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I am very grateful to all those people in national and local statutory, voluntary and private sector organisations who consented to be interviewed and provided information in other ways in support of this study.

I would also like to thank my colleagues at Swansea University, Ioan Humphries for help with the e-questionnaires and Dr. Susan Lambert for her collaborative work, advice and support. Furthermore, I would like to extend my gratitude to Sarah Stone and Joanna Stevens at the Older People’s Commission for Wales for their understanding and commitment to the project.

This study was commissioned and funded by the Older People’s Commissioner for Wales.

For more information about this study please contact:

**Andrew Dunning**
Centre for Innovative Ageing
School of Human and Health Sciences
Swansea University
Singleton Park
Swansea
SA2 8PP

Email: a.m.dunning@swansea.ac.uk
As the Older People’s Commissioner for Wales I have a particular interest in the arrangements bodies have in place for the provision of advocacy for older people.

I recognise the critical role that advocacy plays in improving older people’s lives by enabling their enjoyment of rights, choices and interests. In addition, advocacy provision is key to ensuring older people have access to advice, information and services.

My objectives set out in the 2010/13 Strategic Plan are to promote awareness of the interests of older people in Wales, promote the provision of opportunities for, and the elimination of discrimination against, older people in Wales and encourage best practice in the treatment of older people in Wales.

In order to support this work I commissioned this Scoping Study of Advocacy Arrangements in Wales from the Older People and Ageing Research and Development Network at Swansea University. This report is a companion document to a report on the scoping of complaints and older people produced as part of the same research project.

This Report identifies what services are in place at present, the current context and what the best opportunities are for the Commission to make real progress in the provision of advocacy services for older people in Wales. The work examines gaps and weaknesses as well as strengths and good practice examples.

I am committed to looking at the provision of advocacy services in Wales with a view to seeking any improvements required to make sure that the voices of those older people in the most vulnerable settings are not left unheard. This Report represents the start of this important work.

Ruth Marks
Older People’s Commissioner for Wales
Aims and Objectives

The overall aim of the initial scoping study on advocacy has been to inform the work of the Older People’s Commissioner for Wales by identifying the current context and what is in place at present - including gaps and weaknesses as well as strengths and good practice examples - and what the best opportunities are to make progress in particular areas.

The objectives of the study have been to provide:

1. A working definition of advocacy, as referred to in the Commissioner for Older People (Wales) Act (2006)
2. An identification of principles against which current arrangements can be judged.
3. An overview of Welsh Assembly Government guidance or regulation on advocacy arrangements in local authorities, the health service and care providers.
4. An overview of how advocacy arrangements are measured, monitored and reviewed.
5. An overview of the actions being undertaken by the Welsh Assembly Government, Local Authorities and others in relation to advocacy procedures and processes and the availability of advocacy across Wales.
6. An indication of variation across Wales.
7. Information on the nature and type of advocacy being commissioned.
8. Information on the outcomes for older people of advocacy arrangements.
9. An overview of recent research evidence about the operation and adequacy of advocacy arrangements.
10. Issues of note for the Older People’s Commissioner for Wales regarding the operation of current arrangements around advocacy with older people to form the base for a decision upon which to focus more detailed work in future.

In order to help to inform its work on advocacy and complaints, the Older People’s Commissioner for Wales commissioned the Older People and Ageing Research and Development Network (OPAN) at Swansea University to undertake preliminary scoping studies. This report provides an Executive Summary of the full report on the scoping study of advocacy for older people (Dunning 2010). It is a companion document to a report on the scoping of complaints and older people produced as part of the same research project (Lambert 2010). It also complements work being carried out by on behalf of the Older People’s Commissioner for Wales by Age Cymru on the production of Advocacy Counts 3, a survey on the availability of advocacy services for older people in Wales.

Methods

The scoping study involved a mix of research methods, including:-

- A desk top literature search and secondary data analysis of academic research publications and other documents;
- A web-based search of Welsh Assembly Government and local health and other care organisations’ policies and procedures, evidence of operation and outcomes;
- Electronic surveys undertaken with older people’s strategy co-ordinators and officers in national and local government, health and voluntary organisations; and
- Telephone and face to face interviews with stakeholders in national and local government, health and voluntary organisations using the key informant technique.

Responses relating to advocacy given by complaints officers and other participants in the companion scoping study on complaints procedures were also incorporated within this analysis.
Context

Older people might need advocacy for several compelling reasons, including: protection from abuse; combating age discrimination; obtaining and changing services; securing and exercising rights; and being involved in decision making and being heard, particularly at points of transition in care and living arrangements.

Advocacy with older people has been subject to increasing attention since the 1990’s due to the evolving legislative and policy context, the support of progressive professionals, the rise of the advocacy movement and the expressed demands of older people themselves. However, whilst there has been a growth in the number of advocacy schemes working with older people over the past two decades, there remain significant challenges for policy and provision in this area.

Key Findings And Issues

Meanings and Models

- Definitions of advocacy are dynamic and subject to debate.
- The Older People’s Commissioner for Wales might draw upon definitions devised by the advocacy movement (eg OPAAL and Action for Advocacy) or enshrined within legislation elsewhere (eg Scotland).
- The chosen definition should incorporate components such as: being independent of service provision; one to one with an individual older person/s; long term or short term involvement; paid or voluntary advocates; supported by an advocacy scheme or organisation; free to the person requiring advocacy; upholding core advocacy principles.
- Advocacy must be maintained as a highly principled activity. Its broad principles are independence, empowerment and inclusion.
- The Advocacy Charter developed by Action for Advocacy with the wider advocacy movement contains a detailed set of principles for practice.
- The main advocacy roles are instrumental and expressive - both are needed and valued by older people.
- A number of models of advocacy provision have been developed.
There is a lack of specialist advocacy schemes for specific issues such as dementia, physical and sensory impairment; generic advocacy schemes for older people who are not eligible for statutory services; and peer advocacy projects run by and for older people in Wales.

Advocacy and Legislation

Legislation with duties to provide advocacy, granting people rights to advocacy and giving advocates legal status has been implemented since 2005 by way of Independent Mental Capacity Advocacy (IMCA), Independent Mental Health Advocacy (IMHA) and the new Mental Health (Wales) Measure.

The current legislative framework remains far from comprehensive and is only applicable to a limited number of older people within qualifying groups. Both IMCA and IMHA involvement is short term in nature and limited in scope.

These legislative initiatives are under researched and, notwithstanding their relatively recent development, a more substantial evidence base is developing in England than in Wales.

In contrast with arrangements in England, there is no readily accessible database, dedicated official or annual report for IMCA in Wales.

Respondents to this scoping study stated that most IMCA referrals were concerned with older people.

The new Mental Health (Wales) Measure will extend the group of qualifying patients eligible to receive IMHA support, to include all patients subject to the formal powers of the Mental Health Act 1983 as well as voluntary and informal patients not detained under the Act.

Advocacy organisations and other respondents to the recent Mental Health (Wales) Measure highlighted a number of issues of concern which pertain to advocacy provision more widely. They include challenges with regard to advocacy principles, scope, strategy, funding, capacity and training.
Citizenship and Participation

- A citizenship approach broadens the scope of advocacy to include a wider range of services, issues and groups of older people as citizens as well as service users.
- Advocacy is a means of operationalising or putting into practice the citizenship of older people.
- The objective of a comprehensive advocacy services strategy within the Welsh Assembly Government Third Dimension strategy action plan has not been delivered.
- Older people are doubly disadvantaged as there is no comprehensive national advocacy strategy to include them and no stand alone national strategy for advocacy for older people (in contrast with children and young people and other groups).
- Second tier advocacy organisations in Wales lack organisational capacity to fully engage with the development of policy and practice development.
- Advocacy organisations in England and Wales have developed a manifesto calling for a national framework for advocacy.
- Advocacy was not included in the Strategy for Older People in Wales, despite apparent synergies. However, some local authorities have developed advocacy strategies or services under its auspices.

Human Rights and Equalities

- Human rights and equalities are a crucial part of the context for advocacy and broaden its concerns beyond the health and social care of older people.
- The United Nations Principles for Older Persons do not explicitly mention advocacy, but can be drawn upon by advocates in supporting older persons with regards to the promotion and protection of independence, participation, care, self fulfilment and dignity.
- Advocates are drawing upon the Human Rights Act 1998 in representing the older person in letter, decision making meetings and other situations.
- A human rights approach in advocacy with older people has been encouraged by the House of Lords and House of Commons Joint Committee on Human Rights and is supported by training materials and opportunities for advocates.
Advocates will be able to draw upon the Equality Act 2010 which extends the circumstances in which people are protected against discrimination and places an equality duty on a range of public bodies and related organisations. This also allows for a wider consideration of protected characteristics including the position of gay and lesbian older people and black and minority ethnic elders.

The Equality and Human Rights Commission includes independent advocacy within its strategic priorities and is committed to ensure that such advocacy is available as part of a social care system based on equality and human rights - particularly with regard to older people and other protected groups.

The Older People’s Commissioner for Wales is widely welcomed but respondents suggest that more work is needed to raise awareness and clarify the nature of the advocacy role of the Commissioner and to develop relationships with advocacy organisations across Wales.

Health and Social Care

The broad strategic framework for health and social care supports the engagement and empowerment of older people as service users and citizens, and can be complemented by the provision of advocacy.

The National Service Framework for Older People includes the availability and use of advocacy within Standard 1 regarding rooting out age discrimination, but does not require or resource local provision.

As yet, advocacy has not been formally linked to the Dignity in Care agenda, but has received support from the Dignified Revolution campaign group.

Older people with mental health problems might be denied advocacy support if they fall outside the terms of statutory provision, including those seeking access to mental health services in the first place.

Similarly, older people with dementia might be unable to access advocacy if they do not meet the criteria for IMCA and other statutory provision, including those needing such support on an ongoing, long term basis.
Whilst the National Dementia Plan for Wales and establishment of dementia advisers might improve awareness of advocacy services, such provision has to be available and capable of meeting demand.

The Welsh Assembly Government (Welsh Assembly Government) Statement on Policy and Practice for Adults with a Learning Disability (2007) recognises the significant ageing of the population of people with learning disabilities and highlights the importance of advocacy in supporting people in making their needs known.

Despite the Welsh Assembly Government Advocacy Grant Scheme for advocacy groups working with people with learning disabilities, the availability and sustainability of such groups remains uncertain.

There is no statutory right to advocacy on the basis of physical or sensory impairment - the prevalence of which increases with age - and there is a dearth of provision in these areas.

The Welsh Vision Strategy Implementation Plan 2010-13 includes advocacy in its objectives. Some local authorities have sought to take account of the advocacy needs of older people with physical and sensory impairments within their commissioning, wellbeing and advocacy strategies.

Older people comprise a significant proportion of carers. Despite legislation and policy developments to support carers in assessment and the provision of information and advice, there is no entitlement to advocacy to ensure that their voices are heard.

Some advocacy schemes working with older people more generally do represent issues raised by older people who are carers and the carers’ movement has developed advocacy skills training and other initiatives.

Advocacy can be crucial in making a decision about entering a care home, whilst living in a care home or in the event of leaving a care home due to its closure or change of circumstances.

The National Minimum Standards for Care Homes for Older People in Wales (2002) require that service users are assisted in accessing advocacy services, but the availability of such services is variable and inspection reports by CCSIW do not always include reference to their use.
Independent living has been promoted by the disability movement and Welsh Assembly Government has developed citizen centred support through direct payments and other means. Advocacy can help to support older people living in the community to exercise choice and control.

**Adult Protection and Safeguarding**

- Advocacy in relation to adult protection is an under-researched area.
- Advocacy can be a vital component in the prevention of and protection from abuse.

The current review of *In Safe Hands* and consultation on the creation of unified policy and procedures for adult protection provides a significant opportunity to promote the development of advocacy for older people in Wales.

- The CSSIW national overview of adult protection gives little reference to advocacy and coverage in local inspection reports is variable.
- There is no legislation on adult protection in Wales (or in England or Northern Ireland), whereas in Scotland there is such legislation which also includes provision of advocacy.

**Complaints and the Public Services Ombudsman for Wales**

- Advocacy can provide a means of support for older people in making a complaint and in negotiating the complaints process.
- Advocacy may be preventative in supporting an older person to achieve a positive outcome before a complaint has to be made or finding resolution early in the complaints process.

The Social Services Complaints Procedures (Wales) Regulations (2005) places a duty on the authority to make available to any complainant information on how to contact an advocacy scheme, but not a duty to arrange such provision.

- Local authority complaints officers and NHS complaints officers acknowledge that access to advocacy would make complaints procedures more accessible.
Older people aged 60 years and over comprise 50% of all complaints supported by Community Health Councils (CHC’s). However, less than 40% of the total number of complaints to the NHS were supported by CHC’s.

Uniquely, in Powys the CHC has been commissioned to provide IMCA and IMHA services as well as CHC Complaints Advocacy services.

There have been variations in the way in which issues involving the abuse of older people have been subject to complaints or adult protection procedures. Advocates can have a role in helping to ensure that the appropriate channels are pursued on behalf of the older person.

Housing agencies have developed complaints procedures and mechanisms for tenant participation and representation. However, such representation tends to be on a collective rather than individual level and there is little evidence of arrangements to facilitate access to independent advocacy.

The Public Services Ombudsman for Wales has identified a number of concerns regarding advocacy for older people in Wales, including the patchiness of provision; lack of access within a range of settings and situations; lack of resources and capacity of some advocacy services; as well as the need to raise awareness.

Funding and Commissioning

There is a general view that advocacy with older people is under resourced and that funding for non-statutory advocacy in particular is insufficient.

Most non-statutory advocacy schemes working with older people receive funding from more than one source. Whilst this can protect independence and bring flexibilities in provision, it also entails more time spent in securing funding and adhering to funding requirements.

Reliance upon short term funding arrangements can place advocacy schemes in a vulnerable position.

The funding and commissioning of advocacy for older people by Welsh Assembly Government, local authorities and health boards has been subject to varying degrees of attention and prioritisation.
Advocacy organisations have raised concerns about funding based upon “number mapping” of the population and caseload statistics without consideration of rurality, geography and language.

There is a marked contrast between the legislative and policy position, funding status and level of service provision of advocacy with older people and that of other groups, particularly children and young people.

An overarching advocacy strategy across all groups would highlight gaps and inconsistencies in the funding and provision of advocacy throughout the life-course of all citizens.

The current economic climate, public service cuts and uncertainty surrounding the continuing levels of funding through the Strategy for Older People in Wales, has heightened concerns that advocacy outside statutory obligation, or outside very tight prioritisation set by statutory bodies, will not be commissioned.

Wider benefits of advocacy could be highlighted, including its role in helping to meet Welsh Assembly Government objectives of citizenship, empowerment and inclusion; supporting improvements in person centred care and service quality; and providing consumer feedback.

There has been a lack of funding for second tier advocacy organisations to support the development of advocacy in general and with older people in particular. In contrast, the Scottish Government directly funds the Scottish Independent Advocacy Alliance.

AdvantAGE, the Big Lottery Fund Cymru programme provides a generous and unprecedented funding opportunity for the development of advocacy with older people in Wales. However, there are concerns that the initiative should not become a substitute for a substantive advocacy strategy or funding from statutory sources.

Standards and Outcomes

The Advocacy Counts 2 survey (Age Concern Cymru 2008) showed that 56% of advocacy schemes used standards developed by Action for Advocacy, whilst the remaining 44% used a variety of frameworks including those developed by Welsh Assembly Government and host organisations.
Some advocacy schemes have sought external quality marks such as Investors in People, the Community Legal Service Quality Mark and Practical Quality Assurance System for Small Organisations Quality Mark (PQASSO).

Statutory advocacy providers have quality standards set down by Government. These quality standards were largely developed in consultation and engagement with the advocacy movement.

The Action for Advocacy Quality Performance Mark (QPM) has attained widespread recognition and has so far been awarded to six advocacy providers working in Wales.

Advocacy schemes are variously monitored and reviewed using frameworks they themselves put in place, by their host organisations or by funders and commissioners.

Advocacy schemes can be evaluated in a variety of ways, including the Action for Advocacy Quality Performance Mark, evaluative research by academics and consultants, as well as user engagement and feedback initiatives.

In the evaluation of advocacy, it is important to maintain core principles, to consider process as well as outcomes and to avoid overly simplistic or mechanistic measures of results.

A national advocacy qualification was launched in 2009, aiming to ensure quality and consistency in the training of advocates. The qualification was developed by the Department of Health in partnership with Welsh Assembly Government and involving advocacy organisations in the process.

Whilst there has been growing recognition of the need for such training and engagement by the advocacy movement, there have been concerns about the professionalisation of advocacy, replicating traditional forms of service provision and becoming removed from its more radical roots.

Advocates and those running advocacy schemes need supervision, support and opportunities for development in order to deal with the substantial ethical, legal and practical challenges and dilemmas they frequently face.
Suggested priority areas for future work

Definition
The Older People’s Commissioner for Wales will need to consider the typology of forms, key elements and meanings as presented within the scoping study in order to determine the working definition of advocacy ultimately to be employed by the Commission.

Principles
The Older People’s Commissioner for Wales might reasonably utilise the overarching advocacy principles of independence, empowerment and inclusion along with the more detailed principles for practice as developed by Action for Advocacy, against which current arrangements can be judged.

Approach
The Older People’s Commissioner for Wales should maintain an approach based upon citizenship, human rights and equalities. Such an approach widens the scope of advocacy and broadens the rights and representation of diverse groups of older people beyond those of being users of health and social care alone.

Legislation
The Older People’s Commissioner for Wales should note the evolving but still extremely limited legislative status of advocacy. The Commissioner might consider the need for more comprehensive legislation to meet the advocacy needs of older people more widely. This might include the extension of entitlement to areas such as adult protection, as is already the case in Scotland.

Strategy
The Older People’s Commissioner for Wales should note the absence of national strategy for advocacy and the variations in local strategy development. The Commissioner might consider the need to champion a national advocacy strategy for older people and for a comprehensive strategy for advocacy through the life course. Support for second tier advocacy organisations to assist in the development of advocacy at national and local levels might also be considered.
Policy
The Older People’s Commissioner for Wales should note that advocacy is contained within a number of relevant policy documents at national and local level. In some policy areas the Commissioner might seek to strengthen the position or application, for example with regard to support for complainants or in the inspection of care homes. The recent revision of adult protection procedures refers to advocacy and provides an opportunity for its use in this field. Furthermore, there might be scope for the Commissioner to facilitate the sharing of best practice in policy development on advocacy across sectors, authorities and organisations.

Provision
The Older People’s Commissioner for Wales might highlight the gaps, shortages and variations of provision in advocacy for older people. Such limitations are apparent within a range of social groups, situations and settings as well as between local authority areas. The Commissioner might also encourage the appropriate training and supervision of advocates and the maintenance of suitable quality standards by advocacy schemes.

Funding
The Older People’s Commissioner for Wales might not only seek to protect the funding of existing advocacy services but also to make the case for funding beyond statutory provision - albeit at a time of shrinking public expenditure. Furthermore, the Commissioner might help to ensure that advocacy is being commissioned in accordance with advocacy principles, processes and outcomes. Close working links with the Big Lottery Fund Cymru AdvantAGE programme might also be beneficial in terms of strategic and service development.

Research
The Older People’s Commissioner for Wales should note that advocacy with older people is an under-researched subject. The Commissioner might wish to consider the need to undertake further conceptual, empirical and evaluative studies. Given the prevalence of older people within its workload, an annual national report on IMCA might be produced in Wales as is already the case in England. The Commissioner might also facilitate the sharing of learning locally, nationally and internationally through events, publications and web pages.
Role of the Older People’s Commissioner for Wales

There is a need to raise awareness about the advocacy role of the Older People’s Commissioner for Wales. The Commissioner can be seen to embody a public advocacy role but there also appears to be a need to further clarify understanding about the nature of individual or casework advocacy being undertaken. In addition, relationships with the advocacy movement might be further consolidated through sharing information, networking and joint initiatives. Furthermore, the Commissioner might play a key role in “advocating for advocacy” for older people in Wales, amongst politicians, policy makers, commissioners, providers, older people and wider population.

Older People’s Perspectives

It is essential that older people’s views and experiences help to shape the development of advocacy. The Older People’s Commissioner for Wales has already embarked upon a process of listening and gathering older people’s perspectives on advocacy, with a call on the website of the Commission and by other means. Given the pace of change and pressing nature of matters facing advocacy with older people, a further event with older people to the fore might be a timely and welcome part of this process. As one older respondent remarked,

“Things have been happening for older people in Wales in recent years. But we are behind on this. And this (advocacy) is something that is needed, really needed. They (advocates) are just not available or known to all who might need one. Any of us might need an advocate sometime. We need to get up and do something about it for ourselves and others.”

Andrew Dunning, Centre for Innovative Ageing, School of Human and Health Sciences, Swansea University, SA2 8PP a.m.dunning@swansea.ac.uk
September 2010
1. Introduction

1.1 Aims

One of the key roles of the Older People’s Commissioner for Wales is to ensure that the interests of older people in Wales, who are aged 60 or more, are safeguarded and promoted. Amongst the unique legal powers of the Older People’s Commissioner for Wales is that of being able to formally review the adequacy of arrangements for advocacy, complaints and whistleblowing in particular bodies and regulated services. The Commissioner is committed to looking at these areas with a view to seeking any improvements necessary over the coming years. In general, the Commissioner’s approach is to ask:

“What needs to change to make things better for older people and what is the Commissioner best placed to do to help?”

In order to help to inform its work on advocacy and complaints, the Commissioner commissioned the Older People and Ageing Research and Development Network (OPAN) at Swansea University to undertake a preliminary research project. This report discusses the findings of an initial scoping study of advocacy for older people in Wales.

It is a companion document to a report on the scoping of complaints and older people in Wales produced by Dr. Susan Lambert as part of the same research project. It also complements work being carried out by Age Cymru for the Office of the Older People’s Commissioner Wales on the production of Advocacy Counts 3, a survey on the availability of advocacy services for older people in Wales.

The overall aim of the initial scoping study on advocacy, as discussed in this report, is to inform the work of the Older People’s Commissioner for Wales by identifying the current context and what is in place at present - including gaps and weaknesses as well as strengths and good practice examples - and what the best opportunities are to make progress in particular areas.
1.2 Objectives

The objectives of this initial scoping study of advocacy for older people have been to provide:-

1. A working definition of advocacy, as referred to in the Commissioner for Older People (Wales) Act (2006)

2. An identification of principles against which current arrangements can be judged.

3. An overview of Welsh Assembly Government guidance or regulation on advocacy arrangements in local authorities, the health service and care providers.

4. An overview of how advocacy arrangements are measured, monitored and reviewed.

5. An overview of the actions being undertaken by the Welsh Assembly Government, Local Authorities and others in relation to advocacy procedures and processes and the availability of advocacy across Wales.

6. An indication of variation across Wales.

7. Information on the nature and type of advocacy being commissioned.

8. Information on the outcomes for older people of advocacy arrangements.

9. An overview of recent research evidence about the operation and adequacy of advocacy arrangements.

10. Issues of note for the Commission regarding the operation of current arrangements around advocacy with older people to form the base for a decision upon which to focus more detailed work in future.
1.3 Methodology

The scoping study involved a mix of research methods, including:-

- A desk top literature search and secondary data analysis of academic research publications and other documents;
- A web-based search of Welsh Assembly Government and local health and other care organisations’ policies and procedures, evidence of operation and outcomes;
- Electronic surveys undertaken with older people’s strategy co-ordinators and officers in national and local government, health and voluntary organisations; and
- Telephone and face to face interviews with stakeholders in national and local government, health and voluntary organisations using the key informant technique. (Appendix 1)

Responses relating to advocacy given by complaints officers and other participants in the companion scoping study on complaints procedures (Lambert 2010) were also incorporated within this analysis.

The key informant technique was employed due to the exploratory nature of this scoping study and the relative dearth of research and development in the field and the breadth of issues to be considered. There is further discussion of the technique in Appendix 2.

The research and report writing for this scoping study was undertaken over a period of 25 days between January and June 2010.

The study was informed by ethical guidelines of the Social Research Association. Informants were assured of confidentiality but gave permission for the title of their organisation to be used in examples of good practice. A full list of organisations participating in the complaints and advocacy for older people study is provided in Appendix 3.

