegation (Barber and Wallace, 2012)	Shared vision/common goals/aims/purpose/values/ shared energy (Tsasis, 2009; New Philanthropy Capital, 2018)	
Trust and commitment to agreed solutions e.g. through 'fitness functions' such as ranking	New models & roles e.g. wellbeing worker(Barber and Wallace, 2012); Change navigator (O'Halloran, 2016; Oskman & Hujala, 2017)	Time to build relationships- through consensus (Tsasis, 2009; Tong et al, 2018) and co-production (Bhaumik et al, 2011)	

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
contribution of agencies (Montoya et al, 2015; Prammer, 2012)			
Carefully designed processes step by step (Montoya et al, 2015; Prammer, 2012)	Whole systems approach e.g. micro, meso, macro level agreements, development of norms through experience exchange, development of guidelines (Nicolaisen, 2016); without boundaries (O'Halloran, 2016)	Informal cooperation (Hansson et al. 2010).	
A common understanding (Dickinson and Neal, 2011; Montoya et al, 2015)	Case management (Dubuc et al, 2016, Hebert et al, 2012, Hebert 2015)	Formal structure rather than informal structure of network (Henttonen et al. 2016)	
Criteria based recruiting (Prammer, 2012)	Computerised pathways (Citrin et al, 2018)	Shared expertise (Tong et al, 2018)	
Addressing power inequalities (Abendstern et al, 2016; Prammer, 2012)	Coordination (Christensen et al, 2018; Oskman & Hujala, 2017)	Good governance structures/manuals (Tong et al, 2018)	
Pointing out conflicts of loyalty (Montoya et al, 2015)	Single point of entry and integrated practice arrangement e.g. automatic referrals lead to efficient service (Abendstern et al, 2016; Dubuc et al 2016)	Sufficient resources including time and capacities (Tong et al, 2018)	
Providing an 'all party approach' with clear definition of participant roles and responsibilities (Montoya et al, 2015; Prammer, 2012).	Multiple partners statutory and non-statutory (Abendstern et al, 2016; Christensen et al, 2018)	Good communication- senior level management engagement (New Philanthropy capital, 2018; Tong et al, 2018)	

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
Building up work capacity step-by – step with opportunity for learning and readjusting (Prammer, 2012)	Integrated care (Nicolaisen, 2016; O'Halloran, 2016)	Strong shared norms commitment, motivation, giving reputation, shared energy (Choca, et al, 2004; Tsasis, 2009; New Philanthropy capital, 2018)	
Circular planning process (Prammer, 2012)	Find a common cause (Turnhout et al, 2016; Barber and Wallace, 2012)	People in the team knowing and happy with their role/ defined role/shared understanding (Tsasis, 2009)	
Consensus /cooperative decision making requiring time and energy (Dickinson and Neal, 2011; Prammer, 2012)	Develop a persuasive vision (Oskman & Hujala, 2017)	Strong leadership and network coordination (Tong et al, 2018).	
Specific roles-Joint coordinators and network for coordination (Hansson et al, 2010); 'honest broker' to nurture, 'matchmaker' of relationships, diplomat, deliver new joint services, boundary watching, providing strong consistent leadership (Dickinson and Neal, 2011)	Develop shared narrative, prioritised common values (e.g. directed towards self-direction and willingness, growth and development) (Turnhout et al, 2016); common language without jargon (Barber and Wallace, 2012).	Having the right people in the team – personalities, attitude, perceptions and specialist roles (e.g. boundary spanners) (Tsasis, 2009).Individual values v institutional rules (Lintz, 2016)	
Strong sponsorship from government policy and high level public management (Montoya et al, 2015)	Establish shared leadership/strong leadership (Beacon, 2015)	Trust – not building expectations which create mistrust (Choca, et al, 2004); stabilises relationships (Tsasis, 2009)	

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
Stability of workforce assigned to the coordination system (Montoya et al, 2015)	Create time and space to develop understanding and new ways of working (Barber and Wallace, 2012)	Comprehensive multiagency plan to meet population needs (Choca, et al, 2004).	
Quality indicators to promote integration (Tsutsui et al. (2017)	Identify services and users groups where potential benefits are greatest (Barber & Wallace, 2012)	History of collaboration with shared vision or goals (Choca, et al, 2004; Kings Fund, 2019; Tong et al, 2018)	
	Build from bottom up as well as top down (Turnhout et al, 2016)	Clarity in roles and responsibilities (Choca, et al, 2004; Tsasis, 2009; Tong et al, 2018).	
	Pool resources to enable commissioners and integrated teams to use resources flexibly (Barber and Wallace, 2012; Hebert, 2015)	Co-production with citizens, communities and charities (New Philanthropy Capital, 2018)	
	Innovate in the use of commissioning, contracting and payment mechanisms and use of independent sector		
	Recognise there is no best way of integrating care		
	Support and empower users to take more control over their health and wellbeing (Turnhout et al, 2016)		
	Use the workforce effectively and be open to innovation. (Barber and Wallace, 2012)		

Working Success Factors and Characteristics			
Co-ordination	**Integration**	**Multi-Agency Working**	**Partnership**
	Set specific objectives and measure and evaluate progress towards these objectives (Beacon, 2015)		
	Be realistic about the costs of integrated care. (Beacon, 2015)		
	Act on all the above as part of a coherent strategy (Kings Fund, 2019).		

In the following sections we will consider the individual, family and carer, care organisation, and policy and governance domains in the context of multiagency working. The chapter has been organised in this way because as a whole system, public and non-public sector services (including their policy and governance) are created and influenced by relationships both between individuals and within the sectors themselves. That is, from the interaction of the individual service user (local level) we see changes for the context of the family, carer which in turn influences change in care organisations and what Cilliers (1998; Preiser, 2016) called 'global structures'(public and non-public sectors). These in turn provide positive or negative feedback which influences the behaviour of organisations, families, carers and individuals at the local level. Considering the complexity of the whole system will help us understand the success factors and challenges, mechanisms and processes required to work together and meet the aims of the Act.

FIVE DOMAINS OF STUDY

In this section multi-agency working is explored through the five domains from the individual, the family and carer, community, workforce, care organisation; and policy and governance. The complex world of working together (its knowledge and function) is developed through the interaction of relationships (Cilliers, 1998; Preiser, 2016). Consequently consideration is given to the fact that knowledge is distributed throughout the whole system and so when considering the characteristic success factors of multi-agency working in public and non-public sector services (identified in Table 6), they can be found (and coordination, integration and partnership) collectively across all the domains below.

INDIVIDUAL

The principle of wellbeing of the individual is a key tenet of the Act (c.f. Section 5). Agencies exercising functions to promote the wellbeing of individuals who need care and support are required to share responsibility for wellbeing with the individual concerned by recognising people as assets and by empowering the individual to achieve their own wellbeing. This section focuses on international literature relevant to the individual and multi-agency working. It includes seven articles (n=7) from public sector housing collaborations (descriptive case studies) for foster youths in transition (Choca et al., 2004), a qualitative phenomenological study of staff interpersonal relationships in inter-organizational collaborations in Canada (Tsasis, 2009), joint co-ordination in networks for mental health services in Sweden (Hansson et al., 2010), a multi-methods evaluation of a single point of access in the UK for procurement to third sector services which improved outcomes for people using them (Dickinson & Neal, 2011), a government food security case study of collaboration and cooperation in Colombia (Montoya et al., 2015), citizen initiatives (Turnhout et al., 2016), and enhancing integrated care to include health (primary and secondary) and social care in Denmark (Nicolaisen, 2016).

Choca et al. (2004) assessed a number of housing collaborations that aimed to improve foster youth outcomes in response to addressing housing issues (especially homelessness) which was the main concern for youths. They found that the lessons learned included 'specific housing needs, training and support, use of existing resources and involving non-traditional partners, and data and research'(2004: 487). To achieve this, new essential relationships had to be formed with child welfare, social services, housing developers and providers. Their approach had been 'thoughtful' with a planned programme focussing on youth needs and evidence emphasizing a formula for success including 'educational attainment, employment preparation and work experience, and personal growth and development' (2004: 491). They found a lack of comprehensive management data to enable them to understand the youths' needs and quantify them, as challenging.

Tsasis (2009) interrogated the importance of interpersonal relationships in the social processes of inter-organizational collaboration and conflict in non-profit organisations. A document analysis and interviews (n=41) included managers and directors who were 'boundary spanners' (across organisations) and then used a snowballing technique to identify others. Tsasis (2009: 8) used work by Alter and Hage (1993) to define the purpose of collaborative relationships that was to 'address mutual benefits or common interests among organizations through a process of information exchange and resource sharing'. Tsais (2009: 18) used 'resource dependence theory' as the conceptual framework for his research, explaining that organizations collaborate with other organizations to reduce uncertainty and manage their own organisational dependence, concluding that inter-organisational relationships require 'a balance of dependence and autonomy'. In addition, beliefs of individual boundary spanners about their organisational goals and interests are related; and how they experience each other's behaviours influences how the inter-organisational relationships are configured. Key to stabilising the relationships is building trust, shared norms, building consensus, commitment and a giving reputation, thereby building on an earlier idea of reciprocal interdependence (Alter & Hage, 1993).

Hansson et al. (2010) described the development and nature of coordination within a mental health and social care consortium in Sweden to assess the impact on care processes and client outcomes. Their findings revealed different factors that assisted or hindered coordination activities across this area of Sweden. Those that assisted were 'the history of local and personal informal cooperation' and evidence of shared responsibilities, implementing joint coordinators and having the ability to adapt. Those that hindered were 'unclear roles and routines'.

Dickinson and Neal (2011) conducted research on the Conwy Collaborative Approach, which brought together statutory, voluntary and community sector bodies to create a single point of access for commissioning and procurement for local specific service user groups (third sector) to support individual health and social care needs. They used a performance framework which included 'outcomes monitoring' and demonstrated that during the pilot (n=136) people using the services had an improvement in self-reported independence and widening of the range of opportunities available to them. Issues included the concern for project sustainability, recognising that longer-term outcomes were difficult to assess, and difficulty in demonstrating prevention. Dickinson and Neal (2011) listed the crucial factors that enabled their success. These included: commitment of time and energy, shared vision (together with co-planning), maintaining integrity of partners, not diverting resources from core business, joint governance, simple structure, co-location of partners, and the role of an honest broker.

Montoya et al. (2013) sought to explore how cooperation and collaboration worked in public management of food security and nutrition in Bogota, Colombia using concepts such as reciprocal altruism, punishment and reward. Their research led them to define the concepts of collaboration and co-operation as 'a shared desirable outcome that unites different agencies in committing efforts and resources to the accomplishment of a common goal for society, as seen in obtaining food and nutrition security for a specific territory' (2013: 916). They accepted that where people have to work together across organisations there will be 'free riders'. That is, those people who are providing unequal collaboration effort within the relationship. Furthermore, they also discussed the role of sanctions and punishments (free riders) in promoting cooperative behaviour and in reducing free rider negative effects.

Nicolaisen (2016) discussed the issues in implementing integrated care in the health care sector in a region of Southern Denmark in 2009. A macro, meso, micro level agreement (Sam:Bo) was designed and implemented to enhance integrated care between primary and secondary health care and social care (home care) to ensure person-centred care. Nicolaisen (2016) concluded that they were able to largely implement the exchange of standardised information at multiple levels. However, continuous monitoring was required, especially at the micro level, where some barriers were encountered. Nicolaisen (2016) recommended that leaders and coordinators should address barriers and convey their knowledge to the micro level together with a plan of how to overcome them.

In the limited number of articles identified which were relevant to the individual in the context of multiagency working, all identified the importance of measuring people outcomes, the need for a jointly planned approach with key roles, time, energy and commitment to working together. The Turnhout et al. (2016) conference paper on citizen initiatives is reported in the *care organisation* section of this review because it describes the organisation of that care through 171 citizen and workforce stories from two case studies. They concluded that the citizen voice changes the collaboration across health and social care. However, it is important to note that the voice of the individual in the other articles is weak and has only been heard in the form of questionnaire and outcomes measures in the data collection. This is surprising considering the main focus of working together in whichever form is to meet the needs of the individual and to be people centred. The literature focuses on professional and organisational success factors that improve individual outcomes.

FAMILY AND CARERS

Family and carers are important partners in supporting people with care and support needs. The Act specifies that agencies that promote individual wellbeing also endorse the wellbeing of carers in need of support. This domain was not represented within the multiagency literature search (n=48). As the original search strategy did not provide any articles for this domain, a hand search of the internet found an example paper by Bhaumik et al. (2011) which focussed on teenagers with intellectual disabilities (ID) who have significantly more health problems than the rest of the population. In addition, many encounter difficulties accessing the services they need during the transition from children's to adult services. The authors' multidisciplinary, interagency study in one area of the UK sought to estimate the number of teenagers with ID between the ages of 16 and 19 years, their levels of mental and physical healthcare needs, their carers' perceptions of the transition process to adult services and unmet needs, and to make recommendations on how to address unmet needs. A mapping exercise was carried out to identify all teenagers aged 16–19 years with ID known to local services; a postal questionnaire was sent to carers of all eligible teenagers; and then in-depth interviews were carried out with a sample of carers. Most of the teenagers had significant levels of ID, required constant supervision, and were using a range of health, social care and education services. However, their carers still reported unmet needs; with half experiencing difficulty in accessing services. Different patterns of service use and unmet needs were found among the various ethnic groups identified in the sample. Only around a quarter of the carers interviewed were satisfied with the transition process. Carers were concerned about the lack of information concerning transition planning and adult services, and wanted earlier, more coordinated transition planning. The data confirmed the need for quality information and validated standardized tools that could be used for transition planning.

Recommendations were that integrated referral systems for health and social care need to be developed, with links to clear care pathways, and that individual and systemic outcomes should be monitored.

COMMUNITY

To promote the wellbeing of individuals requiring care and support, the Act encourages agencies promoting individual and carer wellbeing to work with local communities. This section identified four (n=4) articles which focused on the international literature surrounding multi-agency work and communities from Germany (Lintz, 2015), UK (Abenstern et al., 2016), Denmark (Christensen et al, 2018) and Somerset in England (New Philanthropy Capital, 2018). The paper by Lintz (2015) originates from environmental science where reporting on research on local cooperation between neighbouring communities is uncommon. This German article is a theoretical paper which developed a conceptual framework for analysing inter-municipal cooperation using Mayntz and Scharpf (1995) and Scharpf (1997) actor-centred institutionalist as a theoretical framework. In order to understand political interaction, the underlying policy problem, or its local perception needs to be understood. They argue that interaction-oriented policy analysis investigates how political decisions are made by combining individual agency (and their social norms) and institutional structure equally. Institutions are sets of rules which individuals may or may not adhere to. Modes of interaction include negotiated agreements e.g. information sharing protocols. Where negotiation leads to agreement on a coordinated common action for the benefit of individuals (stakeholders) this is identified as a form of cooperation. Knowledge, power and values are interrelated and influence policy outcomes through the individuals (values, knowledge, beliefs and power) and institutional rules (Figure 3 below).

