



SOCIAL RESEARCH NUMBER:

41/2023

PUBLICATION DATE:

30/03/2023

Voice and Control

Research to support the Final Report of the
Evaluation of the Social Services and Well-
being (Wales) Act 2014

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

OGI © Crown Copyright Digital ISBN 978-1-80535-344-7

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

Voice and Control

Research to support the Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014

Mark Llewellyn,¹ Roiyah Saltus² and Wahida Kent²

Llewellyn M., Saltus R. and Kent W. (2023) *Research to support the Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014*. Cardiff. Welsh Government, GSR report number 41/2023. Available at: <https://www.gov.wales/voice-and-control-research-support-final-report-evaluation-social-services-and-well-being-wales-act-2014>.

Research team drawn from: Welsh Institute for Health and Social Care, University of South Wales; Swansea University; Cardiff Metropolitan University; Bangor University.



Cardiff
Metropolitan
University



The Final Report to which this document relates can be found here:

<https://www.gov.wales/final-report-evaluation-social-services-and-well-being-wales-act-2014>.

Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government. For further information please contact:

Social Services and Integration

Welsh Government, Cathays Park, Cardiff, CF10 3NQ

E-mail: research.healthandsocialservices@gov.wales

¹ [Welsh Institute for Health and Social Care](#), University of South Wales: [WIHSC Staff | University of South Wales](#)

² School of Care Sciences, Faculty of Life Sciences and Education, University of South Wales: [Roiyah Saltus - Faculty of Life Sciences and Education, University of South Wales](#); [Wahida Kent - Faculty of Life Sciences and Education, University of South Wales](#)

Table of contents

Glossary.....	2
1. Introduction	4
2. Findings – literature review	8
3. Findings – evidence from service users and carers	12
4. Findings – views from the workforce	15
5. Findings – research with Personal Assistants	17
6. Summary.....	19
References	21

List of tables

Table 1.1: Five principles of the Act, and the five domains of the study.....	5
Table 2.1: Enablers and barriers for ‘voice and control’ drawn from the literature	11

Glossary

Acronym/Key word	Definition
Advocacy / advocate	Advocacy services can help people to access information and services, get involved in decisions about their lives, explore choices and options, and express their wishes and needs.
Assessments	Assessments are undertaken with individuals to focus on what the individual needs and try to meet those needs, and carers to identify the support they need. The Act states a local authority must offer an assessment to any adult, child, and carer where they may have needs for care and support.
BSL	British Sign Language
CAMHS	Child and Adolescent Mental Health Services
Co-Production	The Act aims for people to be more involved in the design and provision of their care and support. It means organisations and professionals working with them and their family, friends and carers so their care and support is the best it can be.
Direct Payments, DPs	Direct Payments enable individuals and/or their carers assessed as having eligible social care needs to source care that is tailored to their needs, rather than using existing statutory providers. They are intended to provide greater flexibility, independence, and choice and control over the support people receive.
IMPACT	Independent evaluation of the Implementation of the Social Services and Well-being Act
LAs	Local Authorities
Multi-Agency working	The Act aims to strengthen joint working between care and support organisations to make sure the right types of support and services are available in local communities to meet people's needs.
Personal Assistants, PAs	A personal assistant provides person-centred care and support for individuals, so they can achieve personal well-being outcomes where the individual lives.
P-FE	Principles-Focused Evaluation
Prevention and Early Intervention	The Act aims to ensure that people can ask for the help they need when they need it to prevent their own situation from getting worse, and carers can access support to assist them in their caring roles and maintain their own well-being.
Sensory loss	Sensory loss is an umbrella term to describe the loss of the distance senses i.e. sight and hearing. There are four types of sensory loss: hearing, visual, deafblind, deaf British Sign Language (BSL) user.

Acronym/Key word	Definition
SERG	Study Expert Reference Group
Voice and Control	Voice and Control is a principle of the Act which aims to put the individual and their needs at the centre of their care and support, using their 'voice and control' over the outcomes that can help them achieve well-being and the things that matter most to them.
Well-being	The Act aims for people to have well-being in every part of their lives. Well-being is more than being healthy. It is about being safe and happy, having choice and getting the right support, being part of a strong community, having friends and relationships that are good for you, and having hobbies, work or learning.
'What Matters' conversation	'What Matters' conversations are a way for professionals to understand people's situation, their current well-being, and what can be done to support them. It is an equal conversation and is important to help ensure the voice of the individual or carer is heard and 'what matters' to them.
WIHSC	Welsh Institute for Health and Social Care, part of the University of South Wales.

