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# Introduction

Victoria Lloyd, Chief Executive, Age Cymru



Victoria Lloyd

Having voice and control over decisions that affect us and having our views, wishes and feelings respected and taken into consideration are vitally important to all of us. It is essential

that older people feel empowered to speak up about their own choices and views.

Voice, choice and control are about identity, self-determination, self-expression and human rights. The lack of them damages our confidence, self-esteem and our well-being. All older people should feel that they have voice, choice and control over their lives and that they have the right support to make informed decisions, particularly in situations within which they are vulnerable.<sup>1</sup>

Older people have told us:

**“Voice – to be able to have my voice heard.”**

**“Choice – to be able to choose the life I want to live.”**

**“Control – to try and retain control of my life for as long as I possibly can.”**

**“We cannot see what will happen in the future, whether this is losing your mobility which would make you more vulnerable and also losing your mental capacity, this I think frightens people more than anything.”**

We asked some older people what aspects of their independence they most value and want to retain control of to ensure their well-being in growing older:

**“Keeping my mental capacity, keeping mobile, and knowing you have a family and friends who care about you.”**

**“To make sure I have a say as to the care I receive should it be necessary and that I understand clearly the cost implications. Not to be forced to undertake any activities that I find I am not suitable for. Every older person should have access to an advocate if there is not a suitable member of the family.”**

Independent advocacy services can play an important role by helping people to have a voice and regain control in difficult situations. It can help secure their rights and represent their interests. Advocacy can help to prevent discrimination, neglect or abuse by enabling older people at risk to become more aware of their rights and able to express their wishes and concerns.<sup>2</sup>

Advocacy services can help an older person to navigate complex systems, make their voices heard, and build up the confidence and resilience to speak up for themselves and take control of their lives. However, the latest edition of Age Cymru’s ‘Advocacy Counts’<sup>3</sup> reports a continued fall in the number of specialist advocacy providers and advocates for older people in Wales.

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**“I have been unable to get advocacy services for some people in serious need.”**

**“People should naturally have this entitlement without having to suffer and may leave this world not ever benefiting from their entitlement. I feel so sad about this as there are so many and we are not even scratching the surface.”**

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Older people deserve equal respect, rights and the same access to services as the rest of the population. It is essential that older people are aware of their rights and are able to exercise them.

We asked some older people if they would be confident in knowing and understanding their basic human rights and their rights to services or support, and whether they would be able to voice them to professionals:

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**“No. This is a problem that I see regularly in the older people that I have contact with and I am certain that I do not have sufficient knowledge personally.”**

**“I am aware of my Human Rights and have access to the legislation but I would not feel easy voicing them to professionals unless there was some sort of prior knowledge to what they would be expecting from me.”**

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We believe that work is needed to increase knowledge and raise awareness of the rights of older people across Wales. Until people know about their rights they won't be able to exercise them.

In this edition of EnvisAGE we shine a light on the importance of keeping voice, choice and control when growing older. We highlight key policy drivers and initiatives that support Age Cymru's vision of an age friendly Wales, a Wales

where the services that support voice and control are well funded and accessible to all of the older people that need them.

In our opening article Professor John Williams of Aberystwyth University focuses on the importance of older people being able to make choices, and to understand their rights and make informed decisions. The article highlights that dignity and choice are closely related, and concludes that in social care, health care, safeguarding, legal matters and day to day living, the right of older people to make a fully informed and freely made choice must be respected and protected.

Andrew Dunning of Swansea University draws on a personal perspective to reflect on the importance of recognising advocacy as a means of securing and exercising older people's rights. The article provides an overview of social policy relating to voice, choice and control, and highlights a number of issues facing advocacy at a policy level that have an impact for older people in Wales at a personal level.

Gail Hamer and Jill Ball of Age Cymru Powys present an overview of advocacy services for older people in Powys, and Jill provides an insight into her role as an advocate.

Dr Juping Yu and Professor Mark Llewellyn of the University of South Wales draw on findings from a study evaluating the 'Help to be Heard' volunteer-led advocacy service for older people in Carmarthenshire. The article highlights what service users have said about the beneficial impact of advocacy.

Lowri Williams, writing on behalf of the Welsh Language Commissioner and Alzheimer's Society Cymru, focuses on Welsh speakers' dementia care. The article outlines findings of research drawing on the experiences and voices of people living with dementia, and highlights that providing services in Welsh to



people with dementia is a matter of clinical need. The article makes recommendations for improving service provision.

Heléna Herklots, the Older People's Commissioner for Wales, focuses on a recommendation made in the 'Making Voices Heard' report around a call to extend the 'active offer' of advocacy to older people in care homes and awaiting hospital discharge to enable them to exercise their rights and ensure their voices are heard.

In our final article, Louise Hughes of Age Cymru reports on the achievements of the Golden Thread Advocacy Programme, which supports the implementation of the advocacy element of the Social Services and Well-being (Wales) Act 2014. The programme aims to develop a national framework for commissioning independent professional advocacy for adults in Wales, to support and build the capacity of

the advocacy sector in Wales, and to raise awareness of advocacy.

Our thanks to all the authors who have contributed their expertise and shared good practice towards keeping voice, choice and control when growing older.

EnvisAGE is a discussion journal edited by Age Cymru. It aims to explore issues affecting older people, stimulate discussion and share good practice.

**For more information on our vision for an age friendly Wales or any topics covered in this journal please contact us on**  
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# Dignity and choice: the voice of older people

John Williams, Professor Emeritus, Department of Law and Criminology,  
Aberystwyth University

## Introduction

We value our dignity. Similarly, we appreciate the ability to decide for ourselves. We make many choices – where we live, what we eat, relationships with others, how we dress, what we read and so on. Sometimes these choices involve complex medical, social care or legal matters. Of course, there are restrictions on making a choice. Criminal law prevents us from doing certain acts; social conventions may limit our behaviour, and responsibilities for others may restrict choice. Nevertheless, we have considerable freedom to choose and define how we live and relate to others. Dignity and choice are closely related. To deny somebody the right to choose violates dignity. There is dignity in being able to determine the lifestyle we adopt even though others think it is ‘undignified’.

All too often ageism denies older people the right to choose. It may be because of ill-intentioned ageism, or it may be benevolent ageism. In both cases it is ageism.

## Dignity, choice and human rights

The European Court of Human Rights emphasises that the ‘very essence’ of the European Convention on Human Rights is respect for human dignity and human freedom (see *Pretty v. the United Kingdom*). Article 8 of the Convention says that everyone has the right to respect for private life which includes dignity, and the right to be independent and exercise choice. When choosing, we have the right to make what others may think of as

unwise decisions, a principle reinforced in the Mental Capacity Act 2005. The European Convention prohibits discrimination in the enjoyment of rights. To deny or restrict a person’s right to choose because of age is unlawful.