There were some challenges in undertaking this scoping study. Advocacy is relatively under-researched and its development is patchy in terms of policy and provision. There was therefore a need to cast a wide net covering a disparate and diverse group of respondents, documents and data within the timescale. However, the challenges may also be seen to validate the need for the scoping study and the techniques used at this stage of development.
1.4 Context and Content

The National Service Framework for Older People in Wales (Welsh Assembly Government 2006 p20) suggests several reasons why older people may not always speak up for themselves,

- Preconceived and stereotypical ageist attitudes held by service providers which lead to age discrimination in the provision of services and/or medical treatments;
- A reluctance to complain that arises from cultural attitudes held by some older people that “those in authority know best”;
- Fear that complaints will lead to losing what services the older person is receiving;
- Vulnerability and loss of confidence at a time of significant change, such as when entering a residential or nursing care home and other life changing circumstances;
- A feeling that other age groups are more deserving;
- A fear that they will be seen as a burden.

Older people involved in an advocacy user engagement project initiated by the Older Peoples Advocacy Alliance (OPAAL) UK identified a number of reasons why they had needed advocacy (Wright 2006). These related to:-

- **Being protected from abuse**
  Advocacy was seen as being a means of safeguarding the older person from various forms of abuse. It was also a way of protecting older people from over-protection and supporting them to take risks if they chose to do so.

- **Combating discrimination**
  Advocacy can support the older person who has been subjected to age discrimination and other forms of discrimination regarding disability, gender, race, ethnicity, sexuality and other factors.

- **Obtaining and changing services**
  Advocacy can enable older people to obtain services to which they should be entitled and to change them if more appropriate services could be made available to better meet their needs and interests.
Securing and exercising rights
Advocacy is a means of securing and exercising substantive and procedural rights of citizenship - from universal human rights to day to day entitlements as a citizen, consumer or service user.

Being involved in decision making and being heard
Advocacy can help to ensure and support the involvement of the older person in decision making and being heard regarding day to day preferences or at key points of transition such as when institutional care is being considered.

Advocacy with older people has been the subject of growing attention over the past two decades due to a number of factors, including the following:-

- There is an evolving legislative and policy context. Although an actual legal right to advocacy remains limited to very specific circumstances, there are now a plethora of pieces of legislation and policy of relevance to advocacy for adults generally and older people in particular.

- There have been “allies” amongst progressive professionals in statutory and non-statutory sector bodies. They have promoted the need for the voices of citizens and service users to be heard in the policies and everyday practices of their organisations.

- The advocacy movement has been growing since the 1970’s, particularly amongst disabled people. This movement has latterly incorporated the needs and interests of older people demanding a voice.

- The expressed demand for advocacy by groups of older people, for example, through Better Government for Older People (2000) and the Joseph Rowntree Foundation (2004) as well as the current Pensioners’ Charter, which states that older people must have a right to,

  “…advocacy, dignity, respect and fair treatment in all aspects of their lives”. (National Pensioners’ Convention undated)

A scoping study undertaken by the Centre for Policy on Ageing during the early 1990’s identified barely a dozen advocacy schemes working with older people across the UK (Wertheimer 1993), a number now exceeded in Wales alone (Age Concern Cymru 2008). However, despite such apparent progress, there are significant challenges for policy and provision in this area (Dunning 2005;
Scourfield 2008; Age Concern Cymru 2008). It is therefore timely to review the wide ranging sets of arrangements and activities regarding advocacy with older people in Wales today in order to identify gaps and limitations as well as the achievements, strengths and opportunities for development.

Section 2 of this report will explore the meanings of advocacy in terms of its definition, principles and roles, along with an outline of some current models of provision. Section 3 presents the existing legislative framework of advocacy. Section 4 to Section 8 of this report will place advocacy with older people in the context of developments, debates and issues arising with regard to five thematic areas:- citizenship and participation; human rights and equalities; health and social care; adult protection and safeguarding; and complaints and the Public Services Ombudsman for Wales. Then, Section 9 will examine the funding and commissioning of advocacy for older people and Section 10 will focus upon standards and outcomes. Finally, Section 11 will draw together the findings and propose areas for future work by the Older People’s Commissioner for Wales with regard to advocacy and older people. Each Section concludes with a summary of key issues and findings which are also collated in Appendix 4.
2. Meanings and models

This Section will explore the meanings of advocacy with regard to definitions and principles of advocacy and the roles of advocates themselves. It will also identify some of the models of advocacy provision for older people that have been developed in Wales to date.

2.1 Definitions of Advocacy

Advocacy might be straightforwardly seen as “speaking up”. However, closer analysis of developments in research, policy and practice reveals that the meaning of advocacy is more complex and has long been subject to debate (Gathercole 1987; Brandon 1995; Atkinson 1999). It is important to clarify what is meant by advocacy for several reasons:-

- To support older people themselves in knowing what to access when they need it;
- To establish whether legal duties concerning advocacy are being fulfilled and if official guidance is being followed by relevant bodies;
- To specify the nature of what is being commissioned or funded and to ensure that resources are allocated appropriately;
- To assist in the measurement of quality standards and in the assessment of outcomes; and
- To observe changes and challenges to existing definitions.

A broad definition is that,

“Advocacy generally involves people making a case for themselves and advancing their own interests, or representing others and supporting them to secure and exercise their rights on an individual or collective basis.” (Dunning 2005 p10)
Over the past twenty years or so there has been a growth and diversification in forms of professional, lay and self advocacy. The meanings are dynamic and sometimes blurred within the literature and in the language used about advocacy in practice. However, the main types of advocacy might briefly be described as follows:-

**Legal advocacy** - the most established and widely recognised form of advocacy which is undertaken by trained lawyers on a legal casework basis.

**Public advocacy** - the activities of organisations e.g. Age Cymru which campaign on behalf of a particular group of people or broad issue.

**Paid or professional advocacy** - the work of staff paid by their employing advocacy scheme or organisation to advocate for a number of people on an individual casework basis, usually on short term issues or “crises”.

**Citizen advocacy** - a one to one, long term partnership between an independent, trained and unpaid citizen advocate and a partner in need of such support, who are matched and assisted by the advocacy scheme.

**Independent volunteer and crisis advocacy** - undertaken by independent, trained and unpaid advocates recruited and supported by an advocacy scheme or organisation to advocate for a number of people on an individual casework basis, usually on short term issues or “crises”.

**Peer advocacy** - this takes place where one person advocates on behalf of another who shares a common experience, treatment or condition and is supported by an advocacy scheme or organisation.

**Self advocacy** - speaking up for oneself in order to represent one’s own needs, wishes, and interests on an individual basis. Sometimes it might be necessary for advocacy organisations and others to provide training and support in order to enable individuals to advocate for themselves.

**Collective advocacy** - a wider form of self advocacy which involves groups, forums and organisations that provide their members with mutual support and development in making a common call for change in their shared interests.

Advocacy may also be described in a variety of terms relating to particular issues (e.g. complaints advocacy and hospital discharge advocacy) or conditions (e.g. mental health advocacy and dementia advocacy).
An important distinction needs to be made between instructed and non-instructed approaches to advocacy. Usually, advocates are instructed by the service user, even if the latter has not referred themselves to the advocacy scheme. Together, they are able to establish a relationship and identify the advocacy issues, goals and intended outcomes in accordance with the wishes and preferences of the user. Non-instructed advocacy may be needed when matters of communication and capacity mean that instruction and the expression of choices and concerns are not forthcoming. Henderson (2006) defines non-instructed advocacy as,

“...taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.”

Non-instructed advocates may adopt different approaches to representing the person, based upon human rights, being person centred, keeping a watching brief or acting as a witness and observer.

Older people might require different forms or types of advocacy at different times and might even benefit from using more than one at the same time. In order to ensure that older people are empowered and remain in control of their own situation, advocates should support the person to speak up on their own behalf wherever possible.

For the purposes of developing a working definition of advocacy, as referred to in the Commissioner for Older People (Wales) Act (2006), the following components might be required:-

- independent of service provision
- one to one with an individual older person/s
- long term or short term involvement
- paid or voluntary advocates
- supported by an advocacy scheme or organisation
- free to the person requiring advocacy
- upholds core advocacy principles (see section 2.2)
This definitional approach encompasses paid/professional advocacy, volunteer citizen/crisis advocacy and peer advocacy. It excludes legal, public and collective types of advocacy. However, it may have a relationship with each and all of them in accordance with the needs, choices and interests of the older person.

Definitions for such one to one forms of advocacy have been developed within the advocacy movement itself. Action for Advocacy states that,

“Advocacy is taking action to help people to say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and justice.” (www.actionforadvocacy.org.uk)

Similarly, the Older People’s Advocacy Alliance (OPAAL) UK defines advocacy as being

“A one to one partnership between a trained, independent advocate and an older person who needs support in order to secure or exercise their rights, choices and interests.” (www.opaal.org.uk)

It is illuminating to look at definitions of advocacy utilised in relatively advanced areas of policy and provision for other groups in Wales. The British Institute of Learning Disabilities (BILD) used the following definition in reviewing the impact and effectiveness of the Welsh Assembly Government Advocacy Grant Scheme for people with learning disabilities:

‘Advocacy means “to speak up for someone or to support them to speak up for themselves” and refers specifically to people with a learning disability. In general there are two ways that this happens:-

**Advocacy:** Having an advocate to speak up on one’s behalf (this can be referred to as citizen or volunteer advocacy, crisis advocacy, issues based advocacy or professional advocacy).

**Self Advocacy:** Developing the confidence and skills to speak up for oneself, either as a member of a group or as an individual.

For the groups of people for whom disempowerment is often just a way of life, (for example people with learning disabilities, users of mental health services, the elderly) advocacy provides the
opportunity to take greater control. It encourages those who are isolated and excluded to become valued members of their local community.’ (BILD 2005 p5)

Similarly, definitions of such advocacy can be found within legislation in other countries, including Scotland. Chapter 3 of the Code of Practice produced by the Scottish Government to accompany the Adult Support and Protection (Scotland) Act 2009 sets out key considerations for adult representation including the duty to provide advocacy. It states that:

- The definition of “independent advocacy services” is where they are not provided by a local authority, NHS Board or a member of the local authority or NHS Board. The adult should never be expected to pay for the services (Para 5).

- Independent advocacy aims to help people by supporting them to express their own needs and make their own informed decisions. Independent advocates support people to gain access to information and explore and understand the options available to them (Para 6).

- Independent advocacy is provided by specialist organisations that do not provide any other services. It is however recognised that some organisations, such as voluntary sector disability rights groups, who may provide (non-independent) advocacy may also provide housing, financial advice and support services. In such cases it is important to establish any potential conflicts of interest. (Para 7)

This legal definition can be seen to closely resemble the grassroots definition developed by the advocacy movement in Scotland, as follows:

“Independent advocacy is a way to help people have a stronger voice and to have as much control as possible over their own lives. Independent advocacy organisations are separate from organisations that provide other types of services. An independent advocate will not make decisions on behalf of the person/group they are supporting. The independent advocate helps the person/group to get the information they need to make real choices about their circumstances and supports the person/group to put their choices across to others. An independent advocate may speak on behalf of people who are unable to do so themselves.” (Scottish Independent Advocacy Alliance undated)
In Wales, some local authorities have attempted to raise awareness and seek common agreement about what is meant by advocacy. In Wrexham County Borough Council, a multiagency Advocacy Reference Group consulted widely in the production of an Advocacy Plan in 2007. The consultation document included a working definition of advocacy and a list of forms of advocacy to be considered. Consultees were asked if they agreed or disagreed with the given definition as well as aspects of service design and delivery. Similarly, Caerphilly County Borough Council is currently developing an advocacy strategy and has sought to ensure that all stakeholders are aware of and agree to the definitions of advocacy included at the outset.

It can also be important to highlight what advocacy is not about, as there is sometimes a lack of clarity of understanding about differences between advocacy and other activities, including advice, mediation, counselling and befriending:

**Advice** is usually provided by someone with expertise in a specific subject who can give information and make recommendations about available options and courses of action. Advocates act as an aide rather than an advisor to the person, seeking out and sharing information and advice from various sources in order to support their case or decision making.

**Mediation** concerns arbitration or conciliation between two parties attempting to resolve a dispute. Advocates act in the interests of the person alone and support them in getting their views across and achieving their goal.

**Counselling** involves a therapeutic relationship between a counsellor and client. Advocates endeavour to develop a relationship with the person in order to better represent them in securing and exercising their rights.

**Befriending** is an activity usually undertaken by volunteers who provide companionship and share in social activity with another person. Again, advocates will try to build trust and rapport with the person, but their main focus for support is concerned with rights and representation.

As well as being mindful of the distinctions however, it is also important to recognise the relationships that can exist between these different forms of support. Older people might benefit from one or more of the above, as partially recognised by the UK Government LinkAge programme. Advocacy can be a vital component within such “circles of support” (Dunning 2005).
2.2 Principles of Advocacy

Advocacy is necessarily a highly principled activity. The Older People’s Advocacy Alliance (OPAAL) UK identifies the overarching principles of advocacy in broad terms as being independence, empowerment and inclusion (www.opaal.org.uk). Thus, with reference to each of these principles,

“Advocates should be free of conflicts of interest to ensure that the needs and interests of the advocacy partner remain paramount. Advocacy seeks to enable people to have a voice, to have a say in the decisions that affect their lives and take control of their circumstances. It is also about protecting and promoting citizenship and human rights.” (Dunning 2009 p5)

A clear and comprehensive set of advocacy principles for practice has been devised by Action for Advocacy. These principles form the basis of the Advocacy Charter which was launched in 2002. Over 75 organisations worked with Action for Advocacy in the development of the Advocacy Charter. In setting out a set of core principles for advocacy, the Advocacy Charter was designed:-

- To inform advocacy practice and training;
- To raise awareness of the value of advocacy;
- As a tool for negotiating with funding and commissioning bodies; and
- As a quality assurance mechanism.
These principles are as follows:

**Action for Advocacy Charter Principles**

**Clarity of purpose**
The advocacy scheme will have clearly stated aims and objectives and be able to demonstrate how it meets the principles contained in this Charter. Advocacy schemes will ensure that people they advocate for, service providers and funding agencies have information on the scope and limitations of the schemes’ role.

**Independence**
The advocacy scheme will be structurally independent from statutory organisations and preferably from all service provider agencies. The advocacy scheme will be as free from conflict of interest as possible both in design and operation, and actively seek to reduce conflicting interests.

**Putting people first**
The advocacy scheme will ensure that the wishes and interests of the people they advocate for direct advocates’ work. Advocates should be non-judgmental and respectful of peoples’ needs, views and experiences. Advocates will ensure that information concerning the people they advocate for is shared with these individuals.

**Empowerment**
The advocacy scheme will support self-advocacy and empowerment through its work. People who use the scheme should have a say in the level of involvement and style of advocacy support they want. Schemes will ensure that people who want to, can influence and be involved in the running and management of the scheme.

**Equal opportunity**
The advocacy scheme will have a written equal opportunities policy that recognises the need to be proactive in tackling all forms of inequality, discrimination and social exclusion. The scheme will have in place systems for the fair and equitable allocation of advocates’ time.
**Accountability**
The advocacy scheme will have in place systems for the effective monitoring and evaluation of its work. All those who use the scheme will have a named advocate and a means of contacting them.

**Accessibility**
Advocacy will be provided free of charge to eligible people. The advocacy scheme will aim to ensure that its premises, policies, procedures and publicity materials promote access for the whole community.

**Supporting advocates**
The advocacy scheme will ensure advocates are prepared, trained and supported in their role and provided with opportunities to develop their skills and experience.

**Confidentiality**
The advocacy scheme will have a written policy on confidentiality, stating that information known about a person using the scheme is confidential to the scheme and any circumstances under which confidentiality might be breached.

**Complaints**
The advocacy scheme will have a written policy describing how to make complaints or give feedback about the scheme or about individual advocates. Where necessary, the scheme will enable people who use its services to access external independent support to make or pursue a complaint.

The Advocacy Charter has been adopted by many advocacy organisations across the UK. It has also been used by some policy makers, commissioners and other bodies to guide their work on advocacy.

In Wales, the Advocacy Counts 2 survey conducted by Age Concern Cymru (now Age Cymru along with the former Help the Aged in Wales) in 2008, noted that just over half (56%) of advocacy groups who responded worked to standards developed by Action for Advocacy. This would entail adherence to the definition and principles promoted within the above Charter.
Several key informants highlighted the significance of the principle of independence. This emphasis on the need for advocacy schemes to be free from conflicts of interest - and for advocates to be loyal to the advocacy partner - is highlighted within the wider advocacy literature (Henderson and Pochin 2001). It is also echoed by older people themselves when asked (Dunning 2005; Wright 2006).

However, a number of tensions and challenges have emerged in maintaining the principle of independence in practice. These include the following areas:-

- **Funding** - if funding is obtained by an advocacy scheme from a statutory organisation such as a local authority or local health board, what happens if an issue arises for an older person supported by the scheme concerning a service provided by that same organisation?

- **Provider organisations** - can advocacy be independent if it is provided by an organisation - whether voluntary or statutory - which also provides direct care and support services such as domiciliary care, day care, befriending and transport to older people in the local community?

- **Partnership arrangements** - should advocacy schemes be part of or remain outside multi-agency systems and structures such as adult protection?

### 2.3 Advocacy roles

Advocates may be seen to carry out two main sets of roles - instrumental and expressive (O’Brien and Wolfensberger 1979; O’Brien 1987). Instrumental roles are generally more formal roles and are about “doing” e.g. representative, spokesperson, appointee. Expressive roles are more informal and concerned with “being” e.g. enabler, witness, confidante.

Instrumental roles might be seen as being more task centred and will be at the forefront of advocacy for older people at a point of crisis or when issue based work or when a formal approach is required. Expressive roles are utilised in order to get to know and provide emotional support for the person in reaching decisions and representing their needs and choices. Both sets of advocacy roles might be required by the same person in order to advocate effectively for them.

Both instrumental and expressive roles are valued by older people (Wright 2006; Dunning 2009). The instrumental role helps to get things done,
however, the expressive role is crucial in developing trust, getting to know what is “normal” for the person, establishing meanings and ways of communicating as well as enhancing the advocacy relationship. This might need to be developed over a longer period of time. It can be particularly important in supporting people with progressive illnesses such as dementia, for those with whom there are difficulties in communication and engagement or when needs are likely to continue to be present over the longer term.

Advocacy has been accorded legal status in some defined situations, including for those fitting the criteria for Independent Mental Capacity Advocacy (IMCA) and Independent Mental Health Advocacy (IMHA). In many places throughout Wales advocacy is also being commissioned for older people in other circumstances, including for those older people living in care homes. However, there are concerns that advocacy needing a more expressive approach is being misunderstood as being befriending and that funding priorities are geared towards more formal and instrumental approaches.

2.4 Models of Provision

A number of organisational models of advocacy provision have emerged in Wales in recent years. They include:-

- Independent specialist advocacy including older people, e.g. Mental Health Advocacy Pembrokeshire (MAP)
- Third Sector service providers for older people, including an advocacy scheme amongst their services e.g. local Age Concern organisations
- Statutory specialist advocacy including older people e.g. Community Health Council (CHC) Complaints Advocacy, IMCA, IMHA

In Wales there is a lack of stand alone independent advocacy schemes for older people. There is a lack of specialist advocacy schemes with a focus upon some specific issues, such as dementia, physical and sensory impairment. There are few generic advocacy schemes for older people who are not eligible for statutory services.

This scoping study has also been unable to locate an advocacy scheme run by older people for older people. Such peer advocacy initiatives have been undertaken by several organisations of older people in England, including Lewisham Pensioners Forum, Sefton Pensioners Advocacy Centre and Linkage in North Manchester.
2.5 Select Comments from Respondents

- “There are a number of interpretations of advocacy. Some providers considering themselves to be advocates are not - they are a befriending service. That’s not to say that there isn’t a place for them. We just need to be clear about definition and the specific outcomes.”

- “Some organisations call themselves advocacy but they are not. They are advice and information, not advocacy. It has to be proper advocacy, properly defined as such.”

- “Advocacy projects have been working to a definition. When “Advocacy Counts” was undertaken the first time around, very few did. By the second time around 90% of them were doing so. The next time it is likely to be all of them.”

- “We used the principles in the Action for Advocacy Charter by applying them to the evaluation of tenders. They informed the standards and arrangements we expected.”

- “We would highlight independence, empowerment and inclusion. This is about bringing about full citizenship. The principles in Advocacy Charter provide explanations which link these notions directly to practice. They have been useful in pulling together values and the activities of advocacy in one place.”
2.6 Summary of Key Findings and Issues:-

- Definitions of advocacy are dynamic and subject to debate.

- The Older People’s Commissioner for Wales might draw upon definitions devised by the advocacy movement (e.g. OPAAL and Action for Advocacy) or enshrined within legislation elsewhere (e.g. Scotland).

- The chosen definition should incorporate components such as being independent of service provision; one to one with an individual older person/s; long term or short term involvement; paid or voluntary advocates; supported by an advocacy scheme or organisation; free to the person requiring advocacy; upholds core advocacy principles.

- Advocacy must be maintained as a highly principled activity. Its broad principles are independence, empowerment and inclusion.

- The Advocacy Charter developed by Action for Advocacy with the wider advocacy movement contains a detailed set of principles for practice.

- The main advocacy roles are instrumental and expressive - both are needed and valued by older people.

- A number of models of advocacy provision have been developed.

- There is a lack of specialist advocacy schemes for specific issues such as dementia, physical and sensory impairment; generic advocacy schemes for older people who are not eligible for statutory services; and peer advocacy projects run by and for older people in Wales.
This section will explore legislation which provides direct rights and duties regarding the provision of advocacy. It will begin with a brief commentary on the evolving legal status of advocacy. There will then be a consideration of the current legal provisions for IMCA, IMHA and the new proposed Mental Health Measure.

3.1 The Development of Advocacy Legislation

There has long been a call for legislation to ensure the provision of advocacy and to secure the legal status of advocates (Wertheimer 1993; Brandon 1995; Henderson and Pochin 2006). There were several missed opportunities to initiate and implement such legislation during the 1980’s and 1990’s. These included new laws on disability and community care as well as charters and consultations.

The Disabled Persons (Services, Consultation and Representation) Act 1986 included the right of disabled people aged 18+ to the appointment of an authorised representative or advocate. However, the key sections of the Act regarding representation were never to be fully implemented and the Government failed to grant legislative powers to deter lack of compliance by local authorities in making necessary provision. The NHS and Community Care Act 1990 and Citizen’s Charter (1991) suggested support for advocacy but there was no imperative to do so. Also during the early 1990’s a series of consultations by the Law Commission on mental capacity and decision making highlighted the role of advocacy but were not acted upon at that time (Law Commission 1991, 1993, 1995).

The twenty-first century has heralded the first advocacy legislation to be implemented in Wales, albeit in limited circumstances. The Mental Capacity Act 2005 introduced Independent Mental Health Advocates and the Mental Health (Independent Mental Health Advocates) (Wales) Regulations 2008 introduced advocates for patients qualifying under specific terms of the Mental Health Act 1983. The recent Mental Health (Wales) Measure has
further extended the group of qualifying patients eligible for the support of Independent Mental Health Advocates. Also of direct relevance to advocacy is the Commissioner for Older People (Wales) Act 2006 and the provision for Community Health Council (CHC) Complaints Advocacy made by the National Health Service (Wales) Act 2006, which will be further discussed in Sections 5 and 8 respectively.

The IMCA, IMHA and Mental Health Measure initiative will now be briefly considered in turn. Whilst they represent a welcome advance, it must be stressed that the right to independent advocacy, the duty to provide independent advocacy and the legal status of advocates, remains far from comprehensive. It is also evident that these legislative initiatives are under researched, notwithstanding their relatively recent development. There is, for example, a contrast between the more substantial published reporting and evidence base developing on IMCA in England than that in Wales (Gorczynska and Thompson 2007; Redley et al 2008; Department of Health 2008, 2009).

3.2 Independent Mental Capacity Advocacy (IMCA)

The IMCA service is a statutory form of advocacy introduced by the Mental Capacity Act 2005. The IMCA service is available in England and Wales. Both countries have regulations for setting up and managing the service. The role of the IMCA as set out in legislation is supported by the Mental Capacity Act 2005 Code of Practice (Department for Constitutional Affairs 2007) from which the descriptive elements of the following discussion are drawn.