1. Introduction

- 1.1 The Welsh Government commissioned a partnership of academics across four universities in Wales and expert advisers to deliver the evaluation of the *Social Services and Well-being (Wales) Act 2014* (hereafter referred to as ‘the Act’).
- 1.2 The independent national evaluation – the [IMPACT study](#)³ – has been running since November 2018 and is led by Professor Mark Llewellyn, Director of the Welsh Institute for Health and Social Care (WIHSC) at the University of South Wales alongside Professor Fiona Verity, Professor of Social Work and Social Care, Swansea University.
- 1.3 The partnership also includes colleagues from Cardiff Metropolitan and Bangor Universities and PRIME Centre Wales, and it is supported by the [Study Expert Reference Group](#) (SERG)⁴ with its three citizen co-chairs.

Context

- 1.4 The Act sets out the Welsh Government vision to produce ‘transformative changes’ in social service policy, regulation and delivery arrangements across Wales. It has 11 parts and is informed by five principles and aligned to it are structures, processes and a series of Codes of Practice.
- 1.5 It is really important to note the nature of the principles and how they are manifested in the experience of service users, carers and the workforce. The five principles do not exist in isolation – they are inter-related and inter-connected. There are overlaps between the underpinning philosophy of each, and as such in the experiences of people it is sometimes difficult to isolate one principle from another.
- 1.6 For example, it is almost impossible to conceive of how co-production as a principle can operate without first ensuring that people have voice and control over their care and support. Similarly prevention often presupposes that a multi-agency ‘offer’ will be in place for people in order that prevention of crisis can occur. And of course, all of the principles ultimately aim to deliver better well-being outcomes for people, which is a principle itself.

³ A bilingual introductory film explaining the structure of the study can be found here: [Ffilm gwerthuso'r Ddeddf / Act evaluation film – WIHSC - YouTube](#)

⁴ For more on the SERG, see: [Study Expert Reference Group | University of South Wales](#)

- 1.7 As such, when reading this report, whilst it is ostensibly about voice and control, there are occasions below when evidence concerning other principles is referenced. This reflects the inter-connected nature of the principles as noted above. Such evidence will be synthesised in the Final Report which draws material from this and the reports produced on the other principles.
- 1.8 Alongside the five principles, we have identified five domains within which the principles of the Act ‘meet’ the people or organisations for whom the Act should be having an impact – individuals in need of care and support, their carers and family members, the communities in which they live, the workforce that supports them, and the organisations that have responsibilities and duties to discharge as outlined by the Act and associated Codes of Practice:

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

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

1.9 The evaluation study represents an independent and objective assessment of the implementation of the Act and the way in which it has impacted the well-being of people who need care and support and their carers. In order to bring this about, we draw upon the approach espoused by Michael Patton (2018) in his ‘Principles-Focused Evaluation’ (P-FE) framework which we are using as the theoretical and conceptual underpinning of our study.⁵ There are three key questions that Patton encourages us to consider as part of any P-FE (2018, pp.27-29):

1. To what extent have meaningful and evaluable principles been articulated?
2. If principles have been articulated, to what extent and in what ways are they being adhered to in practice?

⁵ For more on P-FE see Patton, M. Q. (2018). *Principles-Focused Evaluation - The GUIDE*. New York: Guilford Press. For how P-FE relates to this study, see Chapter 2 in Llewellyn M., Verity F., Wallace S. and Tetlow S. (2022) *Expectations and Experiences: Service User and Carer perspectives on the Social Services and Well-being (Wales) Act*. Cardiff. Welsh Government, GSR report number 16/2022. Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: expectations and experiences](#).

3. If adhered to, to what extent and in what ways are the principles leading to the desired results?

1.10 There is a clear connection between Patton’s questions, the areas for inquiry in our study, and the five principles underpinning the Act. These connections are considered in detail on a principle-by-principle basis in a series of reports, of which this is one. This report focuses on the principle of voice and control, and has been authored by a sub-team within the IMPACT evaluation study group who have a special interest and expertise in this topic.