The Human Rights Act 1998 makes it unlawful for a ‘public authority to act in a way that is incompatible with a Convention right’. When working under the Social Services and Well-being (Wales) Act 2014 or the Mental Capacity Act 2005, local authorities must demonstrate that they are respecting Convention rights – including the right to choose. The term ‘public authority’ includes the NHS, local authorities and the police. As a result of changes to the law in the English Care Act 2014, it now covers private providers of residential and domiciliary care if the local authority is paying for it or has arranged it.

## Well-being and choice

Section 2 of the Social Services and Well-being (Wales) Act 2014 introduced an overarching duty to ‘seek to promote’ the well-being of people needing care and support and carers needing support. This duty is important, although limited by being overarching rather than an individual duty. Also, it is a duty to ‘seek’ to promote rather than promote. However, well-being is in many respects the point of reference for service users and practitioners. Well-being under the 2014 Act covers many aspects of daily living. Welsh Government Guidance states that to discharge the well-being duty, responsibility for well-being must be



shared with people needing care and support and carers needing support. Local authorities and practitioners must empower people to contribute towards achieving their well-being with appropriate support. It is essential that what matters to the individual, and their desired personal outcomes are understood by the authority (Welsh Government, 2015 paras 28-29). The National well-being outcome statements emphasise that the individual's voice is heard, that they can speak for themselves, and can do the things that matter to them. This underlines the centrality of the individual's human right to make choices. The words of the Guidance have a legal context through the article 8 right discussed above. One of the aspects of well-being listed in the Act is securing rights and entitlements. Choice is a crucial right. If the state wants to interfere with this right, it requires a legal, compelling and well-defined reason for doing so.

### **Exercising the right to choose**

The law requires three things before there is a valid consent or refusal. The person must have mental capacity under the Mental Capacity Act 2005; this is discussed below. Secondly, the person must be given any information necessary to exercise choice. The law is clear that practitioners must provide people with information so they can make an informed

choice. So, if the decision is between remaining at home or entering residential care, they must be informed of the implications of each option. It is important that the person is made aware of risks. Direct questions must be answered openly and honestly. As far as doctors are concerned, in *Montgomery v Lanarkshire Health Board*, the Supreme Court said,

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**'...the doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments.'**

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Whether something is material depends upon whether a 'reasonable person in the patient's position would be likely to attach significance to the risk...'.

Finally, the law requires that the person must exercise their right to choose free of any external pressure. The notion of undue influence or what is now referred to as coercive or controlling behaviour is a constant feature in safeguarding cases. In intimate or family relationships it may amount to an offence (Serious Crimes Act 2015). In most, if not all cases of abuse or neglect of older people the abuser exercises control over the survivor's right to choose. The controlling or coercive behaviour may be open or may be subtle. It means the survivor is not exercising free choice in financial or legal matters, intimate relationships, the way they live, medical treatment and whether they wish to engage with safeguarding enquiries. In safeguarding it is important not to concentrate on the last act, but rather to look at the history of the relationship and identify whether the survivor is free to choose or not. Practitioners and family must also be alert to the danger that they may be unintentionally over-influential when advising.

## Mental capacity

Research by Dewis Choice at Aberystwyth University found that older people lacking mental capacity experiencing abuse or neglect are at heightened risk within the criminal justice system. Independent Mental Capacity Advocates are under-used. Assessments of capacity tend to be too general, and re-assessments are not undertaken to reflect the fact that capacity is both time and decision sensitive. When seeking justice, older victims of abuse and neglect often fare badly; if they also lack capacity, there is a double jeopardy. Things tend to be done to them rather than with them (see Clarke, Williams, Wydall and Boaler 2012).

The Mental Capacity Act 2005 enables decisions to be made for a person who lacks capacity in their best interests. One of the principles in the Act is '(A) person is not to be treated as unable to make a decision unless all practicable steps to help [him or her] to do so have been taken without success.' The emphasis is on doing everything possible to assist the person to choose rather than have a decision imposed upon them. Decision makers must demonstrate what they have done to support the person. In deciding best interests, the decision maker must, so far as reasonably practicable, permit and encourage the person to participate or to improve his or her ability to do so as fully as possible. The person may lack capacity, but has a point of view that must be heard.

The United Kingdom has signed and ratified the Convention on the Rights of Persons with Disabilities. Under article 12 persons with disabilities (for example, lack of mental capacity) enjoy legal capacity on an equal basis with others. The assumption that if a person lacks mental capacity, he or she also loses legal capacity is challenged. Under the Convention, states must support persons with disabilities in exercising their legal capacity; this may be

through a trusted person or a network of people. The overriding principle is that the decision maker should be the person who lacks mental capacity.

Unlike the Human Rights Convention, the Disabilities Convention is not part of our law. However, the principle of supported decision making can be used to reinforce the requirement under the 2005 Act to do everything possible to enable people to decide for themselves and to listen to those who lack mental capacity.

In the longer term, the Disabilities Convention challenges the basis of the 2005 Act and requires us to rethink how we protect the right of all people to make choices on an equal basis.

## Conclusion

Well-intentioned benevolence or ill-intentioned behaviour may deny older people their right to make choices. This reinforces an ageist perception that older people are frail and dependent and contributes to them being undervalued and undervaluing themselves. In social care, health care, safeguarding, legal matters and day to day living, the right of older people to make a fully informed and freely made choice must be respected and protected.

# The recognition of advocacy as a means of securing and exercising older people's rights – a personal perspective

Andrew Dunning, Senior Lecturer, Public Health, Policy and Social Sciences, Swansea University

Almost thirty years ago I jumped ship from statutory social services as it became clear that the NHS and Community Care Act (NHSCCA) 1990 was not going to deliver on choice let alone voice and control, and that clients or citizens were instead to become 'consumers'.

I was aware of the disability movement and the development of advocacy with people with learning difficulties throughout the 1980s. I had also seen the problems encountered by people who had grown older in long stay institutions and the abuse and discrimination endured. So, in 1992 I became the co-ordinator of an advocacy project for older people with mental health problems and dementia, one of the first grassroots advocacy projects working specifically with older people in the UK.

During this time there was no real legislative or policy framework for advocacy to thrive. Relevant sections of the Disabled Persons' (Services, Consultation and Representation) Act 1986 had never been implemented. The NHSCCA 1990 failed to include advocacy amongst its provisions, simply suggesting in its guidance that local authority social services managers might support its development. In a written answer to the House of Commons in 1991, Health Minister Virginia Bottomley stated that the cost of advocacy for those assessed under the terms of the community care reforms was prohibitive.