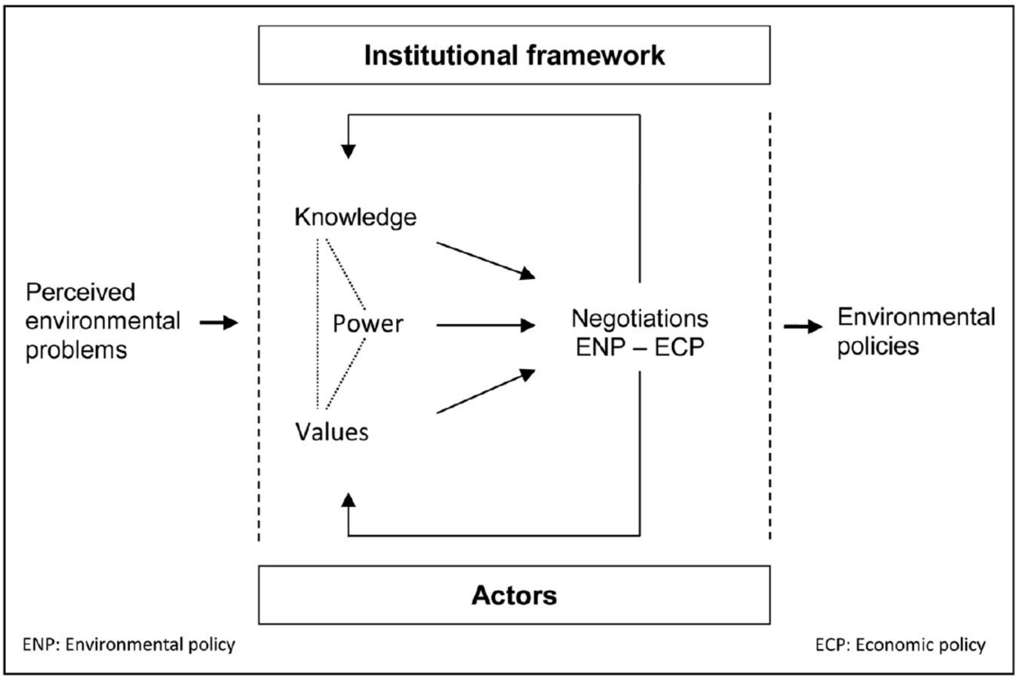


Figure 3: Conceptual framework for analysing inter-municipal cooperation on the environment

Abendstern et al. (2016) undertook a grounded theory approach to investigate the role and contribution of the non-statutory sector (defined as voluntary or community) in providing care coordination for adults and older people. They conducted semi-structured interviews with managers from 17 services including large national third sector organisations, local community organisations and social enterprises in the form of community interest companies (CIC). Four themes were identified: commissioning arrangements undermined non-statutory sector development, working relationships between statutory and non-statutory services required time and energy to navigate and sustain, the establishment of a niche role in the larger network of provision, and tensions relating to future developments. There was a considerable gap in what commissioners thought was required and what the public said that they wanted. The managers prided themselves on their knowledge of local communities but were not provided with the appropriate level of influence in the commissioning process. They felt that there was a lack of awareness regarding their organisational expertise; it took a long time to earn respect from the statutory organisations and to build and retain organisational visibility. Without partnership arrangements including information sharing, recognition and status, voluntary organisations became frustrated about time wasted in trying to contact statutory services, the high turnover of staff in statutory services which made regular and formal meetings a challenge, contract renewals at short notice and the lack of increase in budget over the years. They saw their role as advocates, liaising with a range of services in accordance with what people needed, providing services for those ‘hard to reach’.

New Philanthropy Capital (2018) provided a report that explored the Richmond Group’s collaborative work in Somerset whilst using in-depth interviews. Drawing from the 2016 Untapped Potential report, which ‘highlighted the need to bring the voluntary sector’s strengths to health and care transformation' this report aimed to capture the work conducted by the Richmond Group, supported by Public Health England, exploring successful collaboration between Voluntary Councils and statutory health services in practice. A key conclusion from the report was the need to work co-productively with citizens, communities, charities and statutory organisations to make and manage change. Their achievements included: clarity on aims and values, a sense of shared energy and excitement, senior level engagement, an improved sense of the challenges faced and organisational ways of working, the charities led the Somerset work (giving hope and confidence). The identified challenges were in cascading the messages down to smaller local charities, a lack of resources and disparate perceptions of success held by different people. Although the organisations had made significant progress in their readiness to collaborate, there were tensions from external and cultural factors which threatened trust building and the embedding of collaboration.

Christensen et al. (2018) sought to derive lessons from inter-sectoral integration and collaboration in a community-based health promotion network in Denmark – the Health in All Policies (HiAP) approach and used data from 11 observations (meetings and events) and 9 semi-structured interviews. The data were analysed using Axelsson and Axelsson (2006) theoretical framework to identify aspects of integration and differentiation between organisations. The case study is described as the Husum Health Network in the HUSUM neighbourhood (40,000 inhabitants) in Copenhagen, which is an area of high unemployment with the lowest self-rated health in Copenhagen. The network brought together local health, education and social professionals to organise network meetings for knowledge sharing, interaction and resource use, and to develop and implement shared activities amongst partners e.g. exercise for families. The researchers found that the network structure was weak which reduced its sustainability. The study gives insights into the structure and function of the network leading to sharing of knowledge and coordinated activities.

This section has highlighted the challenges experienced by organisations working in the community, the vertical flow of communication, the need to consider knowledge, values and power when working with the communities and non-statutory organisations and not just the statutory services. It is supported by the notion that health and wellbeing is everyone's business to ensure that all stakeholders within the community are encouraged to work together to promote and achieve change and in some cases step in with alternate support where there is a gap in statutory provision.

WORKFORCE

The Act focuses on the social care workforce developing a coherent and consistent Welsh approach. This section focuses on the (n=5) international articles surrounding multi-agency working and the workforce. It includes learning, the equality of relationships between staff and across statutory and non-statutory services, the whole system approach, team coaching, and new roles.

In 2012, Barber and Wallace published an article on the configuration of the integrated support and wellbeing worker for the Gwent frailty service in Wales. They reported on three tasks conducted by the Frailty workforce group, staff engagement, identifying the support and wellbeing worker training needs and scoping the employment options for the new role. They advised those facing the same challenges that there were three key principles: having a unifying theme, time spent on early staff and trade union engagement gave positive messages of their value in the role configuration and developing the integrated health and social care role meant that core training had to be consistent to engender confidence for safe delegation.

O'Halloran (2016) conducted research on the Change Academy in north west London, which is a development programme for health staff to enable them to deliver a new person centred integrated care service, 'a whole system without boundaries' (O'Halloran 2016: 1). The new service includes a change navigator role to develop the new approach with team coaching. The change academy programme included modules on: leading across boundaries, problem solving techniques, data to improve how care is delivered, dealing with conflict and health coaching. Findings suggested that 'early evaluation of the Change Academy is demonstrating the effectiveness of the approach to develop integrated care teams'.

Oskman et al. (2017) delivered a conference paper on the Better Everyday Life project in Finland. This project sought to 'support high needs/high costs clients in everyday life by developing client-centred, integrated care for them'. The project sought to support professionals by having them work together in teams, supported by coaches and project seminars, aiming to develop tools for integrated care. They concluded that professionals need to collaborate if they are going to identify clients who have 'high needs', otherwise it becomes difficult. These clients are often using multiple services but professionals may not be aware that another service is involved with the same patients care.

The Abendstern et al. (2016) paper, mentioned earlier, provides insights into multi-agency working and the workforce by looking at commissioning arrangements and working relationships between statutory and non-statutory services in care coordination for adults and older people. Beacon (2015) also sought to illuminate on issues in multi-agency working and the social care workforce, by conducting research on the development of 'of multi-disciplinary Practice-Integrated Care Teams (PICT)'. They found that 'the integrated care teams developed in Central Manchester have started to make significant changes to the ways that 'professionals work together, to the experience that patients have and to the costs of urgent care provision'. The authors also identified that 'the model which has been developed centres around the role of general practice, and has enabled primary care to take a key role in the development of an out-of-hospital integrated care system'. A key question that this paper raises is - where is the voice of the citizen and family in the design and development of these services and the strategy to plan them?

Citrin et al. (2018) conducted research on a community healthcare worker-driven digitally enabled integrated care system for municipalities in rural Nepal. Key insights included ‘community healthcare workers continuously engaging with populations through household visits every three months; community healthcare workers using digital tools during the routine course of clinical care; individual and population-level data generated routinely being utilized for program improvement; and being responsive to privacy, security, and human rights concerns’ (Citrin et al. 2018: 197). They concluded that ‘that it is feasible to deploy such a system for pregnancy and early childhood healthcare in a resource-limited rural setting’. The authors end by stating that ‘larger questions of acceptability, affordability, and sensitivity will need to be addressed if this type of approach is going to be effectively scaled in Nepal and beyond’ (Citrin et al. 2018: 203).

This section has highlighted the need for investing time in providing opportunities for learning and team development when developing a new role; engaging with the right people at the right time in the development and delivery of projects was essential if the projects were to meet their organisational outcomes; and the essential role of a coach to help build values, especially trust.

CARE ORGANISATIONS

This section of the literature review focuses on international literature concerning multi-agency working and care organisations. There are fifteen (n=15) articles included which consider interdependence in Austria and Sweden (Prammer, 2012; Carlsson-Wall et al., 2011), digital computerised mechanisms within care organisations in Canada (De Guinea et al., 2011; Dubuc et al,. 2016; Hebert, 2012, 2015), types of care organisation (Lyon, 2013; Turnhout et al., 2016; Compton et al., 2017), collaboration in primary and community based services in California (Southby & Gamsu, 2017; Weinberg et al., 2009), an insight into non-profit organisations in England and Canada (New Philanthropy Capital, 2018; Tong et al., 2018), quality indicators and measures in Japan (Tsutsui et al., 2017), and economics of coordination in England (Fernandez et al., 2018).

Care organisations internationally struggle with the notion of interdependence as they attempt to work together across statutory and non-statutory or private organisations to support people centred care. Prammer (2012: 26) discusses the challenges in organisational change cooperation. Managing the interfaces between organisations is a challenge because of ‘different traditions, culture and work logic’. This Austrian paper states that the use of cooperation is useful in establishing coordination and a way in which they can react to their complex issues and their (organisations) need for reciprocal interdependence. The challenges of cooperation can be supported by contracts, streamlining the administration and implementing work process rules competences. Non Governmental Organisations (NGOs) and private organisations have increasing difficulties as they try to navigate statutory organisations management hierarchy. NGOs in addition are dependent on market principles due to their ‘private business’ type organisation but also challenged by politics and efficiency and function for clients and staff. Success factors have to be top-down and well as bottom-up and include trust and commitment to agreed solutions, carefully designed step-by-step processes, a common understanding, criteria based recruiting, addressing power inequalities, pointing out conflicts of loyalty, providing an ‘all party approach’, building up work capacity step-by-step with opportunity for learning and readjusting, circular planning process, consensus/co-operative decision making , joint consideration of issues, analysis and decision-making, teamwork, and temporary isolation (no information communicated externally) during certain phases of development.

Carlsson-Wall et al. (2011) provides a grounded account of inter-organisational controls and work practices in the public sector to complement previous literature's strong focus on inter-organisational customer–supplier relationships in the private sector. They used Hopwood's (1974) administrative, social and self-controls as a theoretical framework to analyse the influence of non-managerial controls on behaviour. A case study of inter-organisational cooperation between home help units and health centres was analysed.

Most inter-organisational controls were developed locally and involved a mix of administrative, social and self-controls. Intra and inter-organisational social and self-controls were important forms of control which impacted on intra and inter-organisational work practices. Carlsson-Wall et al. (2011) also reported the need for a broad conceptualisation of control (Van der Meer-Kooistra & Scapens, 2008). Inter-organisational social controls created an informal hierarchy that by-passed the formal hierarchies of the two organisations. Self-controls reinforced the importance of being flexible to accommodate pensioner's wishes and needs in specific care situations. The authors also showed the importance of the internal financial situation of home help units for the analysis of the interdependencies of intra and inter-organisational controls and work practices.

Examples of digital computerised mechanisms within care organisations are shared from Canada. De Guinea et al. (2011) discuss the issue of e-collaboration in relation to multi-agency working. They discuss how it is multilevel in nature (De Guinea et al., 2011) and note the dangers of research using a single-level focus only (De Guinea et al., 2011). Dubuc et al. (2016) explored the development of a computerized integrated-care pathway system to support people-centred and integrated care which aims to promote fair access, promote independence for frail and disabled people living in the community through prevention and support services in the PRISMA model. They noted that integrated service networks (ISNs) have been established for older people in Quebec, Canada. PRISMA is the only example of a coordinated-type integrated care model (at no additional cost) which has been implemented and fully evaluated (Macadam, 2015). Challenges still experienced are reducing unmet need for case management and home care services, creating incentives for community physicians to participate in care planning and improving the computerised client chart. Dubuc et al. (2016) concluded that computerization was a key component of the integrated care pathways (ICPs) and that the new Quebec RSIPA solution (clinical and management computerised system) incorporating the ICPs was an example of promising new technologies 'that support integrated-care delivery through better assessment, planning, organization, and monitoring' (Dubuc et al. 2016: 2).

Establishing a computerised integrated care pathway (ICP) system has been an integral part of the PRISMA 'coordinated type' model (Hebert, 2015) which has been developing over the last 20 years to meet the needs of frail and disabled older people. Dubuc et al (2016) go on to state that there remain some gaps when assessing, planning and delivering health and social care 'despite trying to reflect client's values and preferences within the developing health and care organisations in Quebec. They developed a computerised integrated care pathway system to support the model of single point of entry, case management and coordination. In addition a 29-item scale to measure functional ability of older people called the SMAF (Functional Autonomy Measuring System). This was followed by the Iso-SMAF which consists of a case-mix classification system (14 profiles) based on the needs of the people and the SMAF data. Each profile is associated with a specific number of hours of care support, supervision and other costs linked to the individual's care. These profiles (based on individual scores of functional ability) are used to identify service eligibility and to calculate the budget's required. Thus reflecting people centred planning and health and social care delivery (Hebert et al., 2012).

Care organisations vary in their structure and type. Examples from social enterprises (Lyon, 2013), citizen initiatives (Turnhout et al., 2016); and locality hubs delivering integrated care (Compton et al., 2017) are provided. Many view social enterprises as being more collaborative than the private sector. However, there is limited understanding of the processes by which trust is built up and maintained in these contexts. Lyon (2013) examined the relationships between commissioners and providers, users/beneficiaries/customers (vertical relationships), and relationships between providers (horizontal relationships) and provides a framework for understanding collaboration. The issues of building relationships in quasi markets and in an environment of emerging competition (e.g. the moral economy and morality of products) and the risks of dependence on public sector funding are explored by looking at the case of self-employment support provision in the UK.

In the Netherlands, citizens increasingly develop initiatives with each other in the community so that they can live at home for longer (Turnhout et al., 2016). One way of achieving this is by organizing health and welfare services themselves, for and by citizens, and based on engagement and reciprocity. Since February 2015, these citizen initiatives in (long-term) health care, social care and welfare have increased from 63 to 174.

North West Surrey CCG (NWSCCG) has been establishing Locality Hubs – physical buildings offering a fully integrated GP-led, multi-disciplinary 'one-stop-shop' services in the community for a defined cohort of frail elderly patients with multiple core morbidities. Hubs will deliver proactive and reactive care, available 24 hours a day, 365 days a year There has been a 3.6% reduction in non-elective admissions across acute providers in NWS in the over 75 years age group for Woking, compared with an increase in activity in the other localities, which equates to a saving of £89,967 (Compton, et al., 2017).

In 2016, the Untapped Potential report highlighted the need to bring the voluntary sector's strengths to health and care transformation (New Philanthropy Capital, 2018). It made practical recommendations around properly integrating the voluntary and community sector (VCS) offer into the future health and care system, creating evidence-based solutions that will help to bring about the vision set out in the NHS Five Year Forward View, and doing so in the context of scarce resources. The Richmond Group of Charities (The Group), supported by Public Health England, has been working with partners in Somerset to explore what a successful health and care collaboration between the VCS and statutory health services could look like in practice. NPC was commissioned to help capture early learning from the initial stages of this work. The report outlines the main findings, with the aim of supporting future decision making and understanding the potential to roll out this approach in other areas. This is reported earlier.