The aim of the IMCA service is to provide independent safeguards for any person, aged 16 or over, who lacks capacity to make certain important decisions and, at the time such decisions need to be made, have no-one else (other than paid staff) to support or represent them or be consulted. IMCAs must be independent. The service came into effect in 2007.

In Wales, the Welsh Assembly Government (Welsh Assembly Government) delivers the service through local health boards, whom have financial responsibility for the service and work in partnership with local authority social services departments and other NHS organisations. The local health boards commission the service from independent organisations, usually advocacy organisations. Local authorities or NHS organisations are responsible for instructing an IMCA to represent a person who lacks capacity. In these circumstances they are called the ‘responsible body’.
An IMCA must be instructed, and then consulted, for people lacking capacity who have no-one else to support them (other than paid staff), whenever:-

(i.) an NHS body is proposing to provide serious medical treatment,

or

(ii.) an NHS body or local authority is proposing to arrange accommodation (or a change of accommodation) in hospital or a care home, and the person will stay in hospital longer than 28 days, or they will stay in the care home for more than eight weeks.

These circumstances extend to the involvement of an IMCA as part of the Deprivation of Liberty safeguards which apply in respect of people, “who lack capacity specifically to consent to treatment or care in either a hospital or care home that, in their own best interests, can only be provided in circumstances that amount to a deprivation of liberty, and where detention under the Mental Health Act 1983 is not appropriate for the person at that time” (Welsh Assembly Government 2009 p3).

An IMCA may be instructed to support someone who lacks capacity to make decisions concerning:-

(a.) care reviews, where no-one else is available to be consulted,

or

(b.) adult protection cases, whether or not family, friends or others are involved.

As the IMCA’s role is to support and represent the person who lacks capacity, they have the right to see relevant healthcare and social care records. They also have the right to see the person in private. Any information or reports provided by an IMCA must be taken into account as part of the process of working out whether a proposed decision is in the person’s best interests.
The Code of Practice goes on to state that in carrying out their role, the IMCA will:-

- be independent of the person making the decision;
- provide support for the person who lacks capacity;
- represent the person without capacity in discussions to work out whether the proposed decision is in the person’s best interests;
- provide information to help work out what is in the person’s best interests; and
- raise questions or challenge decisions which appear not to be in the best interests of the person.

In Wales it is the responsibility of the local health board to approve the appointment of an IMCA. Organisationally, the agencies commissioned to provide the IMCA service will work to appropriate standards set down within the contracting/commissioning process. Individually, IMCA’s must have:- specific experience; IMCA training; integrity and good character; and also be able to act independently.

Whilst acknowledging that IMCA services would be building on good practice developed in the independent advocacy sector, the Code of Practice offers some useful distinctions between IMCA’s and other advocates. The IMCA:-

- provides statutory advocacy
- is instructed to support and represent people who lack capacity to make decisions on specific issues
- has a right to meet in private the person they are supporting
- is allowed access to relevant healthcare records and social care records
- provide support and representation specifically while the decision is being made, and
- act quickly, so their report can form part of decision-making.
The following organisations are currently providing IMCA services across Wales:-

**IMCA Providers in Wales**

- **North Wales Advice and Advocacy Service**  
  Anglesey and Gwynedd
- **IMCA Wales at Mental Health Matters Wales (South West Wales Consortium)**  
  Bridgend, Neath Port Talbot and Swansea
- **IMCA Wales at Mental Health Matters Wales (South East Wales Consortium)**  
  Blaenau Gwent, Caerphilly, Cardiff, Merthyr Tydfil, Monmouthshire, Newport, Rhondda Cynon Taf, Torfaen, Vale of Glamorgan
- **Advocacy Experience**  
  Conwy, Denbighshire and Flintshire
- **Wired**  
  Wrexham
- **3 Counties IMCA Service**  
  Carmarthenshire, Ceredigion and Pembrokeshire
- **Brecknock and Radnor CHC and Montgomery CHC**  
  Powys

Using the key informants approach, it became apparent that older people are the largest group being supported and represented by an IMCA. It was suggested by one respondent that up to two thirds of the work of the IMCA service is with older people. Another respondent supplied annual figures for one IMCA service which showed that out of a total of 183 referrals, 58 people were aged 65-79 and 67 were aged 80 and over. Amongst those referrals, there were 89 people with dementia.

IMCA providers in Wales meet quarterly in order to share information, discuss common issues and developments, training opportunities and messages to Welsh Assembly Government. The networks appear to be strong between IMCA providers and increasingly with other advocacy networks. It is also possible for IMCA providers to talk directly to policy makers within Welsh Assembly Government.
However, the concerns expressed by respondents included:

- There is currently no Welsh Assembly Government lead officer on IMCA (though there had been when it was being established), whereas the Department of Health has key officers and the Social Care Institute for Excellence (SCIE) has an IMCA development officer for England.

- As yet, there has been no IMCA annual report for Wales, whereas the Department of Health has published an annual report for the past two years on IMCA in England.

- The national database run by the Department of Health includes returns from IMCA services in Wales, but does not provide information or feedback for them, so Welsh IMCA services have created their own database for reporting.

- The short term and specific nature of the IMCA role means that there is often a need to work with other advocacy schemes, but there is a lack of comprehensive advocacy strategy and provision of non-statutory advocacy is patchy.

- An apparent lack of available care options for older people in the community relative to younger adults limits choices IMCA’s can explore on behalf of the older person.

### 3.3 Independent Mental Health Advocacy (IMHA)

The Mental Health (Independent Mental Health Advocates) (Wales) Regulations 2008 were introduced following an amendment to the Mental Health Act 1983 by section 30 of the Mental Health Act 2007. The service is available in England and Wales, with each country producing regulations for setting up and managing the service. The service came into effect in 2008. The aim of the IMHA service is to provide further safeguards for “qualifying patients”. IMHAs must be independent. The role of the IMHA as set out in legislation is supported by the Mental Health Act 1983 Code of Practice for Wales (Welsh Assembly Government 2008). The descriptive elements below have largely been drawn from Chapter 25 of the Code.

In Wales, local health boards have been given responsibility for commissioning IMHA, working closely with local authority social services departments and other NHS organisations. The IMHA services are provided
by advocacy organisations that are independent of the NHS and local authorities. The Code of Practice states that qualifying patients should be informed as soon as practicable by the “responsible person”.

The “qualifying patients” for IMHA are those,

- detained or liable to be detained under the Mental Health Act 1983
- subject to guardianship under the Act
- community patients subject to community treatment orders
- conditionally discharged
- being considered for section 57 or 58A treatments but are not otherwise subject to the Act (i.e. an ‘informal’ patient)

A qualifying patient may ask for the support of an IMHA at any time. Patients may want to consider accessing an IMHA in the following circumstances:

- as soon as practicable after their arrival in hospital under one of the relevant sections of the Act;
- before the initial discussion with their clinician about the proposed treatment plan;
- when the use of electroconvulsive therapy (ECT) is being considered;
- when an application has been made or is being considered to the Mental Health Review Tribunal (MHRT) for Wales or to the hospital managers;
- when they choose not to be legally represented at a tribunal hearing;
- when they want to make, or have made, a complaint;
- when they want to discuss any aspect of their care or treatment;
- when they want to apply to displace their nearest relative;
- when they are consulted about the conditions to be attached to a community treatment order (CTO);
- when a CTO is renewed, revoked, or its conditions are varied; and
- when a meeting is held to discuss after-care.
Certain professionals (the responsible person) have a duty to tell qualifying patients that independent mental health advocacy is available, how they may obtain it and to support them in doing so if needed. The responsible person might differ according to circumstance, as follows:-

<table>
<thead>
<tr>
<th>Qualifying Patient</th>
<th>Responsible Person for Informing Qualifying Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient liable to be detained</td>
<td>The hospital managers</td>
</tr>
<tr>
<td>A patient who is likely to be detained but has been voluntarily discharged</td>
<td>The responsible clinician for the patient</td>
</tr>
<tr>
<td>Patient subject to guardianship</td>
<td>The responsible local social services authority</td>
</tr>
<tr>
<td>A community patient</td>
<td>The hospital managers of the responsible hospital</td>
</tr>
<tr>
<td>A patient for whom treatment under section 57 is proposed, if they do not already fall under one of the categories above</td>
<td>The registered medical practitioner or approved clinician with whom the patient first discusses the possibility of such treatment</td>
</tr>
</tbody>
</table>

(Source Welsh Assembly Government 2008 p152)

The IMHA provides support to qualifying patients to ensure they understand the Act and their own rights and safeguards. The Code of Practice suggests that this may include support in obtaining information about any of the following:

- the patient’s rights under the Act;
- the provisions of the Act under which the patient qualifies for an IMHA;
- any conditions or restrictions which affect the patient;
- the medical treatment the patient is receiving, or which is being proposed or discussed, and the reasons for this;
- the legal authority for providing such treatment; and
- the requirements of the Act which apply to treatment.
In common with the IMCA, independent mental health advocates must be an appropriate person with experience and training. In the case of IMHA that includes previous experience of working in advocacy, particularly mental health advocacy; previous experience of working with people with mental health needs; and successful completion of an advocacy qualification. On the latter point, a national advocacy qualification has recently been developed. The course is modular in structure and is competency based and reliant on practical experience. It is recognised that not all IMHAs will have completed the IMHA module before they begin to practice, but it expected that they should have done so by the end of their first year.

In carrying out their role, the Code states that the IMHA will:

- ensure that the patient’s voice is heard by supporting the patient to articulate their views and to engage with the multi-disciplinary team;
- support patients to access information, and to understand better what is happening and what is planned, and to understand better the options available to them;
- support patients in exploring options, making better-informed decisions and in engaging with the development of their care plans;
- supporting the patient to ensure they are valued for who they are; and
- support the patient to counteract any actual or potential discrimination.

IMHAs have certain rights in order to enable them to carry out their role effectively. These include being able to:-

- visit and interview the patient in private (patients should have access to a telephone to speak to an IMHA in private);
- visit, interview and get the views of anyone professionally concerned with the patient’s medical treatment;
- have access to the unit and ward where the patient under detention is staying;
- have access to facilities in the community where the patient is a community patient;
- attend relevant meetings and ward rounds when asked to do so by the patient;
have access and inspect the patient’s relevant records (under certain conditions).

The following organisations are currently providing IMHA services across Wales:

**IMHA Providers in Wales**

- **South Wales Mental Health Advocacy and MAP**
  Bridgend, Carmarthenshire, Ceredigion, Neath Port Talbot, Pembrokeshire, Swansea and the western Vale of Glamorgan

- **South Wales Mental Health Advocacy**
  Cardiff, Merthyr Tydfil, Rhondda Cynon Taf, Vale of Glamorgan

- **Mental Health Matters Wales**
  Blaenau Gwent, Caerphilly, Monmouthshire, Newport, Torfaen

- **UNLLAIS with Gwynedd and Anglesey Mental Health Scheme, Conwy and Denbighshire Mental Health Advocacy Service and Flintshire Mental Health Advocacy Services**
  Gwynedd, Anglesey, Conwy, Denbighshire, Flintshire and Wrexham

- **Brecknock and Radnor CHC and Montgomery CHC**
  Powys

Again, research in this new area of advocacy provision is limited. However, some initial work was carried out by Barnes and Steven to map independent mental health advocacy services in England and Wales, promote good practice, provide guidance for commissioners and work towards the national advocacy qualification (www.goodadvocacypractice.org.uk). At the end of 2009 the Department of Health invited tenders to review the quality of independent mental health advocacy services over a two year period in England only.
3.4 Mental Health (Wales) Measure

This Measure is a uniquely Welsh development. It extends the group of “qualifying patients” so that all patients subject to the formal powers of the Mental Health Act 1983 are able to receive IMHA support. This includes patients on shorter term, emergency sections. Furthermore, the Measure enables voluntary or informal patients not detained under the Act receiving care and treatment for mental health problems in hospital to have access to independent and specialist advocacy and creates a statutory duty for such help and support to be available. The Measure was introduced in March 2010 and was scheduled to complete stage 1 of its passage through the National Assembly for Wales in July 2010.

The Measure has been broadly welcomed by the advocacy movement in Wales, for extending advocacy provision and increasing recognition of the role that advocacy can play in empowerment and protection. However, written evidence submitted by advocacy organisations and others to the public consultation highlighted a number of issues of concern, not merely with regard to the Measure, but to advocacy services more widely. Many of these issues echo comments made by respondents to interviews and questionnaires as part of this scoping study. They can be summarised as follows:-

■ **Principles**

Respondents highlighted that care would be needed to avoid compromising some of the principles set out in the Advocacy Charter by Action for Advocacy. There is a risk that commissioning arrangements for statutory forms of advocacy will be overly prescriptive and challenge the independence of advocacy. There are also concerns that statutory advocacy for a few will deny the choice of other forms for the many.

■ **Scope**

The Measure extends entitlement to mental health advocacy support to any person receiving treatment in hospital as well as compulsory patients. In its evidence to the public consultation Age Cymru called for clarity about the position of older people not in hospital (detained or otherwise) but being cared for in the community (including care homes, their own homes and other settings). They also argue that older people might need advocacy support in order to refer themselves back to mental health services or to be engaged in writing their care plan.
## Strategy

The lack of an overarching advocacy strategy for all groups - or any strategy for advocacy for older people - allows an uneven development of policy and provision to prevail. The development of current forms of statutory advocacy is not set within a wider vision or framework. There is a concern that non-statutory and non-mental health advocacy services will be “downgraded” and decommissioned as a result of new statutory provision. In particular, community based advocacy schemes might struggle to survive despite their value to older people and other groups.

## Funding

Conversely, there are fears that with the development of statutory commissioned forms of advocacy, charities and trusts might be disinclined to fund advocacy and innovation will be thwarted. Furthermore, commissioning arrangements have introduced competition between advocacy organisations that might not always be in the interests of service users. There is a developing trend towards bigger provider organisations gaining contracts and commissions. This could be at the cost of smaller, innovative and community based advocacy schemes.

## Capacity

IMCA, IMHA and now the Measure have required local services to develop rapidly from a limited base. Some advocacy schemes have also had to move from an essentially ‘office hour’ provision to evening and weekend service provision. Evidence submitted by South Wales Mental Health Advocacy highlighted the limited provision under which current IMHA services are being delivered. Fewer than 20 full time equivalent staff currently deliver the IMHA service across Wales - the largest provider has 6.6 full time equivalent staff, the smallest less than one full time equivalent. The need to increase capacity rapidly whilst maintaining current services will place immense pressure upon current providers.

## Training

The introduction of IMCA, IMHA and now the Measure all call for training of advocates and also all staff whose role is affected by the new statutory provision. The latter group might run into thousands of people, so a large scale effort and resources will be required. There was an extremely short
timetable for implementation of IMHA, whereas the Measure will be phased in over two years. This is crucial as it will allow a process of recruitment, training and deployment of staff. South Wales Mental Health Advocacy point out that it is rarely possible to recruit a trained advocate - no such pool of staff exists - and comprehensive training for advocates can take a year.

3.5 Select Comments from Respondents

- “There needs to be some statutory basis for the provision of advocacy services or it won’t flourish. It should not be so fragmented and depend on which local authority you are in.”

- “There needs to be a statutory right to advocacy regardless of capacity. It is too tightly defined now - to IMCA and IMHA.”

- “The IMCA role is fairly narrow. Once a decision is made we have no further role. We try to refer people on to a local advocacy scheme if one exists. We have worked alongside existing advocates who know the person already. But that is only if the schemes are out there.”

- “Where is the IMCA annual report for Wales? There is one for England but not Wales. We need to know the numbers and what is happening for older people. Anecdotally, they (older people) are two thirds of IMCA’s clients.”

- “The new IMCA and IMHA arrangements are statutory and seem to serve people who need them very well. It’s what happens to people outside these arrangements that concerns me.”

- “The Mental Health Measure means that more older people will pick up on mental health advocacy if they fall within its terms.”

- “Perhaps advocacy is gaining momentum. The Mental Health Measure is an example of this. It shows political and legislative support. It also highlights weaknesses. By expanding provision through the Measure it shows what is not available for this issue or group. Older people might have mental health problems but they might also have issues associated with sensory or physical impairment.”
3.6 Summary of Key Finding and Issues

- Legislation with duties to provide advocacy, granting people rights to advocacy and giving advocates legal status has been implemented since 2005 by way of IMCA, IMHA and the new Mental Health (Wales) Measure.

- The current legislative framework remains far from comprehensive and is only applicable to a limited number of older people within qualifying groups. Both IMCA and IMHA involvement is short term in nature and limited in scope.

- These legislative initiatives are under researched and, notwithstanding their relatively recent development, a more substantial evidence base is developing in England than in Wales.

- In contrast with arrangements in England, there is no readily accessible database, lead official in government or annual report for IMCA in Wales.

- Respondents to this scoping study stated that most IMCA referrals were concerned with older people.

- The new Mental Health (Wales) Measure will extend the group of qualifying patients eligible to receive IMHA support, to include all patients subject to the formal powers of the Mental Health Act 1983 as well as voluntary and informal patients not detained under the Act.

- Advocacy organisations and other respondents to the recent Mental Health (Wales) Measure highlighted a number of issues of concern which pertain to advocacy provision more widely. They include challenges with regard to advocacy principles, scope, strategy, funding, capacity and training.
This Section discusses the development of advocacy with older people in the context of the wider public policy agenda for Wales. The policies considered here include One Wales, the Third Dimension and the Strategy for Older People in Wales. The significance of exploring such initiatives is that older people are viewed as citizens as well as service users, extending the remit of advocacy beyond a narrow focus upon health and social care related issues. It also situates advocacy with older people with the grain of Welsh public policy for all citizens.

4.1 One Wales and Beyond

The One Wales: A Progressive Agenda for the Government of Wales document represents a programme for government agreed by the Labour and Plaid Cymru groups in the National Assembly in 2007. The programme highlights principles of social justice, sustainability and inclusion, “of the whole of Wales and for all its people” (p5). It covers a range of substantive policy areas, including health, social care, transport, learning for life and housing. The programme aims towards creating a “fair and just” Wales by promoting equality and enhancing citizenship and community cohesion.

The document states that,

“Our vision is of a fair and just Wales, in which all citizens are empowered to determine their own lives and to shape the communities in which they live.” (p26)

Clearly there are synergies between this programme and the purposes of advocacy with older people - as citizens and as actual or potential users of a range of services. One Wales is seen to complement the aspects of the Welsh Assembly Government framework document for public services Making the Connections: Delivering Beyond Boundaries (2006) in response to the Beecham review - particularly in the development of citizen
centred services. Advocacy also resonates with some of the core principles and aims of strategies such as **Designed for Life**, the Welsh Assembly Government vision for health and social care services in the 21st century (2005) and **Fulfilled Lives: Supportive Communities** the Welsh Assembly Government social services strategy (2007), promoting citizen engagement, empowerment, person-centred care and joined up services.

Advocacy is not explicitly mentioned within **One Wales**. However, it can be seen as a means of operationalising citizenship as envisioned within this and other important documents. It provides a way of ensuring that disengaged, disadvantaged and disempowered older people can indeed have a say in determining and improving their own lives like other citizens.

The citizenship approach enables advocacy to work with older people across a wider range of services and issues. It also opens up the possibility of advocacy working with a wider range of older people. Kalaga et al (2007) note that despite legal, policy and practice developments in advocacy in Scotland, these measures are not fully inclusive,

“Perhaps the largest gap in independent advocacy concerns “hidden” groups that fall outside the better known groups of vulnerable adults, such as homeless people, people with a substance abuse problem, offenders leaving prison, refugees and asylum seekers, and other marginalised individuals. Care must be taken to provide these groups with effective communication and to not contribute further to the marginalisation that these groups experience.” (p43)

### 4.2 Third Dimension

The Welsh Assembly Government strategy and action plan for supporting and working with the Third Sector - **The Third Dimension** (2008), is a highly significant document in the development of advocacy in Wales. According to its Foreword, the Third Sector has a crucial role to play in helping to deliver the One Wales programme. The document focuses upon five key areas:-

- valuing and promoting voluntary action;
- strengthening and empowering communities;
- enhancing opportunities for citizens to be heard;
- supporting and accelerating social enterprise; and
- making public services more citizen-centred and accessible.
In terms of personalising public services, the Strategy states that the Third Sector can promote accountability by providing “a challenge and advocacy role on behalf of citizens at the margins of society” (4.48). The Sector is also recognised for engaging with citizens with multiple disadvantages which prevent them engaging with “traditional” service providers (4.51).

More specifically and crucially, however, the development of a comprehensive strategy for advocacy in Wales sits within this document. Part 5e of the strategy action plan calls for,

“Development of effective strategic approaches to improve the coverage, independence and quality of information, advice and advocacy services”.

A specific indicator or output towards this end was stated as being the, 

“...adoption of an Advocacy Services Strategy for Wales”.

The deadline for the delivery of the Advocacy Services Strategy for Wales was set for September 2008. Those responsible for its development were listed within the Action Plan as being the Welsh Assembly Government Third Sector Group, Advocacy Wales, Welsh Council for Voluntary Action (WCVA), County Voluntary Councils (CVCs) and Third Sector networks.

Documentary searches and interviews with participants in undertaking this scoping study revealed that the Advocacy Services Strategy has not been developed. It appears that whilst Welsh Assembly Government had intended Third Sector partners including Advocacy Wales to work up the Strategy, there was no capacity for them to do so without resources being made available (See Section 9). There is now an intention to collate a document comprised of those individual advocacy strategies already drawn up in parts of Welsh Assembly Government, including advocacy strategies for children and young people and for mental health.

Advocacy for older people appears to be deeply disadvantaged in two respects in the current circumstances. Firstly, the drawing up of a comprehensive Advocacy Services Strategy would necessarily have included groups for whom there is no substantive stand alone strategy at present - including older people. Secondly, those sections of Welsh Assembly Government with a remit for older people’s policy have not been commissioned to develop a strategy for advocacy with older people.
Part 6a of The Third Dimension action plan calls on each Welsh Assembly Government Department to work with the Third Sector to “clarify the actions it will take in response to the strategic action plan to further its remit”. It also recommends that they should challenge local authorities and other public bodies to take similar action. It is difficult to comprehend how this might be done in respect of the Advocacy Services Strategy for all groups or older people in particular.

The lack of comprehensive legislation or policy providing older people and other citizens with a right to independent advocacy has been highlighted by advocacy organisations. A Manifesto for Independent Advocacy Services in England and Wales was launched following a national sector wide conference held in March 2010. It was drawn up by Action for Advocacy, Dementia Advocacy Network, Gateshead Advocacy and Information Network, Age Concern Cymru Elder Abuse Project, Advonet, Newcastle Advocacy Centre and the Older Peoples Advocacy Alliance (OPAAL) UK.

The Manifesto was further developed and supported by a number of national and regional advocacy networks as well as local advocacy schemes and individual advocates. It states that,

“A national framework is required to ensure that independent advocacy is seen as a right, not a privilege, with local bodies having a duty to provide flexible, inclusive independent advocacy that can meet the needs of diverse communities.”

(Action for Advocacy et al, 2010)

It should be noted that in lieu of a comprehensive advocacy strategy at national level, some local authorities have sought to develop their own, as in the following example:-

Caerphilly County Borough Adult Advocacy Commissioning Strategy

The stated aim is “To develop a strategy where all adults eligible for, or receiving Health and Social Care Services within Caerphilly County Borough, are able to access an appropriate advocate or advocacy service”.

The Borough Council has undertaken a thorough and extensive mapping, consultation and engagement exercise in developing the strategy with key stakeholders.
4.3 The Strategy for Older People in Wales

The first phase of the **Strategy for Older People in Wales 2003-2008** was groundbreaking in its citizen focus and its reach across a range of service areas. Indeed, it states that one of its key themes is that of “a programme of citizenship for older people”. Some of its strategic aims were conducive to advocacy, though no explicit mention of advocacy is made anywhere in the document. In particular, the strategic aim of Valuing Older People was stated as,

> “Reflecting the United Nations Principles for Older People, to tackle discrimination against older people wherever it occurs, promote positive images of ageing and give older people a stronger voice in society.” (p14)

The second phase of the **Strategy for Older People in Wales - Living Longer: Living Better (2008-2013)** continued many of the key themes of the first. The appointment of the Commissioner for Older People in Wales is noted amongst the policies and programmes towards Valuing Older People. The document again states the intention to combat age discrimination as well as promoting positive images of ageing and social inclusion, nurturing intergenerational relations and developing the civic engagement of older people.