Nevertheless, advocacy was being increasingly mentioned in policy documents published by The Department of Health, the Social Services Inspectorate and even in John Major's much maligned 'Citizen's Charter'. It was also highlighted by the Law Commission in its review of mental capacity in the mid-1990s. Also, in 1995 I wrote the first code of practice on advocacy with older people commissioned by the Department of Health and published by the Centre for Policy on Ageing.

Meanwhile, the Human Rights Act (HRA) 1998 heralded a shift in thinking about rights and whilst advocacy was not explicitly mentioned, it was clearly a way in which to operationalize such rights in practice. A growing number of advocacy organisations started to use the HRA to support older people to secure and exercise their rights, often simply by showing statutory authorities the ways in which they were being denied or over-ridden.

Finally during this era, the advocacy movement galvanised itself from the grassroots towards the creation of national advocacy bodies, not only to campaign but to take responsibility for the development of principled, high quality advocacy. The consultees for the aforementioned code, drawn from advocacy projects, older people's forums and other bodies, were to become the founder members of the Older People's Advocacy Alliance (OPAAL) UK. Age Concern developed an advocacy co-ordinators





network. An initial steering group was convened for what was to become Action for Advocacy, going on to create the Advocacy Charter and quality standards owned by the movement itself.

The first decade or so of the new millennium brought a plethora of legislative and policy developments as well as a growth in the number of advocacy organisations working with older people. Advocacy was included within a range of the devolved Welsh Government policy documents, from the In Safe Hands adult protection guidance (2000) to the National Minimum Standards for Care Homes for Older People in Wales (2004) and the Welsh Assembly Government Statement on Policy and Practice for Adults with a Learning Disability (2007).

Key legislation implemented at this time included Regulation 16 of the Social Services Complaints Procedures (Wales) Regulations (2005) and the National Health Service (Wales) Act 2006 bringing Community Health Council Complaints Advocacy; the Mental Capacity Act 2005 and Deprivation of Liberty Safeguards (2009); the Mental Health (Independent

Mental Health Advocates) (Wales) Regulations (2008) and later Mental Health (Wales) Measure (2011). Clearly, the official recognition long sought after by many local advocacy organisations and bodies such as OPAAL and Age Concern (later Age Cymru) Advocacy Co-ordinators Network was beginning to be fulfilled, albeit within specific policy parameters.

Another crucial development at this time was the establishment of the first Older People's Commissioner in Wales – a first in the UK (2001). As well as having a public advocacy function, the Commissioner for Older People in Wales has promoted the development of independent advocacy organisations. The Commissioner has also commissioned and conducted research into advocacy, including the first scoping study of advocacy for older people in Wales I authored in 2010, and has subsequently published a range of reports relating to advocacy as a means of voice, choice and control by and for older people.

In more recent years, alongside the Equality Act 2010, the most significant legislative developments regarding advocacy with older

people (and indeed other groups) in Wales has been the implementation of the Social Services and Well-being (Wales) Act 2014 (SSWBA) and the Regulation and Inspection of Social Care (Wales) Act 2016 (RISCA), with attendant codes of practice and guidance. The SSWBA aims to transform social services and well-being, changing the relationship between the individual and services, promoting co-production and partnership towards solutions and creating a paradigm shift in balance of power. In Section 10 of the SSWBA, advocacy is seen to play an essential role in delivering on these intentions for people in need of care and support. RISCA meanwhile makes advocacy, as provided in the terms of the Act, a regulated service.

So where are we today in 2019? I am reflecting on this not only as a longstanding advocacy activist and academic, but also as a carer of a mother with Parkinsons and dementia and in my own ageing with on-going mental health problems. There seem to be a number of issues facing advocacy at a policy level that have an impact for older people in Wales at a personal level. They might be summarised as follows:

### **Colonisation**

Advocacy has grown from being a grassroots response to the rights and representation of older people to becoming a statutory, regulated service. Whilst advocacy has certainly achieved more official recognition and more older people now have a right to such support than was the case three decades ago, there is a risk that something is being lost at its soul. This is of course a dilemma faced by a number of movements. Incorporation into the mainstream might demand compromise and re-casting in order to fit the imperatives of politicians and policy makers within 'co-production'. Having campaigned for advocacy as a right for so long, I find myself contemplating the phrase, "be careful what you wish for".

### **Competition**

Closely allied to the first point is the rise in competition between advocacy providers to secure contracts and possibly also between forms of advocacy for resources. The early advocacy projects were funded by grants and other means, whereas they now pitch to be commissioned to provide services. In so doing there are risks of compromising independence, losing partnerships and belonging less to the local communities in which they are based. The current legislation tends to privilege one-to-one forms of advocacy and there is a statutory obligation on local authorities to make such services available. But what about the support of self-advocacy and collective advocacy by older people's forums – and will such vital forms of advocacy actually be included within local population needs assessments?

### **Citizenship and life-course**

The statutory provision of advocacy is focused upon a specific set of situations and settings and there are differences in what is available between population groups. There has, for example, been the 'active offer' of advocacy to children and young people which has yet to make its way to adults, despite the SSWBA covering all ages. Although it emphasises general 'well-being', the Act seems to require advocacy with regard to more narrow definitions of 'care and support'. Securing a range of rights to areas such as transport, learning and community participation would entail a broader approach to advocacy for citizenship across the life course.

### **Capacity and quality**

The raft of legislation giving rights to advocacy needs to be matched with a sufficient number of advocacy organisations and advocates to meet need. The work of Age Cymru through 'Advocacy Counts' reports has shown that this is not the case and indeed the number of

advocates working with older people has declined in some areas. The issue of capacity might also encompass training and ensuring that all advocates are sufficiently skilled to provide high quality advocacy. It is also essential that relevant statutory professionals are trained to have an understanding of advocacy and their own role and relationship towards it. The Golden Thread project has been immensely significant in this regard, supplemented by resources such as advocacy tools for professionals on the Social Care Wales website.

### **Collaboration and co-ordination**

At a time of immense change for the advocacy sector in terms of legislation and policy, it is regrettable that the advocacy movement itself is without its own coherent voice. The demise of Action for Advocacy at a UK level along with Advocacy Wales nationally means that there is no single umbrella organisation for advocacy at the very time when such a body is needed. We need to develop a Wales-wide advocacy alliance across all groups, including older people, to share information and learning, to influence policy, to further develop and monitor our own quality standards – and to advocate for advocacy.