Collaborative working between general practice (GP) and voluntary and community sector (VCS) organisations is increasingly championed as a means of primary care doing more with less and of addressing patients' "wicked problems" (Southby & Gamsu, 2017). Using a case study design to examine the lived-experience of GPs and VCS organisations working collaboratively, four cases each consisting of a GP and a VCS organisation with whom they work collaboratively were identified. While there were similarities across cases in their use of, for example, health trainers and social prescribing, the form and function of GP-VCS collaborations were unique to their local context. The identified factors affecting GP-VCS were shared understanding, time and resources, trust, strong leadership, operational systems and governance and the "negotiation" of professional boundaries. While the current political environment may represent an opportunity for collaborations to develop, there are issues yet to be resolved before collaboration (especially more holistic and integrated approaches) becomes systematically embedded into practice.

Tong et al. (2018) assessed the process and extent to which four non-profit organisations collaborated to meet service objectives related to older adults in a local area. Successful inter-agency collaborations involved: shared vision; effective communication; time to build relationships; shared expertise and resources; and strong leadership. Factors that jeopardised inter-agency collaboration included: misinformed understanding of goals; meetings seen as a waste of time; not sharing resources; and a lack of organisational resources. Successful collaborations are about a process that includes relationship building, sharing of resources and establishing a shared vision.

Weinberg et al. (2009) examined interagency collaboration between child protective services (CPS), local education agencies (LEAs), and other public agencies in seven California counties. These agencies were assigned to provide technical assistance to remove barriers impeding the education of children in foster care and to improve the children's educational outcomes. Results of this study suggested that making changes to remove educational barriers for foster children and to improve their educational outcomes required successful collaboration between CPS and LEAs and strong leadership within at least one of the agencies.

Quality indicators and measures include the Readiness for Integrated Care Questionnaire (RICQ), an instrument to assess readiness to integrate behavioural health and primary care (Scott et al., 2017). Integration of behavioural health and primary care services is a promising approach for reducing health disparities. The growing national emphasis on care coordination has mobilized efforts to integrate behavioural health and primary care services across the United States. Drawing from their work on a multiyear integrated care initiative (Integrated Care Leadership

Program; ICLP) and an implementation science heuristic for organizational readiness (Readiness, Motivation General Capacity and Innovation-Specific Capacity; R = MC2), the authors describe the development and implementation of a tool to assess organizational readiness for integrated care, referred to as the Readiness for Integrated Care Questionnaire (RICQ). Piloted with 11 health care practices that serve vulnerable, underprivileged populations, initial results revealed that participating practices were generally high in motivation, innovation-specific capacities, and general capacities at the start of ICLP. Additionally, analyses indicated that practices particularly needed support with increasing staff capacities (general knowledge and skills), improving access to and use of resources, and simplifying the steps in integrating care so the effort appears less daunting and difficult to health care team members.

Tsutsui et al. (2017) discusses the development of a quality indicator for adult day services to promote the community-based integrated care system in Japan. Incentives through the long-term care and medical fee system already promoted collaboration between healthcare facilities and community-based long-term care services, and the new reform of the system in 2012 reinforces this integration of care. However, in large cities, long-term care benefit costs are increasing with the increasing elderly population ratio. In Japan, long-term care providers are increasing rapidly, especially those who provide services for elderly people with low levels of care, as they can run the business at a relatively small scale and their income is firm. As a result, there is a problem of increasing number of the providers in cities. Tsutsui et al. (2017) suggest that they need to control the number of these providers through the assessment of the quality of the services they provide.

In this research, Tsutsui et al. (2017) attempted to develop a quality indicator for adult day services in the community-based integrated care system. The 25 item index comprised of categories, staff support, care techniques, awareness of providers, and awareness of community residents. They asked all providers who participated to submit data concerning the activities of daily living and quality of life (ADL/QOL) of all their services users in these indicators and at the two points in 2015 (August and February). Furthermore, the researchers state that ‘O-city prepares to make financial incentives to use the quality evaluation by indicators’ (Tsutsui, et al, 2017).

Fernandez et al. (2018) discuss the economics of coordination and integration with social care in England and the effect on post-operative length of stay. They used a Markov queuing model and data collected from administrative records to estimate the link between two proxy indicators of across-sector complexity of discharge arrangements and post-operative length of stay in hospital for older people undergoing hip replacements. Results suggested that the number of local authorities involved in care planning and commissioning of social care services for discharges from a given hospital is significantly positively correlated with longer post-operative lengths of stay. A particularly strong effect was found between variability through time in the number of authorities involved in discharges from a given hospital and lengths of stay. The results suggest that improving information systems and joint assessment processes used during the discharge of patients with social care needs is likely to achieve significant efficiency gains in the health care system as a whole.

This section has highlighted the struggle of interdependence, the role of inter-organisational controls (self, social and quality) and the variety of care organisations developing from both bottom up and top down. All have to consider how they work together, how they manage their interfaces, and their processes.

POLICY AND GOVERNANCE

This section focuses on international literature relevant to the theme ‘policy and governance’ and multi-agency working. It includes eighteen (n=18) articles which provide an insight into policy transfer and policy translation between European countries, USA and UK. They are (Lai Meng & Cameron, 2019; Drysdale, 2017; Sarquella et al., 2016; Leichsenring et al., 2016) networks in Haiti, Finland (Nolte et al., 2012; Henttonen et al., 2016; Keeling et al., 2012; Hansson et al., 2010), measurement tools and frameworks in UK, Ireland (Rosansky et al., 2017; Keeling et al., 2017; Collaborate Foundation, 2018; Lintz, 2016; Lennox-Chhugani & Crossley, 2017) Integrated care development and implementation in Greece, Belgium, UK (Tsartsara, 2016; De Ridder et al., 2017; Deloitte,2019); inter-organizational information sharing in Sweden (Karlsson et al., 2017) .

The number of studies researching the mechanisms involved in policy transfer and policy translation in integrated care development are limited (Lai Meng & Cameron, 2019). This international literature review documented the influence of policy transfer on integrated care development, its global occurrence and shifts towards integrated care. They argue that understanding integrated care through a policy lens is important to understand structural, environmental and cognitive challenges in the transfer process. It is important because it can also consider the replication and transferability of ideas, scaling up of ideas and contextual issues when policy is implemented. These considerations are important as they could determine what is transferred, by whom, and who benefits and losses in the process.

Leichsenring et al. (2016) asked the question ‘how compatible (if at all) is integrated health and long-term care delivery with increasingly fragmented provider markets stimulating user choice in a competitive environment?’ Comparing three international case studies in Germany and Sweden, the authors concluded that short-term projects are unlikely to be successful. Although there are quite different approaches to integrated care it is possible to build common values of mutual understanding, enhance trust and joint working. It takes time to build cooperation and agree a ‘common ground’.

Drysdale (2017) described an international collaboration between Boston and Washington (USA) and Oldham (UK). They have similar economic features but the USA models have significant differences in the progress, development and deployment of sustainable systems models of integration. Oldham has taken international learning of best practice to better shape its urgent care system using a multi-agency approach. They were able to demonstrate sustained quality improvements for people and system flow via a number of innovative, transformational approaches that had a sustained positive impact on a reduction in unplanned admissions in excess of the National expected average (3.5%).

Sarquella et al. (2016) recognise that Government policy in Europe is moving from a health policy agenda to integrated health and social care, especially for those people with chronic disease. Whilst acknowledging the difficulties of undertaking this in practice, they describe an approach between Catalonia in Spain and Scotland to work together through a signed memorandum of understanding (MOU) and a series of workshops to promote shared learning and cooperation in integrated care policy and practice implementation (e.g. ICT) to improve the wellbeing of their citizens.

The disaster management in Haiti in 2010 used a UN cluster system to centralise and coordinate activities. This included a centralising mechanism for databases, a web portal and google groups; and other sub networks formed due to common cultural backgrounds (Nolte et al., 2012). They defined network coordination as task and network management, clear understanding of roles and responsibilities, effective meetings and shared resources. This mixed methods study analysed the responses of 291 aid workers to a questionnaire and qualitative interviews to test the process model to network performance after the earthquake. The literature had told them that there were four success factors to network activity: having a predisposition to cooperate, incentives (e.g. perception that information will be shared), leadership and equality (equal power and equal participation in decision making). Both incentives and quality were the two factors that positively affected network coordination. Small organisations were most likely to meet the challenges due to their flexibility, whilst very large and public sector organisations were most likely to take leadership roles. They recommended that there was a need for mechanisms that enabled smaller and non-profit organizations to participate in network coordination and leadership (Nolte et al., 2012).

Henttonen et al. (2016) identified that there was a gap in understanding how networks were governed. They explored exchange theory (Levine & White, 1962), resource dependency theory (Emerson, 1962) and inter-organisational equilibrium (Bensen, 1975) as underpinning theoretical frameworks. They identified four governance mechanisms for multi-party collaboration of public organizations, domain consensus, ideological consensus, positive evaluation and work coordination. The contextual issues they identified were cultural organisation, the stage of network development, human capital and financial resources.

Hansson et al. (2010) described coordination in networks for improved mental health service. Well-organised clinical cooperation between health and social services has been difficult to achieve in Sweden as in other countries. An empirical study of a mental health coordination network in one area in Stockholm, the aim was to describe the development and nature of coordination within a mental health and social care consortium and to assess the impact on care processes and client outcomes. The findings revealed different coordination activities and factors both helping and hindering the network coordination activities. One helpful factor was the history of local and personal informal cooperation and shared responsibilities evident. Unclear roles and routines hindered cooperation.

This study contribution is an empirical example and a model for organisations establishing structures for network coordination. One lesson for current policy about integrated health care is to adapt and implement joint coordinators where full structural integration is not possible. Another lesson, based on the idea of patient quality by coordinated care, is specifically to adapt the work of the local addiction treatment and preventive team (ATPT)—an independent special team in the psychiatric outpatient care that provides consultation and support to the units and serves psychotic clients with addictive problems.

Technology is a necessary component for multiagency working across organisations for various reasons including service and people outcomes data collection along the pathway. They contribute to the discussion around quality assurance, governance and commissioning. Whether or not an organisation, or a system, is ready to work together i.e. collaborate, coordinate or integrate, will make a difference. The measurement tools and frameworks identified within the literature review included a 7-dimensions framework to assess integration preparedness in Ireland (Keeling et al., 2017), an integration scorecard (Rozansky et al., 2017) and a Collaboration Readiness Index (Collaborate Foundation, 2018), a readiness assessment tool for implementing integrated care (Lennox-Chhugani & Crossley, 2017), and a conceptual framework to assess inter-municipal cooperation on the environment (Lintz, 2016) is reported in the community section.

Keeling et al. (2017) describe an international collaboration with the International Foundation of Integrated Care, the University of Italian Switzerland and the Health Service Executive in Ireland. The 7-dimension framework assists organisations in identifying facilitators and barriers to integrated care implementation. It is based on best practices of successfully implemented integrated care projects across Europe. This project differed as it used the framework to assess a complete health and care system in Ireland, and in sites with no special preparedness or commitment to structured integrated care. The objective was to conduct a SWOT analysis to assess the current situation within Ireland with respect to integrated care. The research included a survey and ten focus groups with discussion guided by the framework on the degree to which these dimensions were in place and in identifying service planning barriers. Outcomes were related to agreed proxy measures of a lack of integrated care (e.g., bed blocking, readmissions). Results of the project gave an indication of the state of readiness for integrated care practice in Ireland and a picture of the factors that needed addressing, but did not provide any details as such.

The integration scorecard developed by Rozansky et al. (2017) used desk top research, in-depth case studies of three areas (n=3), interviews with experts and workshops (n=3) with policy holders, national and regional stakeholders of the whole system. The authors developed a logic model and supporting metrics for improvement and signposting people to other resources. The logic model included enablers of integration, components of integrated care, outcomes (people, services, system) and impacts. The identified 'enablers of integration' were local contextual factors, strong system wide governance and leadership, integrated electronic records and sharing across the system, empowering users to have choice and control, shared decision making and coproduction, integrated workforce (joint approach to training and upskilling of workforce), good quality and sustainable provider market, joined up regulatory approach, pooled or aligned resources, joint commissioning of health and social care.

The Collaborate Foundation (2018) undertook a study to validate a framework which would examine the state of collaboration in the UK. The Collaboration Readiness Index, comprises six categories of readiness that are required to survive and thrive in this more complex operating environment: Collaborative Behaviours, Citizens, Systems, Services, Places and Markets. The aim was to use the Collaborate Readiness Index to ascertain the extent to which people were indeed ready and the extent to which they do have the commitment, skills and support to work together to deliver integrated services and improve outcomes for citizens. The authors found that where collaboration between agencies was successful, the categories of the Collaboration Readiness Index did comprise of key elements of the new ways of working together to produce better outcomes. However, results also indicated that the State of Collaboration in the UK is far from "ready" to fulfil the political demands for integration. There is a need for managerial and political commitment to collaborate with others, including a meaningful engagement of citizens, for greater skills and greater understanding of the multi-sector provision of service, and for leadership support of the people on the ground who are actually trying to make a difference.

Tsartsara (2016) explored the regional governance structures in a region of Greece under economic crisis. The activities were aimed at shifting to a community based care bundle in personalized care management, a community nurse based care and at home model, and rehabilitation and assisted living services by creating Health Ecosystems with regional health policy coordination that would favour the creation of spin-off structures for their autonomy at a local level called the 'One Living Lab'. They concluded that poorer regions need to set structural reforms that do not rely on resources.

In Belgium, Ridder et al. (2017) described a whole country approach with a co-productive process combining of bottom-up ideas (staff, no mention of members of the public included) and entrepreneurship with guidance from policymakers and encouragement for collaboration. It included 20 pilot projects covering a third of the Belgian population. They were provided with funding and coaching and coordination support from a paid external consultant.

In the UK, the paper published by Deloitte (2019) makes the argument for using population health management (PHM) as a change management approach to transitioning systems towards integrated care in England. Population health management embraces the quadruple aims of health care, which are to: improve the health of the population, the experience of care, the health and wellbeing of the workforce, and reduce the overall costs of care. While population health is not a new concept, attempts to tackle it have been fragmented, with health policy still largely focused on treatment rather than actions to address the wider social determinants of health. The PHM is a patient-centric, data-driven approach to optimise the physical and mental health of populations over individual life spans and across generations. The authors argue that there is a need to develop a common language, empower patient activation and monitor and challenge progress against metrics. Furthermore, leadership should invest in relationship building skills, funding infrastructure, prioritise primary care as an asset closest to the community, appoint executives with responsibility for innovation and quality, communicate with the information governance framework and ensure informed board members.

Inter-organisational information sharing is essential in the public sector. Karlsson et al. (2017) investigated the reshaping of social and organisational factors of inter-organisational information sharing in the public sector over four years in nuclear waste management. They traced how factors in the model proposed by Yang and Maxwell (2011) were reshaped over time. Two factors in the model – concerns of information misuse and trust – were frequently assessed by organisations and were the most likely to change in addition to legislation and policies in the long term. Policies need to be designed for the context they are used in. For example, a low trusting context requires different policies to a high trusting context.

CONCLUSIONS

Most international literature published has a strong health care focus although alternative insights are offered from housing, environmental industry, and nuclear waste management. The question asked at the beginning of the review was 'What are the characteristic success factors of multi-agency working in public and non-public sector services?' Multi-agency being defined as '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). A definition which relates to the complex integration of relationships within and across multiple domains including individual, family, professional organisation and strategic partnerships. There are multiple success factors which are common across multiagency working, coordination, integration and partnership; and across statutory and non-statutory services, and private and not for profit sectors. These predominantly include organisational and individual values of trust and equality. There are examples of best practice sharing across countries. Not one study has sought to identify the success factors of a country's workforce working towards multiagency working.