Purpose, method and scope

1.11 This report, focusing on the principle of voice and control, draws material from a number of reports already published across the study in order to focus in on this area:

- insights from the published literature review;⁶
- evidence from service user and carer perspectives, particularly from Black, Asian and Minority Ethnic people, and from those with sensory loss;^{7,8}
- workforce perspectives on how the principle of voice and control operates across social services;⁹ and
- evidence from a research study on the experiences of Personal Assistants (PAs) who are employed to support people with Direct Payments.¹⁰

1.12 As noted above, the report will primarily focus on voice and control, but there may be reference to the ways in which some of the other principles of the Act (co-production, prevention and early intervention, multi-agency working and well-being) inter-relate with voice and control in the evidence considered here.

1.13 The methodology and analysis for the various elements included in this report (literature review, service user and carer perspectives, workforce perspectives, and evidence from [Direct Payment recipients and PAs](#)) can be read in detail in each of

⁶ Llewellyn, M., Verity, F. and Wallace, S (eds). (2020b).

⁷ Llewellyn M., Verity F., Wallace S. and Tetlow S. (2022).

⁸ Llewellyn M. (2022)

⁹ Llewellyn M., Verity F., Wallace S. and Tetlow S. (2021)

¹⁰ Wallace, S., Llewellyn, M., Garthwaite, T, Randall, H. and Sullivan. S. (2022)

the published reports.¹¹ The different reports are united in taking a thematic approach to analysis as informed by Braun and Clarke's (2006) six steps.

- 1.14 The scope of this report is to draw the evidence around voice and control together, providing a focal point on this principle for those who may be interested in it. We draw such themes together in the Summary of this document, and provide recommendations that are specific to voice and control. These need to be seen in the context of the overall findings, conclusions and recommendations made in the Final Report (Llewellyn et al., 2023).¹²

¹¹ Llewellyn et al (2020b), Llewellyn et al. (2022), Llewellyn (2022), Wallace et al (2022) op. cit.

¹² It is also important to note that this report on voice and control is slightly different when compared to the others in this series given that it draws only from previously published material, whereas those on the other principles report (in part) on new and additional evidence. This document therefore acts as a digest of the evidence and findings collected throughout the study.

2. Findings – literature review¹³

Definitions

- 2.1 In respect of the concept of ‘voice’ and ‘control’, the Act provides no formal definition. There are fragments of definitions within different Parts of the Act, and the Codes of Practice. For example, Part 6 of the Act provides a number of key statements which are useful proxies to be considered in lieu of formal definitions, and in addition, the Code of Practice for Part 2 draws from the National Outcomes Framework in identifying key aspects of what it means to exercise ‘voice’ and ‘control’:
- A right to be heard as an individual...to have control over their daily lives
 - My voice is heard and listened to
 - I speak for myself and contribute to the decisions that affect my life or have someone who can do it for me.
- 2.2 Our working definition of voice and control is therefore based on having one’s voice heard and listened to as a basic right, having control over daily life by contributing to decisions and, if needed, receiving support to be heard.
- 2.3 On the whole, the published literature does not provide clear definitions of the terms ‘voice’ and ‘control’ (Vamstad, 2016; 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.
- 2.4 While most of the literature available does not explicitly use or define the terms ‘voice’ or ‘control’, a number of similar or related concepts surfaced in the literature, for example, 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).

Categories of literature

- 2.5 We structured the literature review on voice and control around four principal categories which became apparent after our analysis of the evidence. These mirror a number of the domains for the study that we have identified (see 1.8 above).

¹³ Llewellyn et al. (2020a)

Individuals who use social services

- 2.6 The literature review explores how drives to increase voice and control manifest and impact on the lives of individuals, with a focus on those requiring support and care provision. The findings covered a range of population groups, for example older people with more/less voice and control, and people with intellectual disabilities (Callaghan et al., 2014; Vamstad, 2016; Darby et al., 2017; Dunér et al., 2019).
- 2.7 Issues like quality of life (Reindl et al., 2016; Morris et al., 2017) and self-advocacy (Tideman and Svensson, 2015; Hamilton et al., 2017) were also identified in the review. The literature identified the complexity of implementing voice and control principles across different care settings and with different demographic groups; the challenges in sharing control across organisations and individuals in different social care settings; and the importance of advocacy and self-advocacy in creating a sense of voice and control for individuals.
- 2.8 Evidence from these papers suggests that feelings of being able to express a viewpoint (and being listened to) about the care and support people receive, can impact positively on a sense of self-reported well-being, whether that is due to advocacy being provided, or them having personal control over the small things in life – like what they want to wear, or when they eat.