# Jill's story – Advocate at Age Cymru Powys

Gail Hamer, Chief Officer, and Jill Ball, Advocate, at Age Cymru Powys

Age Cymru Powys is the largest voluntary sector organisation providing support to people over 50 in Powys, Mid Wales.

The organisation works to sustain and improve the quality of life of vulnerable older people in Powys. It believes that older people should be respected and valued as individuals in terms of their dignity, status, personal autonomy, diversity of needs, aspirations and expectations.

Independent Professional Advocacy is a service that can support someone to participate fully in decisions about their well-being and ensure that their views, wishes and feelings are heard, respected and taken into account.

Age Cymru Powys offers a free, independent and confidential advocacy service for those aged 60+ living in Powys which can help people to:

- access support through the social care system
- get continuing health care funding
- decide whether they should move into residential care
- get home from hospital and be involved with the discharge planning process
- support people's wishes and rights in regards to residential care
- raise concern about how people are being treated.

The advocacy service can represent people and accompany them to appointments with other professionals; it can help people to access services, information and benefits to which they may be entitled, and can assist people with challenging decisions and making complaints.

The role of the advocates at Age Cymru Powys is to take action to help people say what they want to say, secure their rights, represent their interests and obtain the services they need. They meet with people daily and listen to the issues that are of concern to them. They provide information and discuss the available options. If required they can provide assistance with contacting third parties and with written correspondence.

Jill Ball is an Advocate based at the Age Cymru Powys centre in Newtown. She covers the north of Powys county, whilst a colleague covers the south of Powys. Jill provides us with an insight into her role as an advocate:

## What is it like to be an advocate?

The work is varied and interesting, as people consult the advocacy service for many different reasons. They may wish to investigate what other accommodation is available to them, now that their own needs have changed, which may be due to bereavement or an escalation of care needs. A client may be unhappy about the care they are in receipt of, and need assistance with knowing who to contact and may need assistance with getting their voice heard. We support clients when there may be conflict in their family, to reinforce their wishes.

What is joyful about the role is supporting others to access the services they may need or helping them to resolve an issue that has been of concern to them.

### **What kind of support might people need?**

Someone who can listen to what their needs are, and then to provide them with up to date and accurate information on what is available to them. They are then able to make informed choices whether that is in relation to their health, care, finances or social needs. If they need support to access a particular service, Age Cymru Powys can guide them through this process. We work closely with a number of organisations, both locally and nationally, that can provide support to people.

### **How can the kind of support Age Cymru Powys offers impact on people's physical and emotional well-being?**

People are less anxious and have more confidence because they have the support and knowledge to face whatever problem they may be experiencing. The service is accessible and people say they enjoy the face to face contact and build up a good rapport with staff members.

Age Cymru Powys' information and advice service provides benefits information and assistance in completing forms. With financial security comes peace of mind. We also provide an extensive range of literature on all subjects relating to older people, from adaptations to their home, to power of attorney information. When people are informed they are then able to make decisions about their future which impacts on their well-being.

### **What is the most rewarding work you have done at Age Cymru Powys?**

I have enabled an older lady to stay in the care home of her choice. I have supported a lady with hearing loss to solve her internet problems, so that she can email her family in South Africa and keep in touch with her grandchildren. I helped someone to understand all the care and accommodation options available to them, as they were given notice on their rented property. They are now living independently within a complex that has someone on the premises 24 hours a day and should they require a greater level of support in time, this will be available to them.

#### **Further information**

Age Cymru Powys' advocacy service is free, independent and confidential and is for people over the age of 60 living in Powys. People can self refer into the service or can be referred by a third party, with their consent. The service has an advocacy drop in session every Tuesday at the centre in Newtown, and they also visit clients at home or in a care home, wherever they reside.

South/Mid Powys Telephone 01597 825908  
email: [enquiries@acpowys.org.uk](mailto:enquiries@acpowys.org.uk)

North/Mid Powys Telephone 01686 623707  
email: [support@acpowys.org.uk](mailto:support@acpowys.org.uk)

# A volunteer-led advocacy service for vulnerable older people in Wales: what did service users say about the beneficial impact of advocacy for them?

Dr Juping Yu, Research Fellow, Faculty of Life Sciences and Education,  
and Mark Llewellyn, Professor of Health and Care Policy, University of South Wales

Drawing findings from a study evaluating a volunteer-led advocacy service for older people in Wales, in this article we focus on what service users said about the beneficial impact of advocacy for them.

## The project – Help to be Heard

Established in 2014, Help to be Heard was a 3-year project (July 2014 to May 2017) run by Age Cymru Sir Gar providing generic advocacy to older people in Carmarthenshire, south-west Wales. The project developed a volunteer-led service, and was managed by one full-time advocacy manager with support from a part-time administrative assistant.

In total, 14 volunteers were recruited and trained. Eight left for various reasons at different stages, while six remained until the end of the project. Of these, four were involved in the project from the beginning, demonstrating continuity and a high level of commitment from these volunteers. A rolling training schedule of every three to four months was developed for the advocates. Each training session looked at a specific topic in more detail to develop volunteer advocates' skills and knowledge in that particular area.

Volunteer advocates were allocated to the cases according to their location in relation to

the case, availability, and capability/skills in relation to the needs of service users.

## Who used the service?

In total 441 referrals were made from diverse sources (Table 1). These included the individual themselves, family members, friends, health and social care services, and other public, voluntary, or private organisations. The majority of referrals came from users themselves, followed by families and friends. Only around one in five referrals came from an organisation. The primary issues for referring were related to financial problems. Some users were referred based on more than one issue.



Table 1: Information about referrals

|                                     | n   | %    |
|-------------------------------------|-----|------|
| <b>Referral source</b>              |     |      |
| Self-referral                       | 270 | 62.4 |
| Family and friends                  | 66  | 15.2 |
| Voluntary organisations             | 58  | 13.4 |
| Saturate organisations              | 29  | 6.7  |
| Private organisations               | 10  | 2.3  |
| <b>Primary issues for referring</b> |     |      |
| Financial                           | 110 | 19.6 |
| Access to services                  | 85  | 15.2 |
| Consumer                            | 70  | 12.5 |
| Lasting Power of Attorney (LPA)     | 59  | 10.5 |
| Housing                             | 55  | 9.8  |
| Residential/nursing home            | 39  | 7.0  |
| Support for carer                   | 27  | 4.8  |
| Safeguarding                        | 9   | 1.6  |
| Hospital                            | 7   | 1.3  |
| Other                               | 99  | 17.7 |

n = number of respondents.

Most service users were female (64.2%). The largest proportion of users were aged 65-74 (26.8%), and three users were over 100 years old. Over half of the users lived alone (59.4%). In terms of marital status, the largest proportion were married or in civil partnership (35.8%). Nearly all users were either white British (64.6%) or white Welsh (32.2%).