Once more, there is no specific reference to the development of advocacy services for older people. Nevertheless, advocacy can be seen to complement the context and intentions of the Strategy. Indeed, a few local authorities decided to use some of their Strategy monies to support the development of local advocacy strategies and schemes, as follows:-

**Bridgend County Borough Independent Advocacy Project for Older People**

As part of the implementation of **It’s Never Too Old Strategy for Older People** in Bridgend County Borough, the local authority has supported an independent advocacy project for older people. The project is hosted by Age Concern Morgannwg.

The project aims to ensure that older people, “...irrespective of physical or mental disability, will have access to advice, support and encouragement that will allow them to express their needs, wishes and exercise their rights”.


Elsewhere, advocacy for older people has been considered as part of the health, social care and well-being agenda, for example:

4.4 Select Comments from Respondents

- “Independent advocacy is not just about social services. It is about life and independent living more widely.”
- “Seeing older people as citizens - and older people seeing themselves as such - is like looking through fresh eyes. Advocacy can help people see things in new ways to make improvements and find solutions.”
- “The Third Dimension would have brought meaningful engagement between the advocacy movement and Welsh Assembly Government in developing a strategy for advocacy in Wales. But it was hugely disappointing. There was not even money to pay travel expenses to attend meetings.”
- “No single advocacy organisation could take forward the work on an All Wales advocacy strategy (as proposed in the Third Dimension). So various parts of Welsh Assembly Government have ploughed their own furrow and gone ahead as experts in their particular fields.”
- “No advocacy strategy for older people has been commissioned (within Welsh Assembly Government). There has been investment in advocacy for children and in mental health and learning disabilities.
- “There are developments at local level, but no overarching policy or strategy for advocacy with older people in Wales. This is mainly to do with the development of the Older People’s Commissioner role. It is part of her role to act as an advocate for older people.”
- “It shocked me that advocacy was not in the Strategy for Older People, the first or second time around.”
4.5 Summary of Key Findings and Issues

- A citizenship approach broadens the scope of advocacy to include a wider range of services, issues and groups of older people as citizens as well as service users.

- Advocacy is a means of operationalising or putting into practice the citizenship of older people.

- The objective of a comprehensive advocacy services strategy within the Welsh Assembly Government Third Dimension strategy action plan has not been delivered.

- Older people are doubly disadvantaged as there is no comprehensive national advocacy strategy to include them and no stand alone national strategy for advocacy for older people (in contrast with children and young people and other groups).

- Second tier advocacy organisations in Wales lack organisational capacity to fully engage with the development of policy and practice development.

- Advocacy organisations in England and Wales have developed a manifesto calling for a national framework for advocacy.

- Advocacy was not included in the Strategy for Older People in Wales, despite apparent synergies. However, some local authorities have developed advocacy strategies or services under its auspices.
5. Human rights and equalities

Human rights and equalities are a crucial part of the context for advocacy. Recent legislation has compelled public bodies to consider human rights and equalities issues in policy and provision. In common with the previous section on Citizenship and Participation, matters of human rights and equalities broaden the concerns of advocacy beyond health and social care service provision. This section will explore Human Rights and Equalities with reference to the UN Principles, the Human Rights Act 1998, Equality Act 2010 and the work of the Equality and Human Rights Commission as well as the position of the Older People’s Commissioner for Wales. It will also include a comparative example of human rights and advocacy with older people in Australia.

5.1 United Nations Principles for Older Persons

The Annual Review of the Older People’s Commissioner for Wales 2008-09 emphasises that,

“Policies affecting older people must reflect the United Nations Principles for Older Persons” (p2).

The United Nations Principles cover a range of circumstances and situations in the lives of older people (Appendix 5). They are concerned with:

- Independence
- Participation
- Care
- Self fulfilment
- Dignity.
Advocacy is not given explicit mention, but the Principles can clearly be drawn upon by advocates in supporting older persons to secure and exercise their rights, choices and interests. For example,

Principle 13: “Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.”

Principle 18: “Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.”

Furthermore, there is an increasing groundswell amongst politicians, policy makers, non-governmental organisations and activists, for a new UN Convention on the rights of older persons. This would bring the interests of older people in line with other social groups covered by other Conventions, including the UN Convention on the Rights of the Child (1989) and the UN Convention on the Rights of Persons with Disabilities (2006).

“This would strengthen what we have with the Principles and the position of older people. It would make a difference globally and locally. Advocates would have further backing in their work with the older person.” (Laura Watts, International Federation for Ageing conference, Melbourne, 2010)

### 5.2 Human Rights Act 1998

The Human Rights Act (HRA) 1998 gives further legal effect to rights and freedoms contained within the European Convention on Human Rights of 1950. Anyone who resides in the UK for any reason has fundamental human rights and freedoms which government and public bodies are legally obliged to respect. The Human Rights Act 1998 means that:-

- Convention rights and responsibilities form a common set of binding values for public authorities right across the UK;
- Public authorities must have human rights principles in mind when they make decisions about people’s rights; and
- Human rights must be part of all policy making.

(Department for Constitutional Affairs 2006 p6)
Advocacy might be seen to play an important part in making a reality of building “a new culture of rights and responsibilities” (DCA 2006 p11) in the dealings that Government and public bodies have with individual citizens, young and old.

Rights protected by the HRA are stated as follows:

<table>
<thead>
<tr>
<th>Article</th>
<th>Right Description</th>
</tr>
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<tbody>
<tr>
<td>Article 2</td>
<td>right to life</td>
</tr>
<tr>
<td>Article 3</td>
<td>prohibition of torture, inhuman and degrading treatment</td>
</tr>
<tr>
<td>Article 4</td>
<td>prohibition of slavery and forced labour</td>
</tr>
<tr>
<td>Article 5</td>
<td>right to liberty and security</td>
</tr>
<tr>
<td>Article 6</td>
<td>right to a fair trial</td>
</tr>
<tr>
<td>Article 7</td>
<td>no punishment without law</td>
</tr>
<tr>
<td>Article 8</td>
<td>right to respect for private and family life, home and correspondence</td>
</tr>
<tr>
<td>Article 9</td>
<td>freedom of thought, conscience and religion</td>
</tr>
<tr>
<td>Article 10</td>
<td>freedom of expression</td>
</tr>
<tr>
<td>Article 11</td>
<td>freedom of assembly and association</td>
</tr>
<tr>
<td>Article 12</td>
<td>right to marry and found a family</td>
</tr>
<tr>
<td>Article 14</td>
<td>right not to be discriminated against in relation to any of the rights contained in the European Convention</td>
</tr>
</tbody>
</table>

| Article 1 of Protocol 1 | protection of property |
| Article 2 of Protocol 1 | right to education     |
| Article 3 of Protocol 1 | right to free elections |
| Article 1 of Protocol 13| abolition of death penalty |
Counsel and Care (2010) notes that a number of these rights are particularly pertinent to advocacy with older people in practice. They might include the following:-

**Article 3:**
“*No-one shall be subjected to...inhuman or degrading treatment.*”
e.g. An advocate supporting an older person in their absolute entitlement to be treated with dignity and respect for toileting arrangements in hospital.

**Article 8:**
“*Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right...(except in circumstances, such as in accordance with the law and the needs and protection of the rights of others).*”
e.g. An advocate supporting a local authority funded older person denied access to personal effects such as displaying family photographs in a care home.

**Article 10:**
“*Everyone has the right to freedom of expression.*”
e.g. An advocate assisting an older person who has difficulties in expressing themselves to be able to do so.

**Article 14:**
“*Rights and freedoms...should be enjoyed without discrimination on any ground.*”
e.g. An advocate supporting an older person who has been discriminated against and denied access to a screening programme because they are thought to be too old. It should be noted that Article 14 can only be cited when another Article is breached, in this instance a failure to screen may be a breach of the absolute right to life (Article 2).

Action for Advocacy has produced a Human Rights toolkit (Huijbers 2009). The toolkit was developed with support from a range of organisations including the British Institute of Human Rights, MIND, BILD and the Older People’s Advocacy Alliance (OPAAL) UK. It was funded by the Equality and
Human Rights Commission. The toolkit aims to help advocacy schemes and advocates to further their understanding and make use of existing resources in promoting and practicing human rights in their work.

Advocates now more frequently refer to the human rights dimension in representing the older person in letters, decision making meetings and other situations. This approach is encouraged by the House of Lords and House of Commons Joint Committee on Human Rights (2007), which called upon the UK government to ensure the provision of,

“...sufficient independent advocacy services to older people, with particular priority to older people with mental health problems or who are unable to communicate in English. These advocates should have a understanding of human rights principles and the positive duties of service providers towards older people.” (p70-71)

In Wales, the Welsh Local Government Association (WLGA) equalities team initiated some joint work with the British Institute of Human Rights and ran a series of regional workshops towards gaining a better understanding of human rights in relation to older people. The workshops were attended by older people and staff from each local authority area, including hospitals, care homes and other settings. The WLGA and older people’s strategy coordinators have also worked with MerseyCare NHS Trust to share best practice in using a human rights approach to work with older people and people with mental health problems in policy and practice.

### 5.3 Equality Act 2010

The Equality Act received Royal Assent in April 2010. The explanatory notes to the Act state that discrimination law has been developing in Britain for over 40 years, since the first Race Relations Act 1965. Domestic law and European Directives have subsequently provided further protection in areas such as sex discrimination, disability discrimination and employment equality on age. The new Equality Act has two main purposes - to harmonise discrimination law and to strengthen the law to support progress on equality.

The Act sets out the characteristics which are protected. They are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation
Older people might benefit from a number of duties and measures to be introduced by the Act, including:-

- a new duty on certain public bodies to consider socio-economic disadvantage when making strategic decisions about how to exercise their functions;

- extension of the circumstances in which a person is protected against discrimination, harassment or victimisation because of a protected characteristic;

- extension of the circumstances in which a person is protected against discrimination by allowing people to make a claim if they are directly discriminated against because of a combination of two relevant protected characteristics;

- a new equality duty on listed public bodies when carrying out their functions and on other persons when carrying out public functions to have due regard to how their policies, programmes and service delivery will affect people with the protected characteristics;

- allowing an employer or service provider or other organisation to take positive action so as to enable existing or potential employees or customers to overcome or minimise a disadvantage arising from a protected characteristic; and

- ending unfair age discrimination for those over the age of 18 in the provision of goods, services and facilities in the public, private and voluntary sectors.

The Act therefore represents a significant advance in terms of combating age discrimination. It moves beyond existing age discrimination legislation in relation to employment and into the provision of goods and services and other matters.

Advocates will be able draw upon the Equality Act in similar ways to their use of the Human Rights Act in their work with older people. They will be able to support the older person in questioning whether a public body has given due regard to them in their policies, programmes and service delivery - for example, whether they have received the same care and attention for a medical condition as would a younger person.
The Equality Act also allows advocates to support people not only in relation to their identity as users of health and social care services but in combating discrimination and promoting equality more widely as combinations of protected characteristics are considered, for example the position of black and minority ethnic elders or gay and lesbian older people.

In Wales, Welsh language will also be of significance to some older people. Although language is not a protected ground under the Equality Act, similar principles might apply to in relation to Welsh language in Wales through the provision of existing and pending legislation. Human rights legislation might also be applied to language.

5.4 Equality and Human Rights Commission (EHRC)

The EHRC was formed in October 2007, bringing together the work of the three existing equalities commissions (race, disability and sex/gender) and extending its remit to include further aspects of equality - age, sexual orientation, religion or belief as well as human rights. In fulfilling its vision of, “A society built on fairness and respect. People confident in all aspects of their diversity”, the EHRC has powers to enforce equality law. It also influences the development of law and government policy, promotes good practice, runs public campaigns on particular equality issues, fosters better relations and develops understanding and evidence (www.equalityhumanrights.com).

Independent advocacy is promoted within the strategic priorities of the EHRC, namely with regard to “Improve life chances and reduce inequalities” (Strategic Priority Three). The EHRC has also stated a commitment to ensure that independent advocacy is available to everyone as part of a social care system based on equality and human rights. It is particularly concerned about advocacy provision for the seven “protected groups” for which it is responsible - including older people.

In September 2009 the EHRC commissioned the Office for Public Management to conduct a study on advocacy in social care. The study aims to:-

- Explore the extent to which advocacy organisations provide services for, and meet the needs of, members of the protected groups;
- Explore the extent to which advocacy services specifically address human rights and equality issues;
Determine if local advocacy providers are working in a joined-up way to help people access advocacy services that meet their needs;

Develop recommendations about how gaps in provision should be filled and how more collaborative local arrangements might be achieved.

The study will involve a survey of advocacy providers and commissioners in Wales as well as England and Scotland and case study work in local areas. The final report is due for publication in the summer of 2010.

5.5 The Older People’s Commissioner for Wales

The Commissioner for Older People (Wales) Act 2006 created the role of the Commissioner for Older People in Wales. For the purposes of the Act, an “older person” is a person aged 60 or over and is ordinarily resident in Wales. The general functions of the Commissioner within the legislation are to:-

- promote awareness of the interests of older people in Wales and of the need to safeguard those interests;
- promote the provision of opportunities for, and the elimination of discrimination against, older people in Wales;
- encourage best practice in the treatment of older people in Wales; and
- keep under review the adequacy and effectiveness of law affecting the interests of older people in Wales.

The Welsh Assembly Government website and others describe the Commissioner as being a “source of information, advice and support for older people in Wales”. She is also seen as being “an ambassador and an authority on older people’s issues”, who will enable older people to have “a stronger voice”. Sections on functions, review of arrangements and assistance contained within the Act certainly entail an advocacy role - both in terms of public advocacy and in some cases allowing for the direct provision of representation for individuals, for example where the case raises issues which may have a wider impact on older people. Some relevant passages from these Sections are considered below.

Section 5 states that the Commissioner may review arrangements in fields in which the Welsh Assembly Government has functions and the operation of such arrangements for the purpose of ascertaining whether, and to what
extent, the arrangements are effective in safeguarding and promoting the interests of relevant older people in Wales. The Commissioner may also assess the effect on relevant older people of a person’s failure to make any such arrangements. These include advocacy arrangements (S.5(2)(a)), described as being arrangements made by a person for making persons available:-

(a.) to represent the views and wishes of relevant older people, and

(b.) to provide relevant older people in Wales with advice and support of a prescribed kind (S.5(4)).

In Section 8, regarding assistance, regulations may confer power on the Commissioner to give assistance to an older person in making a complaint or representation to or in respect of the Assembly. The Commissioner might also give such assistance in other situations such as to an older person making a complaint or representation to or in respect of a person providing regulated services in Wales, regarding the provision of those services; or in any procedures or proceedings or prospective as prescribed. Furthermore, Section 10 states that regulations may make provision,

“for the examination by the Commissioner of the cases of particular persons who are or have been older people in Wales, in connection with the Commissioner’s functions under this Act”. (S. 10(1))

The creation of the post of Commissioner for Older People in Wales was much anticipated and the Annual Review 2008/09 highlights a number of developments and achievements in the first year of office. It is also believed that this is the first such post in the world, so it is groundbreaking in nature.

Some respondents to the scoping study suggested, however, that work needs to be continued on raising awareness and clarifying the role. This particularly concerned managing expectations around direct casework advocacy to be undertaken by the Commissioner and relationships with advocacy organisations across Wales.
Human rights, law and advocacy with older people in Australia

In Australia, there are very close working relationships between advocacy organisations for older people and lawyers with an interest in elder law and human rights. For example, Seniors Rights Victoria aims to prevent elder abuse and to safeguard the rights, dignity and independence of older people in the State. It is a free, independent service that provides individual support, advocacy and legal services to meet its stated aims. It is State funded through the Department of Planning and Community Development and Victoria Legal Aid. Individual support includes assistance with personal safety, security, confidence and wellbeing. Advocacy support is provided on a one to one basis with a member of the advocacy team. Legal services are provided by the Senior Rights Victoria legal practice, a community legal service or by legal firms engaged with the assistance of the Public Interest Law Clearing House. Legal firms undertake a significant amount of pro bono work for older people through the advocacy scheme. The organisation also has close links with the Council of the Ageing (COTA) Victoria which enables collective advocacy and representation. (www.seniorsrights.org)

5.6 Select Comments from Respondents

- ‘The human rights work we have been doing is about advocacy with a little “a”. It needs to be linked in with advocacy with a big “A”.’

- “It became clear from the strategy co-ordinators and older people’s forums that there were real concerns about behaviour and treatment towards older people. ..The big thing about finding out more about human rights was that a particular Article that seems fluffy and distant can be used and become very powerful.”

- “Authorities have become aware that they must meet their obligations under the terms of the Human Rights Act. Advocates have been one way of ensuring that they do. The new equalities legislation is likely to have a similar effect. For older people and their representatives it will be a way of holding authorities to account.”
“Advocates may question whether an older man or woman is being treated equally in getting access to goods and services. This brings parity with other equality issues.”

“There is a real sense from older people and the forums that cases would be taken up by the Older People’s Commissioner to advocate. A desire for her to intervene and a weight of expectation from older people’s forms and others. I’d like to see a real clarity and detail of meaning of the Commissioner’s role and its relationship with advocacy. There is a real lack of understanding about this.”

“The Welsh Assembly Government website says that the Commissioner for Older People is a source of information, advocacy and support. But this makes it an unclear message. Does it all rest with the Commissioner, all of us at different levels of government, local advocacy schemes?”

“Advocacy is about treating people as human beings, with dignity and respect. It can help others to do so if they forget, they’re too busy or just don’t care.”
5.7 Summary of Key Findings and Issues

- Human rights and equalities are a crucial part of the context for advocacy and broaden its concerns beyond the health and social care of older people.

- The UN Principles for Older Persons do not explicitly mention advocacy, but can be drawn upon by advocates in supporting older persons with regards to the promotion and protection of independence, participation, care, self fulfilment and dignity.

- Advocates are drawing upon the Human Rights Act 1998 in representing the older person in letter, decision making meetings and other situations.

- A human rights approach in advocacy with older people has been encouraged by the House of Lords and House of Commons Joint Committee on Human Rights and is supported by training materials and opportunities for advocates.

- Advocates will be able to draw upon the Equality Act 2010 which extends the circumstances in which people are protected against discrimination and places an equality duty on a range of public bodies and related organisations. This also allows for a wider consideration of protected characteristics including the position of gay and lesbian older people and black and minority ethnic elders.

- The Equality and Human Rights Commission includes independent advocacy within its strategic priorities and is committed to ensure that such advocacy is available as part of a social care system based on equality and human rights - particularly with regard to older people and other protected groups.

- The Older People's Commissioner for Wales is widely welcomed but respondents suggest that more work is needed to raise awareness and clarify the nature of the advocacy role of the Commissioner and to develop relationships with advocacy organisations across Wales.
6. Health and social care

Designed for Life, the Welsh Assembly Government vision for health and social care services in the 21st century (2005) and Fulfilled Lives: Supportive Communities the Welsh Assembly Government social services strategy (2007), ostensibly provide a positive direction for policy and provision which promotes the engagement and empowerment of service users. The Strategy for Older People in Wales discussed in Section 4 is also a part of this overarching agenda. The evolving legislative framework for advocacy and of human rights and equalities outlined in Sections 3 and 5 supplements and strengthens the position of older people as citizens as well as users of health and social care services.

This section explores a wide range of advocacy-related developments in health and social care. This will begin with an outline of key aspects of the National Service Framework for Older People in Wales. There will then be a brief consideration of developments pertaining to particular groups of older people, including older people with mental health problems, dementia, learning disabilities, physical impairments, sensory impairments and older people as carers. This will be followed by an examination of advocacy for older people in care homes and older people in community settings.

6.1 The National Service Framework for Older People in Wales

The National Service Framework (NSF) for Older People in Wales is a ten year framework which sets evidence based standards for the health and social care of older people in Wales (Welsh Assembly Government 2006). The NSF is developed and monitored locally through partnerships comprised of a number of stakeholders. During the year 2010/11 partnerships will prepare further interim action plans. There will also be a review of the NSF undertaken by HIW and CSSIW with a final report due in the summer of 2010 to inform the direction from April 2011 onwards.
Advocacy is regarded as being a “key intervention” in Standard 1 of the NSF, Rooting Out Age Discrimination. The standard states that,

“Health and social care services are provided regardless of age on the basis of clinical and social need. Age is not used in eligibility criteria or policies to restrict access to and receipt of available services.”

The availability and use of advocacy services is identified as being an outcome measure to be assessed by review. Objective 4 of the standard states that advocacy services are to be available, publicised and accessed when appropriate. The deadline for action to be taken on this objective was by the end of March 2008. Advocacy can also be seen to complement other components of the NSF for Older People, such as Standard 2 regarding person centred-care.

However, analysis of documents, websites and interviews undertaken as part of this scoping study suggested that the NSF has not created significant impetus for the further development of advocacy services. The lack of any requirement or additional resources for local authorities or health bodies to do so was seen to be a major reason for this shortfall.

Dignity is a theme which cuts across all ten standards of the NSF. Advocates can undertake their instrumental and expressive roles to help the wider endeavour to maintain respect for and dignity of older persons. A Dignity in Care National Co-ordinating Group was established and work is currently progressing under the umbrella of the NSF but it is unclear whether advocacy is being considered as part of the agenda of the group.

More explicit support for advocacy has so far been voiced by the campaign group, A Dignified Revolution. The group aims to ensure that the dignity and respect of older people is a key priority for health and social care professionals. The group also aims to encourage the general public to challenge unacceptable attitudes and inappropriate care. It calls for investment in,

“independent advocacy services for older people and their relatives. This is particularly important for those involved in continuing care assessments.” (www.dignifiedrevolution.org.uk).
6.2 Older People with Mental Health Problems

As discussed in Section 3, advocacy for people with mental health problems has recently attained a legislative basis in the provision of IMHA and the Mental Health (Wales) Measure. Older people with mental health problems might also be eligible for support of an IMCA or the CHC Complaints Advocacy service. It has been recognised that whilst IMHA is welcomed, its terms are relatively restricted. The Mental Health Measure extends entitlement to include voluntary and informal hospital patients not detained under the Mental Health Act 1983.

These statutory initiatives represent a significant advance and go some way towards addressing concerns about the lack of advocacy services for older people with mental health problems highlighted by the Audit Commission in Wales in Losing Time (2002) and Developing Mental Health Services for Older People in Wales (2004). In the latter report it was noted that progress had been slow and that older people were still being referred to generic adult mental health advocacy services which might not be “fully responsive” to meeting their specific needs (Audit Commission in Wales 2004 p11).

However, older people with mental health problems who do not come under the auspices of the more recent IMHA legislation and Measure might yet need advocacy support. Projects such as the Moving Out of the Shadows initiative have highlighted the barriers older people with mental health problems face and the need for a proactive approach in order for them to be overcome (Bowers et al 2005). Sometimes, for example, older people might require advocacy even to be able to access appropriate mental health services in the first place.

A wider approach to the provision of advocacy is suggested within the Adult Mental Health Strategy and NSF for Mental Health. Although it is written for “adults of working age”, the document emphasises that its principles and intentions - including those relating to accessibility, inclusion and empowerment - also apply to older people with mental health problems. Similarly, Standard 10 of the NSF for Older People regarding mental health, states that,

“It is essential to ensure that older people using mental health services are involved in making decisions about their individual assessment and care plan and should have access to advocacy...
services including those suitable for people with a cognitive impairment. The voluntary sector has a particular role to play in the provision of independent advocacy services.” (p135-136)

### 6.3 Older People with Dementia

In common with the broader field of mental health, older people with dementia will have access to independent advocacy if they fall within the remits of the IMCA, IMHA, the Mental Health (Wales) Measure or use the CHC Complaints Advocacy service as patients of the NHS. However, there are a number of situations and circumstances that may give rise to older people with dementia needing advocacy outside such statutory entitlement. In the case of IMCA, for example, capacity is not an “all or nothing” concept and such support might not be available to the older person with dementia on a long term basis.

Dunning (1997), Cantley et al (2003), Wells (2006) and Dunning and Steven (Forthcoming) have outlined the need for advocacy to empower and protect people with dementia and traced the development of dementia advocacy as a distinctive area of support. Debates concerning directed and non-directed advocacy can also be particularly pertinent with this group, given the possibilities of fluctuating capacity and longer term decline in decision making abilities (Henderson 2006). Demographically too, it can be seen that the need for advocacy is likely to rise as the number of people with dementia in Wales is set to increase by 31% by 2021 (Dementia UK 2007).