Key Messages

- 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.

VOICE AND CONTROL

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

INTRODUCTION AND REMIT

In conducting the literature review, a number of things informed our search criteria. This started with reviewing the Act and its associated Codes of Practice, and technical papers written to support communication around the Act.

The remit of the scoping review is defined in the method statement earlier in the report. All the papers included have relevance for the circumstance and the context of Wales, even though material is drawn from the rest of the UK, Europe, North America and other places. The terminology therefore varies, but the concepts discussed are germane to the situation in Wales. Relevant ideas around voice and control that emerge from outside the context of social care and social services are also included. The review covers a range of client population groups, with sections covering specific groups e.g., older people and carers. This structure allows us to tentatively pull together literature covering some groupings, whilst exploring possible cross-cutting themes. Of equal importance, we have sought to structure the review based on what we refer to as ever widening spheres of influence.

VOICE AND CONTROL – MEANING AND PRINCIPLES

Our review starts with the Act. 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 (Social Services and Well-being (Wales) Act, 2014: 7):

> *"in so far as is reasonably practical have regard to the individual's views, wishes and feelings"*
>
> *"have regard to the importance of promoting and respecting the dignity of the individual"*
>
> *"have regard to characteristics, cultures and beliefs"*
>
> *"have regard to the importance of providing appropriate support"*
>
> *"have regard to the importance of beginning with the presumption that the adult is best placed to judge the adult's well-being"*
>
> *"the importance of promoting the adult's independence where possible"*

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 and contribute to the decisions that affect my life or have someone who can do it for me.*

Our framing 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.

DEFINITIONS IN THE PUBLISHED LITERATURE

On the whole, the literature does not provide clear definitions of the terms 'voice' and 'control'. However, there are a number of key contributions.

Vamstad (2016: 2164) cites Hirschman as describing voice as 'any attempt to change, rather than escape from, an objectionable state of affairs'. Callaghan et al (2014) refer to choice and control within their research as being related to control over one's daily life. They cite a number of other authors to describe choice for older people as having less to do with managing by oneself and more to do with having control over the delegation of their care and responsibilities, and influencing how and when care and support is delivered (Bamford and Bruce, Quereshi et al, Gabriel and Bowling, Quereshi and Henwood, all cited by Callaghan et al 2014). Furthermore, they highlight that studies examining control have used a variety of different methods and scales to measure this concept, as well as many studies using this term interchangeably with other related concepts such as autonomy, independence, and locus of control (Skinner 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. 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). Some of these key terms are introduced below.

Person-centred care

Hanga et al (2017) refer to person centred-ness as an individually tailored, holistic approach to meeting a person's needs and recognising the person requiring support as an active participant. It is an approach to care that centres is rooted in an active respect for and integration of individual differences when delivering care (Lauver et al 2002, McPherson and Siegert 2007, all cited by Hanga et al 2017). Washburn and Grossman (2017) go further, describing this approach to care as a way of being with the individual rather than exclusively 'doing' for him or her, and requires a relationship-centred approach. In developing their framework, Hanga et al state that person-centred care involves understanding that the person or client is a unique individual with their own characteristics, needs, values, beliefs, and preferences, responding flexibly by delivering interventions that are responsive to clients' initial and changing needs and preferences. The framework they adopt involves four components: the person is treated as the expert in their own life and as the centre of the services; the person's individual characteristics, values, beliefs, preferences, and changing needs are central in delivering services; the professional is empathetic and shares equal partnership (in terms of power and responsibilities) with the person; and the clients are empowered in making choices, planning and implementing care. Washburn and Grossman (2017) also refer to person centred care, which they describe as requiring a relationship-centred approach.

Empowerment

Keyes et al (2015) focus on the concept of empowerment which they define in line with the social model of disability as aiming for relationships between disabled people and the services they access to be rooted in independence and autonomy. They also rely on the concept of 'relational autonomy' (which is defined by Christman, 2004: 143, cited by Keyes et al 2015) as 'what it means to be a free self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of interpersonal relations and mutual dependencies'. Keyes et al therefore define empowerment and autonomy not in terms of self-sufficiency, but on the basis that in order for people accessing services to be empowered, the locus of control within services must remain with the person accessing those services, while also acknowledging the significant role of interdependent caring relationships in realising people's relational autonomy, thereby enabling choice and control.

Personalisation

Personalisation is defined by the Department of Health (2015) as tailoring care and support to what individuals choose as a means of helping them to live their normal life. In line with this they recommend that those being supported in this manner should have as much voice, choice and control as they want in their own unique circumstances, which means avoiding assumptions about people's wishes and abilities and avoiding rigid, impersonal approaches. Instead, the focus should be on building relationships with people. Personalisation according to Glenndinning et al (2015) aims to empower people (in this case, older and disabled people) to exercise control and choice over their support arrangements, with Hamilton et al (2017) define personalisation as a re-conceptualisation of the public sector, "starting with the person rather than the service" (Carr, 2010: 67, cited by Hamilton et al, 2017). However, there has been criticism that the personalisation agenda has to date been largely transactional and this limited. O'Rourke (2016) states that personalisation of social care has become associated with a form of consumerism in which independence is constructed as minimal reliance on others, and where choice is narrowly constructed as choice of services within a competitive marketplace. In this context, they state that control often consists of managing a personal budget. Recognising the role of personalisation and the potential personal budgets to empower people, Gridley et al (2014) state that such empowerment entails a radical shift in power, from professionals to individual service users and their families, although with the most emphasis on person-centred care.

Shared-decision making

Having control over one's life, and making and as necessary sharing decision making is a recurring theme. Shared decision-making is derived from healthcare and is described by Brogan (2018) as a process involving the patient and provider sharing preferences and evidence to reach agreement in treatment. Pavlo et al (2019) also describe shared decision-making, defining it as a collaborative approach to making decisions in healthcare, and as a cornerstone of person-centred care. They state that it involves self-determination and choice, and requires a shift from paternalism to a more dynamic and interactive decision-making process.

Summary

This section highlights a number of key messages around defining voice and control:

- Contested terminology, with a lack of consensus in the literature as to what voice and control means; and
- Conceptual overlap with other terms which provide insight into linked dimensions and components of how voice and control is given meaning/manifested.

INDIVIDUALS

This section of the literature review focuses on literature surrounding voice and control and the way in which this concept can have positive impacts on the well-being of individuals. This section is concerned with how drives to increase voice and control manifest and impact on people's lives, with a focus on those requiring support and care provision. The section is subdivided into overarching themes that came up in the literature review: impact, situations where people are more or less likely to have voice and control, and quality of life and self-advocacy.

Impact

There was evidence of impact across a range of demographic groupings; this section focuses on literature concerning social care for older people, impact, and voice and control.

Vamstad (2016) examined the extent to which older people assume the role of a 'consumer' of home care. As a result, older people with care needs were found to not act like consumers, with participants being unfamiliar with the choice, not knowing how to choose and not understanding why they should choose. This was reported to be due to lack of ability and interest, a sense of gratitude and general satisfaction, and also the circumstances in which such a choice is typically made, e.g. during illness or facing time restraints. Few claimed to be dissatisfied, which indicated gratitude. However, many still had complaints or opinions about their home care, with some stating that they had an opinion that they did not communicate with anyone else. While some participants used 'voice' as a strategy, many reported that they had no opinions at all or that they had opinions they did not bring up. Therefore, this suggests that voice is not a particularly significant source of influence, even if it is more accessible than 'exit' as a strategy. Furthermore, relatively few of those who expressed their opinions felt that their concerns were considered by the provider. The 'exit' approach was considered almost entirely irrelevant in selecting home care services, as older people very rarely switched from one service to another. This was thought to be due to gratitude and personal bonds to the staff, in addition to lack of ability and the individuals' circumstances. Where exit was not possible, it was suggested that older people should voice their concerns to alter their care, and while there were some signs of this occurring, it was not to the extent that might be expected

O'Rourke's (2016) qualitative study of cases in two local authority areas in England exploring older peoples' experience of using a personal budget (in the form of a direct payment), revealed that participants experienced personalisation and their needs were accommodated. This was mostly achieved despite the consumerist aspects of personalisation rather than because of them, and often gave rise to risk and dilemma. Findings emphasised the importance of holistic assessment and commissioning for quality rather than for maximising choice. As noted earlier, personalisation is one of the terms that has conceptual overlap with voice and control, and the use of personal budgets is a key strategy that has been used to increase the sense of voice and control that some service users have. However, as O'Rourke explores, there are problems with this strategy, particularly its reliance on consumerist models of individualism.

Darby et al (2017) reported on a study of older patients discharged from an acute medical unit. Older people reported having ongoing unresolved health and daily living needs after discharge, even with the additional geriatrician support which aimed to conduct a comprehensive health assessment specific to the problems and needs of the older people. Informal carers therefore had to assist patients with these needs but patients expressed their wishes to regain independence with these activities. This paper explores the ways in which voice and control may be diminished after older people are discharged from an acute medical unit, due to ongoing health and daily living needs, and the ways in which informal carers could assist older people in regaining independence and implicitly a better sense of voice and control.

Lastly, the literature also reveals the impact made in other service areas. For example, Lonbay (2018) examined older adults' involvement in adult safeguarding and found that whereas participants considered involvement in general social work practice to be about full inclusion in decision making, in adult safeguarding the meaning of involvement changed to just be about hearing the person's voice as they were typically viewed as being unable to participate fully. This 'hearing the voice' concept was achieved through pen pictures, advocacy, or representation by a family member. Direct involvement by the older person was reported as rarely occurring, as participants felt that older adults are unable and unwilling to be involved. Involvement was therefore viewed as inviting citizens' opinions, but retaining the power to judge how legitimate these inputs were. Reasons why involvement occurs in this way had to do with the characteristics of the older people, such as whether they had capacity and whether they were able to make an informed choice about their involvement. The authors claim that conceptions of 'vulnerability' reaffirm a power hierarchy whereby vulnerable people have safeguarding done to them rather than being empowered and involved in decision-making. Furthermore, for older people, issues associated with ageism further undermine their autonomy, eroding personhood and perpetuating paternalistic discourse, which may reduce involvement. These issues obviously negatively impact this particular group's sense of voice and control.

Situations where people are more/less likely to have voice and control: older people

This section focuses on literature regarding situations where older people are more or less likely to have control.

Callaghan et al. (2014) reported that setting had a significant effect on older people's sense of control, with residents in care homes and extra care housing reporting greater control, than those receiving care at home, even after other factors were controlled for. Other factors associated with feeling more in control over daily life were being less dependent, and rating health more positively. Discrete choice experiments (DCE) were used with older people with dementia and their carers, and can be used to inform clinical practice regarding their preferences. DCEs enable taking into account the trade-offs that occur when choosing between different packages of support. However, they are cognitively complex which can cause difficulties in administration, particularly for those with advanced dementia. The complexities of applying voice and control principles with people living with dementia are apparent from this paper, and for certain groups applying voice and control principles presents more complex challenges than for others.

According to Dunér et al (2019), a 'test and revise' approach enabled those involved to continually adapt the initial decisions to the ongoing and changing needs of users, and so promoted voice, choice and control. Enabling older people to have 'choices in the moment' allowed service users flexibility to decide what services they wanted, in collaboration with the staff. However, their voice and choice in this context could be limited by staff unwillingness, insufficient information, and limited time. 'Quality improvement through competition' offered the opportunity to choose and change service providers. This was used to an extent by some service users, but overall participants felt that flexibility regarding how care and services were provided was the most important aspect to enable users' choice and control. Factors which affected users' choice and control in achieving this included organisational routines, paternalistic attitudes, and users' subordinated positions.

Quality of Life and Self-advocacy

This section looks at literature surrounding quality of life and self-advocacy as it relates to individuals, impact and voice and control. We found evidence of impact across a range of demographic groupings; this section focuses on literature concerning social care for those with intellectual disabilities.

A study of supported living schemes for people with intellectual disabilities was conducted in the Netherlands by Reindl et al (2016), which focused on parent-initiated supported housing schemes. These aimed to stimulate self-advocacy and autonomy for the tenants. However, overprotective and paternalistic attitudes were noted and structural constraints affected these schemes, creating obstacles to the tenants' personal development. The main motivation among parents for starting such initiatives was to have greater power to choose and decide about care and housing, in contrast to the lack of attention that parents considered was given to the consumers' wishes and opinions in classical care institutions. Some parents did however, express concern regarding their children's lack of ability to make decisions. One father highlighted how too much choice could be overwhelming for tenants. This was considered to be particularly relevant for tenants with autism. The tenants themselves expressed that they felt their opinion was considered enough, and none seemed to feel restricted their freedom or autonomy. All expressed that they felt in control of their life and were grateful for the support given by their parents and caregivers. The paper highlights that developing self-advocacy and self-determination skills is not sufficient to achieve social inclusion for people with intellectual disabilities. Rather, integration requires collaboration between the individual and the community, and the eradication of barriers. These issues and strategies impact individuals' sense of voice and control.

Morris et al (2017) sought to develop standardised self-report measures of quality of life for residents of long term care facilities. Their study revealed that most (70%) felt they had personal control over key activities most of the time, with over 80% reporting that they could be alone when they wanted, they could decide on the clothes they wore, and decide how to spend their time. However, only 43% reported that they could decide when to bathe most/all of the time, due to institutional rules or routines. We can see that for this group of social care users, they felt they had different levels of voice and control over different elements of their care and their daily activities.

Tideman et al (2015) explored the significance of self-advocacy groups for young adults with intellectual disabilities. Participation in such groups opened up new roles and identities, and strengthened the participants' control over their daily lives, which would result in positive outcomes in respect of voice and control. According to Dillon et al (2016),occupational therapists stated that promoting self-advocacy among clients enabled those clients to learn skills that would help the to overcome barriers, and sustain them in the future even after occupational therapy services were no longer being used by the client.

In their research, Hamilton et al (2017) state that people with intellectual disabilities desired independence, and experienced contextual constraints on their independence and agency. They also highlighted fragmented social networks due to budget cuts, and so experienced increased isolation and exclusion. We can see that the desire for independence from this demographic dovetails with concepts surrounding voice and control, and the challenges presented to providing voice, control and independence for this demographic due to fragmented social networks and budget cuts.

Greig (2015) provides a commentary on a paper by Miller (2015) that investigates the impact of self-advocacy on culture. Miller suggests that self-advocacy can be a powerful tool in changing the culture of organisations, if there is the appropriate funding and support for self-advocacy to occur. Miller's study was based on the experiences of one NHS clinic for adults with learning difficulties. A self-advocacy group for patients was set up with the help of researchers, and the findings from this group were reported to change the attitudes of the staff and senior management through creating a culture of greater transparency for patients and including patients in the design of the service provided to them. However, Greig questions whether the study can actually demonstrate if the culture of this NHS clinic was altered following self-advocacy. Greig has identified three issues with the study. First, Greig suggests that the study actually demonstrates a change in practice, rather than culture. Secondly Greig refers to the fact that ward staff were not included in the research, and that they were reported as not wanting to alter the way they behaved in their role. Greig suggests if they were included, and subsequently changed their behaviour then this would equate to a change in culture. Finally, Greig argues that carrying out this study in one organisation that is a low-secure in-patient service is not sufficient to demonstrate a culture change, as these organisations are quite separate from others have a constantly changing culture as patients leave and arrive. Greig concludes that a larger scale study across organisations needs to be conducted, alongside more thought and consideration of what culture change looks like. The issues raised by Greig in this analysis all contribute to an understanding of whether voice and control is impacted by self-advocacy strategies, and the challenges and complexities of successfully implementing and researching such a strategy.