Carers

- 2.9 The literature centred around how voice and control is enhanced or diminished for carers (Rand and Malley, 2014; Glenndinning et al., 2015; McNeilly et al., 2018; Watts and Cavaye, 2018). Given the focus on the importance of enhancing voice and control in the Act, the challenges of assessment tools and processes (Seddon and Robinson, 2015; Ewing et al., 2016), and of resources and budgets (Glendinning et al., 2015; Larkin, 2015; Galiatsatos et al., 2017; Singleton and Fry, 2019), are positioned within the literature as key factors shaping how the voice and control of carers may be enhanced or limited.
- 2.10 The key messages from this section of the literature review are the need to find the appropriate balance between notions of citizenship and having greater financial control; the challenges of having control over finances in giving carers and cared-for individuals voice and control; and the importance of quality social care practice in empowering carers to gain a sense of voice and control.

Workforce

- 2.11 The review examined voice and control and the workforce across social care settings. It explored policy and practice in supporting staff to foster empowerment and share control and decision making (Gridely et al., 2014; Keyes et al., 2015; McCarter et al., 2016; Brogan, 2018), and the barriers and enablers in both the development of person-centred care (Gridley et al., 2014; Hanga et al., 2017; Washburn and Grossman, 2017; Dunér et al., 2019) and advocacy (Eades, 2018).
- 2.12 The key messages that came from this section are the importance of person-centred approaches in fostering voice and control principles for service users; the challenges inherent in implementing policy informed by voice and control principles; and the importance of the relationship between practitioner and service user in creating a good sense of voice and control for service users.

Organisations

- 2.13 The final section of the review discussed the role of care and health organisations in voice and control. The literature focused on one key area, assessment, and the ways in which assessment of care needs (Darby et al., 2017; Hanga et al., 2017), self-assessment (Keyes et al., 2015), and approaches to the assessment process (Skills for Care, 2018), impact voice and control principles and practice for care organisations (Seddon and Robinson, 2015; Tucker et al., 2018).
- 2.14 The key findings were that there are challenges in instilling voice and control principles in health and social care assessments; and that person-centred practice and conversational approaches can provide a good platform for voice and control principles to be implemented in social care.

Enablers and Barriers

- 2.15 Overall, the voice and control literature review highlighted a number of barriers and enablers (see Table 2.1 overleaf) that can hinder or assist individuals who are receiving care and support to have greater input into their care (voice) and a greater say over what happens (control).

Table 2.1: Enablers and barriers for ‘voice and control’ drawn from the literature

Barriers to voice and control	Enablers of voice and control
Lack of clear definition in literature as to what voice and control means	Undertaking self-advocacy and having access to advocacy support and services
Complexity of applying voice and control principles in different social care settings	Quality social care practice in giving a sense of voice and control
Inability and unwillingness to share control between the organisation and service user in social care settings	Person-centred approaches, such as ‘what matters’ conversations
Unwarranted variation in implementing voice and control principles with different service user groups, e.g. older people with dementia, or young children	Trusted relationships between practitioner and service users
Voice and control principles absent from health and social care assessments	Conversational approaches to social care practice
Devolved forms of payment (e.g. personal budgets) giving individuals voice and control	

3. Findings – evidence from service users and carers

- 3.1 The way in which service users and carers experience voice and control varies significantly. The experiences and expectations of the wider population of service users and carers was provided as part of the [‘Expectations and Experiences’](#) report.¹⁴ It presented evidence indicating that people’s experiences of voice and control are moving towards the goals of the Act, but genuinely being able to exercise voice and control remains very much a work in progress.
- 3.2 There are however particular groups of service users and carers who are more disadvantaged than others when it comes to having their voice heard. In this report, focusing particularly on voice and control, we provide perspectives from two such groups: people in receipt of care and support and their carers who make use of services who are from Black, Asian and Minority Ethnic backgrounds, and people who have sensory loss. Their perspectives provide especially valuable insight and understanding of the issues they faced around voice and control when accessing and receiving care and support. These perspectives provide important insights as to where the system may be most challenged in being able to respond to people in a culturally sensitive and appropriate way. It was also an opportunity for these two groups to express their voices and be heard.