A service mapping project of dementia advocacy conducted by the Dementia Services Development Centre Wales, Bangor University and commissioned by the National Assembly for Wales highlighted a lack of provision (Dementia Services Development Centre Wales 2003). The researchers identified 9 services offering advocacy for people with dementia - 5 specifically for people with dementia (including one for younger people with early onset dementia only) and the remainder having a broader remit. In the more recent Advocacy Counts 2 survey, out of a total of 28 respondents (including some IMCA providers), 19 specifically provided a service to older people and 13 reported that they worked with people with dementia within their client group (Age Concern Cymru 2008).

The recent development of a National Dementia Action Plan for Wales represents a significant Welsh Assembly Government policy response to the
needs of people with dementia. In October 2008 the Minister for Health and Social Services established a multi-sectoral Dementia Task and Finish Group to set out what was needed in order to improve care and to plan for people with dementia. Consultation on the Plan was completed in September 2009. Four stakeholder groups have subsequently been established to propose actions for delivery in four key areas identified during the consultation process, one of which is that of,

“improving access to information and support for people and ensuring greater awareness of advocacy services”.

In common with the National Dementia Strategy in England, the Plan and corresponding targets introduce the establishment of dementia advisers. These advisers work at local level to support people with dementia and carers as information aides and navigators on an ongoing basis. Such work is useful and would seem to complement the role of the advocate. However, the development of dementia advocacy services is given relatively little attention. Respondents to this scoping survey expressed concerns that awareness of advocacy services will be of little use if such services are not in place or are unable to cope with potential demand as is currently the case.

Other developments of significance have emerged from the grassroots advocacy movement and people with dementia themselves. These include the formation of the Dementia Advocacy Network (DAN) and the Dementia and Advocacy Support Network International (DASNI) which have a national and international reach.
Grassroots Developments in Dementia Advocacy

The Dementia Advocacy Network (DAN) is a UK wide network for people involved in dementia advocacy to share a forum to discuss issues, share ideas and learn from each other’s experience. There are regular meetings and a newsletter. DAN promotes good practice and provides guidance, training and support. DAN is currently hosted by Advocacy Plus (formerly WASSR) in London.

The Dementia and Advocacy Support Network International (DASNI) was founded in 2000 and is an international group of people with dementia. It is an internet based support network established to:-

- Promote respect and dignity for persons with dementia;
- Provide a forum for the exchange of information;
- Encourage support mechanisms such as local groups, counselling groups and Internet exchanges;
- Advocate for services for people with dementia; and
- Assist people to connect with their local Alzheimer’s Association.

6.4 Older People with Learning Disabilities

The Welsh Assembly Government Statement on Policy and Practice for Adults with a Learning Disability (2007) builds upon 1983 and 1994 strategy documents and is the key document regarding advocacy and older people in this field. It is also consistent with the proposals for a service framework for people with learning disabilities contained within the Fulfilling the Promises report (2001) and subsequent Section 7 Guidance on service principles and service responses (2004).

In the Preface to the Statement, All Wales People First highlights advocacy amongst topics of vital importance. The Statement maintains three longstanding key principles relating to: rights to an ordinary pattern of life, to be treated as individuals and to the provision of additional help and support to maximise potential, as
“All people with a learning disability are full citizens, equal in status and value to other citizens of the same age.” (2.5)

The Statement notes that learning disability registers indicate that there has been a rise in the number of people with a learning disability and that this group is ageing. Since 1990 there has been an increase in the numbers of people with severe learning disabilities by 15%-25% in every age band between 35 and 64 years; a doubling of those between 65 and 74 years and, “the beginnings of a significant very old population” (4.8).

In a section entitled “Putting People First: Person Centred Planning, Accessible Information and Advocacy”, the Statement remarks that, “the transition from mid-life to old age and the bringing together of the mechanisms for reviewing and commissioning services and support for older people with learning disabilities are becoming increasingly relevant as people with learning disabilities live longer” (6.3)

The same section emphasises that advocacy plays an important role in supporting people to make their views known (6.7). It calls upon statutory authorities and non-statutory authorities to ensure that access to an appropriate range of advocacy services is available to give a voice to individuals and to ensure their views are fully taken into account. Indeed, it states that the empowerment of individuals so that they can play a full role in decisions surrounding and affecting their lives is a key element of the Welsh Assembly Government strategic approach (6.8). Whilst the Statement goes on to acknowledge that authorities across Wales have made good progress in the provision of information and advocacy, it encourages use of Welsh Assembly Government guidance and stresses that it is, “important to sustain and build on these improvements” (6.9).

A Learning Disability Implementation Advisory Group was set up in 2002 to oversee the Welsh Assembly Government response to Fulfilling the Promises. The broad aim of the group is to ensure that learning disability issues remain high on the agenda. It also advises Welsh Assembly Government on learning disability issues and promotes the rights of people with learning disabilities in Wales. Advocacy is clearly of interest within this remit. The group is comprised of people with learning disabilities and carers as well as representatives from education, health, local authorities, research, the voluntary sector, service providers and individuals. (www.ldiag.org.uk)
Alongside local commissioning arrangements, a significant feature of the funding of advocacy with people with learning disabilities is the Advocacy Grants Scheme. The scheme has been funded by Welsh Assembly Government and administered by the British Institute for Learning Disability (BILD). In the first phase of the scheme from 2003-2006 a total of £1,150,000 was allocated to 33 independent advocacy organisations in 21 local authority areas, including self advocacy, citizen advocacy, crisis advocacy and others. Amongst the key findings and conclusions of an evaluation of the impact and effectiveness of the scheme at that time were the following-

- Advocacy did not seem to have been given the same status inferred by government documents;
- Two-thirds of advocacy organisations working with people with learning disabilities were exclusively funded by the Advocacy Grants Scheme;
- Long term funding for advocacy continued to elude the sector;
- Advocacy schemes should be completely independent of service providing agencies;
- There was not enough advocacy support to meet demand;
- There were large gaps in advocacy provision;
- More work was necessary in order to meet the needs of those most at risk of social exclusion including people form black and minority ethnic groups, those with profound and multiple learning disabilities, people with mental health problems and those in the criminal justice system;
- Any future advocacy grants should be distributed centrally to ensure consistency in service provision;
- Conflicts of interest could be an issue if funding was distributed at a local level;
- Equal access to good quality advocacy required development of agreed national standards and recognised evaluation process;
- More strategic planning was needed for the development of advocacy across Wales; and
- More evidence based research was needed.

(BILD 2006)
The current round of the Welsh Assembly Government Advocacy Grant Scheme (2008-2011) includes an additional small grants programme for advocacy groups (maximum £5,000) to cover training, evaluation or equipment costs. Larger awards are available for revenue costs for a period of 1 or 2 years. Applications are particularly encouraged from groups offering advocacy for people with learning disabilities from black and minority ethnic groups, those with complex needs or on the autistic spectrum. There is no explicit mention of schemes working with older people with learning disabilities.

Furthermore, in evidence to the Independent Commission on Social Services in Wales this year, Learning Disabilities Wales notes that whilst there is a network of learning disability advocacy organisations being assisted by the Welsh Assembly Government grant, it remains fragile and the sustainability of groups constantly in question. Learning Disability Wales calls for the Welsh Assembly Government grant to continue and for assistance to improve the capability and capacity of such advocacy organisations. (www.learningdisabilitywales.org).

**6.5 Older People with Physical Impairments and Older People with Sensory Impairments**

In contrast with groups of older people with mental health problems, dementia or learning disabilities, older people with physical or sensory impairments are invisible within legislation on advocacy and given relatively little attention in policy. Yet advocacy might be needed not on the basis of a “condition”, but in order to combat discrimination, confront mistreatment and promote empowerment. Had the Disabled Persons Act 1986 been fully implemented, this lack of attention might to some extent have been addressed. At present, however, there is neither a specific statutory requirement to provide nor a right to advocacy for people within these groups.

This absence of entitlement is particularly pertinent to older people, as the prevalence of physical and sensory impairments increases with age. Though not inevitable, the onset of chronic illness and impairments such as arthritis, respiratory problems and heart disease can debilitate and disempower. According to a recent Sense report, 18,850 people in Wales have a visual and hearing impairment and there will be an 87% increase in the number of people over 70 with both by 2030 (www.sense.org.uk). Official statistics of
Local Authority Registers of People with Disabilities published by Welsh Assembly Government show that as of the 31st March 2009:-

- More than three quarters of people who are registered as sight impaired or severely sight impaired (76%; n= 5,905) are aged 65 or over;
- Of 799 adults registered as being hearing impaired as well as sight impaired, 700 are aged 65 and over;
- There are 12,700 people of all ages registered with hearing impairment only - 9,366 of whom are aged 65 and over (including 8,461 hard of hearing, 710 deaf with speech and 195 deaf without speech).

(www.wales.gov.uk/statistics)

The Social Services Improvement Agency website hosting the Physical and Sensory Impairment network of Welsh local authorities in this field includes a report on priority areas for development, highlighting the empowerment of users but not advocacy (www.ssiacymru.org.uk). However, there have been some positive developments in policy and practice at national and local level. These include the Wales Vision Strategy Implementation Plan launched in 2010, local commissioning strategies and specialist projects.

The Wales Vision Strategy Implementation Plan 2010 to 2013 sets out the Welsh commitment to deliver against the priorities of the UK Vision Strategy. The UK Vision Strategy was led by RNIB in response to the World Health Assembly resolution to reduce avoidable blindness by 2020 and improve support and services for blind and partially sighted people. A unified action plan has been co-ordinated across all four nations of the UK. The Wales plan has been produced by the Wales Advisory Group of stakeholders involved in delivery services for people with sight loss and those involved in prevention of sight loss.

One of the three key outcomes of the Implementation Plan is that of inclusion, participation and independence for people with sight loss - including advocacy. This is captured in the following objectives:-

**Objective 3.1:** “Development of peer support groups for people with eye care needs and their carers”. The action plan to achieve this is to establish best practice guidance from advocacy and peer support agencies; to pilot delivery of peer focused support models; and then to recommend and develop an affordable model for adoption throughout Wales by 2012.
Objective 3.5: “Reduce levels of poverty associated with visual impairment by maximising the take up of benefits among people with sight loss”. The action plan is stated as being that existing services are developed to ensure timely and quality access to welfare rights advice/advocacy support, again by 2012.

At a local level, some authorities have sought to take account of the advocacy needs of older people with physical and sensory impairments. Wrexham Joint Commissioning Strategy for Older People’s Services 2009-2014 has adopted and jointly commissioned a generic advocacy services for older people, including people with sensory and physical impairments. Similarly the Denbighshire advocacy services have been commissioned as part of the wider health social care and well-being of all older people. As discussed in Section 4, Caerphilly County Borough Council has been developing a comprehensive advocacy strategy. The emerging strategy incorporates specialisms and the authority has also been contracting Deaf Association Wales to provide Deaf advocacy services.

Deaf Association Wales Deaf Advocacy Service

Deaf Association Wales provides an advocacy service for deaf and hard of hearing people. The Association is an organisation run by deaf people for deaf people. It provides both personal and collective advocacy, training and supporting deaf people to speak up for themselves. It seeks to educate and culturally empower deaf people to become independent and to challenge policies and services. Deaf advocates have personal experience of discrimination and are able to empathise with service users. The service includes support completing forms, setting up forums/consultation for deaf/hard of hearing people and service providers, support with the relevant legislation, support with complaints and support at meetings. It adheres to the Action for Advocacy charter, principles, values and standards. It is also an accredited training provider of deaf advocacy. However, additional capacity is needed, as coverage is far from comprehensive across all local authorities in Wales.
6.6 Older People as Carers

There are 340,745 carers in Wales (Census 2001). About 70% of those who are being cared for are aged 65 years or over (General Household Survey 2000). However, many carers are themselves older people - caring for spouses, partners and across generations. Women have a 50:50 chance of being carers by the time they are 59; men have the same chance by the time they reach 75 years old (www.carersuk.org). There can be a number of negative impacts of caring including financial hardship, ill health and social exclusion (Carers UK 2008; Hirst 2004).

Carers have acquired certain statutory rights and entitlements since the mid 1990’s. The Carers (Recognition and Services) Act 1995 gives carers who are providing ‘regular and substantial care’ the entitlement to request an assessment of their ability to care. Local authorities must take this carer’s assessment into account when looking at what support to provide the person in need of care. The Carers (Equal Opportunities) Act 2004 (England and Wales) aims to ensure that work, life-long learning and leisure are considered when a carer is assessed; gives local authorities new powers to enlist the help of housing, health, education and other local authorities in providing support to carers; and places a duty on local authorities to inform carers of their right to an assessment.

Welsh Assembly Government launched its first Carers Strategy in Wales Implementation Plan in 2001. In 2007 a Carers’ Strategy Action Plan was introduced to refocus and update the original Strategy. The Action Plan identified key priority areas as being health and social care, information, support, young carers and carers and employment. At present Welsh Assembly Government is scrutinising a proposed Carers’ Strategies (Wales) Measure, introduced by the Deputy Minister for Health and Social Services in January 2010. The Measure places a duty on the NHS and local authorities to work jointly to prepare, publish and implement a joint strategy relating to carers. The strategy will focus on information and advice to carers and engagement with them in decisions about the provision of services to them or the person they care for.

Whilst these advances in carers’ recognition and rights are welcome, they do not include explicit reference or provision for carers’ advocacy. The new Measure might have provided an opportunity for doing so, as advocacy
would seem to wholly complement its purposes. However, documents and deliberations thus far have continued to focus upon information, advice, “support” and engagement - but not advocacy - in order to ensure that carers can secure and exercise their developing range of rights.

It should also be noted that there have been some advocacy-related initiatives taken by the carers’ movement. Carers Wales provides information and advice for carers and performs a public advocacy function in campaigning for changes to improve the lives of carers. The organisation has also presented training events on effective advocacy skills, carers and their rights and carers and advocacy. Similarly, those advocacy schemes working with older people more generically can represent issues raised by older people as carers. Overall though, the position of older people who are carers is another area in which there is a paucity of advocacy policy and provision.

### 6.7 Older People Living in Care Homes

Older people might need advocacy in care home settings for several reasons. These include issues regarding adult protection and complaints as discussed in sections 7 and 8 to follow. Advocates might also play a preventative role in being witness to life in the home. They ensure that the older person’s voice is heard in order to participate and make day to day choices as well as bigger decisions concerning care and living arrangements. Advocacy can help to uphold the human and citizenship rights of the older person resident in a care home (Wright 2005; Scourfield 2007).

Manthorpe and Martineau (2009) conducted a scoping review of research relating to advocacy and older people’s entry into care homes in England. They note that decisions about entry can all too easily be made by relatives and professionals whose interests and views might not concur with those of the older person. Such decisions might also be taken whilst the older person is in a particularly vulnerable position, such as at the point of hospital discharge. Similarly, in an evidence review of access to advocacy, Townsley et al (2009) acknowledge its potential benefits when entry into residential care is a possibility. Both studies also highlight the lack of empirical research in this area.

The Office of Fair Trading undertook a market study of care homes for older people throughout the UK which includes substantial reference to advocacy (OFT 2006). The study looked at how well the care homes market serves
people 65+ within the context of government policies for older people. It was initiated following a super-complaint by Which?. Major concerns were raised with regards to information about moving into a home; authority obligations concerning advice and support; price transparency; contracts; and access to making complaints.

Section 7 of the OFT report discusses advocacy in some detail, including aspects of its purpose and availability. Whilst the discussion takes place in relation to complaints, the wider role of advocacy is also considered. The investigators found that:

- The experience of groups who are involved in advocacy is that older people find complaints procedures more accessible when an advocate is working on their behalf. (7.59)

- Advocacy allows older people to make their voice heard more easily and they can enjoy support through difficult situations they may not otherwise have had the confidence or ability to address. (7.59)

- Advocacy can prevent complaints from escalating by providing a source of mediation between the care home and resident, ultimately resolving the issues more quickly to everyone’s benefit. (7.60)

- By actively demonstrating that they promote and encourage the use of advocates by residents, care homes could develop an advantage over other homes less keen to do so. (7.60)

- Across the UK as a whole, the existing provision of advocacy services is variable, particularly in terms of services for older people in care homes. (7.65)

- With the exception of Scotland where funding comes from the Scottish Executive via individual authorities, projects are reliant upon funding from charitable donations and grants which limits their scope and the number of people they can assist. (7.65)

- Providing all older people with access to an advocate, particularly those without friends or relatives would give them a source of help and support in navigating through complaints procedures. (7.65)
Ultimately, the OFT report recommends that,

“the Department of Health and the devolved administrations should run pilot projects to measure the benefits to older people, care homes and Authorities of advocacy services being provided to older people entering or living in care homes as well as the costs of providing such services” (7.67).

It is also important to note that advocacy might be needed by older people compelled or choosing to leave a care home. Williams et al (2003) highlight the variability in the availability of advocacy and other forms of support in situations in which such establishments are voluntarily closed. The authors found that those paying for their own care are even more likely to be denied assistance. In addition, advocacy might be required to support the older person when the care home no longer meets their needs or when the person wishes to move out to another setting.

In Wales, Standards 8 (Autonomy and Choice) and 11 (Rights) of the National Minimum Standards for Care Homes for Older People in Wales (2004) require that service users are assisted in accessing advocacy services when needed,

- **Standard 8.3**
  Service users and their relatives and friends are assisted in contacting external agents (e.g. advocacy) who will act in their interests.

- **Standard 11.1**
  The registered person ensures that service users have their legal and civic rights protected, are enabled to exercise their legal rights directly and participate in the civic process if they wish.

- **Standard 11.2**
  Where service users lack capacity, the registered person facilitates access to advocacy services.

Whilst these standards ostensibly promote the use of advocacy, respondents to this scoping study highlighted shortcomings in practice. These included some doubts expressed as to whether the standards pertaining to advocacy are as rigorously inspected as others by CSSIW. Concerns have also been raised not only by advocacy bodies and voluntary organisations, but by care providers themselves about the lack of available advocacy support when the care homes standards are applied.
Northway et al (2004) conducted a small scale exploratory study of advocacy for older people living in seven residential care homes in Wales. They found that there was a need to raise awareness about advocacy and the role of independent advocates amongst older people, their families and care staff. Again, in raising awareness, there is a commensurate need to ensure availability of services to meet potential demand.

The following advocacy schemes provide examples of existing provision for people in care homes:

Age Concern North East Wales provides a specialist advocacy service for older people over the age of 50 years living in nursing and residential care homes. The service also supports older people who are in hospital and need support, especially when decisions need to be made about where the person will live when they are discharged. The scheme recruits, trains and supports volunteer advocates. It is funded by a grant from Comic Relief.

Age Concern Gwent, Blaenau Gwent County Borough Advocacy Service provides advocacy support to older people already living in, or considering a move to, a care home within the County Borough. The service is also open to the families, friends and carers of the older person. Advocates routinely visit the local care homes. The service is run by a part time service manager and a part time deputy service manager, and delivered by a team of caseworkers.

South Wales Mental Health Advocacy is currently running an advocacy pilot scheme in two care homes in Neath Port Talbot. The scheme is part of the Older Person Advocacy Project. The Older Person Advocacy Project was commissioned by Neath Port Talbot Council on behalf of the Neath Port Talbot Older Persons Consultation Forum and Implementation Group using funds from the Strategy for Older People Implementation Fund. A project co-ordinator was appointed in August 2009 for one year. Other elements of the project include:- research in current provision, including gaps in service and additional areas of good practice; identification of current and future funding streams available for advocacy; and preparation of a business case for a comprehensive and sustainable advocacy provision for older people within Neath Port Talbot.
6.8 Older People and Independent Living

Over the past decade there have been significant policy developments in arrangements and provision for people requiring support to live independently in the community. *Designed for Life* (2005) and *Fulfilled Lives: Supportive Communities* (2007), together with the *Strategy for Older People in Wales* and the *National Service Framework for Older People* emphasise individual empowerment of service users to have far more control over determining the services that they need and how they are provided in order to remain active citizens. A Framework of Services for Older People is now being developed - led by Welsh Assembly Government and guided by a multi agency group. The new Framework is intended to be used by commissioners and providers so that they may see what kinds of services older people want to help them live independently.

The idea of independent living has been developed by the disability movement since the 1970’s. It is informed by the social model of disability and seeks to remove barriers of disablism. Being able to live independently as a full and active citizen is now at the heart of the personalisation agenda including the use of direct payments and self directed care - increasingly known in Wales as being “citizen centred support”. Welsh Assembly Government has sought to adopt an approach which reflects Welsh cultural norms and social care principles; favours collaboration over market competition; and maintains the responsibility and accountability of social services.

Disability Wales along with other organisations have raised concerns about the relatively slow pace of change, despite stated intentions. They have launched an Independent Living Now campaign, raising awareness about independent living and calling for a National Independent Living Strategy amongst other strategic aims. This might be particularly pertinent to the position of older people. The Welsh Assembly Government website, for example, features a Direct Payments Survey report published in 2008, which shows that just 269 older people aged 65+ (excluding those with mental ill health) and 25 older people with mental ill health had taken up direct payments in Wales as a whole, with wide variations between local authorities. Take up amongst older people was significantly lower than by other adults.

Miles (2009), Horton (2009) and others have highlighted the role of advocacy in the promoting and supporting of independent living. A SCIE briefing co-
produced by Advocacy Partners (2009) proposed that personalisation would have the following implications for advocates:-

- working alongside people who use services to ensure that there is a genuine shift of control and decision making in their favour, rather than falling back into traditional service centred ways;

- increasing the scope of advocacy activity to ensure that advocacy is available to people who fund their own care, or fall below the eligibility criteria for public funding;

- possible changes to the type of support that people ask their advocates for - there may be a greater need for support from advocates to enable people to consider how money is spent and support organised;

- enabling people to access support beyond that offered by conventional, more traditional services - this could mean supporting people to increase their contribution to and participation in community life; enriching both the life of the individual and the community;

- considering the implications of - and opportunities for - developing specialist support brokerage roles; and

- having a key frontline role in ensuring that personal choice and control is achieved.

(www.scie.org.uk)

Centres of Independent Living have been developed by disabled people to provide a range of services and supports to independent living. These might include information, training, personal assistance, peer support, direct payments support and independent advocacy. A few Schemes or Centres for Independent Living have been established in Wales, including an Independent Living Scheme run by Cardiff and Vale Coalition of Disabled People, Porthmadog Centre for Independent Living in Gwynedd and the Dewis Centre for Independent Living based at Pontypridd in the County Borough of Rhondda Cynon Taf.
Dewis Centre for Independent Living (CIL)

Dewis Centre for Independent Living is a non-profit making voluntary organisation. It came into being as a CIL in 2001, having originally been established as a third party organisation by disabled people employing personal assistants for disabled people in 1996. Contractual agreements for services have been made with five local authorities - Rhondda Cynon Taf, Powys, Vale of Glamorgan, Merthyr Tydfil and Newport. It works in partnership with the Social Services Departments of each of these authorities. It has a management committee composed of disabled people who use its services and non-disabled people who are supporters of its ethos and values. Dewis CIL services include information, direct payments support scheme, payroll service, recruitment service, Independent Living Fund support scheme, client account management, CRB disclosure service, training and advocacy.

6.9 Select Comments from Respondents

- “Documents like the NSF say advocacy should be provided by the local authority against ageism. But it is not a statutory requirement so it is Welsh Assembly Government versus the local service providers.”

- “I don’t think that the NSF in itself has driven change on advocacy. It has perhaps worked better in some of the other areas.”

- “Some of our members work in mental health advocacy projects. If they are supported by commissioners they can have a broad remit, for example, homelessness of young or older persons if it could be affecting their mental health, they could get involved. But that’s to do with local commissioners. It is not universal. Some can only work with those with a diagnosed mental health problem.”

- “A typical referral comes from hospital, looking at accommodation choices and where to discharge. If the patient was 35 with a learning disability there would be no question of institutional care, she’d be going home to support in the community. But because she is in her 70’s with dementia
she’s likely to go into institutional care. This doesn’t happen with other groups and IMCA shows that up because they work across age groups.”