Tideman and Svensson (2015), explore the role of self-advocacy through interviewing 12 members of two self- advocacy groups for individuals with intellectual disability in Sweden, over a 10 year period. These self-advocacy groups involve members meeting through their own initiative, to help to increase the control they have over their own lives, and with the aim of changing society's attitudes towards them. The findings from these interviews revealed a number of positive outcomes from group membership. For example, members reported that the group helped to change their sense of identity; they discussed feeling reduced to a disability by society, and felt that the views of other members helped them. The groups made them feel part of a fellowship, and through this peer support members felt they could reconstruct identifies for themselves. Members discussed opportunities of having further control over their lives, and how they could be involved in care meetings or decide for themselves who they want to spend time with. Overall, the study suggested that self-advocacy groups can improve the health and well-being of members through sharing experiences, discussing rights and increasing their control and power over their lives.

Wright and Taylor (2014) examined parental advocacy (n=76) of young children with disabilities (from birth to 6 years). Parental advocacy of children with disabilities has been defined as "A non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction and contribute to creative solutions to problems existing in human services systems" (Munro, 1991, cited in Nachshen and Jamieson, 2000: 39). The study aimed to find out which settings parents advocate in, what the advocacy processes are, and their effectiveness. The study revealed that 71% of parents had advocated for their children in schools, 73% in medical clinics, 58% in social services 51% on social media and 22% in politicians' offices. Advocacy processes in these different settings involved the parents educating themselves about their child's needs and the services they could receive (e.g. occupational therapist sessions in schools), informing others about their child's needs, and seeking external support to assist them. Parents were asked about the level of effectiveness of their advocacy, and the highest rates reported were in schools (19% of advocacy efforts were perceived as highly effective) and the lowest in politician's offices or community events (both 4%). Consequently, the study suggests that parental advocacy for children with disabilities occurs in early childhood (before the age of 6) and that parents require knowledge about their child's condition and needs, skills such as problem solving, and support from external agencies in order to advocate for their child. Here, the issues of voice and control are blurred slightly, with the parents and children both needing to feel a sense of voice and control in this social care setting.

Summary

This section of the review has looked at literature surrounding individuals and voice and control. Some of the key messages here are:

- 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
- The challenges involved in implementing voice and control principles with different service user demographics, e.g. older people with dementia, or young children

CARERS

This section looks at the issues and literature around voice and control for carers. Given the focus of this in the Act, assessments, resources and budgets are explored as key factors shaping how voice and control may be enhanced or limited.

Assessments: Tools and Challenges

Seddon and Robinson (2015) highlighted deficits in the conduct of carer assessment such as reliance on structured problem-focused assessment protocols that restrict discussions and fail to capture the complexity of carer's lives, hindering the hearing of the carer's voice, and failing to capture the reciprocal nature of caring relationships. They also don't take into account the broader support network of individuals who may be involved in helping to care for someone. Furthermore, they are stated to constrain the narrative approaches that capture the affective dimensions of caring, the meanings carers attach to their various roles and how these might change over time.

Significant tensions highlighted by the authors regarding the carer assessment process include practitioner ambivalence towards the carer assessment process, supporting carers in and beyond their caring role, capturing the dynamics of care-giving and caring relationships, and distinguishing between carer willingness and ability to continue caring. This critique of problem-focused assessment protocols presents challenges in implementing voice and control principles in carer assessments, due to the limitations placed on the hearing of the carer's voice and the complexity of the carer's life circumstances.

Ewing et al (2016) discuss the Carer Support Needs Assessment Tool (CSNAT) which when used routinely with all carers has the potential to normalise assessment and support of carers, and allows practitioners to be more responsive to carers' individual needs. However, the authors highlight that the use of this tool alone is not sufficient to bring about benefits; benefits result from a change in the assessment process to an approach that is facilitated by practitioners, but led by carers. This therefore creates space for carers to identify their own support needs, separate from those of patients, and provides an opportunity to discuss their priorities. This is crucial when foregrounding the sense of voice and control that the carer has. Although practitioners initially expressed some concerns regarding the potential negative impacts of the CSNAT, after implementation impacts were shown to be positive, as it made support needs visible, legitimised support for carers and opened up different conversations with carers. This was achieved by the CSNAT creating space for the separate needs of carers, providing an opportunity for carers to express their support needs, and responding to carer's self-defined priorities.

Resources and Budgets

Glendinning, Mitchell and Brooks (2015) investigated the role of carers in personal social care and personal budgets (PBs) through interviewing 14 adults with disabilities and their carers. PBs are part of social care practice in England, akin to direct payments in Wales. The study found that carers played important roles in helping to plan the PBs of the service users, but that the PBs did not seem to provide the carers themselves with support. Although the authors note that government policy surrounding PBs has indicated that they should provide opportunities for carers themselves to have their needs met in ways that suited them (e.g. through having opportunities to learn new skills), the study suggests that this is not happening in practice. Very few carers interviewed in the study had been asked in detail about their own needs during visits from social services, and few carers had experienced assessments of their own. Those carers that had their own assessments reported that they were not asked about their wider goals (e.g. regarding employment, learning or leisure) as required by law (the Carer's Act, 2004). Glendinning, Mitchell and Brooks conclude that the needs of carers are often treated as secondary to the needs of the service users, and that while service users are having greater control and empowerment this is not felt by their carers. This obviously has a negative impact on the voice and control of carers. The authors further argue that social care services should be consistent in their approaches to discover the needs of the carers themselves, such as through systematic needs assessments.

Larkin (2015) explored the effect of PBs on service users and their carers, and found both positive and negative effects of PBs on the carer-service user relationship. Over half of the 23 carers interviewed stated that PBs had improved their carer-service user relationship. Carers described how the PBs gave them more "flexibility" and the opportunity to "take a break" from each other as alternative support could be paid for when needed which could be seen as having a positive effect on voice and control for carers and service users. It was also the case that two thirds of carers found PBs negatively affected the carer-service user relationship as they felt "redundant" or "pushed-out" and that they lacked confidence in the replacement care. This point presents a challenge to voice and control principles. However, several carers acknowledged that when they felt more confident in the replacement care, they did not view PBs negatively. A further negative identified by over half the carers was the stress induced by the increase in paperwork and administration following PBs. Carers often referred to time consuming and "complicated procedures" as well as difficulties with finding and retaining staff. Larkin concludes that PBs have been demonstrated to improve the lives of carers, but the study also suggests that carers need to be confident in the quality of the staff that provide the additional care, and that many carers may also need additional support regarding administration, recruitment and staff management. The careful implementation of PBs, alongside the other important elements suggested by the authors, could be positive for on carers' and service users' sense of voice and control.

O'Rourke (2016) explored eight older service users' (60 years old or more) experiences of personal budgets through direct payments and how this related to their sense of 'self'. O'Rourke argued that the idea of personalisation is essentially "consumerism in which independence is constructed as minimal reliance on others" (2016: 1010) and the management of a personal budget works for the state as it helps to get services (such as paid carers) at a cheaper cost than the state previously had to pay for. The study found that personal budgets were not a precursor to feeling a sense of self, but that they could help individuals to improve the situation with their long term paid carers through supporting their relationships with them. This improvement of the service user-carer relationship improved the service user's sense of self, as O'Rourke states, "Self is made and seeks validation through connections with other Selves" (2016: 1022). One example of this is that some service users mentioned difficulties with paying their established preferred carers before they had direct payments through a personal budget. O'Rouke concludes by stating that quality over quantity is vital for social care services, as quality care is essential for service-users to experience personalisation and a sense of self through carers that understand the "special requirements of Self" (2016: 1023). If this quality of care is delivered, then a surer sense of voice and control may be apparent for service users.

Larkin (2015) reports that just over half of the carers interviewed in their study felt that a personal budget, as a form of personalisation, enhanced the carer-service user relationship. While many reported other positive outcomes such as feeling happier, healthier, and having more control over their lives, many also experienced negative feelings about having less involvement in the service user's care. Over half of carers found administering the budget stressful. Findings also highlighted the importance of carers having confidence in the quality of care accessed through personal budgets. The most problematic issues were paperwork, recruitment, and staff management, and so many carers therefore require additional support. Recommendations to improve the outcomes of personalisation for carers and service users include supporting carers regarding the use of the personal budget, as well as training and support for carers in relation to paperwork, recruitment and management of staff. They also recommend streamlining local authority self-directed support processes for carers. We can see from this paper the challenges presented by personal budgets, and the ways in which these challenges can limit the sense of voice and control, for the carer and service user.

Singleton and Fry (2019) explore the role of Carer's Allowance (CA) in the UK and how this funding helps carers not only financially but also through providing them with a sense of identity and recognition for the role they play. The authors are also concerned with the role of CA in a wider sense of UK citizenship. This study is based on data from a series of focus groups held in the UK for carers in 2011. Altogether, 73 carers participated, and all were CA claimants. The study found that carers differed in their perceptions of CA. For some CA was viewed as recognition of their role in society by the government, or alternatively viewed as a basic income for their services. For others, CA was perceived as a "token gesture" that they believed was a way for the state to convince them to continue caring. Other carers believed CA to be an affront as it was not equivalent to the minimum wage and suggested that carers' work was not considered to be "worth" minimum wage. There were also carers that felt guilty for receiving money to care for a relative. When interpreting the data through the perspective of UK citizenship, the authors note that the respondents' views of CA and the effect on their identity are related to wider perceptions of citizenship. For example, the view frequently expressed by carers that CA was lower than the minimum wage, which they believed suggested that they had a low place in society, is related to the perception that paid employment is essential to be a full and valued citizen. The authors conclude that welfare benefits have a significant impact on the recipients' sense of identity and recognition as citizens and important members of society, and this should be recognised when welfare reforms are made. The authors suggest that opportunities for paid employment outside of caring may be welcome for some, but that ultimately it is important that future measures help carers and their communities view the value of their caring roles and the contribution they make to society. These measures would potentially increase the sense of voice and control that carers feel they have.

Singleton and Fry (2015) examined the perspectives of carers receiving Carer's Allowance (CA) and demonstrated that CA provides financial support but also contributes to normative conceptualisations of citizenship. The study highlights the primacy of paid work in UK citizenship and the stigma associated with receiving benefits. Carers expressed the symbolic value of the CA and its importance in receiving official recognition of carers' contributions to society, as well as helping to meet basic income standards of their households. However, many distanced themselves conceptually from other welfare recipients that they deemed less worthy. The authors conclude by claiming that changes to UK benefits need to consider a 'recognition' aspect, by reformulating the idea of what constitutes a worthwhile contribution to society. Again, issues around CA are tied to issues of citizenship in UK culture, and perhaps speak to a need for change in perceptions of those receiving benefits and the voice and control that they may have.

Galiatsatos et al (2017) reported that caregivers who received support from the Called to Care approach expressed enthusiasm about their experience, and that by enhancing the resources they provide to carers, organisations could help to make caregiving more organised and minimise caregiver burnout. This could then assist in implementing voice and control principles for carers.

However, the authors state that they do not have the results yet of a formal evaluation focusing on these types of outcomes.

Voice and control of carers

Glenndinning et al (2015) claim that aspirations of enhancing voice, choice and control do not appear to extend to carers. According to carers, routine assessment, resource allocation and support planning appear to focus primarily on addressing service user needs and aspirations, with carers assigned a subsidiary role, i.e. carers played an important role in service users' assessments and resource planning but were less likely to receive assessments or support themselves. This paper speaks to the challenges in affording carers a sense of voice and control, as well the people they care for.

According to McNeilly et al (2018), parents of disabled children wanted to be involved in all aspects of decision making and highlighted many examples of good practice, but also found there were times they did not feel listened to or didn't have enough information to inform decisions. This obviously negatively impacts their sense of voice and control. Parents reported the need to fight for their child, and partnership approaches to care that recognise parents' expertise were valued by parents. Mothers took the lead role in making decisions with professionals in relation to their child, but fathers were found to play a vital role in supporting mothers in this decision making. McNeilly et al therefore recommend that professionals have an important role to play in fostering the participation of fathers and in the decision making process.

A pilot project conducted by Montgomery et al (2017) showed how an initiative which captures the experiences of patients, service, users, carers, and staff in the health and social care sector (10,000 Voices) could be successfully adapted for adult safeguarding. Results highlighted the importance of communication, with service user feedback incorporated into local and regional service model improvement plans. The study also highlighted the importance of professionals understanding the outcomes desired by the service user or carer. This understanding of outcomes desired by the service user or carer will therefore help or hinder the sense of voice and control that they have.

Rand and Malley's (2014) study of carers showed that their experience of social care support and services affects their quality of life. They welcomed the recognition of carers as 'co-clients' who should be able to access support needed to maintain their wellbeing through the introduction of the minimum eligibility threshold for publicly funded services. However, introduction of this policy approach must address barriers to access of social care support, and ensuring that publicly funded support is effective in maintaining carer's quality of life and wellbeing. Key issues that need to be addressed in relation to the direction of this carer's strategy are the choice to care, stigma in communities, barriers to accessing support the relationship between carer's and service user's quality of life, and balancing the needs and preferences of individuals when making decisions regarding care provision. These are all key issues that need to be properly addressed in order to successfully implement voice and control principles for carers. The paper also highlights the increased pressures on social care budgets as a result of this approach, and that this will be a challenge to the realisation of this strategy.

Watts and Cavaye (2018) reported on a qualitative study of the experiences of former carers in the UK, which highlighted the need for support after the end of caregiving due to feelings of abandonment, lack of purpose and lack of motivation to move forward with their lives. Physical and mental health issues are also a long term concern for former carers, and many face financial losses which negatively affects their wellbeing. This highlights the complexity of issues for former carers, and implicit impact on their sense of voice and control once their caregiving responsibilities are concluded.

Galiatsatos et al (2017) describe the intervention Called to Care, in which three steps were taken for and with informal carers. The team first established partnerships between a hospital and community institutions. They then organised caregiver support groups to understand their attitudes, beliefs and concerns, and carers were encouraged to express what resources would help to make caregiving more organised and more enjoyable. The main resources described as being desirable were carer respite, and ensuring a healthy diet for the carer and the person they cared for. Finally, the team worked on attracting and matching appropriate resources to assist carers. Elements of this intervention could all assist in giving carers a greater sense of voice and control, particularly in the form of the carer support groups.

Pearl et al's (2018) study of social work students in Wales showed that feedback by service users and carers towards students was overwhelmingly positive. The findings of this study highlighted that this feedback can potentially be used as a learning tool. They therefore recommend increasing service user and carer involvement in gathering feedback about students on practice learning opportunities, such as attendance at workshops, and reviewing of the methods and tools for gathering such feedback. The ability to feedback like this may have had a positive impact on carers and service users' perception of voice and control.

Summary

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

- Finding 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
- The importance of quality social care practice in empowering carers to gain a sense of voice and control

WORKFORCE

This next section focuses on the literature surrounding voice and control and the workforce, across social care settings. It explores policy and practice in supporting staff, barriers and enablers, person-centred care, and advocacy in relation to voice and control.

Supporting staff: policy and practice

The Department of Health (2015) gives a number of recommendations for direct healthcare staff to promote voice, choice and control, based on the principles of care, compassion, competence, communication, courage, and commitment. Recommendations for other care staff include maximising health and wellbeing, helping people to stay independent, and working with people to provide a positive experience. These recommendations all help to foreground principles of voice and control at a policy level.