Approach

- 3.3 We worked closely with EYST Wales (Ethnic Minorities and Youth Support Team) to support the work in this evaluation with Black, Asian and Minority Ethnic older people and carers of older people.¹⁵
- 3.4 Similarly, the Wales Council for Deaf People (WCDP) brought together two focus groups, which included 10 WCDP members, four of whom had hearing loss, and six of whom who were deaf. A topic guide developed by the study team was used and a British Sign Language (BSL) simultaneous interpreter signed questions posed by the researcher to deaf participants and relayed individual responses back verbally.
- 3.5 In presenting the findings, we recognise that these reflect only the perspective of the individuals we heard from. It is not possible nor sensible to draw conclusions beyond that which is justified by this purposive sample and based on these

¹⁴ Llewellyn et al., 2022.

¹⁵ More information about this focus group can be found in the [full report of findings](#).

experiences and the views expressed. However, it is important to recognise the authenticity of the perspectives provided. Evidence on the experiences of care and support was sought from these key informants which when brought together can highlight key characteristic patterns (Patton, 2015).¹⁶

- 3.6 It is also important to note that the data collection took place during the COVID-19 pandemic, in September 2021.

Key issues and themes – Black, Asian and Minority Ethnic older people and carers

- 3.7 There were a number of very powerful and challenging reflections on people's experiences of voice and control within the social care system. There were a range of issues expressed which in many ways could have been experienced by any service user and carer – like not feeling heard or having a voice. Commonalities also existed in the views expressed about pressures within the system leading to challenges over the lack of timely responses.
- 3.8 However, there was a particular issue experience by the Black, Asian and Minority Ethnic older people and carers we spoke to. Despite trying to communicate with the 'system', participants reflected on troubling experiences they had had which made them call into questions some of the assumptions that were being made about them, their ethnicity, and their cultural background which they felt were inappropriate and racialised.

Key issues and themes – people with sensory loss

- 3.9 Similarly, key challenges around the lack of voice and control emerged from the experiences of care and support of sensory loss service users.
- 3.10 Whether or not services recognised and exercised their duty under the Act to provide interpreters for all sensory loss service users and carers when accessing provision was at the heart of these experiences.
- 3.11 Four particular issues emerged from their evidence:
- Crucially, people with sensory loss felt that they had very limited means of ensuring their voice was heard. They lacked the consistent mechanisms to support communication and were often unable to express their views, which significantly impeded their voice, control and agency. There was a sense of

¹⁶ Patton, M. Q. (2015). *Qualitative Evaluation and Research Methods*. Thousand Oaks, CA: Sage.

inequality compared to those without sensory loss, and the lack of a dedicated social worker to advocate on their behalf was seen as a considerable barrier to achieving voice and control.

- The Covid-19 pandemic and associated lockdown restrictions served to intensify some of the communication and information sharing challenges referred to within the first theme, which in turn, further inhibited participants achieving voice and control.
- The role and support of specialist third sector providers were seen as being central in ensuring that people feel heard and valued. As well as practical support and guidance, third sector providers offered opportunities to connect with others and learn new skills. Nonetheless, short-term funding meant uncertainty about the longevity of those providers and whether they would be able to offer continuity of care.
- Participants reflected on geographical variation (within Wales and between Wales and England) with regards to access to equipment, information, and support services to allow them to feel they have a sense of control over their care and support.

4. Findings – views from the workforce

4.1 Building on the specific evidence from service users above, and drawn from the *Process Evaluation* report,¹⁷ the following excerpts provide insights from the workforce on the ways in which the principle of voice and control operates (or doesn't operate) in the day-to-day work of social services and social care across Wales. This short chapter provides an insight into the kinds of issues that arose from the discussions with the workforce, to be considered alongside the service user and carer perspectives.

Variations in exercising voice and control

4.2 It was suggested by the workforce that the extent to which people are able to exercise voice and control may vary according to the phase of their engagement with social services. There are perhaps four different stages of involvement:

- When people first contact the local authority;
- During the assessment process;
- When developing the care and support plan and how that is designed; and
- In the way that the workforce responds to people following the commencement of the care and support package.

Conversations and engagement with citizens

4.3 Examples were given of positive interpretations of the impact resulting from the Act's focus on 'voice and control' – where advocacy works well for people being the preeminent of these, alongside an enhanced focus on what matters to people. There was also more awareness of how supporting voice and control could be better undertaken, and turned into practice.

4.4 There was considerable discussion about the implementation of the advocacy requirements under the Act. There was a viewpoint that these measures are working well, with increased use of advocacy services by a broader group than before, increased awareness of the need for and importance of advocacy, and incorporation of advocacy into social care practice such that an 'active offer' of independent advocacy is made to service users and carers.