- “Advocacy for physical and sensory issues is backwards and behind. There is no advocacy availability for many, just a few beacons.”

- “Advocates go into care homes. It is almost like cold calling, particularly if the older person is isolated and not much visited.”

- “Look at the monitoring reports from individual care homes from different places. Have a look at advocacy data and it will be scant!”

- “Often service providers end up advocating for their service users. This can be regarded with suspicion, but it is often the only way for people to get their needs known in the absence of independent advocacy.”

- “There is a lack of (advocacy) provision in the community. It tends to be based in care homes, hospitals or certain situations known to services. Older people in the community are not in a position to call on help or know where to get it from.”

- “Without independent living and independent advocacy, people are left languishing in the dark ages.”
6.10 Summary of Key Findings and Issues

- The broad strategic framework for health and social care supports the engagement and empowerment of older people as service users and citizens, and can be complemented by the provision of advocacy.

- The National Service Framework for Older People includes the availability and use of advocacy within Standard 1 regarding rooting out age discrimination, but does not require or resource local provision.

- As yet, advocacy has not been formally linked to the Dignity in Care agenda, but has received support from the Dignified Revolution campaign group.

- Older people with mental health problems might be denied advocacy support if they fall outside the terms of statutory provision, including those seeking access to mental health services in the first place.

- Similarly, older people with dementia might be unable to access advocacy if they do not meet the criteria for IMCA and other statutory provision, including those needing such support on an ongoing, long term basis.

- Whilst the National Dementia Plan for Wales and establishment of dementia advisers might improve awareness of advocacy services, such provision has to be available and capable of meeting demand.

- The Welsh Assembly Government Statement on Policy and Practice for Adults with a Learning Disability (2007) recognises the significant ageing of the population of people with learning disabilities and highlights the importance of advocacy in supporting people in making their needs known.

- Despite the Welsh Assembly Government Advocacy Grant Scheme for advocacy groups working with people with learning disabilities, the availability and sustainability of such groups remains uncertain.
There is no statutory right to advocacy on the basis of physical or sensory impairment - the prevalence of which increases with age - and there is a dearth of advocacy provision in these areas.

The Welsh Vision Strategy Implementation Plan 2010-13 includes advocacy in its objectives and some local authorities have sought to take account of the advocacy needs of older people with physical and sensory impairments within their commissioning, wellbeing and advocacy strategies.

Older people comprise a significant proportion of carers. Despite legislation and policy developments to support carers in assessment and the provision of information and advice, there is no entitlement to advocacy to ensure that their voices are heard.

Some advocacy schemes working with older people more generally do represent issues raised by older people who are carers and the carers’ movement has developed advocacy skills training and other initiatives.

Advocacy can be crucial in making a decision about entering a care home, whilst living in a care home or in the event of leaving a care home due to its closure or change of circumstances.

The National Minimum Standards for Care Homes for Older People in Wales (2002) require that service users are assisted in accessing advocacy services, but the availability of such services is variable and inspection reports by CSSIW do not always include reference to their use.

Independent living has been promoted by the disability movement, whilst Welsh Assembly Government has developed citizen centred support through direct payments and other means. These initiatives have made relatively slow progress amongst older people in Wales. Advocacy can help to support older people living in the community to exercise choice and control.
7. Adult protection and safeguarding

This Section examines the position of advocacy in relation to arrangements and initiatives in adult protection and safeguarding. At the time of undertaking the scoping study, adult protection strategy, policy and procedure was subject to fundamental review. The Section begins with a brief overview of literature within this specific area. The national strategic framework for adult protection in Wales - In Safe Hands (2000), is then outlined along with relevant findings of the recent independent review of its operation. Recent inspection reports on adult protection produced by CSSIW and HIW are featured for their content on advocacy. Finally, work on adult protection policies and procedures at regional and local level are explored, including the development of a unified document.

7.1 Research literature and reports

There is very little research specifically exploring advocacy and the abuse of older people. However, advocacy with older people has been seen to play an important part in the prevention of and protection from abuse (Dunning 2009).

Penhale et al (2007) include advocacy within a study of multi agency working and the regulatory framework in adult protection. A local study of safeguarding adults within the care sector undertaken by Darwin and Pickering (2008) in the North West of England showed that service users and carers emphasised the importance of independent advocacy and the need for it to be more readily available to support people through the adult protection process.

These findings complement the work of Jeary (2004) who argues for the voices of victims of abuse to be heard within adult protection case conferences. Similarly, Williams and Nash (2001) highlight the advocacy needs of people abused by health and social care staff.
A report on elder abuse published by the House of Commons Health Committee (2004) stated that in tackling such abuse, “We strongly endorse any measures that make available advocacy services for older people” (para 101). The Committee also called for more advocates on abuse to be drawn from black and minority ethnic communities (para.113).

The House of Lords House of Commons Joint Committee on Human Rights report on the Human Rights of Older People in Health Care locates adult protection within a human rights framework and states,

“We conclude that older people, especially those who are the most vulnerable, would greatly benefit from the assistance of independent advocates in order to secure their human rights on the same basis as the rest of society...These advocates should have an understanding of human rights principles and the positive duties of service providers towards older people.” (2007 para.249)

7.2 In Safe Hands

In 2000 In Safe Hands, strategic guidance on the protection of vulnerable adults was issued to authorities by the then Social Services Inspectorate Wales. It established a national framework for the development of local policies and procedures. In part 5 regarding interagency working, the guidance states that,

“Where these agencies provide services as well as advocacy these functions should be clearly separated so that independent advocacy can be provided to all service users including those using their other services” (5.6).

In part 6 on service culture, advocacy is highlighted within a list of areas of practice which, “determine a culture which helps to safeguard vulnerable people” (6.6).

Amongst the Appendices, the All Wales Registration and Inspection Units Procedure for Responding to the Alleged Abuse of Vulnerable Adults in Registered Premises states that,

“Where a resident/patient has no one to represent them, the services of an independent advocate will be offered to the individual. The Social Services Department will normally have the responsibility for co-ordinating any arrangements”.
A visit by inspectors to the resident/patient of a home in which abuse has been alleged will consider, “the need for the services of an advocate for the vulnerable person”.

A decade on, the In Safe Hands guidance has been subject to review initiated by the Welsh Assembly Government, to ensure the ongoing effectiveness, appropriateness and robustness of adult protection policies and procedures. This wide-ranging review process has included:

- The commissioning of independent researchers to review the guidance and to look at the statutory basis for adult protection in Wales.
- The establishment of an Adult Protection Project Board to review Welsh Assembly Government adult protection policies and guidance and to consider the final report of the independent review. The Board will also take account of the findings of recent inspections of adult protection undertaken by both CSSIW and HIW in making recommendations to Welsh Ministers.

The independent review of In Safe Hands was published in February 2010 (Magill et al 2010). Overall the reviewers acknowledge the groundbreaking nature of In Safe Hands, but conclude that it is now only partially effective, inappropriate in some respects and not sufficiently robust. Amongst the recommendations of the report, the reviewers call for new legislation to provide a statutory framework for safeguarding adults, including “a duty to consider advocacy support” (Recommendation 2).

In terms of access to justice for victims and perpetrators, the reviewers state that,

“In all cases involving adults at risk, victims will be offered advocacy support and special measures for court appearances, including the use of intermediaries if needed (and) perpetrators will be offered advocacy support and special measures for court appearances, including the use of intermediaries if needed, if they are themselves adults at risk” (Recommendation 8).

For self funders, the reviewers state that,

“Regulated providers should notify proposed self-funders to the person concerned’s local authority so that they can be offered...
assessment and regular review of their needs. Self-funders who are socially isolated, or who have lost their links with their families should be offered advocacy support” (Recommendation 11).

The reviewers note that there was widespread support for advocacy amongst the various developments discussed in the fieldwork. Furthermore, in discussion about access to justice, they state that,

“The availability of advocacy support for victims was thought to be very important in supporting people who have been abused, especially if prosecution is one of the outcomes sought. The availability of high quality advocacy support is thought to be patchy and fragile. Independent Mental Capacity Advocates are valued, but are only available to those who lack capacity. This argues for capacity building in relation to people who have capacity but need advocates and those who lack capacity and whose abuser might be a family member.”

(p159 para.426)

7.3 CSSIW and HIW

The CSSIW National Inspection of Adult Protection: All Wales Overview report published in March 2010, gives little attention to advocacy. Indeed, direct reference is confined to a discussion about meetings being called “case conferences”, “if they involve the vulnerable adult and/ or their carer, family or advocate” (p16). By contrast the Commission for Social Care Inspection (CSCI) was more unequivocal in emphasising the significance of advocacy in the review of safeguarding adults in England,

“...councils, care providers and regulators all have crucial roles to play in ensuring that the essential elements of prevention and early intervention are in place, namely people being informed of the right to be free from abuse; and supported to exercise these rights, including having access to advocacy”. (CSCI 2008 p9)

As part of this scoping study, a web search was undertaken of CSSIW inspection reports on individual care homes and providers for older people as well as adult protection overviews of the effectiveness of the arrangements for adult protection in local authority social services areas. The search yielded explicit mention of advocacy in some but by no means all documents (www.cssiw.org.uk ).
For example, there is no mention of advocacy in CSSIW reports providing an overview and evaluation of adult protection in Gwynedd or Blaenau Gwent. However, the overview of Ceredigion County Council recommended that the use of advocacy should be developed to support victims of abuse through what might be a lengthy and distressing process. The report on adult protection in the Isle of Anglesey County Council noted the prominent part played by advocacy services in supporting service users through the care management system and within the adult protection process in particular.

The Healthcare Inspectorate for Wales (HIW) report, *Safeguarding and Protecting Vulnerable Adults in Wales: A review of the arrangements in place across the Welsh National Health Service* was published in March 2010. In a discussion about procedures for empowering those who are vulnerable and for raising concerns, the report notes that,

“One of the most important aspects of safeguarding is ensuring that those who are vulnerable are given a voice” (Para 4.31).

It goes on to say that,

“the limited availability of advocacy support generally across Wales means that vulnerable adults often have no-one to support them to raise concerns about their care” (Para 4.32).

Ultimately, the HIW report recommends that,

‘NHS organisations must ensure that those who are vulnerable are given “a voice” by putting mechanisms in place that provide support to enable them to raise concerns. Such mechanisms should include advocacy arrangements and opportunities to discuss issues with individuals without carers or relatives present’ (Recommendation 16).

### 7.4 Regional and Local Policy and Procedures

There are four regional adult protection forums in Wales, established to co-ordinate adult protection policy; promote shared understanding and practice across agencies within the region; contribute to an all-Wales understanding of POVA practice; and promote a joined up approach to training. The forums cover the regions of North Wales, Dyfed Powys, South Wales and South East Wales. At a local level there are multi-agency Area Adult Protection Committees.
The Protection of Vulnerable Adults site on the Social Services Improvement Agency website (www.ssiacymru.org.uk) has been established to share information about policy and procedures as well as providing links to organisations, research and resources across Wales and more widely. North Wales and South Wales Fora policies and procedures on the site do not discuss the role of advocacy (North Wales Vulnerable Adults Forum 2005; South Wales Adult Protection Forum 2004).

South East Wales Forum policies and procedures do feature advocacy as part of the prevention of abuse and creation of “positive service cultures” (South East Wales Executive Group for the Protection of Vulnerable Adults 2003). Part 5.1 states that vulnerable adults should be supported to protect themselves by, “having an advocate who can speak up and take action on their behalf if needed” (p18). Advocacy schemes are also included amongst the agencies with roles and responsibilities in adult protection, including advocates taking part in case conferences.

However, the most comprehensive coverage on advocacy is contained within the second edition of the Policies and Procedures for the Protection of Vulnerable Adults from Abuse developed by the Dyfed Powys Adult Protection Forum (2007). A substantive section on the responsibilities of agencies includes advocates and Independent Mental Capacity Advocates and states that:-

Formal or citizen advocates work with vulnerable adults in a variety of contexts. They should:

- undertake Adult Protection awareness training and be fully conversant with the Policies and Procedures;
- report any concerns they have of possible abuse to social services, or to the police if a crime may have been committed;
- cooperate fully to assist with any investigative procedures;
- continue in their advocacy role with the vulnerable adult throughout such processes, supporting them and helping them to understand what is going on.

Sometimes advocates are specifically appointed to support vulnerable adults because they may have been abused and will need their support to understand and cope with the investigative process. Adult protection
procedures should focus very much upon the possible victim and their needs but the involvement of an advocate can help to ensure that the procedures do work in this way.

In some cases there are suspicions of abuse and there are disputes within families about the best interests of a vulnerable adult or between families and statutory agencies. An Independent Mental Capacity Advocate (IMCA) may be asked by the chair of a Strategy Meeting to become involved. The role of the IMCA is set out in the Mental Capacity Act code of practice. (Dyfed Powys Adult Protection Forum 2007 p33)

At the time of carrying out this scoping study of advocacy, a consultation was being completed on the production of a single unified All Wales Policies and Procedures document to replace the four regional documents currently in use. The writing of the new document was commissioned by the four Wales Adult Protection Forums and undertaken by a Task and Finish Group comprised of nominated members from of each of the regional forums and the lead police officer for adult protection in Wales.

The draft All Wales Adult Protection Policies and Procedures out for consultation during March and April 2010, states that it had been created by taking the most effective parts from each of the four existing regional documents. It aims to enable professionals to adopt a more consistent approach throughout Wales, serving as a handbook for practice as well as providing links to many other relevant documents in this complex field. It outlines the principles and values underpinning adult protection, roles and responsibilities of each agency, the stages of the adult protection process and guidance on arrangements for Serious Case Reviews.

The Task and Finish Group stated that they were mindful that the document may need updating following the completion of the review of In Safe Hands and the future of adult protection by the Welsh Assembly - whose response is due by the end of 2010. Nevertheless, it was intended to be a useful document, which would help to unify practice in Wales in the interim.

The draft document for consultation contained numerous sections and references to advocacy. They include the above extract regarding advocates and IMCA's from the Dyfed Powys document (Section 7.22). The report also highlights the need to support self advocacy and to provide advocacy services to help protect adults from abuse (Section 8.1). The report states
that Designated Lead Managers are responsible for ensuring victims and others affected by abuse are supported through the adult protection process, including making arrangements for an advocate or specialist advocate (Section 10.1), IMCA (Section 10.1.1) or IMHA (Section 10.1.2). The support offered by local Age Concern advocacy services is discussed (Section 10.1.6). Within the procedures on responding to abuse (Sections 13 - 22), there is explicit reference to the involvement of advocates at various stages of the process, including those of making a referral, reconvened strategy meetings, case conferences and outcomes.

**Adult protection and advocacy in Scotland**

In Scotland, there is substantive adult protection legislation and advocacy is included within its provisions. In the terms of the Adult Support and Protection (Scotland) Act 2009, Section 6 places a duty on the council, if it considers that it needs to intervene in order to protect an adult at risk of harm, to consider the provision of appropriate services, including independent advocacy services, to the adult concerned, after making enquiries under Section 4 of the Act. Chapter 3 of the Code of Practice produced by the Scottish Government to accompany the Act, sets out key considerations for adult representation including the duty to provide advocacy and a definition of advocacy.

**7.5 Select Comments from Respondents**

- “The proposed new national set of policies and procedures on adult protection has quite a bit to say on advocacy and rightly stresses its importance.”

- “The IMCA person is on our adult protection committee and Age Concern is part of the committee too.”

- “We are into getting an advocate for people who need them at the outset of the (adult protection) process - even people with capacity.”

- “Advocates can be used in identification and prevention as well as in the process.”
“Advocacy is only part of the solution to elder abuse. Other things are terribly important too - robust legislation, rigorous inspection, staff training and so on.”

‘Flintshire and Wrexham councils have included advocacy in practical ways in the adult protection process. For example, it is on the forms, which ask “Does this person need an advocate?”.’

### 7.6 Summary of Key Findings and Issues

- Advocacy in relation to adult protection is an under-researched area.
- Advocacy can be a vital component in the prevention of and protection from abuse.
- The current review of In Safe Hands and consultation on the creation of unified policy and procedures for adult protection provides an opportunity to promote the development of advocacy for older people in Wales.
- The CSSIW national overview of adult protection gives little reference to advocacy and coverage in local inspection reports is variable.
- There is no legislation on adult protection in Wales (or in England or Northern Ireland), whereas in Scotland there is such legislation which also includes provision of advocacy.
8. Complaints and advocacy

This section largely draws upon the companion document on complaints and older people (Lambert 2010), produced as part of the same scoping project. It also discusses the findings related to complaints from the advocacy scoping study. This section will begin by outlining the relationship between advocacy and complaints. It will then briefly explore advocacy and complaints in local authority and health services and further relevant bodies. Variations in the use of complaints and adult protection procedures will be highlighted. Finally, the role and perspective of the Public Services Ombudsman for Wales will be considered.

8.1 Linking Complaints and Advocacy

Advocacy can provide a means of support for older people in making a complaint. Advocates can also help the older person in negotiating their way through the complaints process. Advocacy may also be preventive in supporting the person to achieve a positive outcome before a complaint has to be made or finding a resolution of a complaint before it goes further along the process. It is important to highlight that, as indicated in Sections 1 and 2 of this report, advocacy is not solely concerned with complaining.

The UK Joint Parliamentary Committee on Human Rights report on the *Human Rights of Older People in Health Care* (2007) cited evidence from Help the Aged that older people faced systematic and institutional barriers with,

“...no clear or accessible mechanism for raising issues of concern” (para.242).

The Committee acknowledged evidence that there was an imbalance of power between older people and care staff upon whom they depended for their ongoing care, which made it difficult to complain. Older people without family and friends, with mental health problems or dementia, or from black and minority ethnic groups, were deemed to be particularly vulnerable. Thus, a number of witnesses had supported the suggestion that,
“...greater use should be made of independent advocates to help older people to express themselves, raise concerns and stand up for their rights.” (para.245)

In a study of the social services complaints process in Wales, Clough et al (2009) noted that,

“The need for or the importance of providing independent support, advice and advocacy to inform complainants about the different stages of complaints, and to also guide them through the practical elements - such as form completing - emerged as a theme from a number of respondents. It was suggested that this could provide a way of ensuring that complainants are briefed and fully understand the purpose of each stage and the overall process. Also it could ensure that Investigating officers have access to personal support and guidance in relaying important contextual information about the complaint.” (p35-36)

8.2 Local Authority Complaints

The Social Services Complaints Procedures (Wales) Regulations (2005) underpin Listening and Learning, the Welsh Assembly Government guidance for local authority social services complaints procedures (2005). The guidance sets out a three stage process, including local resolution dealt with by front line staff, formal resolution investigated by a senior member of staff and finally an external Independent panel hearing for unresolved complaints. The guidance includes sections on the Older People’s Commissioner for Wales (Section 5) and on Advocacy and Support (Section 6.4).

The guidance recognises that the law is different for children and adults, as Welsh Assembly Government has powers to require more help in securing advocacy support for children than for adults. Regulation 16 of the Social Services Complaints Procedures (Wales) Regulations (2005) places a duty on the authority to make available to any complainant information on how to contact such advocacy services as may be available - but not a duty to arrange such provision. However, the guidance states,

“Of course, this does not stop an authority from helping an adult complainant to find an advocate. Or the authority could arrange this support itself.” (Section 6.4.3)
In her survey of Local Authority complaints officers Lambert (2010) shows that respondents suggested a number of ways of making complaints procedures more accessible to older people. Several highlighted the need for dedicated advocacy services for older people as a legal requirement, adequately resourced and available to support older people through the complaints system and more widely. Some of these responses are included in Section 8.8 below.

8.3 CSSIW and Complaints

CSSIW has a role in the investigation of complaints in accordance with the Care Homes (Wales) Regulations (2002) and the Domiciliary Care Agencies (Wales) Regulations (2004). The National Minimum Standards for Care Homes for Older People (2004) also state that inspectors should assess whether residents have access to a robust complaints procedure and rights to use those procedures. All providers of care for older people and other groups must have complaints procedures in place and report complaints and their outcomes to CSSIW. Providers must supply service users or their representatives - who might include advocates - with a copy of the complaints policy.

In 2008/09 CSSIW received 200 complaints, mainly concerning care practice (94); staffing and management (88); premises (59); nursing care (17); medication (14) as well as the admission process and records (8); food (7); care planning (6) and activities (5). Complaints in care homes with nursing were largely attributable to standard and delivery of nursing care including treatment of pressure areas, continence management and nutrition (Lambert 2010).

If service users are dissatisfied with the way in which their complaint is being dealt with by the provider, they should be told that they may take it to CSSIW or the local authority that has arranged the care package. They may also need to use the NHS complaints procedures in some circumstances, for example where the local health board is funding nursing in a care home. Again, an advocate may be needed to support the service user through such processes which could be protracted and complex.
A senior member of CSSIW staff interviewed as part of the scoping study of complaints acknowledged that whilst there had been an increase in the number of complaints received from older people, challenges remained in terms of changing the culture of complaints amongst providers and overcoming the concerns of older people themselves about “rocking the boat” (Lambert 2010). The independence and support of an advocate might help to do so.

8.4 NHS and Complaints

Within the NHS all Health Boards and NHS Trusts employ complaints managers, whilst in primary care complaints are dealt with by practice managers or healthcare professionals themselves in the first instance. If complaints are not resolved locally at the first stage, a Stage Two Independent Review investigates the matter or complainants have the right to go to the Public Services Ombudsman for Wales. As this scoping study was taking place there were significant developments relating to NHS complaints and more widely, including the consultation document Putting Things Right (Welsh Assembly Government 2010) and draft National Health Service (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2010 (www.wales.gov.uk).

Complaints officers surveyed by Lambert (2010) cited the most common complaints as being staff attitudes and behaviour, poor standards of care, communication as well as issues such as level of service, waiting times, loss of personal items and standard of driving in ambulances. They also raised concerns about complaints which involved more than one part of the health sector or across other agencies such as social services, due to the different processes involved.

The complaints officers said that most complainants were supported by a relative or advocate. When asked to identify advocacy organisations that supported older patients in the complaints process, in addition to the CHC, Age Concern was the most frequently identified organisation. The NHS complaints officers echoed colleagues in suggesting that in order to make complaints more accessible, the provision of advocacy should be automatically available to those requiring such support.

Part 13 of the National Health Service (Wales) Act 2006 makes provision for CHC Complaints Advocacy services. CHCs are the public’s independent...
“watchdog” in the NHS in Wales, representing the public interest and influencing the way in which health services are planned, delivered and improved. As well as undertaking a strategic role, CHCs in Wales support individuals through their Complaints Advocacy services across local health board areas. In this respect, CHC Complaints Advocacy can be viewed as being a statutory form of advocacy provision.

According to the annual report of Board of CHCs, the CHC Complaints Advocacy services reported 1,483 complaints and 1,673 incidents across Wales (Board of CHCs 2009). Several incidents might be comprised within one complaint, but the possible involvement of several organisations could result in a separate complaint against each of them. Older people comprise a substantial percentage of complainants supported by CHCs, with 50% of all complainants being 60 years of age and older, as shown below:-

Age bands of NHS Complainants supported by CHC

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Percentage of complainants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 50</td>
<td>37%</td>
</tr>
<tr>
<td>50 - 59</td>
<td>14%</td>
</tr>
<tr>
<td>60 - 69</td>
<td>20%</td>
</tr>
<tr>
<td>70 - 79</td>
<td>16%</td>
</tr>
<tr>
<td>80 - 89</td>
<td>12%</td>
</tr>
<tr>
<td>90+</td>
<td>2%</td>
</tr>
</tbody>
</table>

(Source: Board of CHCs 2009)

Half of referrals were made by the patient themselves, with spouses/ partners and family members making up the remainder. Most complainants wanted an explanation, whether an apology was also required or not. The complainant was still undergoing treatment as a patient in 46% of cases. In an analysis of complaints by service area, medicine yielded the highest percentage (33%) and the highest number of incidents within this particular service involved the care of older people (20%).

A significant finding of the scoping study of complaints was that CHCs support less than 40% of the total number of complainants to the NHS
(Lambert 2010). It is unclear whether and to what extent other advocacy services are involved in providing support to the remaining 60% or so of complainants.

It is also important to note that in some areas CHCs are undertaking advocacy work beyond Complaints Advocacy. In Powys, for example, Montgomery CHC and Brecknock and Radnor CHC have been commissioned to provide IMCA and IMHA services - the only CHCs in Wales to do so.