### Service users' self-reported well-being scores

Table 2 shows users' self-reported scores on eight statements relating to well-being indicators. Well-being indicators are a way of measuring change in a number of important aspects of people's lives which can be measured quantitatively (as in Table 2), but also expressed qualitatively (as demonstrated in the following section). For Help to be Heard, a set of well-being indicators was identified to help

understand the impact of the volunteer-led advocacy service, drawing on the Senses Framework (Nolan et al, 2006) and the Welsh Government's National Outcomes Framework (Welsh Government, 2016).

The data were collected twice, once before and once after receiving advocacy support. The score on each statement showed an increase after advocacy, indicating an improvement of users' well-being over time. The increase ranged from 1.4 (statement 6 – I have a social life and can do the things that I choose.) to 2.5 (statement 1 – I have voice and control.).

### What did service users think about this advocacy service?

Telephone interviews were conducted with 22 service users to explore their experiences of using the advocacy service.

## The need for advocacy support

The service users were older people living in Carmarthenshire who had a range of support needs. Many had physical disabilities through old age or illness: **“I have short term and long term memory loss and I am disabled”** whilst others were socially isolated and had no wider family support due to bereavement or geographical distance:

**“There is nobody left in my family.”**

**“My children are quite spread out so it was difficult for them to assist me.”**

All but one users contacted Age Cymru Sir Gar directly to seek support with their personal crisis. Specifically, for some their crises were legal in nature:

**“My wife and I are both 84 and we thought we should look into power of attorney.”**

**“I had been told on the phone that I owed money and was going to be taken to court. I received a threatening letter which was very unpleasant.”**

Table 2: Scores on well-being indicators\*

| Well-being indicators |  | Pre-advocacy |      | Post-advocacy |      | Score increase |
|-----------------------|--|--------------|------|---------------|------|----------------|
|                       |  | n            | Mean | n             | Mean |                |
| 1                     | I have voice and control.  | 231          | 3.9  | 227           | 6.4  | 2.5            |
| 2                     | I feel able to have my say and my opinions are listened to.      | 81           | 4.0  | 56            | 6.4  | 2.4            |
| 3                     | I am safe and protected.   | 31           | 5.2  | 22            | 7.6  | 2.4            |
| 4                     | My dignity is respected.   | 38           | 4.7  | 27            | 7.1  | 2.4            |
| 5                     | I am OK and find things to appreciate in life.                   | 38           | 4.3  | 27            | 6.7  | 2.4            |
| 6                     | I have a social life and can do the things that I choose.        | 32           | 4.2  | 24            | 5.6  | 1.4            |
| 7                     | I am confident in managing my money and personal administration. | 62           | 4.0  | 51            | 6.1  | 2.1            |
| 8                     | I get the help I need, when I need it, in the way I want it.     | 40           | 4.7  | 28            | 6.9  | 2.2            |

\*scored 1-10, where 1 is lowest and 10 is highest.  
n = number of respondents.





Whilst for others, it was issues surrounding their accommodation. As such, two users sought support in relation to issues surrounding their current homes:

**“I had a problem with a garage roof that I’d had repaired. It appeared that the man who repaired it, a neighbour, used shed roof felt rather than the higher grade felt he should have used. I had 28 leaks at one point. As a tradesperson he was hopeless.”**

**“I’d been trying for ages, 8-10 months, to get the council to collect the bins from the corner of my house. It’s difficult for me to get to the top of the lane because the bins are heavy. Then I had mice. I had a letter from my GP, which cost me, but they still wouldn’t come out. I got in touch with my local councillor as she knew of somebody but still nothing happened.”**

## The support service users received

All users interviewed were extremely positive about the advocacy support that they had received. Most reported that they would recommend the service to people in a similar situation, saying it was ‘helpful’, ‘pleasant’ and ‘reassuring’:

**“To be honest it scored on all points. They were able to get me in on an appointment straight away. There was no hanging about. They found a person to deal with the problem and I saw them within a few days. They did everything that they said they would.”**

**“It has given me peace of mind to know there are people who care for the elderly... to know that there is an organisation like this has given me a lot of comfort and reassurance.”**

The majority of service users reported that they received practical assistance with filling in forms and writing of letters:

**“[Age Cymru] help[ed] me fill in forms for PIP (previously Disability Living Allowance).”**

**“[Age Cymru staff] helped us to draft letters that I need to stay here.”**

**“Recently I used Age Cymru to help me with some letters – corresponding with the council... My memory loss has meant that I have lost my letter writing skills, grammar and spelling, so the man from Age Cymru – well he came and helped me to write the letters.”**

This support was invaluable for one individual as it enabled her to understand the financial implications surrounding her husband’s recent passing and further enabled her to resolve the issue and re-establish a sense of control in her life.

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**“I give [Age Cymru] a call to help me filling in some forms and to assist me in dealing with a company called [xxxxx]. I’ve had some problems since my husband passed away a year ago. My husband had a life insurance policy with them and it paid out each month. They were quick to tell me when I lost my husband that the payments would stop from the day that he died. I had expected them to go on but my husband dealt with all that sort of thing. Mysteriously it appeared that he had also taken out another policy that I knew nothing of. They sent me various bits and pieces that I was having trouble understanding and I had some questions. I phoned Age Cymru and [Age Cymru staff member] made an appointment to come along and see me, and my word he certainly did help me. He spoke to them and wrote to them on my behalf until in the end it was sorted out.”**

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The notion of expertise was remarked upon by a number of users: **“they had the knowledge and skill to fill the forms in”**. This expertise manifested itself in processing applications speedily and efficiently, but also in respect of opening up different avenues within which older people could experience support:

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**“With the help of Age Cymru they pointed me in a different direction that I wasn’t aware of and some of the things they told me I could claim for amazed me. They are very helpful people from my point of view.”**

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## **Positive experiences with this advocacy service**

The service users highly praised the volunteer advocates, whether they provided a practical support or advice and guidance. The advocates were described as being polite, helpful and approachable:

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**“The representative came armed with a colleague and they were both admirable – exemplary.”**

**“He brought all the forms we needed and went through them in detail – he was very thorough.”**

**“We’ve found him brilliant – kindly and not at all pressured.”**

**“We’ve been absolutely delighted with his advice... the man who came was calm, approachable, and patient and went through things a couple of times to make sure we understood everything.”**

**“[Age Cymru staff member] was absolutely fantastic so kind and helpful. He didn’t rush me and in the end I came to think of him as a friend.”**