According to Keyes et al (2015), exploring service contexts rooted in empowerment highlighted the need to redress imbalances between services and people accessing those services, breaking down barriers to inclusion and promoting citizenship. They highlight that empowerment is achieved by focusing on the views of the people accessing services, placed in the contexts of the interdependent relationships between social workers and service users. This was thought to be more beneficial than the use of self-assessment forms which, although designed to promote autonomy, actually limited people's participation in the assessment process and their ability to identify their own needs. Two of the social workers interviewed in this study highlighted the central role of the relational approach. It was demonstrated that individual empowerment was achieved through recognition of relational autonomy and actual autonomy, rather than individualised autonomy, as well as elements of care at a micro level, such as attentiveness, and responsiveness. The relational approach and improvement in empowerment described in this paper, if successfully implemented, would assist in the sense of voice and control achieved by service users.

The Skills for Care report (2018) highlighted the importance of conversational assessment which helps to discover what matters to people and enable targeting of resources to ensure the best impact. This places the person at the centre of discussion and enables them to be the expert in their own life. It helps to explore and understand how the person's skills and experiences can be used in their care and support. This involves development of a relationship between the person and the care and support worker, having conversations led by the person. There are six key principles of conversational assessment: it is about people's lives, not just their needs; it recognises that people are experts in their own lives; it is founded on trust, honesty, and openness; it starts with a 'blank sheet', i.e. led by what is important to the person, although care workers can prompt and shape the discussion; it needs sufficient time and resources; it takes place within the context of the person's whole life and their community. These principles are key to people feeling that their voice leads to greater control for them.

The report gives a range of recommendations and advice for facilitating conversational assessment. They suggest that organisations should recognise and value the expertise of the person in relation to their strengths and how their needs are met; allow sufficient time for people and workers to develop relationships and build confidence; ensuring that commissioning systems are open and flexible, with resources shaped around what people want and built on the assets they already have; manage accountability through supervision and clear frameworks for workers to operate within; efficient paperwork and recording systems; ongoing discussions with external agencies to ensure accountability systems and paperwork meet everyone's needs; train and support workers in carrying out conversational assessments; involve people who have contributed to conversational approaches to contribute to learning and development; ensure a good balance between accountability and autonomy; give workers the opportunity to reflect and learn; ensure leaders support conversational assessment; and ensure the organisation and its systems demonstrate trust in the conclusions of the assessment including managed risk taking. We can see here how support for social care workers from their organisations can help to foster voice and control in service users supported by those organisations.

Sharing control

This section focuses on literature that explores aspect of sharing control in social care settings. Gridely et al (2014) outlined several features of good social care at various levels. At the level of every-day support, this includes person-centred ways of working; meeting practical, emotional and social needs; staff attitudes and approaches; reliable well-coordinated delivery; continuity of support; and sufficient resources. At the level of service organisation, good social care consists of flexibility, a timely proactive approach, specialist expertise and information, and care management and coordination. At the level of commissioning this requires specialist expertise, crossing boundaries, and communication. These strategies for good social care will all have an impact on the amount of voice and control that social care users may have, depending on their application and resources.

Strategies for applying voice and control principles are also needed in health care settings. Brogan (2018) reported that shared decision-making was only possible when patients explicitly open the conversation. Uncertainty regarding the process of shared decision-making was given as the reason health care professionals lacked involvement in this type of approach. It was also reported that factors relating to the organisational systems of care (such as workload pressure and the impact of a disconnected context of care delivery and decision-making) impeded shared decision-making due to de-prioritising it, which impacted on healthcare professionals' confidence to engage with the process and led them to underestimate their key role in the process.

Havlicek et al (2018)'s investigation of youth participation in youth advisory boards suggests that boards which are adult-driven with only input from young people enable these young people to voice their opinions, but this often does not lead to them having the power to actually drive changes or decision-making. In boards that strive for 50-50 adult-youth partnerships, adult facilitators deliberately create opportunities for youth to share in decision-making, not just sharing their views. Here again we see some of the limitations in attempts for social care organisations to share control with their service users.

Barriers and enablers

Clifford et al (2018) examined the perspectives of community support staff, regarding the barriers and facilitators of moving adults into community services, as part of the Transforming Care agenda. These staff identified difficulties in balancing patients' rights, safety and quality of life needs, and felt that the system's expectations of them were hard to deliver given the resources, legislation, values and support models available to them. They further highlighted a number of ideological challenges and contradictions such as being in a 'double bind', coping with choice and the potential contradiction between ideology and practice in relation to patient choice, and issues around the pace and planning of transitions. These challenges would obviously present a challenge to fostering a sense of voice and control in service users in community services.

Washburn and Grossman (2017) critiqued the current conceptualisations of PCC and found that the competencies developed by the Council on Social Work Education do not fully incorporate the key elements necessary to make them truly person centred. Enabling true person centred approaches is necessary in implementing voice and control principles for service users. They recommended grounding social work practice in Rogerian person-centred therapy, and adopting an expanded conceptualisation of personhood incorporating Kitwood's work on persons with dementia. They highlight the importance of the relationship between the caring professional and the care recipient as vital to the model of care being authentically person centred. This relationship need to be foregrounded in order to foster a good sense of voice and control for service users.

Lonbay (2018) also highlighted that heavy caseloads and time constricts were suggested to impact on involvement, as social workers need time and space to be able to involve people meaningfully. As a result of this. Lonbay suggests that the complexity of cases must be recognised within policy and practice guidance in order to acknowledge the additional time needed to support reflective practice and build relationships necessary for involving older people within safeguarding enquiries. These challenges in policy and practice would need to be addressed in order to successfully implement voice and control principles for social workers and their service users.

There are also barriers and enablers to voice and control in health services as well as social care. The Health Research and Educational Trust (2016) proposes a new approach to community health needs assessments, involving engaging patients and community members throughout the process and so obtaining insights that would otherwise be missed, obtain increased community buy-in, and develop more effective programs to improve community health. This process involves a series of steps: identify and engage stakeholders; define the community; collect and analyse data regarding social determinants of health, disparities, and vulnerable populations; selecting priority community health issues; documenting and communicating results; planning improvement strategies; implementing improvement strategies; and evaluating progress made. The Trust describes this approach as being important to help hospitals, community stakeholders and patients to work as partners to improve the health of their communities. This may enable a greater sense of voice and control for communities as well, in respect of community health.

Further issues surrounding voice and control are highlighted by McCarter et al (2016). They conducted a qualitative study to identify barriers and facilitators of participation in cancer treatment. Participants were nurses and nurse practitioners from oncology settings. Facilitators (‘promoters’) of shared decision making participation were having a multidisciplinary team approach, having a nursing voice during shared decision-making, , having a high level of knowledge of the disease and treatment involved, and personal valuation of shared decision making participation. Organisational support and having a system-wide culture of shared decision-making (SDM) were considered essential. However, many barriers were also identified which prevent/hinder oncology nurses from participating in shared decision making. Findings identified barriers related to practice, patients, institutional policy, professional barriers, scope of practice, insurance coverage, and administrative barriers.

Practice barriers included lack of uniform standards for nursing participation on cancer SDM. Patient barriers included patients lacking emotional and mental readiness to participate in SCM, and some patients having a preference for a physician during the cancer SDM process. Institutional barriers included institutional policy requiring physician supervision instead of collaboration between physician and nurse practitioners, as well as undefined roles for nurses which resulted in a lack of direction for nurses participating in the SDM process. Professional barriers included lack of professional training and experience, and a professional culture that is not conducive to nurses’ participation in cancer SDM. Scope of practice barriers involved nurses or nurse practitioners not being able to administer /initiate new therapies or practice independently due to regulations. Insurance coverage barriers included lack of insurance cover leading nurses to having to see more patients, thereby introducing time constraints and increased patient volume, and lack of coverage influencing which treatment options are possible. Administrative barriers included lack of adequate resources or staff support and empowerment to nurses. We can see here the barriers to decision making, and therefore voice and control, for nurses and patients in this context.

Webber et al (2015) utilised ethnographic field methods to investigate how workers helped people recovering from psychosis to enhance their social networks, and identified themes as worker skills, attitudes and roles; connecting people processes; the role of the agency; and barriers to network development. More equal relationships between workers and service users were considered important in supporting them to develop their network. However, in the NHS, professional held considerable power which was often considered problematic. This may be a barrier to enabling voice and control for patients recovering from psychosis. In relation to the processes of connecting people, once a relationship had been formed the worker and service user set goals together.

Tucker et al (2018) reported the findings of two national surveys capturing local authorities’ early experiences of providing social care and support for prisoners. While specialist social care staff (primarily social workers) were widely engaged in prisoner assessments, many LAs had delegated their responsibility for identifying prisoners with social care needs to prison healthcare staff, and there was considerable variation in how social care and support were delivered. Implications for social work practice were identified, including the need for greater active care finding and further evaluation of the impact of these arrangements on prisoners’ outcomes. The context of social care for prisoners also presents challenges for implementing voice and control principles, due to the explicit power differences in the prisoners and those dealing with their care. This is especially relevant in the light of the Act's extension of duties and responsibilities for the well-being of those in the secure estate within the public bodies.

Person-centred care

Gridley et al (2014) describe the process of shifting power from professionals to service users, mainly through the allocation of personal budgets. However, participants in their study of social care for adults with disability and older adults with severe and complex care needs revealed that ongoing person-centred support was also deemed extremely important, such as by a specialist key worker or case manager, in order to coordinate different services and ensure good practice at the organisational level. This included facilitating access to fragmented services and facilities, advocating and liaising with services, and coordinating support across boundaries. However, to deliver holistic social care requires considerable staff input and adequate funding, and person-centred ways of working were deemed to have more to do with staff's time, attitude, expertise, and the flexibility of wide systems, than whether someone had a personal budget. It was clear from this study that the participants desired a longer term relationship built on knowledge and trust, not a short term input. These kinds of relationships, along with the conditions described in the paper, could potentially facilitate a greater sense of voice and control in these service users.

Dunér et al (2019) analysed the processes and practices of individualised eldercare in Sweden in order to understand the preconditions for older people's choice and control. They found that the choice and control available to older users emerged as decisions about 'what' care and services, 'who' should provide the care and services, and 'how' the care and services should be performed. Approaches to enable older people to have this choice and control were as follow: test and revise, whereby decisions about care and services could be adapted; choices in the moment whereby users could choose services at each occasion; and quality improvement through competition, as competing providers develop attractive services. Overall, flexibility regarding how care and services were carried out was considered most important to enable users' choice and control over their situation. Although staff expressed intentions to respond to users' voice, a number of factors limited users' choice and control, such as standardised organisational routines, paternalistic attitudes, lack of time and staff continuity, and users' subordinated positions.

Aspects of person-centred care were also reported by participants in a study conducted by Hanga et al (2017) in which a rehabilitation needs assessment process allowed participants to experience a person centred process, to have an opportunity to talk about their situation and to feel their story was heard. Specialists had more time with each participant, enabling them to ask the questions necessary to understand the person's life and situation. Participants experienced equality and partnerships in setting rehabilitation goals, and planning and making decisions. Overall this process required understanding clients and meeting their individual needs; connecting and partnering with clients; providing appropriate and adequate information; and addressing issues of power and empowerment. The authors therefore recommend that person-centeredness should be implemented as a quality component of the initial rehabilitation needs assessment, and in providing all disability services; that person centeredness should be fixed in legislation, quality standards and work regulations; and that person centeredness should be an integral part of specialists' training. This also requires allocation of sufficient time and resources for specialists, and supervision among specialists to support their casework. This links back to earlier assertions of the importance of person-centred care in implementing voice and control principles for service users.

Parents and Families

A study by O'Connor et al (2014) examined factors influencing practitioner decision making in child and family social work practice, and showed the power of individual and diverse voices involved in the social work process. Participants also focused on service user voice and what influenced this being heard. Perceptions of how vocal, articulate or informed a service user was deemed significant. Power or absence of such voices were related to complex dynamics such as class, race, education, access to information, levels of aggression, compliance, and perceptions of whether they were deserving. A triangular relationship was identified between the practitioner, service user and manager, highlighting tensions in the power relationship and in the practitioner's capacity to challenge, and emotional responses to whose voice appeared strongest.

Practitioners identified other practitioners, organisations and managers as having powerful voices that were listened to more favourably than their own. This lack of voice and sense of powerlessness was evident and legal and medical professionals in particular were identified as having greater power and status. Student voices were not given weight by others, and students received contradictory messages about their power to contribute to influential decisions. There was therefore a context of ongoing tension relating to voice and power, professional autonomy, identity and confidence to challenge decisions. Findings also expressed the potential value of reflection in managing multiple influences and tensions involved in balanced an informed decision-making.

Ryan and Quinlan (2018) examined parental perceptions of communication and collaboration between parents and health and education staff in the context of an imminent reconfiguration in disability services. Parents wanted greater collaboration between parents and professionals, characterised by mutual cooperation, shared expertise, shared information and shared decision making. However, there were gaps identified between the desire for this type of approach and the reality. Participants identified that a keyworker would be a potential solution to the current system which was not very child-centred. This would enable parents to have a supportive professional to act as an advocate, and bridge the divide between parents and professionals, as well as acting as an adviser and secure base for them. This advocate could be key when extending parents sense of voice and control in this context. Many parents felt that professionals didn't listen to them and adopted a sense of 'us vs them' as a result. Also within this theme was the notion of advocating for their child, parental stress, having to be more aggressive being more effective, in-group membership, and a divide between parents and professionals. A lack of child or family centeredness was identified in relation to bureaucracy, and unmet needs even when these needs were communicated. Other issues identified were a lack of resources, uncertainty about accessing and navigating a complex system, and uncertainty regarding future changes. These issues all present challenges to fostering a sense of voice and control for parents.

Advocacy

Sherwood Johnson (2016) considered independent advocates' perspectives on their roles in Scottish adult support and protection work, and the facilitators and barriers impacting on those roles in practice. Participants felt independent advocacy could complement statutory advocacy work, and wanted to work in partnership. Participants reported variations in understanding of advocacy between local authorities, teams and individuals' statutory workers, which suggest the need for awareness raising and training strategies. Where resistance to advocacy is identified, reasons for this need to be considered, such as whether statutory staff are working to timescales that struggles to accommodate independent advocacy, or are impacted by other factors related to the boundaries of their roles. The late stage of the process when referrals to advocacy were made was a cause for concern, and raised the question of whether the appropriate balance is being struck between procedures to ensure timeliness, and the flexibility to foster person centred practice. Additionally, some participants reported that they considered lack of understanding to be linked to some decisions not to offer advocacy, particularly if the person involved did not have capacity. However, participants stressed that even in such cases, participants may have a view and it is important for them to be supported to voice that view. This ability for participants to voice their view is key to implementing voice and control principles.

Occupational therapists (OT) described their role in using advocacy as assisting clients who were struggling with access to equipment, services or funding, as well as fostering the development of self-advocacy among people with disabilities. They also stated that advocacy involved helping their clients to help themselves. Advocacy was defined as involving occupational therapists working 'with' and 'for' people with disabilities, i.e. both collaboration and representation. Although they were willing to advocate on behalf of their clients, they preferred to use a range of strategies such as discussion, encouragement, problem solving, and role playing in order to assist their clients to advocate on their own. The participants stressed the importance of clients learning skills to help themselves sin the future, after OT services were no longer being used.

Eades (2018) investigated the impact of an Independent Mental Health Advocacy (IMHA) service in a high secure hospital on self-reported changes to patients' self-determination. Eades defines self-determination as being "autonomous" and having "personal freedom and ability to make and take responsibility for the decisions and choices that affect the direction of our life". Self-determination theory states that there are three psychological needs that need to be met in order to achieve self-determination, these are relatedness, competence and autonomy. The study sought to examine whether an IMHA service could help mental health patients to reach self-determination through using self-determination theory to measure the impact of the service using a questionnaire. Competence was measured through exploring whether patients understood their rights; relatedness was measured through looking at whether communication improved between patients and their care team; and autonomy was measured by finding out if patients became more involved in decisions about their care and treatment. The results of the study revealed that 70% of patients surveyed (N=115) experienced an increase in self-determination as a result of IMHA service support, as measured by the patients' self-report of experiences of competence, autonomy and relatedness. Additionally, 55% of patients stated they experienced satisfaction across these three domains. Eades concludes that self-determination is important for patients detained with mental health difficulties, who often feel that they lack power and control over their lives. These strategies could be used to foster a greater sense of voice and control in this particular group of service users.