8.5 Advocacy, Complaints and Adult Protection

Both the scoping study of complaints (Lambert 2010) and this scoping study of advocacy have ascertained that there have been variations in the way in which issues have been subject to complaints or adult protection procedures. Reviews undertaken by CSSIW and Health Care Inspectorate Wales (CSSIW 2010, HIW 2010) have highlighted that definitions and thresholds for intervention were not always commonly understood or consistently applied in practice. This means, for example, that an older person subject to emotional abuse in a health care setting might be channelled through a complaints procedure rather than the more appropriate adult protection procedure. These might be very different experiences in terms of process and outcome.

Whilst the relevant authorities seek to address these matters, advocates might have a role to play in ensuring that the appropriate channels are pursued - be it a complaint about a service or an alert about an abuse. As discussed in Section 7 above, advocates can play a significant role in adult protection, not only in making an alert but in supporting the older person through the process. Similarly, advocates can be alongside the older person as they move through the complaints process.

8.6 Advocacy and Complaints in other agencies - housing

Regulations under the Care Standards Act (2000) require providers and managers of registered services to have their own complaints procedures. This does not only include domiciliary care agencies and care homes in the local authority, private and independent sector but also Registered Social Landlords (RSL’s). Whilst the other aforementioned providers are registered
and inspected by CSSIW, the governance arrangements of RSLs are regulated and inspected by the Wales Audit Office.

In the field of housing, tenant participation and representation are highlighted in handbooks and other materials for tenants and wider audiences. Tenants' charters are also common place. However, tenant participation and representation tends to be a collective endeavour, with relatively little attention to individual advocacy. Similarly, whilst the tenants' charters and complaints procedures state that tenants can attend meetings and be supported by a friend or representative, they do not generally facilitate access to local advocacy schemes.

8.7 Public Services Ombudsman for Wales and Complaints

The Public Services Ombudsman for Wales (PSOW) service deals with complaints about the public sector in Wales. It seeks redress for individuals who have experienced injustice. It also identifies broader lessons to ensure public service improvement in published accounts of investigations and serious case reviews. The PSOW has powers over private sector care providers where they are providing contracted out services funded by social services or Health Boards. However, it does not yet have legal powers to investigate complaints by people who self-fund their home care package from a domiciliary agency or live in a private residential home.

Older people comprise a significant percentage of complainants reaching the PSOW. In 2009-2010 29% of complaints to the PSOW were from people aged 56-64 years and 29% were from people aged 65+. Most complaints dealt with by the PSOW are about local authorities (n = 979), concerning planning, housing, roads and transport as well as social services. Complaints regarding NHS bodies accounted for 292 cases, including issues such as clinical care, hospital discharge and transfer arrangements. Social housing yielded 98 complaints, including housing allocations, estate management, repairs, maintenance, neighbourhood nuisance and anti-social behaviour. Other cases involved Welsh Assembly Government and Welsh Assembly Government sponsored bodies (70) and CHCs (27).

Lambert (2010) interviewed PSOW staff, and reported the following:-

- There was a clear recognition that some complainants had good access to resources and complaints procedures, but others lacked access to advocacy support and advice about how to complain.
There was an expressed concern about a lack of advocacy as well as advice and other forms of support for older people receiving services from private care providers and in non-regulated sectors such as day centres.

Advocacy services to support complainants were seen to be patchy across Wales in terms of the sectors they covered and the services that could be provided. Smaller advocacy agencies lacked capacity to respond in a timely way to the needs of all complainants and to the organisations dealing with the complaint. Some agencies were under resourced and struggled to cope to meet deadlines.

In general funding for advocacy services varied across Wales. Health and mental health were seen to be better resourced than social care and there are gaps for people living in residential care and using day care services. Housing advocacy is under resourced and agencies could be funded to provide robust services across Wales.

The PSOW has attempted to raise awareness about the role of the Ombudsman’s service, meeting with advocacy groups and voluntary organisations more widely.

8.8 Select Comments from Respondents

“Make sure older people feel it is ok to complain...To have an advocate to support a person purely because they are an older person.”

“What is needed is more resource in local government in terms of complaints staff, publicity budgets and advocacy.”

“A statutory requirement to provide advocacy services for the elderly, especially in the complaints process..”

“CHC’s are statutory bodies and that is hugely influential. The way the rest of the organisation (the NHS) operates is now more in line with the advocacy service, which has always operated on the basis of listening to the patient.”

“Adult protection in hospitals is being taken through internal complaints not POVA. It should be the latter, but it is the former. It might be bad practice but it might be criminal activity.”
“The complaints process would be made easier if automatic advocacy is (made) available to those who need it.”

“We always offer a meeting to the complainant, advice from the CHC advocacy services and remain patient-focused in working towards outcomes.”

“We need a consistent level of advocacy to pursue complaints. We need to close the gap between the articulate people and the vulnerable that need advocates too.”

8.9 Summary of Key Findings and Issues

- Advocacy can provide a means of support for older people in making a complaint and in negotiating the complaints process.

- Advocacy may be preventative in supporting an older person to achieve a positive outcome before a complaint has to be made or finding resolution early in the complaints process.

- The Social Services Complaints Procedures (Wales) Regulations (2005) places a duty on the authority to make available to any complainant information on how to contact an advocacy scheme, but not a duty to arrange such provision.

- Local authority complaints officers and NHS complaints officers acknowledge that access to advocacy would make complaints procedures themselves more accessible.

- Older people aged 60 years and over comprise 50% of all complaints supported by CHC’s. However, less than 40% of the total number of complaints to the NHS were supported by CHC’s.

- Uniquely, in Powys the CHC has been commissioned to provide IMCA and IMHA services as well as CHC Complaints Advocacy services.
There have been variations in the way in which issues involving the abuse of older people have been subject to complaints or adult protection procedures. Advocates can have a role in helping to ensure that the appropriate channels are pursued on behalf of the older person.

Housing agencies have developed complaints procedures and mechanisms for tenant participation and representation. However, such representation tends to be on a collective rather than individual level and there is little evidence of arrangements to facilitate access to independent advocacy.

The PSOW has identified a number of concerns regarding advocacy for older people in Wales, including the patchiness of provision; lack of access within a range of settings and situations; lack of resources and capacity of some advocacy services; and the need to raise awareness.
This section looks at the funding and commissioning of advocacy for older people at national level, for local advocacy schemes and for strategic advocacy bodies in Wales. This includes an overview of sources and sufficiency of funding; priorities and conditions; financial insecurity and cutbacks; second tier advocacy organisations; and the Big Lottery Fund AdvantAGE programme.

### 9.1 Sources and Sufficiency

In the Advocacy Counts 2 report, 26 schemes responded to questions regarding their funding status. The schemes reported that they received funding from the following sources:-

<table>
<thead>
<tr>
<th>Source of Funding</th>
<th>Percentage Response</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charitable Trusts (e.g. Comic Relief, National Lottery)</td>
<td>20%</td>
<td>10</td>
</tr>
<tr>
<td>Local Authority</td>
<td>24%</td>
<td>12</td>
</tr>
<tr>
<td>Local Health Board</td>
<td>10%</td>
<td>5</td>
</tr>
<tr>
<td>Welsh Assembly Government</td>
<td>30%</td>
<td>15</td>
</tr>
<tr>
<td>Fundraising &amp; Donations</td>
<td>2%</td>
<td>1</td>
</tr>
<tr>
<td>Other grants (e.g. Supporting People)</td>
<td>6%</td>
<td>3</td>
</tr>
<tr>
<td>Other (e.g. WCVA)</td>
<td>8%</td>
<td>4</td>
</tr>
</tbody>
</table>

Most non-statutory schemes received funding from more than one source. There are advantages to this situation in terms of protecting the independence of advocacy, avoiding over-reliance upon a single funder.
and bringing flexibility in the activities of the schemes. However, it might also indicate the insufficiency and fragility of funding. Schemes have to spend time seeking various funding sources to survive and also spend time responding to various monitoring, review and evaluation mechanisms - time that is then not spent on the day to day running of the project.

With regard to the duration of funding, the Advocacy Counts 2 report shows that the largest percentage of schemes (35%, n=10) were funded for one year; 34.6% (n=9) for three years; and 26.9% (n=7) for over three years - though it should be noted that several statutory advocacy schemes responded to the survey and might account for the longer term funding. It was also noted that 2 schemes expected their funding to be reduced and that 3 expected it to come to an end within 12 months.

The Advocacy Counts 2 survey also asked respondents to rank how much an issue funding was to them on a scale of 1 to 5 (where 1 is not an issue and 5 is a big issue). The results showed that out of 26 respondents over 15% (n=4) ranked funding as a 4 and over 42% (n=11) of ranked funding as a 5. The researchers concluded that,

“Funding continues to be of great concern to advocacy providers. It is important for commissioners to recognise the need to reflect on the implications of short term funding...Longer term funding will help to ensure that services are given an opportunity to develop and grow, to ensure continuity for older people and to build a highly skilled workforce.” (Age Concern Cymru 2008 p5)

9.2 Priorities and Conditions

The funding and commissioning of advocacy for older people by Welsh Assembly Government and local authorities and health boards appears to have been subject to varying degrees of attention and prioritisation. In some areas, such as Torfaen and Rhondda Cynon Taf, there have been long standing commissioning arrangements for advocacy with older people. In others such as Powys, the commissioning of advocacy specifically for older people is a relatively recent development, even if well established for groups such as younger adults with learning disabilities or mental health problems.

Where advocacy is commissioned in local authorities there are concerns that whilst contracts are appropriately drafted in some areas, they are overly
prescriptive in others. In the latter instance, there might be a restricted focus upon priorities set by the commissioners and authorities rather than those identified by advocacy schemes and older people.

Such variability is not unique to Wales. Both Miles (2007) and Kitchen (2007), for example, note the “common lack of approach” to the commissioning of advocacy services for older people in England. This absence or difference in approach was not attributable to demographic differences between local authorities, but to the place of advocacy for older people within strategic and service priorities.

In Wales, there are some particular domestic considerations for commissioning and funding. Respondents to this scoping study and to the consultation on the Mental Health (Wales) Measure highlighted the risk of significant variation of funding based on ‘number mapping’ of population and caseload statistics. They argued that such approaches to funding and commissioning ignored broader considerations of rurality, geography and language, to the detriment of many older people.

Some local authorities have attempted to be creative in developing advocacy services. In Wrexham, for example, work was conducted on defining and developing advocacy services in a more strategic and inclusive way. The commissioning process utilised a competitive dialogue approach. This allowed commissioners to give feedback to providers so that their bids could be refined and become outcomes based. The Action for Advocacy quality standards for advocacy schemes were used alongside two other criteria to evaluate tenders.

Another significant issue in the discussion of prioritisation and conditions is the place of advocacy for older people in relation to other groups. There are dangers in opening up a debate that might be wrongly construed as setting up competition between groups. However, there are stark differences in the status and development of advocacy between groups in Wales. Advocacy for children and young people, for example, is relatively well resourced with a clear legislative footing, strategy, infrastructure and service - advocacy for older people is not. An overarching advocacy strategy would highlight such gaps and inconsistencies and perhaps help to ensure opportunities for advocacy across the life-course.
9.3 Financial Insecurity and Cutbacks

The current economic climate and cost cutting in the public sector is causing real anxiety within the advocacy movement. There are particular concerns that advocacy outside statutory obligation or very tight prioritisation set by the statutory organisation itself will not be commissioned. This point is echoed by a number of respondents from statutory organisations.

The economies and cuts are also occurring at a time when monies available through the Strategy for Older People are tapering off and the scope for development under the auspices of the strategy has diminished. Local authorities that have invested in some advocacy development through the use of Strategy monies have voiced concerns that their promising initiatives may not survive the next financial year.

The potential of new investment in the advocacy sector brought by statutory initiatives such as the Mental Health Measure might also go unrealised. It is unclear whether new statutory funding will merely substitute funding for select elements of existing non-statutory provision. In particular, whether possibilities exist for moving money into community based non-statutory work which is seen to be under-resourced in addition to the new statutory services.

As well as the costs, at this time there is a need to consider the wider benefits that can be brought about by advocacy. Although this is another scarcely researched area, there is some evidence available. As well as meeting its objects of enhancing empowerment, citizenship and inclusion, advocacy might give providers an indication of service quality and consumer feedback. Westminster Advocacy Service for Senior Residents (now Advocacy Plus) commissioned a piece of work which demonstrated that the benefits of advocacy for older people can outweigh its costs (Jones 2004).

9.4 National Advocacy Organisations

A further factor of significance here is the lack of funding to enhance the capacity of second tier organisations in Wales to promote and support the development of independent advocacy in general and for older people in particular. Given the key areas upon which the Third Dimension is focused, as discussed in Section 4, it is not possible for the sector to engage as full partners with Welsh Assembly Government or other bodies in order to take the agenda forward.
Several groups have an interest in working in Wales. These include UK wide organisations such as Action for Advocacy and the Older People’s Advocacy Alliance (OPAAL) UK. Age Cymru has developed networks and other advocacy initiatives alongside its many other interests, programmes and services for older people in Wales. There are also networks of IMCA and IMHA providers. Advocacy Wales is positioned to take a strategic lead across all groups but lacks capacity to do so.

Advocacy Wales was formed in September 2003 and is a member led organisation which acts as an umbrella body for independent advocacy providers in Wales. The specialisms of its members include mental health advocacy, services for looked after young people, advocacy for clients with sensory impairment, advocacy for older people and those with a learning disability. Advocacy Wales is committed to:

- Raising awareness of the principles and values of independent advocacy;
- Facilitating networking among member organisations and other organisations working in advocacy;
- Lobbying for a strategic approach for supporting and extending independent advocacy in Wales; and
- Providing support for advocacy organisations through organising information events and conferences.

However, the organisation has no paid workers and all events, consultations and other activities on behalf of members are organised by trustees.

The position in Wales contrasts sharply with that in Scotland, where the Scottish Government has supported the development of national as well as local advocacy organisations. For example, The Scottish Independent Advocacy Alliance (SIAA) promotes, supports and defends the principles and practice of independent advocacy across Scotland. It does this by:

- Providing a strong national voice for independent advocacy organisations;
- Supporting the growth of existing independent advocacy organisations;
- Promoting the development of new independent advocacy organisations; and
- Encouraging existing advocacy organisations towards independence.

SIAA is funded by a grant from the Scottish Government.
9.5 The Big Lottery Fund AdvantAGE Programme

The much anticipated Big Lottery Fund AdvantAGE programme for advocacy and befriending provides a major funding opportunity for both activities. The AdvantAGE programme will make £20 million available to successful bids from voluntary and community organisations and to partnerships bids with statutory organisations, where the statutory organisation is not the lead partner.

The overall outcome of the programme is to improve the quality of life of older people by providing access to befriending or advocacy services. Projects applying to the AdvantAGE programme will need to ensure that the results of evaluation demonstrate the impact and promote the development of advocacy and befriending services. In addition, projects must meet two of the following outcomes:

- Reduced loneliness and increased wellbeing through improving social interaction;
- Increased confidence and ability to meet the challenges and opportunities of ageing;
- Increased understanding and use of rights and awareness and uptake of services leading to greater independence and choice for older people.

The programme is widely welcomed by the advocacy sector, local statutory organisations, governmental bodies and groups of older people. It provides recognition and resourcing for advocacy (as well as befriending) with older people. It is also allows for innovation and development to meet existing and emerging needs and challenges.

However, within the advocacy sector there are some concerns about an over-reliance upon this new and significant source as a substitute for government funding, particularly in an era of economies and cuts. There are also concerns that the programme will distract policy makers from the urgent need to develop a coherent advocacy strategy for older people in line with other groups, as well as an overarching strategy across all groups - as one respondent remarked, “the Lottery becomes the strategy”.
9.6 Select Comments from Respondents

- “Advocacy need not be an additional cost. It can be preventative and save money.”
- “The grassroots work by advocates, older people and rights groups will get it all going. But these are the very things that are now under pressure of cuts and the current political environment.”
- “Advocacy is where the axe falls.”
- “Generic and community based projects that were established ten years ago have now disappeared. They have had to apply for further funding to survive and have had to come up with something more specialised and new. So they are more narrow and people who would have had an advocate are missing out.”
- “There need to be protocols for advocacy schemes working with health and local authorities. If people use advocacy schemes to make complaints there is a tension of biting the hand that feeds you. It’s not overt but there are fears that it has been done. There are fears of losing funding by retaining independence. Our independence needs to be more protected and robust.”
- “Gaps in resources means that there are capacity issues for existing advocacy schemes - geographical coverage and the sufficient availability of advocates to meet need.”
- “Older people sometimes fall between the gaps. IMCA is statutory so funding is fine. Funding for other advocacy schemes is patchy and down to local funding priorities.”
- “Funding seems to rely a lot on Comic Relief, the Lottery, perhaps council and other sources. It is fragile, cobbled together, not long term. There are worries about sustainability.”
- “(Older People’s) Strategy funding has decreased rapidly over the past three years - from £2.4 million, to £1.7 million to £1 million. So, there is a need to be very focused in areas of work and cognisant of the situation.”
- “It’s when the money comes and goes is the problem. Advocacy schemes are struggling to get through year on year. Outside statutory provision it is fragmented, time limited, priorities change. The current situation is very bad.”
“The new funding for the Big Lottery is a distraction. It lets commissioners off the hook. The Big Lottery is still short term, not ongoing. It skews the landscape for a few years and then we will be back where we started. It is not the panacea for all ills.”

“Local authorities should be resourced to commission advocacy provision for older people.”

“We need a more generic service in the community generally. But where do you put a marker down? Public money should be targeted. We know cuts are coming and all groups will be making a cogent case about why they should have the money.”

“Advocacy services for older people are hard to access for service providers and service users and their families. They seem underfunded... It depends on local authorities’ commitment to support advocacy in their local area.”

9.7 Summary of Key Findings and Issues

- There is a general view that advocacy with older people is under resourced and that funding for non statutory advocacy in particular is insufficient.

- Most non-statutory advocacy schemes working with older people receive funding from more than one source. Whilst this can protect independence and bring flexibilities in provision, it also entails more time spent in securing funding and adhering to funding requirements.

- Reliance upon short term funding arrangements can place advocacy schemes in a vulnerable position.

- The funding and commissioning of advocacy for older people by Welsh Assembly Government, local authorities and health boards has been subject to varying degrees of attention, prioritisation and limitation.

- Advocacy organisations have raised concerns about funding based upon “number mapping” of the population and caseload statistics without consideration of rurality, geography and language.
There is a marked contrast between the legislative and policy position, funding status and level of service provision of advocacy with older people and that of other groups, particularly children and young people.

An overarching advocacy strategy across all groups would highlight gaps and inconsistencies in the funding and provision of advocacy throughout the life-course of all citizens.

The current economic climate, public service cuts and end of funding through the Strategy for Older People in Wales, has heightened concerns that advocacy outside statutory obligation, or outside very tight prioritisation set by statutory bodies, will not be commissioned.

Wider benefits of advocacy could be highlighted, including its role in helping to meet Welsh Assembly Government objectives of citizenship, empowerment and inclusion; supporting improvements in person centred care and service quality; and providing consumer feedback.

There has been a lack of funding for second tier advocacy organisations to support the development of advocacy in general and with older people in particular. In contrast, the Scottish Government directly funds the Scottish Independent Advocacy Alliance.

AdvantAGE, the Big Lottery Fund programme provides a generous and unprecedented funding opportunity for the development of advocacy with older people in Wales. However, there are concerns that the initiative should not become a substitute for a substantive advocacy strategy or funding from statutory sources.
10. Standards and outcomes

The development and measurement of standards and outcomes of advocacy for older people and other groups has been an area of growth over recent years. Older people involved in a study undertaken on behalf of the Joseph Rowntree Foundation emphasised that good advocacy services should be of an “acceptable, consistent and recognised standard” (Dunning 2005 p53).

Clearly, the last thing that older people who need advocacy require is bad advocacy. There have been several developments from government and grassroots advocacy organisations to help to ensure that this is not the case. However, the endeavour has not been without its tensions and challenges. This section will look at the current arrangements and attendant debates and initiatives in relation to quality and standards; monitoring, review and evaluation - including process and outcomes; and training and support.

10.1 Quality and Standards

When the Advocacy Counts 2 survey was undertaken it showed that 56% (n=14) of the advocacy schemes responding used standards developed by Action for Advocacy. The remaining 44% (11) of the 25 who answered the question (given that they included some statutory advocacy providers) recorded a variety of frameworks including:-

- Standards set by Welsh Assembly Government for CHCs;
- Standards based on the Independent Complaints Advocacy Service (NHS in England);
- Mental Capacity Act Code of Practice standards for IMCA;
- Care and Repair Cymru service standards;
- Alzheimer’s Society service standards;
- Co-ordinated Action Against Domestic Abuse (CAADA) standards;
British Institute for Learning Disability (BILD) Advocacy Standards;

No respondents worked to advocacy standards developed by Age Concern England

(Age Concern Cymru 2008)

Further sets of standards include those set down within contracts and agreements by funders and commissioners in local authorities and trusts. These might be advocacy-specific or follow a format used for services more generically. Some advocacy schemes have also sought external quality marks. These include:

- Investors in People
- Community Legal Service Quality Mark
- Practical Quality Assurance System for Small Organisations Quality Mark (PQASSO).

As types of statutory advocacy, the CHC Complaints Advocacy Service, Independent Mental Capacity Advocacy and Independent Mental Health Advocacy have quality standards set down by government. However, the advocacy movement has played some part in their development and implementation, either through fairly limited consultation or more fulsome engagement. Currently, for example, Action for Advocacy is running an IMCA Support Project in England in order to ascertain what is needed within the IMCA field regarding access, best practice guidance, training and capacity building.

As suggested by Advocacy Counts 2, non-statutory advocacy schemes have largely tried to work with the standards developed by Action for Advocacy and intended for all forms of one-to-one advocacy. These standards have been based upon the advocacy principles presented in the advocacy charter and “owned” by the advocacy movement from its launch in 2002. By 2006 Action for Advocacy had produced Quality Standards for Advocacy Schemes and a Code of Practice for Advocates. In 2008, following further consultation and piloting with advocacy schemes, Action for Advocacy launched the Quality Performance Mark (QPM). (www.actionforadvocacy.org.uk)

More than 300 advocacy organisations have requested the Action for Advocacy QPM self assessment workbook as a framework for quality
management and organisational development - almost 40 of whom are in Wales. The following 6 advocacy providers working in Wales have so far actually been assessed and awarded the QPM:-

- Advocacy Experience (Awarded November 2009)
- Advocacy Matters (Wales) (Awarded September 2009)
- Age Concern Cardiff and the Vale (Awarded May 2010)
- Age Concern Gwent (Awarded February 2010)
- Flintshire Mental Health Advocacy Services (Awarded May 2010)
- Mental Health Advocacy Scheme (Bangor) (Awarded May 2010)

Having acknowledged the need for quality, the advocacy movement has endeavoured to take responsibility in the development of its own standards rather than them being imposed by government or other bodies. These standards are intended to enshrine both the principles and the effectiveness of advocacy. Indeed, the Action for Advocacy QPM has been formally supported by the Charity Commission and referenced within the Social Care Institute for Excellence (SCIE) commissioning guidance.

At a local level in Wales, these standards have been utilised by some commissioners in drawing up contracts and agreements with advocacy schemes. In Wrexham County Borough, for example, the Action for Advocacy Quality Standards for Advocacy Schemes also formed the basis of criteria upon which to evaluate tenders.

10.2 Monitoring, Review and Evaluation

Advocacy schemes and advocates might be monitored in a number of ways. Quality frameworks put in place by the scheme itself may ensure transparency of activities, policies and procedures. If an advocacy scheme is hosted by a large organisation it may be subject to the same methods of scrutiny as other parts of that organisation. Funders and commissioners may also request regular monitoring reports and undertake reviews in relation to particular standards, aims and outcomes.

The Action for Advocacy Quality Performance Mark and other initiatives provide mechanisms for evaluating performance. However, some advocacy schemes have also commissioned research and evaluation of their work.
by academics and consultants (see, for example, Murphy 2001). Other developments have included a user engagement project initiated by OPAAL in order to ascertain the experiences of older people using advocacy services and their views on “what worked” (Wright 2006).