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Specifically, they found the advocacy service to be flexible, with the majority of service users being visited within their own homes:

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**“They responded immediately and came to see us at home. They put us at ease.”**

**“[Age Cymru staff member] made an appointment to come along and see me, and my word he certainly did help me.... Every time I phoned the office he would make a convenient time to see me and he never let me down.”**

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They further felt that the advice and guidance provided by the advocates was impartial, and this was very important for one individual:

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**“It was important to us that the information was impartial.”**

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Without the support from the advocates, many users reported that their personal crises would have caused them greater emotional distress and potentially still be ongoing:

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**“Having them involved definitely made the process easier. It would have taken us much longer and we wouldn’t have been sure where to find the forms or that we were filling them in correctly.”**

**“I would have been a bit lost had I not had the service.”**

**“I would have been climbing the walls by now.”**

**“Having him help has definitely taken the pressure off. It’s made a difference to me and I wouldn’t hesitate to recommend it to other people.”**

**“I wouldn’t have been as far down the line as I am with [the organisation] if it wasn’t for them.”**

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## Summary and conclusion

Overall, the service users were very positive about the advocacy service. For some, simply having someone to explain details in an understandable manner was beneficial in reducing their emotional distress and assisted them in feeling more in control of their own life.

The older people further reported how the support provided helped them overcome their concerns or problems. The vast majority of users described advocates as flexible, impartial and supportive.

Notably, some areas were identified for future service improvements, but on the whole, older people were very satisfied with the service they had received from the advocates. It was evident that the advocates and the advocacy service were seen in very positive terms, with the following key features and qualities being prominent:

- Advocates are easy to contact, expert, and offer them practical forms of support;
- Advocacy is a ‘complete’ service which goes beyond the presenting issue and sees the whole person behind the situation;
- Advocates help in reducing the burden at a difficult time, and stressful times of crisis were made much less stressful through their support; and
- Older people struggle to take on ‘big’ organisations and the advocates were able to negotiate with and influence others, whilst at the same time providing a means to negotiate through issues.



# Welsh speakers' dementia care

Lowri W. Williams, Senior Policy Officer, Welsh Language Commissioner

Article written on behalf of the Welsh Language Commissioner and Alzheimer's Society Cymru

**“It [speaking Welsh] makes people feel good, and maybe people with dementia don't remember what they've been doing, but they know they feel good.”\***

This is what Glenda Roberts said at the launch of the Welsh Speakers' Dementia Care report as she described how speaking Welsh made her feel.

Many of us in Wales have heard about Welsh speakers losing their second language, usually English, as their dementia develops. However, evidence shows that the impact on people's linguistic skills is far more complex than losing a language completely when developing dementia. There is also evidence that bilingual people's linguistic ability deteriorates to the same degree in both languages, and other examples of a second language 'intervening' with people's skills in their first language.<sup>1</sup>

Furthermore, research shows that some bilingual individuals receive different scores when undertaking the same cognitive tests depending on the language of the test.<sup>2</sup>

Therefore, the impact of dementia on linguistic ability is not black and white. The importance of language as an expression of culture should not be forgotten either. With a condition which causes such a variety of symptoms, enabling people to be able to express themselves in the language in which they are most comfortable is vital, as Glenda says. Why should somebody who is vulnerable change the habit of a lifetime, as one contributor to our research said:

**“I want to speak Welsh because that is my first language and I have always used Welsh with my friends and family and during Sunday services since I was young.” \***

It is acknowledged in national strategies that care provision through the medium of Welsh is absolutely vital for Welsh speakers who have dementia, and that it is a clinical necessity and a sign of good quality care. Despite these national strategies, the Welsh Language Commissioner and Alzheimer's Society Cymru wanted to see the nature of the care Welsh speakers received in reality and the degree to which they could receive care through the medium of Welsh. An important part of this was ensuring that we heard the direct experiences of those people across Wales who live with dementia. In that regard, it's important to remember that Welsh speakers with dementia live in every corner of the country and that caring for Welsh speakers with dementia is not only a consideration for those Welsh-speaking heartlands.

As part of the research, eight settings which provide dementia care across Wales were visited. Interviews were held with 14 practitioners and 18 Welsh speakers who had dementia. The researchers interviewed five senior officers from local authorities and health boards, as well as two academics in the areas of dementia, health and social care. In order to hear more about people's views and experiences, the

\*Translated from Welsh



Dyfan Roberts and Mirain Fflur portraying a man living with dementia and his carer in the Theatr Genedlaethol Cymru production, Y Tad. Copyright ©Theatr Genedlaethol Cymru.

Commissioner took part in a special edition of the ‘Taro’r Post’ phone-in show on Radio Cymru. There was much discussion and members of the public rang in to share their own experiences and the experiences of family members in what were often poignant accounts. An event was also held at the Eisteddfod in Cardiff where part of the play ‘Y Tad’ was staged by Theatr Genedlaethol Cymru.

The research showed positive examples of Welsh speakers in some areas receiving a great deal of their care in Welsh and settings doing their best to provide Welsh language services despite constraints. In order to enable this, settings ensured that they knew from the beginning whether people spoke Welsh. This meant that they could plan their workforce in order to ensure that they recruited Welsh speakers and ensured that Welsh speakers were available on every shift. In some settings providers ensured that people had access to Welsh language resources such

as books and S4C, and they invited Welsh language third sector organisations to the settings.

However, in general, it was disappointing to hear that a number of people did not receive much of their care through the medium of Welsh, despite the fact that they would like to do so as the quotation below suggests:

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**“There are hardly any Welsh language services here now. Hardly anyone can speak Welsh here but there are some Welsh language activities. I would be far happier if there were more Welsh language services. It isn’t always easy expressing yourself in English. If I ask, I do sometimes get things in Welsh, but I don’t normally ask”.\***

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The theme that people often had to ask for Welsh language services rather than receive them automatically was highlighted by the

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\*Translated from Welsh



research, showing that the vital principle of an active offer in Welsh has not spread through the sector. The concerns of people afraid to ask for Welsh language services in case they did not receive services at all were also heard. Recording people's preferred language is not common practice in every organisation either and therefore the linguistic needs of residents were not a part of workforce planning and did not extend to the rest of their care package. For example, it became clear that Welsh language services were rarely available from GPs and psychiatrists. Indeed, examples were seen of care workers having to translate during cognitive tests as psychiatrists could not speak Welsh, which is a very worrying practice. In general, the main issue which prevented offering Welsh language services was a lack of staff who could speak Welsh and a lack of awareness of the impact of dementia on Welsh speakers.