Summary

The key messages to be taken 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
- The importance of the relationship between practitioner and service user in creating a good sense of voice and control for service users.

ORGANISATIONS

This final section of the literature review focuses on literature surrounding care and health organisations and voice and control. It focuses on one key area, assessment, and the ways in which this impacts voice and control principles and practices for care organisations.

Assessment

Darby et al (2017) carried out a randomised control trial that focused on finding out whether a comprehensive assessment from a geriatrician (on top of usual care) had an impact on participants' and their carer's perceptions of their care and treatment on an acute medical unit. Previous research had found that assessments from geriatricians are effective in improving outcomes for older patients. These assessments involve a thorough investigation of health problems that are specific to older people, and a subsequent comprehensive health plan. This study explored the views of 18 older people and 6 carers of older people, who had experienced this geriatrician assessment. The findings revealed that participants believed there was a lack of care on the ward, and they had been observed rather than treated. Although participants described enjoying talking to the geriatrician, they could not explain what the role of the geriatrician was or what they did to assist them. Participants were also asked about their ongoing care at home, and expressed a view to be more independent rather than get help from carers. The study demonstrated that the geriatrician assessment did not appear to have an impact on the participants' perceived quality of care at the acute medical unit. This group of patients' sense of voice and control was disrupted or limited by these issues.

Hanga et al (2017) explored participants' experiences of the initial rehabilitation needs assessment process to discover whether they were perceived to be person-centred. This assessment was a new version of a standard assessment used to identify the needs of disabled adults, and sought to be person-focused through understanding patients' needs as an individual, ensuring patients have appropriate and sufficient information, and being actively aware of issues surrounding the power and empowerment of patients. The results of the study found that the 12 participants interviewed naturally used terms associated with person-centeredness, such as feeling that their voices were heard, and they were working with the health professional as a partner, when describing the assessment. The study demonstrated that a person-centred approach can have a positive effect on initial assessments with disabled adults. The authors conclude that person-centeredness should be viewed as a quality component of disabled services in general and should form part of standard training for rehabilitation specialists. As discussed earlier, person-centred practice is crucial to the successful implementation of voice and control principles.

Skills for Change (2018) is a guide produced by skills for care that explains how to use conversations to assess and plan care and support for service users. The guide states that conversational assessment – similar in spirit to the 'what matters' conversations within the remit of the Act – is beneficial through revealing what really matters to the service user, which allows support to be tailor made to the needs of the individual. The conversational approach is also more relaxed and open than a standardised interview and can provide more valuable information. Conversational assessment is described as involving six key principles: (1) it's about people's lives, not just needs; (2) it recognises people are experts in their own lives; (3) it's founded on trust, honesty and openness; (4) it should be led by the serviced user; (5) it needs sufficient time and resources; and (6) it takes place within the context of the person's whole life and their community. After the conversation, the action that is taken depends on what has been discussed. The guide states that sometimes the conversation itself is enough to clarify the service user's needs and existing support, without carrying out further interventions. This practice could potentially allow for a greater sense of voice and control for service users, because of its conversational nature.

Keyes et al. (2015) discuss the role of empowerment in relation to the self-assessment process. Self-assessments were designed to increase the voice and control of service users by enabling them to fill in a form about their needs. However, the data from 24 interviews of older people, carers and social workers' experiences of these forms suggested they were not enhancing the empowerment of service users. Participants described how a 20-page self-assessment form was not appropriate for many service users, whose disabilities inhibited them from filling in the forms. Other participants stated that some service users tended to underestimate their needs as they do not want to appear "needy" or a "burden" to others. It seems then that despite the focus on the individual service user, self-assessment forms do not lead to empowerment. The study also reviewed a second mode of assessment, called "Talking Points". This approach involved emphasising shared discussion and conversation when working out the care needs of the service user. Social workers that took part in the study thought that this approach put the service user and carers at the centre of the discussion, with the care professionals having a supportive role. Consequently, the authors suggest that there can be an interrelationship between service users, their carers, and care professionals, in order to access appropriate services.

Seddon and Robinson (2015) explore carer assessments from the viewpoint of social care practitioners. The study involves analysis of 383 interviews with practitioners across Wales and England over the last 20 years. The results revealed four main problems with the carer assessment process that are restricting its effectiveness. First, social care practitioners were shown to be ambivalent to carer assessments, despite the increase in legislation promoting carer's rights. Secondly, practitioners viewed the assessments as about the carer's caring role, rather than supporting them in and beyond their role, as the assessment was created to do. Thirdly, little time is spent in understanding the emotional and psychosocial aspects of caring. Finally, practitioners conceded that they did not distinguish between carer ability and willingness to continue, which was outlined in policy and practice guidelines. In conclusion, the authors assert that social care reforms that extend carers rights are welcomed, but that in order for these rights to be increased in practice, changes need to be made to the conduct of practitioners. The authors suggest that better aligning the needs of the carer with the needs of the service user would help to provide more holistic support, and wider engagement with the carer assessments. Without these changes, the fostering of carers voice and control may be hindered.

Tucker et al. (2018) explore social care practices in prisons after the changes made with the introduction of the 2014 Care Act. The Act gave local authorities in England the responsibility for identifying, assessing and meeting the social care needs of prisoners. To determine the success of this change, the study investigates the findings of two surveys of local authority managers. Results revealed that 1,800 prisoners were identified as having social care needs in 2014, and that 1,600 were assessed, with 600 found to need support. However, there was considerable variation between authorities in terms of how prisoners with needs were identified, assessed, and who carried out the care needs. These variations may impact the sense of voice and control that prisoners have when it comes to social care provision. In the main social care practitioners took the lead in assessing prisoners, in line with the Care Act, however delivering the care itself was often taken up by in-house prison-teams, which led to very different care and support across individual prisons. The authors conclude that further studies need to be conducted to understand the advantages and disadvantages of the approaches used in different prisons, in order to give a clearer sense of how to identify best practice for managing the social care needs of prisoners.

Summary

Key messages from this section of the literature review are:

- There are challenges in fostering voice and control principles in health and social care assessments

- Person centred practice and conversational approaches can provide a good platform for voice and control principles to be implemented in social care

CONCLUSION

This review has demonstrated the way in which the published literature has identified a number of barriers and enablers for ensuring the people have a greater input into their care (voice) and greater say over what happens (control). To conclude, the table below enumerates these barriers and enablers. It will be interesting to note the extent to which these feature in the primary and secondary data collected in the study.

Table 7: Barriers and enablers of voice and control

Barriers to voice and control	Enablers of voice and control
Lack of clear definition in literature as to what voice and control means	Advocacy and self-advocacy in creating a sense of voice and control for service users
Complexity of applying voice and control principles in different social care settings	Quality social care practice in giving carers a sense of voice and control
Sharing control between the organisation and service user in different social care settings	Person-centred approaches in fostering voice and control principles for service users
Implementing voice and control principles with different service user groups, e.g. older people with dementia, or young children	Relationships between practitioner and service user in creating conditions for voice and control to be effective
Devolved forms of payment (e.g. personal budgets) giving individuals voice and control	
Ensuring voice and control principles feature health and social care assessments	Conversational approaches to social care practice.

FINANCIAL AND ECONOMIC

Ceri Phillips, Malcolm Prowle, Sion Tetlow and Zoe Williams

This section of the literature review explores literature, which may have some relevance to the assessment of the financial and economic implications of the Social Services and Well-Being Act (Wales) 2014. Unfortunately, repeated searches did not find a great deal of published literature which would have a direct bearing on this project. This review is organised into three main sections:

- Methodological issues in 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

This section of the literature review explores literature around methodological issues that occur when considering the financial and economic implications of policy. Frick and Kunz (2008) describe how cost-effectiveness research can be applied to the social work setting. They state that economic evaluation can be used to “inform but not make decisions.” The authors state that the research used to determine cost-effectiveness in social work must use information from a number of studies, such as multiple randomised control trials, and also involve multi-disciplinary teams and peer-reviewed articles, in order to attempt to accurately depict the cost-effectiveness of a social-care service. The article describes in detail four vital elements of cost-effectiveness methodology: (1) the importance of trying to build models to project results into the future; (2) the importance of how to treat cost and effects over time; (3) the importance of translating results into health related quality of life outcomes; and (4) the importance of incremental analysis. The authors conclude by describing some of the pitfalls of cost-effectiveness research in social work. For example, cost-effectiveness itself places a monetary value on the outcomes of a particular social work practice or policy. However, assigning a monetary value to social work outcomes, such as well-being or quality of life, is not straightforward. Frick and Kunz (2008) argue that conclusions must be reached in terms of how to objectively measure these more complex outcomes, and that these measures must be clear and comparable across studies. This has implications when considering the financial and economic implications of the Act (2014), as it highlights the challenges in using a cost-effectiveness methodology to assess the cost-effectiveness of such a broad piece of legislation and policy.

Tsiachristas, Stein, Evers and Molken (2016) describe in detail the importance of understanding the cost-effectiveness of integrated care, and the complexities of conducting economic evaluations of integrated care. Integrated care is described as inventions that seek to improve outcomes for people with chronic health conditions through linking services. The authors argue that economic evaluations of integrated care should be conducted by health economists in order for there to be high quality evidence regarding the cost-effectiveness of integrated care. Health economists explore the efficiency of health interventions, and examine their financial mechanisms alongside changing demand for healthcare, while ensuring the efficient allocation of limited budgets. The paper describes the challenges to be overcome when carrying out economic evaluations of integrated care, including understanding the outcomes from a total societal perspective (i.e. the cost of integrated care on society as a whole) and realising that the outcomes themselves are complex, and extend beyond Quality Adjusted Life Years (QALYs) to involve non-health related issues such as patient satisfaction and ability to cope with disease. The authors conclude that research needs to be conducted now to provide decision makers with evidence of the cost-effectiveness of integrated care models in order to reduce the impact that chronic diseases have on population health and social care budgets. This has implications for the cost-effectiveness of the Act, insofar as it deals with integrated care programmes and their economic implications for social care budgets in Wales.

Knapp (2013) discusses the economic pressures faced by healthcare systems and argues that economic evidence can be used to make important decisions about care and preventative strategies. Knapp describes five elements to the economic approach to decision making: (1) cost-effectiveness, (2) costs, (3) outcomes, (4) equity; and (5) design. Knapp discusses the importance of realising the future savings that can be made by spending money on interventions. For example, Knapp cites a study by Bodin et al., (2011) in which a parenting programme for parents of children with anti-social behaviour, that cost an estimated £1,200, led to an economic return over a 25-year period of between 2.8 and 6.1 times greater than the intervention cost. Knapp concludes by stating that economics evidence needs to play a role in future decision-making regarding healthcare provision through exploring whether preventative healthcare strategies can be cost-effective. This has implications for the implementation of the Act (2014), particularly when considering prevention strategies.

Teresi et al., (2017) explored the methodological issues surrounding how to effectively measure well-being and quality of life in ethnically diverse, older, and cognitively impaired individuals using a brief questionnaire measure called The Feeling Tone Questionnaire (FTQ). The questionnaire measured positive affect (happiness) and negative affect (sadness), and had 9 positively worded items, and 7 negatively worded. The questionnaire was distributed to a large sample of both Hispanic and non-Hispanic community and in-care service users (n=4,960), with a mean age of 82. The FTQ was used as it has been shown in previous research to be easily administered to individuals with communication disorders and cognitive impairment. However, the questionnaire had not previously been used in studies with ethnically diverse populations, and the authors aimed to find out if differences in culture, ethnicity and language could affect how service users responded to the questionnaire items. Secondly, the authors intended to discover if using negatively versus positively worded items had an effect on responses. Confirmatory factor analyses (CFA) with reliability estimates were used to analyse the data. Results revealed that the negatively worded items did effect results, as the items did not load as well as the positive items on to the one factor of ‘affectiveness’.

Essentially, the negative items did not appear to be measuring ‘affectiveness’ in the same way as the positive items were, and could be measuring something else, such as ‘negativity’, as the authors suggest. This meant that the negatively worded items were not informative. This effect was the same for the ethnically diverse participants. Consequently, the study suggests that using only the positively phrased 9 items in the questionnaire is perhaps a more effective means of measuring affect to give an indication of quality of life for ethnically diverse service users. The study additionally demonstrates the complexities associated with attempting to measure quality of life; even focusing on measuring affect as an aspect of quality of life presents with varying methodological issues. This study focuses on the complexities of measuring quality of life and using quality of life indicators, and this has implications for the financial and economic indicators of the Act, for which quality of life and well-being assessment are a predominant part of economic assessment. In 2019, the Welsh Government published a document concerning the future of social care in Wales (Welsh Government 2019). Included in this document were national outcome indicators developed in order to evidence whether the national well-being outcomes are being achieved. These indicators may also contribute to the evaluation of the SSWBA.

Stein, Evers, Molken, Paulus and Tsiachristas (2016) describe in a conference abstract how health economics can be used to understand more about integrated care models, specifically in relation to: (1) economic evaluation and (2) financing, payment and incentive structures. The authors discuss how little is known about the cost-effectiveness of integrated care, but that health economics can help to provide valuable insights. A Special Interest Group Health Economics in Integrated Care group has been created to assist in adapting existing health economic evaluation methods to be used in evaluating and analysing integrated care models. These methods have implications for evaluating economic effectiveness of integrated care programmes developed under the Act (2014). Such implications could include the need to measure such factors as: patient experience and satisfaction, self-management skills, wellbeing as well as costs related to the integration of health and social care or services provided by other sectors. Furthermore, little is known about the cost-effectiveness 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.

Sanders, Grove, Salway, Hampshaw and Goyder (2017) explore using a health economic modelling tool in public health commissioning within a politicised context. The study involved interviews with commissioners (including public health mangers, council members and data analysts) in one local government authority in England, and examined their views on a health economic decision tool for planning services in relation to diabetes. Results revealed that two themes emerged when explaining the obstacles and enablers of using the tool: (1) different evidence cultures (i.e., politicians are influenced by the social care agendas affecting local populations and public health managers prioritise the scientific view of evidence) and (2) system interdependency that complicated decision-making through links between different services. The study also revealed that for modelling tools of interventions to be successful they need to be co-produced by designers of the intervention and the users themselves. The authors conclude that the health economic tool that was tested has the potential to be successful in informing decision-making through providing an evidence base to guide decisions regarding cost and savings, but that it can be viewed as detached from specific local authority priorities. Tools such as this could be useful in for assessing the financial and economic health of the Act and the care services developed in conjunction with it.

It is acknowledged that economic evaluation methods as they have been developed for Health Technology Assessment do not capture all the costs and benefits relevant to the assessment of public health interventions. This paper by Marsh et al (2012) reviews methods that could be employed to measure and value the broader set of benefits generated by public health interventions.

It is proposed that two key developments are required if this vision is to be achieved. First, there is a trend to modelling approaches that better capture the effects of public health interventions. This trend needs to continue, and economists need to consider a broader range of modelling techniques than are currently employed to assess public health interventions. The selection and implementation of alternative modelling techniques should be facilitated by the production of better data on the behavioural outcomes generated by public health interventions. Second, economists are currently exploring a number of valuation paradigms that hold the promise of more appropriate valuation of public health interventions outcomes. These include the capabilities approach and the subjective well-being approach, both of which offer the possibility of broader measures of value than the approaches currently employed by health economists. These developments should not, however, be made by economists alone. These questions, in particular what method should be used to value public health outcomes, require social value judgements that are beyond the capacity of economists. This choice will require consultation with policy makers, and perhaps even the general public. Such collaboration would have the benefit of ensuring that the methods developed are useful for decision makers. These approaches could have consequences for the Act itself, resulting in policy and organisational strategies.