¹⁷ Much greater detail can be found in Llewellyn M., Verity F., Wallace S. and Tetlow S. (2021) *Evaluation of the Social Services and Well-being (Wales) Act 2014: Process Evaluation*. Cardiff. Welsh Government, GSR report number 2/2021. Available at: [process evaluation](#).

Direct payments

- 4.5 Under the Act, direct payments are a key mechanism through which service users and carers can achieve a greater sense of voice and control. If eligible, service users and/or carers can be provided with an amount of money to be used to achieve their well-being outcomes. Within certain parameters, this money can be spent as they would choose, typically through employing a Personal Assistant (PA).
- 4.6 Despite direct payments being highlighted by the workforce as a 'really good' concept in helping to bring about voice and control for service users and carers, a number of challenges were noted. These include, in particular, the burden of responsibility for individuals as employers, recruitment issues of PAs, and the question of the extent to which an individual is actually in control of who they employ.¹⁸

Managing risk and difficult conversations with service users and carers

- 4.7 Participants discussed the approach to risk as part of their reflections on assessment processes, as the Act had encouraged a less risk averse approach in assessing and providing care and support. This change in approach to risk centred on tensions around how voice and control can act in conflict with operational procedures, plans and packages. All too often, the limitations of the system works against what matters to people, leading to conflict with families, through a series of challenging conversations wherein expectations need to be managed.
- 4.8 This led to reflection on the perceived disconnect between legislative rhetoric and operational reality, especially when faced with tensions between what matters to people and local flexibility and interpretation versus centralised control and what services are available and can be provided.

¹⁸ More detail on each of these issues is provided in Chapter 5 below.

5. Findings – research with Personal Assistants

- 5.1 Direct Payments (DP) have been one of the key mechanisms through which service users and carers have been able to exercise greater voice and control over their care and support for many years. Recipients of DPs can employ Personal Assistants (PAs) in order to support them to achieve their personal well-being outcomes and goals. As such, employing PAs is one of the means through which voice and control for service users is achieved.
- 5.2 The Welsh Government commissioned the group of researchers at WIHSC who are leading on IMPACT to deliver a linked study on PAs in partnership with Data Cymru.¹⁹
- 5.3 In a number of different ways, the study identified room for improvement in the way in which PAs are employed, and how DP recipients undertake their employer role. In considering what is working well and what is working less well in the employment of PAs, a number of issues were identified from the analysis.²⁰
- 5.4 What follows is a summary of the findings of the study that are relevant to the principle of voice and control as facilitated and enabled by (or not)
- 5.5 As these issues relate to a key mechanism for achieving voice and control – namely the relationship between a DP recipient and the PA that they employ – they are summarised in the paragraphs that follow.
- 5.6 Pay is a key issue in the data collected in the PA study. Evidence from that work indicates that pay rates are not commensurate with the level of skills and range of tasks PAs undertake, given the challenge of their role. PAs described feeling undervalued as a consequence of their low pay rate.
- 5.7 PAs reported that the terms and conditions contained within their contracts – i.e. employee's entitlements – are either absent or unclear. The study found that PAs note that they do not always receive payment for all the work they undertake, which they linked to the lack of clarity in their contractual position.
- 5.8 A survey undertaken as part of the study revealed that 65% of employers in Wales found it difficult or very difficult to recruit PAs. The issues described above have implications for recruitment and retention as well as achieving continuity of care when replacement PAs are needed to cover absences. The survey identified a clear

¹⁹ Wallace et al (2022), op. cit.

relationship between the remuneration package for PAs and the ability to recruit and retain them, with 85% of employers reporting that terms and conditions were quite or very important in this regard.

- 5.9 Employing a PA via the DP system may well be the first experience many people have of being an employer. The complexities involved are acknowledged by PAs who also recognise the importance of employers being supported and equipped with the skills needed to fulfil their role.
- 5.10 Having a PA offers opportunities for relationship-based care that can lead to enhanced levels of person-centred support, and employers place intrinsic value on the continuity of care and the development of close caring relationships with their PAs. Forming close working relationships with their employers and their families is a central aspect of the PA role. Features working well for PAs are linked to the intrinsically close relationships built with their employers. This close working relationship can be a key mechanism enabling voice and control.
- 5.11 In summary, services users and carers voice and control has been limited by the lack of available PAs. There are also challenges for those who are new to the process of employing a PA, which can stifle the use of DPs, and as such limit the opportunities to express voice and control. However, the close relationships between PAs and employers can be a means of delivering voice and control.