The research showed that a lack of Welsh language services was not a concern for some, even though they would prefer to speak Welsh

and receive more of their care in Welsh. However, unfortunately, the research showed examples where the lack of Welsh language care had a detrimental impact on people. In one case it caused a lot of frustration for one individual who could not be understood by others. There was another devastating example of an individual who did not speak to anybody as his carers did not understand that he had lost his ability to speak English and he did not have any Welsh speaking carers at all. This shows the importance of understanding what people's linguistic requirements are from the beginning.

We believe that adverse and dangerous situations such as this should not occur. They show a lack of respect and care towards people with dementia and do them a great injustice. Furthermore, we believe that legislation and strategies are now in place which should ensure that situations such as these do not occur at all. Therefore, our report ends with a series of recommendations for the Welsh Government, health authorities, health boards, Health Education and Improvement Wales, Social Care Wales and others. The recommendations ask for legislation to be implemented in full and for additional considerations regarding Welsh language care to be incorporated into the Welsh Government's Dementia Action Plan for Wales 2018-22. We very much hope that these recommendations will be adopted so that Welsh speakers who have dementia across Wales get to 'feel good' like Glenda.

# Making voices heard

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**Heléna Herklots CBE, Older People's Commissioner for Wales**  
.....



Heléna Herklots

**There is much we all take for granted in life: our health, our independence, our friends and families. But perhaps most of all, we take for granted our ability – our right – to make decisions**

**for ourselves. Decisions about crucial issues such as where we live, where we go, who we see, what we eat and when we go to bed.**

All older people should feel that they have a voice, and choice and control over their lives, and should have the right support to make informed decisions. Voice, choice and control are important to us all – when services fail to listen effectively, the price paid by both public services and older people themselves, can be very high.

In May 2018, my office published Making Voices Heard,<sup>1</sup> a report on older people's access to independent advocacy. The report found that a significant number of older people were unable to access independent advocacy to ensure that they have voice and control, even where a legal right to such support exists.

Of particular concern was the availability of independent advocacy in situations where older people may find themselves particularly vulnerable and in need of support to ensure that their views and wishes are heard: older people living in care homes and older people awaiting hospital discharge. Older people in these situations are at increased need of

independent advocacy to enable them to exercise their rights and ensure their voices are heard.

Older people living in care homes – especially those who receive little contact from outside services and self-funders who tend not to be in contact with social services – can be particularly vulnerable as they are reliant on other people to meet their day-to-day needs. Ensuring that these older people, who are at increased vulnerability because of their situation, have an effective voice is therefore vital, to not only enable them to have the best possible quality of life, but also to ensure they are effectively safeguarded from abuse and neglect.

Similarly, the need to increase the numbers of available beds in hospitals can, in some instances, lead to inappropriate hospital discharges, with people not being appropriately assessed for care and support needs because they have been deemed 'medically fit'. Ensuring that older people are fully aware of their rights and are adequately supported to have a voice and be fully involved in vital decisions about their lives, such as whether or not to move into a care home on discharge from hospital, can make the difference in avoiding unnecessary harm or reduced independence. Discharge to unsuitable accommodation can increase the likelihood of re-admission to hospitals, for example, most recently highlighted by a thematic report published by Healthcare Inspectorate Wales.<sup>2</sup>

It is therefore important that older people living in a care home or awaiting discharge from hospital have access to independent advocacy.



The importance of having an effective voice is increasingly being recognised at a strategic level in Wales. One of the overarching principles of Social Services and Well-being (Wales) Act 2014 is to ensure that people's views, wishes and feelings are heard. Within healthcare, there is also a growing focus on joint decision-making, through the prudent health-care agenda, and co-production has long been promoted by Welsh Government Ministers.

However, despite the new statutory duty to consider a person's need for advocacy within the 2014 Act, the Making Voices Heard report highlighted a clear need to do more to ensure that the most vulnerable are able to access independent advocacy services.

### **An active offer of advocacy**

The report called for an 'active offer' of advocacy to be extended to older people living in care

homes and older people awaiting hospital discharge, in much the same way as defined groups of children receive an active offer.

The 'active offer' is a sharing of information about the statutory right and entitlement of a child or young person to access support from an Independent Professional Advocate. For Looked After Children and Children on the Child Protection Register, an active offer must be provided by statutory bodies. The information shared during the active offer includes an explanation about the role of Independent Professional Advocacy, what it can and cannot do, how it operates based on their wishes and feelings, its independence and how it works solely for the child/young person, its confidentiality policy (including when confidentiality may need to be breached to protect the child/young person from significant harm). The active offer explains the statutory right of children and



young people to be supported to express their views, wishes and feelings, as well as their right to make a representation or complaint.

The active offer can help to ensure that an informed choice is made about accessing advocacy services. It also provides assurance to statutory bodies that a person's right to independent advocacy has been properly understood and upheld – making real their rights in law.

Extending an active offer to older people in certain circumstances would ensure that older people living in care homes who are without a voice receive a meaningful offer of independent advocacy, allowing them to make an informed choice on whether to engage with an independent advocacy service. For older people awaiting discharge from hospital, extending an active offer would inform them of their rights and enable them to participate in decisions made about them, including when people are considering a move from hospital to a care home, especially for those who do not want, or are unaware of, the option to have contact with social services.

The Social Services and Well-being (Wales) Act 2014 set out to transform the way in which social care is delivered in Wales, putting people at the heart of service delivery and making them an equal partner in co-producing their care. Access to independent advocacy for many older people will be a vital part in ensuring that they are able to participate in decisions that affect them.

Advocacy has a key role to play in helping to ensure that Wales' vision for social care delivers for all people, including those who are most vulnerable. It is therefore vital that the merits of extending an active offer of advocacy to vulnerable older people are fully considered and explored.



# The Golden Thread Advocacy Programme

**Louise Hughes, Golden Thread Advocacy Programme Manager, Age Cymru**

Age Cymru has shown a major commitment to the development and sustainability of independent advocacy services for older people and citizens in general over the last 12 years. We have long since campaigned for greater access to advocacy which has happened with the implementation of the Social Services and Well-being (Wales) Act 2014. In certain circumstances, the local authority now has a requirement to ensure that individuals have access to Independent Professional Advocacy (IPA). Ensuring that people have a voice and control over decisions that affect them and that their views, wishes and feelings are respected and taken into consideration is a

fundamental element to the new legislation. In order to achieve this, people who have or appear to have care and support needs and are undergoing an assessment, care and support planning, a review of their care and support, or a safeguarding enquiry or review, and they have barriers to participating may be referred to the IPA service.

Of course this is a great step forward and we are pleased to see that advocacy has been recognised as a vitally important service in the new Act. However, it is also important to recognise the importance of all advocacy services within the advocacy spectrum (see below).