Summary

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

- Challenges and complexities of using cost-effectiveness models in different social and health care contexts
- The availability and challenges of using different economic tools and models to evaluate the economic health of specific services
- The complexity of assessing cost effectiveness of health and social care services in conjunction with quality of life indicators.

ECONOMIC AND FINANCIAL ANALYSIS OF INTERVENTIONS VERSUS USUAL CARE

This section of the literature review explores literature that compares economic and financial analysis of specific interventions versus usual care. This literature is then assessed against its implications for the Act (2014) and the care services developed in conjunction with its principles.

Bauer (2016) examined the costs and benefits of a help-at-home scheme for older people (aged 55 years and over), to discover whether help-at-home schemes can reduce local government and NHS costs while achieving positive health benefits for older people. Help-at-home schemes have been shown to allow older people to continue to choose to live at home with the necessary support, and therefore enhance well-being and encourage independence as opposed to living in care homes. However, the potential economic advantages of these schemes in conjunction with their effect on well-being, had not previously been explored. The study measured the costs of the scheme versus alternative care, and the quality of life of the older people was measured through the Adult Social Care Outcomes Toolkit at the start and 4-6 months after joining the scheme. Taking the potential costs of local government care and hospital stays into account, the study found that the help-at-home scheme on average was saving the local government and NHS £1568 per person (this value ranged from £273 to £1688). In addition, the study found that the scheme could save the individual on average £2275 (this value ranged from £983 to £2275). The results of the Adult Social Care Outcomes toolkit revealed that participants' needs had reduced from the start of the scheme to the 6 month follow-up, but that this did not reach statistical significance. This could have been because only a small proportion of participants (n=24) completed the follow-up questionnaire. The results did suggest that at 6 month follow-up, some participants stated that their social participation needs were not being met. Overall, the authors conclude that help-at-home schemes are able to meet some of the welfare needs of older people, and are cost-effective, saving money for the local government, the NHS, and the service-users themselves. The help-at-home interventions could have economic repercussions for releasing capacity in domiciliary care services in Wales, residential care services and social care for older people more generally.

Wansink et al., (2016) conduct an economic evaluation to compare the costs and outcomes of an intervention to improve the parenting styles of parents with mental health conditions compared to usual care. Children that have parents with mental health disorders are at increased risk of developing mental health disorders themselves, which poses a considerable burden on youth mental services in terms of the cost and use of resources (Olfson et al., 2003). The increased risk of children developing these disorders was determined to be partially due to parenting quality (Rutter & Quinton, 1984). The study investigates the effect of an intervention called Preventative Basic Care Management (PBCM) on the quality of parenting by parents with mental health disorders. Participants in the study either received PBCM (n=49) or care as usual (n=50), and the cost-effectiveness of both approaches as well as parenting quality were measured. The study also aimed to find out whether cost-effectiveness would differ if viewed from a healthcare perspective (medical costs), social care perspective (caring costs) or wider societal perspective (wider social costs). Results revealed that parenting quality improved for the PBCM group, but lowered for the care as usual group. However, PBCM was more expensive than usual care. Incremental cost-effectiveness revealed that the extra cost of PBCM amounted to either 1,793, 738 or 596 euros depending on whether the perspective was healthcare, social care or societal, respectively. The authors conclude that the study demonstrates that although the intervention is more expensive, it is nevertheless cost-effective in comparison to usual care, due to the level of improvement in parenting quality. This then has a knock-on effect on the impact of mental health problems for children of parents receiving this intervention. This intervention could have an impact on mental health and family services working under the Act.

Summary

This section of the literature review has reviewed the economic consequences of specific interventions across a variety of care settings. The key messages of this section are:

- Specific interventions can have positive impacts on outcomes and cost-effectiveness for social care organisations

- Certain interventions may be more expensive in the short term but offset further costs in the long term (see PBCM intervention)
- Caution may need to be applied to the use of interventions that have limited amounts of research literature supporting their use

STRATEGIES FOR INCREASING CAPACITY IN SOCIAL CARE SERVICES

This section focuses on literature that explores strategies for increasing capacity over a variety of social and health care settings.

Godfrey (2001) discusses the increased interest in preventative services and strategies for older people in order to minimise the extent of government based social care involvement. Godfrey (2001) then explores a potential framework to facilitate prevention that focuses on a core model of successful ageing, surrounded by changes in gains and losses as the individual ages. Within this model, effective preventative services and strategies are perceived as those that enable the individual to achieve valued goals. Godfrey suggests that preventative services should be viewed in terms of compensation and optimisation, and could include help with: (1) managing the limitations in physical or other abilities; (2) addressing the negative impact of significant life changes on social support; (3) maintaining and improving performance in those areas that are valued by the older person; and (4) developing new strategies to compensate for losses. Preventative strategies, on the other hand, are viewed as those that offer opportunities for social contact, and offer ways for older people to continue to access their hobbies or interests. Godfrey concludes by emphasising that using this model to evaluate preventative services and strategies enables the individual to be empowered through focusing on the goals they would like to achieve and how to facilitate these. These models and suggestions for preventative services could be applied to social care for older people in Wales, as well as policy implications for older people.

Burrows (2013) investigated whether health and well-being checks for unpaid carers made a difference to their ratings of stress. Participants were unpaid carers (N=348) and stress was measured at baseline and at the final assessment using the GHQ-12 (General Health Questionnaire). The GHQ-12 asked 12 stress related questions, such as “Have you recently felt constantly under strain?” and participants rated to what extent they agreed with each. Results revealed a small but significant improvement in stress levels at the final assessment. Improvement was greater for carers that were assessed as having lower stress levels at baseline. However, as there was no control group, it could be that other factors influenced participants’ stress levels aside from the intervention itself. Nevertheless, the study suggests that health and well-being checks could improve stress levels for unpaid carers, but further studies are needed. The implications for services in Wales in relation to this paper is around well-being and quality of life measures, and their relevance to economic and financial characteristics of services.

Byrne-Maguire (2017) discusses the purpose of AFFINITY (activating falls and fractures prevention in Ireland together), a national population health improvement project that aims to prevent falls and fractures in older people. Byrne-Maguire states that fractures and falls cost the government a considerable amount of money, but are predictable and preventable incidents. AFFINITY has adopted a whole systems approach that involves collaborative working from service providers and the social care system. The approach involves empowering individuals to manage their needs, changing work practices, and supporting older people to actively age. As noted earlier, such approaches save money and therefore provide for more capacity in other areas.

Rutschmann (2017) discusses a program led by The Swiss Red Cross (SRC) to enable older people to choose to stay in their own homes in Eastern Europe. The scheme promotes "Help to self-help", and is crucial in providing older people with access to services, which is often challenging due to a lack of transportation and funds. The schemes objectives are: (1) strengthening health care systems and enabling access for all, (2) engaging in advocacy for health and social inclusion and (3) the creation of workplaces for nurses and the new profession of home-helpers/care assistants. Rutschmann reports that so far the scheme is in its' early stages and has been implemented in six SRC countries, and approximately 12,000 elderly people are cared for by 60 home care centres that are co-funded by local and national authorities. Rutschmann concludes by explaining that research needs to be conducted to examine the efficacy of the scheme, and that home care staff need appropriate training as this is a new type of care that is being introduced. Implications for Welsh social care organisations and the Act (2014) from these models are cursory, due to this need for further research. However, if the model was successful, it could have impact for care services for older people in Wales, particularly domiciliary care and residential home care services.

Landeiro, Leal and Gray (2015) investigated the relationship between social isolation and delayed hospital discharges for older patients with hip fractures. The authors described how "bed blocking" by older patients was often a problem. For example, in developed countries, around half to two thirds of the total acute hospital beds are used by older patients. Delayed hospital discharges can lead to an increase in health difficulties for older patients (e.g. picking up infections or pain due to inactivity) and also use up hospital resources and funding unnecessarily. The authors aimed to discover whether social isolation was a factor that contributed to the delayed hospital discharges of 278 patients aged 75 years and above that were admitted to a hospital in Portugal with hip fractures. Social isolation was measured using the Lubben social network scale, which measures the perceived social support the patient received from their family and friends. The costs of delayed discharges were estimated using unit costs from national databases. Delayed discharges were measured by the number of days a patient stayed in hospital after they had been declared medically fit to leave. Results revealed that social isolation was significantly associated with delayed discharges. In addition, the study found that the average hospital cost of a patient with a fracture that had a delay in discharge was 77.5 % higher than that of a patient without a delay (or an increase of €3096). Annually, delayed discharges for older fracture patients cost the hospital an estimated €145,812 if patients were moved from the hospital to temporary care after the delay. If the temporary care was itself delayed or not possible, then this cost could rise to between €226,636 and €577,680 respectively. Consequently, the authors conclude that hospital delays result in huge unnecessary expense, and helping to improve the problem of social isolation could have the potential to reduce this expenditure. These findings have implications for hospitals and integrated care programs in Wales, highlighting the expensive nature of delayed hospital discharges for older patients.

Goddard, Jacobs, Santos and Mason, (2016) explored whether the quality of primary care that dementia patients received could affect the duration of their hospital stay. The study notes that dementia patients are spending an increasing amount of time in hospital, and that these hospital stays are often unnecessary as well as costly, and can indicate that effective care has not been put in place. This links to the previous study, by Landeiro et al (2015) on the expenses associated with delayed discharge for older people. Specifically, the study measured the quality of primary care by referring to the annual review by general practitioners for dementia patients. This review identifies the needs of dementia patients and their carers, and seeks to co-ordinate health and social care services to address these needs. The authors suggested that dementia patients would spend less time in hospital if they had had an annual dementia review. The study addressed this hypothesis by utilising national data from 36,000 dementia patients in the UK. Results revealed that there was a connection between length of hospital stays and the annual dementia review. Patients with dementia that had been discharged from hospital had significantly shorter stays if they were cared for by general practices that reviewed a higher percentage of their patients with dementia. However, the effect was small, and was not evident for patients who live in care homes or those who died in hospital. Nevertheless, the study does suggest that the annual dementia review could have the potential to reduce hospital stays for dementia patients and therefore reduce unnecessary hospital expenditure. The annual dementia review could have financial implications for social and health care services who deal with older people living with dementia.

Wistow, Perkins, Knapp, Bauer and Bonin (2016) examined the cost-effectiveness of a scheme called Circles of Support, which aimed to support adults with learning difficulties in the community. The scheme used community resources to promote social inclusion and improve the well-being of adults with learning difficulties and support them to live independently. The study demonstrated the success of Circles, with members and caregivers describing improved mental health, feeling like active members of the local community, and improvements to quality of life. Results also revealed that the annual packages of care at Circles ranged from £7000 to £80,000 (mean £51,000), but were substantially lower than the cost of full-time residential care for adults with learning disabilities, an estimated £139,308 per year. The authors conclude that the study demonstrates the cost-effectiveness of community schemes in supporting adults with disabilities in comparison to long-term residential care. The Circles of Support scheme could have a positive impact on financial health for services supporting adults with learning difficulties in Wales.

Edwards et al., (2014) explore current spending on healthcare in Wales through a detailed review led by a Public Health Wales advisory group, to discover whether individual health improvement programmes were effective or ineffective. This then indicated if programmes should continue to receive investment or be disinvested. This study used Programme Budgeting and Marginal Analysis (PBMA) to find out whether current health care programmes met their objectives and if they were value for money. For example, for each health care programme, PBMA involved examining past and future resource allocation, the health needs of the local population and specified goals. PBMA also helped to discover whether the current level of funding was appropriate, or whether the same programme could continue on less funding, or whether more funding was necessary. The advisory group for PBMA consisted of a panel of 30 experts from across Public Health Wales, the NHS, third sector organisations, Welsh Government and primary care. The panel were tasked with using PBMA to explore 25 public health care programmes, which accounted for £15.1 million of the Minster for

Health and Social Care's budget. The results of the analysis led to the panel recommending complete disinvestment in 7 out of 25 of the programmes, which released £1.5 million of the budget. The panel also suggested partially disinvesting in 3 programmes, which released a further £7.3 million of the budget. The panel did not, however, recommend any increase in funding for any of the programmes. The authors conclude by suggesting that the utility of PBMA in this study indicates that it would be a useful tool for exploring the cost effectiveness of health care programmes at a national level. This has inferences for healthcare services in Wales, and budgeting and investment decisions made about these services by Welsh Government.

Knapp, Iemmi and Romeo (2013) carried out a systematic review of the cost-effectiveness of prevention, care and treatment strategies that have been used to support individuals with dementia. The authors describe how an increase in the number of people with dementia is expected to lead to increases in social care spending, and that the government are looking for ways to maintain or improve care that are cost-effective. The study identified 56 reviews and 29 single studies that focused on this topic. An exploration of the studies demonstrated that pharmacological studies using varying medication to treat dementia were shown to be cost-effective. Additionally, cognitive stimulation therapy, tailored activity programmes and occupational therapy were found to be cost-effective. There was also some evidence to suggest that respite care in day settings and psychosocial interventions for carers were cost-effective. However, the authors found that there were several prevention, care and treatment strategies that had not been examined for cost-effectiveness. For example, although physical exercise programmes for individuals with dementia are recommended as part of a care plan in Wales and England, their cost-effectiveness has not been explored. The authors conclude that there are a number of barriers to improving the cost-effectiveness of care in relation to dementia, such as the lack of studies, the low methodological quality of studies, the narrowness of cost measures (such as looking only at healthcare costs and not the wider societal costs) and poor co-ordination between health and social care providers. These issues have implications for the cost effectiveness of health and social care services for those living with dementia in Wales.

Picco et al., (2016) investigated the cost of multimorbidity among older people in Singapore, and the association with healthcare and societal resource use. In the study, multimorbidity was defined as having two or more chronic health conditions (e.g. heart trouble, high blood pressure etc.), and care was classified as both healthcare (e.g. medical) and social care (e.g. care provided by paid caregivers or family and friends). Data was collected as part of the Well-being of the Singapore Elderly (WiSE) survey, which was completed by 2565 Singapore residents aged 60 years and above. The results of the study revealed that multimorbidity was common amongst older people, with 51.5% of respondents self-reporting two or more chronic health conditions. The study found that health and social care costs of multimorbidity were SGD$15,148 per person annually, compared to SGD$5,610 for those with one chronic condition, and SGD$2,806 for those with no conditions. These results demonstrate the increasing economic burden of multimorbidity as the population ages, and suggest that strategies are needed to address this healthcare challenge. The authors conclude that a better understanding of the complexities of multimorbidity in older people is needed to develop appropriate interventions to prevent and reduce multimorbidity, and to co-ordinate health care services to reduce cost. These strategies could have an impact in health and social care services in

Wales, particularly when considering prevention strategies for healthcare issues for older people, and the cost consequences of multimorbidity for that demographic.

Summary

This section of the literature review has assessed literature relating to strategies to increase capacity across social (and health) care. These papers have explored a variety of care settings and demographics. The key messages from this section are:

- Many interventions have been assessed for cost effectiveness and show positive results
- Long term, preventative strategies may increase capacity
- There are a variety of strategies, models and tools available in the research literature for improving capacity
- Co-morbidity simply means more than one illness or disease occurring in one person at the same time and multi- morbidity means more than two illnesses or diseases occurring in the same person at the same time. 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).

APPENDIX 1 – REFERENCES

INTRODUCTION

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