6. Summary

- 6.1 Voice and control aims to put the individual, including unpaid carers, and their needs at the centre of their care to enable and/or empower them to shape the outcomes that allow them to achieve a sense of well-being and a good quality of life in terms of the things that matter most to them.
- 6.2 The evidence in the chapters above provides a mixed picture of the extent to which the principle has been embedded as part of the process of implementation of the Act.
- 6.3 Having reflected on the evidence drawn from all aspects of the study, we therefore recommend that the following four areas are considered and addressed in order to maximise the impact that the principle of voice and control can achieve:

1. **Champion the ethos of voice and control.** Neither published research literature, nor the Act, its associated Codes of Practice and technical papers provide definitions of the often-twinning concepts of 'voice' and 'control'. This had led to various notions, versions and meanings of 'voice and control' being used in the published literature and in everyday life as evidenced across all the stakeholder groups involved in the evaluation. Dimensions of voice and control – person-centred care, empowerment and shared decision-making – can be used to help personalise and individualise the system. The precise definition matters less than the experience that people have, and as such we strongly recommend that all those who have a duty to promote this principle take every opportunity to do so.
2. **Make voice and control a reality for everyone.** In line with the literature review, our qualitative findings from specific minority population groups (like those with sensory loss, and those from Black, Asian and Minority Ethnic backgrounds) reveal that achieving voice and determining levels of control was shaped in part by social identity (whether age, ethnicity, impairment), professional and organisational competencies and practice models. Minority population groups face additional barriers to being understood or to having their thoughts considered, with long-standing health and social inequalities impacting on whether they engage in any way in formal social care systems, and how those that decide to – or have no other choice than to – then fare. This can be addressed through investing in advocacy, including peer advocacy, alongside

working with, and investing in, the expertise of community-anchored organisations.

3. **Recognise the importance of voice and control ‘cartographies’.** Service users and carers – and to an extent the workforce – are required to map and journey their way through the system, whilst the landscape changes around them. Our evidence points to the fact that people want to be heard and exercise control as they move from first contact with the system, through assessment and support planning, to ongoing engagement with the workforce. Each stage offers opportunities to pilot and further enhance models, practices and processes that foster voice and control in ways that can be mapped, monitored and reflected upon to improve the experience and outcome for all.
4. **Enhance existing – and develop additional – mechanisms for achieving voice and control.** Additional work is needed to foster strength-based conversations about the assessment and provision of care and support. Such development would be enhanced if placed in the context of wider public engagement aimed at more clearly articulating the change of ethos the Act is seeking to bring about in terms of co-designing support systems and processes. As one way – and perhaps the only way for many – to foster control, direct payments remain important and necessary, but our evidence suggest they are not for everyone. Ongoing leadership, support and promotion of direct payments is needed, alongside the development of innovative and alternative models of person-centred, citizen-directed support, perhaps in the form of co-operatives and social enterprises.

6.4 As we carefully explained in our [Framework for Change](#), to seek to evaluate the impact of the Act is to review the unfolding of a suite of policy and legislation put in place over the last decade. With our work on Voice and Control – much like the other principles explored as part of this evaluation – progress has been made, but there is still more to do.

References

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Llewellyn M, Verity F, Wallace S, Calder G, Garthwaite T, Lyttleton-Smith J, and Read S (2023) *From Act to Impact? Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014*. Cardiff. Welsh Government, GSR report number 36/2023. Available at: <https://www.gov.wales/final-report-evaluation-social-services-and-well-being-wales-act-2014>.

Llewellyn M. (2022). *Evaluation of the Social Services and Well-being (Wales) Act 2014: expectations and experiences of Black, Asian and Minority Ethnic service users and carers*. Cardiff. Welsh Government, GSR report number 32/2022. Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: expectations and experiences of Black, Asian and Minority Ethnic service users and carers](#).

Llewellyn M., Saltus R., Blackmore H., Tetlow S., Williams Z. and Wallace S. (2020a). 'Voice and Control' in Llewellyn, M., Verity, F. and Wallace, S (eds). (2020) *Evaluation of the Social Services and Well-being (Wales) Act 2014: Literature Review*. Cardiff. Welsh Government, GSR report number 60/2020. Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: literature review](#).