## Spectrum of advocacy services



While the statutory advocacy provision meets the high level needs of the community, we can see that there are also other advocacy services that need to be supported to ensure that early intervention and preventative action can be taken for others. It is crucial that as much is done as possible to prevent people needing to access high level statutory services and advocacy can do that by supporting people to access information, help them understand it and make informed choices based on their own wishes and to enhance their own well-being. This may also mean accessing and engaging with community services, or even having a voice in how those services are developed to meet the needs of the local community. It could also be about getting adaptations in place, choosing where to live, or making a range of decisions about what matters to that individual.

The Golden Thread Advocacy Programme (GTAP) was established by Age Cymru in partnership with Age Connects Wales and Diverse Cymru in 2016 and funded by Welsh Government to support the implementation of the advocacy element of the Social Services and Well-being (Wales) Act 2014 (SSWBA). To achieve this, three overarching objectives were established:

1. To develop a National Framework for Commissioning Independent Professional Advocacy for Adults in Wales
2. To support and build the capacity of the advocacy sector in Wales, and
3. To raise awareness of advocacy.

The following is a summary of what has been achieved in the first two and a half years of the programme:

### **1. To develop a National Framework for Commissioning IPA**

The GTAP team has developed a framework based on their experiences of working with local authorities and providers across Wales, guided



and advised by a Strategic Reference Group made up of representatives from Welsh Government, Health, WLGA, All Wales Adult Services Heads, a member from the GTAP Board, National Commissioning Board and ADSS Cymru.

This framework is intended to support local authorities and their partners in delivering the requirements of the SSWBA, regulations and associated statutory guidance in respect of commissioning IPA.

The framework:

- sets out the essential components of commissioning Independent Professional Advocacy for adults (what to do), and
- is accompanied by a toolkit which supports local authorities to use the framework (how to do it).

The nature of any framework is that it should allow discretion to meet local circumstances and whilst legislative requirements must be met in all circumstances, the prescription of a 'one size fits all approach' in doing so is neither desirable nor appropriate. Additional advice on applying aspects of the framework is provided in the accompanying toolkit.

GTAP has also facilitated numerous co-productive workshops to support the development of local and regional advocacy strategies as well as to inform the commissioning of advocacy services.

## 2. To support and build the capacity of the advocacy sector in Wales

The National Advocacy Network has been in existence for over 5 years and has membership from across Wales and from across the various advocacy providers. Providers include those working in statutory and non-statutory services, advocates who support people with learning difficulties, with dementia, working in care homes and hospitals, with people lacking capacity or with mental health problems, and many others who need this important service. It is a network that supports each other by sharing case examples where there are challenging issues, learning from good practice, hearing from expert speakers from across a range of sectors who can support and develop the skills and knowledge of advocates. What is also crucial about the national network is that it gives the advocates a voice to comment on important legislative changes through consultations or directly to the people who want to hear their views at the meetings.

GTAP has also supported the development of regional advocacy networks across Wales to provide stronger regional strategic voices. It is intended that the networks will become self-sustaining. Almost the whole of Wales now has a regional network that respond to regional issues and also feed into the national picture.

Through a series called 'Advocacy Counts', over the last 12 years, Age Cymru has been reviewing availability of advocacy services, issues around funding and sustainability, quality of service and training of advocates, advocacy and its role in safeguarding, accessibility in terms of language, and knowledge and understanding of legislative changes in advocacy.

Our evidence has been used to influence grant funders, commissioners, and Ministers in Welsh

Government. We have called for an end to the post code lottery of availability, for a more consistent funding approach, for increased sustainability of the sector and most importantly for people who need the support of these services to have access wherever they are in Wales.

Advocacy Counts 6<sup>1</sup> provides an updated snapshot of advocacy provision in Wales for adults with a particular emphasis on older people. It suggests that the overall number of advocates, people supported, and the number of services funded to deliver advocacy across Wales have all decreased since the last survey was undertaken in 2016.

Of particular concern for Age Cymru is the continued fall in the number of specialist advocacy providers and advocates for older people. The loss of this specialist focus and expertise for supporting older people is unlikely to be replicated to the same extent in a service supporting adults of all ages.

The loss of specialist providers may be an indication of commissioning changes to providers who deliver to all ages across a larger geographical area and the end of funding for the Big Lottery Advantage funded projects.

Approaches to commissioning advocacy across Wales continue to be varied and at different stages of development. At the time of writing this report, six local authorities have commissioned the IPA provision required of them by the Social Services and Well-being (Wales) Act 2014, however most are in the process of developing their future strategies. Both providers and commissioners remain uncertain about the implications of the Regulation and Inspection of Social Care Act (2016).

In light of the new requirements placed upon local authorities it is anticipated that demand

for advocacy services will grow and therefore the availability and sustainability of services is a priority for all involved. The mixture of funding sources, statutory and grant funders is similar to that reported in 2016, with the only significant variation being the decrease in the number of organisations funded by charitable trusts. It would appear that the potential impacts of the new requirements anticipated in Advocacy Counts 5 have yet to come to fruition as those local authorities who have yet to fully comply with the requirements continue to use existing contracts to ensure advocacy support is available.

### 3. Awareness raising

Awareness and understanding of advocacy by the general public and many others still remains a challenge as the term advocacy is often associated with the legal profession or has other incorrect connotations. Instead advocacy is about supporting people to be informed, heard and involved. For someone who needs an advocate, advocacy is about having:

- someone there for them and only them
- someone to listen to them so they can make their own decisions
- someone to support them
- someone to help them access and understand information, and
- someone to represent them when they need it.

A range of bilingual awareness raising tools have been developed by the GTAP team. These so far include leaflets, bookmarks, a visual representation of the range and types of advocacy services and the bi-monthly newsletter. All of these are available to download on the Age Cymru website [www.agecymru.org.uk](http://www.agecymru.org.uk)

The resources are being distributed as widely as possible with a focus on those who may need to understand the role of an advocate and how they can help.

The newsletter is published bi-monthly and provides useful information, updates, and good practice in advocacy. It also provides links to useful documents, training, websites and news all about advocacy.

### In conclusion

GTAP has been funded to continue with our work until April 2020. The team will continue to support commissioners, providers and the advocacy sector in Wales. We will continue to develop our resources and gather evidence of the availability of advocacy.

Advocacy in all its forms will continue to be a much needed service so that those who are without a voice can be heard, those who feel disempowered to choose their own path can make their own decisions, and those who do not feel valued or respected can have their wishes heard and acted on.



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## **Making voices heard**

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## **The Golden Thread Advocacy Programme**

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