Llewellyn, M., Verity, F. and Wallace, S (eds). (2020b). *Evaluation of the Social Services and Well-being (Wales) Act 2014: Literature Review*. Cardiff. Welsh Government, GSR report number 60/2020. Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: literature review](#).

Llewellyn M., Verity F., Wallace S. and Tetlow S. (2021). *Evaluation of the Social Services and Well-being (Wales) Act 2014: Process Evaluation*. Cardiff. Welsh Government, GSR report number 2/2021. Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: process evaluation](#).

Llewellyn M., Verity F., Wallace S. and Tetlow S. (2022). *Expectations and Experiences: Service User and Carer perspectives on the Social Services and Well-being (Wales) Act*. Cardiff. Welsh Government, GSR report number 16/2022. Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: expectations and experiences](#).

McCarter, S.P., Tariman, J.D., Spawn, N., Mehmeti, E., Bishop-Royse, J., Garcia, I., Hartle, L. and Szubski, K. (2016). Barriers and promoters to participation in the era of shared treatment decision-making. *Western Journal of Nursing Research*, 38(10), 1282-1297.

McNeilly, P., Macdonald, G. and Kelly, B. (2018). The participation of parents of disabled children and young people in health and social care decisions. *Child: Care, Health & Development*, 43, 839-846.

Morris, J.N., Declercq, A., Hirdes, J.P., Finne-Soveri, H., Fries, B.E., James, M.L., Geffen, L., Kehyayan, V., Saks, K., Szczerbinska, K. and Topinkova, E. (2017). Hearing the voice of the resident in long-term care facilities – an internationally based approach to assessing quality of life. *Journal of the American Medical Directors Association*, 19(3), 207-215.

Patton, M. Q. (2015). *Qualitative Evaluation and Research Methods*. Thousand Oaks, CA: Sage.

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

Rand, S. and Malley, J. (2014). Carers' quality of life and experiences of adult social care support in England. *Health and Social Care in the Community*, 22(4), 375-385.

Reindl, R.S., Waltz, M. and Schippers, A. (2016). Personalisation, self-advocacy and inclusion: an evaluation of parent-initiated supported living schemes for people with intellectual disabilities and developmental disabilities in the Netherlands. *Journal of Intellectual Disabilities*, 20(2), 121-136.

Seddon, D. and Robinson, C. (2015). Carer assessment: continuing tensions and dilemmas for social care practice. *Health and Social Care in the Community*, 23(1), 14-22.

Singleton, B.E. and Fry, G. (2015). Citizen carer: carer's allowance and conceptualisations of UK citizenship. *Journal of Social Policy*, 44(3), 549-566.

Skills for Care (2018). *Using conversations to assess and plan people's care and support: the principles of conversational assessment*. Skills for Care.

Tideman, M. and Svensson, O. (2015). Young people with intellectual disability – the role of self-advocacy in a transformed Swedish welfare system. *International Journal of Qualitative Studies on Health and Well-being*, 10(1), 1-8.

Tucker, S., Hargreaves, C., Roberts, A., Anderson, I., Shaw, J. and Challis, D. (2018). Social care in prison: emerging practice arrangements consequent upon the introduction of the 2014 Care Act. *British Journal of Social Work*, 48, 1627-1644.

Vamstad, J. (2016). Exit, voice and indifference – older people as consumers of Swedish home care services. *Ageing & Society*, 36, 2163-2181.

Verity, F., Andrews, N., Blackmore, H., Calder, G., Richards, J. and Llewellyn, M. (2019). *Evaluation of the Social Services and Well-being (Wales) Act 2014: Framework for Change Report*. Cardiff. Welsh Government, GSR report number 38/2019 Available at: [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: framework for change](#).

Wallace, S., Llewellyn, M., Garthwaite, T, Randall, H. and Sullivan. S. (2022). *Research on the Employment of Personal Assistants in Social Care*. Cardiff. Welsh Government. Available at: [Research on the employment of personal assistants in social care](#).

Washburn, A.M. and Grossman, M. (2017). Being with a person in our care: person centred social work practice that is authentically person-centred. *Journal of Gerontological Social Work*, 60(5), 408-423.

Watts, J.H. and Cavaye, J. (2018). Being a former carer: impacts on health and wellbeing. *Illness, Crisis & Loss*, 26(4), 330-345.