In the evaluation of advocacy, there has been a long standing debate within the advocacy movement with regard to process and outcomes. This became more acute as advocacy schemes feared that inappropriate outcome measures would be foisted upon them by funders and commissioners. These included concerns about the use of overly simplistic statistical or mechanistic measurements of results. Older people themselves reported the importance of process within the advocacy relationship, including the more expressive elements which might take time to develop and are less tangible within crude measures (Dunning 2005, 2009).

The advocacy movement has itself played an increasingly prominent role in the creation of appropriate means of evaluating the work it does. This has included contributions to guidance for commissioners (e.g. Turning Point 2006). Action for Advocacy has also developed the Lost in Translation Outcomes Toolkit (Action for Advocacy 2009). Such initiatives attempt to capture key elements of the process as well as the outcomes of advocacy. They also maintain advocacy principles at the heart of the measurement of effectiveness.

10.3 Training, Support and Development

There has been growing recognition of the need for a national advocacy qualification to help improve standards and ensure that advocates possess the requisite values, knowledge and skills for practice. Advocacy schemes have long provided informal training and orientation programmes for new advocates. Over the years a variety of advocacy courses have also been provided by some educational establishments such as the University of East London as well as training organisations and consultants.

A national advocacy qualification has recently been developed by the Department of Health in partnership with Welsh Assembly Government, also engaging advocacy organisations in the process. The qualification was launched in 2009 and aims to ensure quality and consistency in the training of advocates (City & Guilds 2009).
The national advocacy qualification is accredited by the City & Guilds at Level 3 Certificate and Level 3 Diploma standard. It is delivered by recognised training centres often in partnership with advocacy training organisations and consultants. Candidates for the level 3 Certificate complete the following four mandatory units:

- Purpose and principles of independent advocacy
- Providing independent advocacy support
- Maintaining the independent advocacy relationship
- Responding to the advocacy needs of different groups of people

They then complete one optional unit to lead to one of the following qualifications:

- Level 3 Certificate in Independent Advocacy-(Independent Mental Capacity Advocacy)
- Level 3 Certificate in Independent Advocacy-(Independent Mental Health Advocacy)
- Level 3 Certificate in Independent Advocacy-(Independent Advocacy Management)
- Level 3 Certificate in Independent Advocacy-(Providing Independent Advocacy to Adults)
- Level 3 Certificate in Independent Advocacy-(Independent Advocacy with Children and Young People)

Candidates for the Level 3 Diploma complete the four mandatory units and the unit on independent mental capacity above, plus a unit in Independent Mental Capacity Advocacy - Deprivation of Liberty Safeguards. At present the Level 3 Diploma in Independent Mental Capacity Advocacy - Deprivation of Liberty Safeguards, is the sole qualification at diploma standard.

It is worth noting that the move towards a national advocacy qualification has not been without its tensions. In some quarters of the advocacy movement there have been concerns that the “professionalisation” of advocacy would align it with more traditional service provision - a position far removed from its more radical grassroots origins (Scottish Human Services 1994; Henderson and Pochin 2001).
As well as initial training, advocates need ongoing support and opportunities for further development. Advocates can face profound ethical, legal and practical challenges that require strong yet sensitive supervision from the advocacy scheme. This was recently highlighted by the needs of participants in the national Advocacy Support Programme (Beth Johnson Foundation 2010). The day to day demands and dilemmas dealt with by advocates were similarly described within an advocacy and adult protection project run by the Older People’s Advocacy Alliance (OPAAL) with Action on Elder Abuse and other contributors, as one participant stated,

“People who give support need support...” (cited in Dunning 2009 p37)

10.4 Select Comments from Key Informants

■ “The need for good quality advocacy is not in question. Advocacy organisations have worked hard to develop appropriate standards and training. Retaining advocacy principles is essential in good practice. It is accountable and stands up to scrutiny.”

■ “Who controls the language of policy in advocacy is a big issue. What is meant by independence? What are impact measures and outcomes that are not just statistics?”

■ “Big organisations sometimes try to use generic quality frameworks and policies but they might not fit advocacy.”

■ “Professionals refer to advocacy provided by an organisation that is known and trusted. There is still some cynicism about advocates amongst some staff.”

■ “We’ve seen some poor practice from advocates in other areas. There is a need for regulation and minimum standards for advocacy. There are moves afoot to take us to where we need to go.”

■ “Advocacy schemes must show evidence of achievement rather than making promises or assuming they are always intrinsically good.”

■ “Advocacy is becoming a profession with its own qualification. It is a service with staff with transferrable skills across groups and situations.”
10.5 Summary of Key Findings and Issues

- The Advocacy Counts 2 survey (Age Concern Cymru 2008) showed that 56% of advocacy schemes used standards developed by Action for Advocacy, whilst the remaining 44% used a variety of frameworks including those developed by Welsh Assembly Government and host organisations.

- Some advocacy schemes have sought external quality marks such as Investors in People, the Community Legal Service Quality Mark and Practical Quality Assurance System for Small Organisations Quality Mark (PQASSO).

- Statutory advocacy providers have quality standards set down by Government. These quality standards were largely developed in consultation and engagement with the advocacy movement.

- The Action for Advocacy Quality Performance Mark (QPM) has attained widespread recognition and has so far been awarded to six advocacy providers working in Wales.

- Advocacy schemes are variously monitored and reviewed using frameworks they themselves put in place, by their host organisations or by funders and commissioners.

- Advocacy schemes can be evaluated in a variety of ways, including the Action for Advocacy Quality Performance Mark, evaluative research by academics and consultants as well as user engagement and feedback initiatives.

- In the evaluation of advocacy, it is important to maintain core principles, to consider process as well as outcomes and to avoid overly simplistic or mechanistic measures of results.

- The national advocacy qualification was launched in 2009, aiming to ensure quality and consistency in the training of advocates. The qualification was developed by the Department of Health in partnership with Welsh Assembly Government and involving advocacy organisations in the process.
Whilst there has been growing recognition of the need for such training and engagement by the advocacy movement, there have been concerns about the professionalisation of advocacy, replicating traditional forms of service provision and becoming removed from its more radical roots.

Advocates and those running advocacy schemes need supervision, support and opportunities for development in order to deal with the substantial ethical, legal and practical challenges and dilemmas they frequently face.
11. Conclusions and considerations for future work

The overall aim of this initial scoping study has been to inform the Older People’s Commissioner for Wales about the current position of advocacy for older people in Wales, including gaps and weaknesses, strengths and good practice examples, as well as key areas upon which to focus future work. The more specific objectives of the study have been to provide:

1. A working definition of advocacy, as referred to in the Commissioner for Older People (Wales) Act (2006)
2. An identification of principles against which current arrangements can be judged.
3. An overview of Welsh Assembly Government guidance or regulation on advocacy arrangements in local authorities, the health service and care providers.
4. An overview of how advocacy arrangements are measured, monitored and reviewed.
5. An overview of the actions being undertaken by the Welsh Assembly Government, Local Authorities and others in relation to advocacy procedures and processes and the availability of advocacy across Wales.
6. An indication of variation across Wales.
7. Information on the nature and type of advocacy being commissioned.
8. Information on the outcomes for older people of advocacy arrangements.
9. An overview of recent research evidence about the operation and adequacy of advocacy arrangements.
10. Issues of note for the Commissioner regarding the operation of current arrangements around advocacy with older people to form the base for a decision upon which to focus more detailed work in future.
In order to meet the above aims and objectives, the scoping study employed a mix of methods. These included literature and web-based searches, secondary data analysis, electronic surveys and telephone and face to face interviews with key informants.

The introduction to this report highlighted that older people might need advocacy for several compelling reasons, including protection from abuse, combating age discrimination, obtaining and changing services, securing and exercising rights, being involved in decision making and being heard.

Advocacy with older people has been subject to increasing attention since the 1990’s due to the evolving legislative and policy context, support from progressive professionals, the rise of the advocacy movement and the expressed demands of older people themselves. However, whilst there has been a growth in the number of advocacy schemes working with older people over the past two decades, there remain significant challenges for policy and provision in this area.

Subsequent sections of this report discussed the findings and addressed the aims and objectives of the scoping study on a thematic basis. The main themes to emerge were as follows:-

- meanings and models;
- advocacy and legislation;
- citizenship and participation;
- human rights and equalities;
- health and social care;
- adult protection and safeguarding;
- complaints and the Public Services Ombudsman for Wales;
- funding and commissioning; and
- standards and outcomes.

The key findings of these thematic areas are summarised at the end of each section and are also collated in Appendix 4.

Part of the overall aims and the final objective of this scoping study are to inform the future work of the Older People’s Commissioner for Wales. The considerable breadth of this scoping study revealed a number of issues and matters of note. However, it is recommended that the priority areas for
consideration by the Commissioner with regard to advocacy for older people concern:

- Definition
- Principles
- Approach
- Legislation
- Strategy
- Policy
- Provision
- Funding
- Research
- Role of the Older People's Commissioner for Wales
- Older people's perspectives

The key considerations within each of these areas will now be outlined in turn.

**Definition**

This scoping study has provided a typology of advocacy and proposed key definitional elements for independent one-to-one advocacy. Definitions widely accepted by the advocacy movement and used in Scottish legislation have also been highlighted by way of example. The Older People’s Commissioner for Wales will need to consider the typology of forms, key elements and meanings as presented in order to inform the decision as to the working definition ultimately to be employed.

**Principles**

Overarching principles of independence, empowerment and inclusion have been highlighted along with the identification of more detailed principles for practice as developed by Action for Advocacy. These principles are widely recognised by the advocacy movement (with who they were developed) and increasingly within policy and academic sources. The Older People’s Commissioner for Wales might reasonably utilise these sets of principles against which current arrangements can be judged.
Approach
In undertaking further work in advocacy for older people, it is proposed that the Older People’s Commissioner for Wales should maintain an approach based upon citizenship, human rights and equalities. Such an approach widens the scope of advocacy and broadens the rights and representation of older people beyond those of being users of health and social care alone. This would then explicitly incorporate the diverse characteristics of “protected groups” within equality and human rights legislation, such as gender, ethnicity, sexuality, disability - as well as age. It would also encompass areas of provision such as income, pensions and benefits, housing, transport, leisure and lifelong learning.

Legislation
The legislative status of advocacy remains restricted to Independent Mental Capacity Advocacy, Independent Mental Health Advocacy as well as Community Health Council Complaints Advocacy and the forthcoming Mental Health measure. Relevant sections of the Disabled Persons Act 1986, which would have given more comprehensive coverage, were never implemented. In some jurisdictions entitlement has been extended, in Scotland, for example, advocacy is included in adult protection legislation. Recent human rights and equalities legislation would be complemented by further advocacy measures. The Older People’s Commissioner for Wales might consider the need to extend legislative provision to meet the advocacy needs of older people.

Strategy
Older people in Wales are doubly disadvantaged by the current position in which there is no overarching strategy for advocacy and no specific strategy for older people. The comprehensive advocacy strategy contained within the Third Dimension Welsh Assembly Government strategy for the voluntary sector has not been delivered. A strategy for advocacy for older people has not been commissioned within Welsh Assembly Government. This position contrasts with that of other groups, particularly children and younger people. The Older People’s Commissioner for Wales might consider a suitable response to the invisibility of advocacy for older people at a national strategic level. The Commissioner could also champion the need for strategy for advocacy throughout the life course. Furthermore, the Commissioner might wish to support the work of second tier advocacy organisations to assist in the development of advocacy at a national level and with local schemes.
Policy
Advocacy is contained within a range of policy documents at national and local level. In some policy areas the position might be strengthened, for example, stating that service users will be supported to secure the services of an advocate, rather than simply stating that they might be represented by an advocate if needed. Similarly, whilst advocacy is included within the National Minimum Standards for Care Homes for Older People in Wales, the policy must be seen to be more explicitly and consistently applied in inspection reports. The current revision of adult protection procedures makes substantial reference to advocacy, providing a significant opportunity for more robust and systematic application in this field. Furthermore, there might be scope for the Older People’s Commissioner for Wales to be instrumental in facilitating the sharing of best practice in policy development on advocacy across organisations, authorities and sectors.

Provision
This scoping study has highlighted variations and gaps in the provision of advocacy as well as examples of good practice. Outside the narrow criteria of statutory provision, there is generally a lack of advocacy services for older people in Wales. A review of web sources, literature and responses to this survey revealed an absence or shortage of advocacy provision for older people. This covers a range of social groups (including black and minority elders and disabled older people with physical or sensory impairments); situations (from support for carers, to making a decision about living arrangements on hospital discharge or making a complaint); and settings (from care homes to living independently in the community). It is also important that where advocacy is provided, advocates are appropriately trained and that the service is of an acceptable standard. The Older People’s Commissioner for Wales might highlight the gaps, shortages and variations of provision. The Commissioner might also encourage the use of appropriately trained advocates and the maintenance of suitable quality standards by advocacy schemes.

Funding
Advocacy services for older people are generally acknowledged as being under-resourced and non-statutory provision as being in a precarious position. Whilst policy initiatives such as the National Service Framework
for Older People in Wales encourage the provision of advocacy, they are without legal requirement or attendant resources. Advocacy provision is now particularly fragile given the context of economies and cuts in state expenditure. Where advocacy is being commissioned, there are concerns that is might be overly restricted by the imperatives of commissioning bodies rather than those of advocacy schemes or older people themselves. The Big Lottery Fund AdvantAGE programme is set to provide a huge boost to the funding of advocacy with older people in Wales, but this should not be seen as being a substitute for a strategy or funding from other sources. The Older People’s Commissioner for Wales might not only seek to protect existing services but to make the case for funding more services outside current statutory provision at a time of shrinking public finance. The Commissioner might also help to ensure that advocacy is being commissioned in accordance with advocacy principles, processes and outcomes. Close working links with the AdvantAGE programme would also be beneficial in terms of strategic and service development.

Research
Advocacy with older people in general is an under-researched area. There are relatively few examples of conceptual or empirical academic work. There are also few evaluative studies or publications to share learning and disseminate “what works”, particularly in Wales. As this scoping study has shown, the dearth of research and evaluation is acute in a number of areas, including a more detailed analysis of models of provision, adherence to principles, roles and relationships, process and outcomes, commissioning and funding, settings and situations, stakeholder responses and the perspectives of older people themselves. The absence of a national report on the work of IMCA in Wales has been highlighted. More opportunities for sharing learning between organisations and sectors locally and nationally are needed. International perspectives are also illuminating, with particularly promising links with academics, policy makers and advocacy providers in Australia, the United States of America and Canada. The Older People’s Commissioner for Wales might wish to consider further research and evaluative studies on areas identified within this report. The Commissioner might also facilitate the sharing of learning locally, nationally and internationally through events, publications and web pages.
Role of the Older People’s Commissioner

There is a need to raise awareness about the advocacy role of the Older People’s Commissioner for Wales. The Commissioner can be seen to embody a public advocacy role but there also appears to be a need to further clarify understanding about the nature of individual or casework advocacy being undertaken. In addition, relationships with the advocacy movement might be further consolidated through sharing information, networking and joint initiatives. Furthermore, the Older People’s Commissioner for Wales might play a key role in “advocating for advocacy” for older people in Wales, amongst politicians, policy makers, commissioners, providers, older people and the wider population.

Older People’s Perspectives

It is essential that older people’s views and experiences help to shape the development of advocacy. The Older People’s Commissioner for Wales has already embarked upon a process of listening and gathering older people’s perspectives on advocacy with a call on the website of the Commissioner and other means. As indicated above, research and evaluation on advocacy commissioned by the Older People’s Commissioner is enhanced by the inclusion of older people at different levels. A seminar on the development of advocacy with older people in Wales hosted by the Older People and Ageing Research and Development Network (OPAN) and the Older People’s Advocacy Alliance (OPAAL) UK was held in Swansea University in 2008. The seminar involved a variety of stakeholders including organisations of older people (available at www.opan.org.uk). Given the pace of change and pressing nature of matters facing advocacy with older people, a further event with older people to the fore might be timely and welcome. As one older respondent remarked,

“Things have been happening for older people in Wales in recent years. But we are behind on this. And this (advocacy) is something that is needed, really needed. They are just not available or known to all who might need one. Any of us might need an advocate sometime. We need to get up and do something about it for ourselves and others.”
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Appendices

Appendix 1: Sample questionnaires

1a. Request and e-questionnaire:-
Advocacy for older people: strategy co-ordinators

The Older People’s Commissioner has the power to look at the adequacy of advocacy and complaints arrangements in Wales (in particular bodies and regulated services). The Commission is committed to looking at these areas with a view to seeking any improvements necessary over the coming years. In general, the Commissioner’s approach is to ask: ‘What needs to change to make things better for older people and what is the Commission best placed to do to help?’

In order to identify the most effective way of making progress, the Commission has commissioned Andrew Dunning and Dr. Sue Lambert of the Older People and Ageing Research and Development Network (OPAN), Swansea University, to undertake an initial scoping study.

The study aims to identify what is in place at present, the current context and what the best opportunities are to make progress in particular areas. It is looking at gaps and weaknesses as well as strengths and good practice examples.

The research involves:-

- Desk top literature search of academic publications and other materials;
- A web-based search of Welsh Assembly Government and local health and other care organisations’ policies and procedures, evidence of operation and outcomes;
- Electronic survey undertaken with leads for complaints / advocacy in national and local health, social care and voluntary organisations; and
Telephone interviews with key stakeholder informants in national, voluntary, health and local government sectors.

The researchers have identified Older People’s Strategy Co-ordinators as a key group to survey regarding the scoping of advocacy. We would be very grateful if you could complete the attached questionnaire by Wednesday 21st April 2010.

The Study report will be placed on the Older People’s Commission website and individual participants will not be named, however, organisations will be named for example to illustrate good practice.

Please do not hesitate to contact me if you require any further information or clarification about this project.

Email: a.m.dunning@swansea.ac.uk
Your involvement is greatly appreciated. Thank you.

1. Contact details
2. Do you have an advocacy strategy in your local area?
3. If yes, does this strategy explicitly include advocacy services for older people?
4. Do you have a specific advocacy strategy for older people in your local area?
5. Are there any organisations providing advocacy for older people in your area?
6. If yes, please list the organisation/s providing advocacy for older people in your area.
7. If yes to Question 5, please also describe the nature of advocacy services for older people being provided (eg. Whether it is for specific groups, settings or situations in which older people need such support).
8. What do you consider to be the strengths of advocacy for older people in your local area?
9. What do you consider to be the gaps in advocacy for older people in your local area?

10. How could the provision of advocacy for older people be improved in your local area?

11. Do you have any messages for the Older People’s Commissioner regarding policy and provision of advocacy for older people in Wales? If so, please comment below.

**1b. Sample e-questions**

**Complaints and older people: Nhs Complaints officers**
(Lambert 2010)

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**8. Advocacy and Older People**

1. Is there an advocacy service for older people in your area? (In addition to the Community Health Council)

   - [ ] Yes
   - [ ] No

2. If yes, what are the names of the advocacy services for older people that you suggest people contact?

3. How many complaints a year are supported by advocates?

<table>
<thead>
<tr>
<th>Number</th>
<th>Older People</th>
<th>All complainants</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 or less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-10</td>
<td></td>
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</tr>
<tr>
<td>11-19</td>
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<td>20-29</td>
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<td></td>
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<tr>
<td>30+</td>
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<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2: Methodology - the key informant technique

O’Day and Goldstein (2005) used the key informant technique in exploring advocacy issues and strategies in disability. They interviewed 16 disability advocacy and research leaders regarding disability legislation and provision in the United States of America, asking them to prioritise top five issues for advocacy.

The UCLA Centre for Health Policy Research states that,

“Key informant interviews are qualitative in depth interviews with people who know what is going on in the community. The purpose of key informant interviews is to collect information from a wide range of people who have first hand knowledge about the community. These community experts with their particular knowledge and understanding can provide an insight on the nature of problems and give recommendations for solutions.”

(www.healthpolicy.ucla.edu)

The advantages and disadvantages of using the key informant technique are set out as follows:-

Advantages:

- Detailed and rich data can be gathered in a relatively easy and inexpensive way;
- Allows the interviewer to establish rapport with the respondent and clarify questions;
- Provides an opportunity to build or strengthen relationships with important community informants and stakeholders;
- Can raise awareness, interest and enthusiasm around an issue
- Can contact informants to clarify issues as needed;
- Candid more in depth answers.
Disadvantages

- Selecting the “right” key informants may be difficult so they represent diverse backgrounds and viewpoints;
- May be challenging to reach and schedule interviews with busy and/or hard-to-reach respondents;
- Difficult to generalize results to the larger population unless interviewing many key informants.

Appendix 3: List of participants in the complaints and advocacy for older people scoping studies

Blaenau Gwent County Borough Council
Bridgend County Borough Council
Caerphilly County Borough Council
Cardiff Council
Carmarthenshire County Council
Ceredigion County Council
Conwy County Borough Council
Denbighshire County Council
Flintshire County Council
Gwynedd County Council
Isle of Anglesey County Council
Merthyr Tydfil County Borough Council
Monmouthshire County Council
Neath Port Talbot County Borough Council
Newport City Council
Pembrokeshire County Council
Powys County Council
Rhondda Cynon Taff County Borough Council
City and County of Swansea
Torfaen County Borough Council
Vale of Glamorgan Council
Wrexham County Borough Council
A Scoping Study of Advocacy with Older People in Wales

Aneurin Bevan Health Board
Abertawe Bro Morgannwg University Health Board
Betsi Cadwaladr University Health Board
Cardiff and Vale University Health Board
Cwm Taf Health Board
Hywel Dda Health Board
Powys Health Board
Velindre NHS Trust
Wales Ambulance Services NHS Trust
Board of Community Health Councils in Wales

Community Housing Cymru
Grŵp Gwalia
Care and Social Services Inspectorate Wales
Independent Complaints Secretariat
Public Services Ombudsman for Wales
Wales Risk Pool
Welsh Assembly Government
Welsh Local Government Association

Action for Advocacy
Advocacy Wales
Age Cymru
Disability Wales
Mental Health Matters Wales
National Pensioners Convention in Wales
Older People’s Advocacy Alliance (OPAAL) UK
South Wales Mental Health Advocacy
Appendix 4: Section summaries of key findings and issues

Section 2: Meanings and Models

- Definitions of advocacy are dynamic and subject to debate.
- The Older People’s Commissioner for Wales might draw upon definitions devised by the advocacy movement (eg OPAAL and Action for Advocacy) or enshrined within legislation elsewhere (eg Scotland).
- The chosen definition should incorporate components such as being independent of service provision; one to one with an individual older person/s; long term or short term involvement; paid or voluntary advocates; supported by an advocacy scheme or organisation; free to the person requiring advocacy; upholds core advocacy principles.
- Advocacy must be maintained as a highly principled activity. Its broad principles are independence, empowerment and inclusion.
- The Advocacy Charter developed by Action for Advocacy with the wider advocacy movement contains a detailed set of principles for practice.
- The main advocacy roles are instrumental and expressive – both are needed and valued by older people.
- A number of models of advocacy provision have been developed.
- There is a lack of specialist advocacy schemes for specific issues such as dementia, physical and sensory impairment; generic advocacy schemes for older people who are not eligible for statutory services; and peer advocacy projects run by and for older people in Wales.
Section 3: Advocacy and Legislation

- Legislation with duties to provide advocacy, granting people rights to advocacy and giving advocates legal status has been implemented since 2005 by way of IMCA, IMHA and the new Mental Health (Wales) Measure.

- The current legislative framework remains far from comprehensive and is only applicable to a limited number of older people within qualifying groups. Both IMCA and IMHA involvement is short term in nature and limited in scope.

- These legislative initiatives are under researched and, notwithstanding their relatively recent development, a more substantial evidence base is developing in England than in Wales.

- In contrast with arrangements in England, there is no readily accessible database, lead official in government or annual report for IMCA in Wales.

- Respondents to this scoping study stated that most IMCA referrals were concerned with older people.

- The new Mental Health (Wales) Measure will extend the group of qualifying patients eligible to receive IMHA support, to include all patients subject to the formal powers of the Mental Health Act 1983 as well as voluntary and informal patients not detained under the Act.

- Advocacy organisations and other respondents to the recent Mental Health (Wales) Measure highlighted a number of issues of concern which pertain to advocacy provision more widely. They include challenges with regard to advocacy principles, scope, strategy, funding, capacity and training.
Section 4: Citizenship and Participation

- A citizenship approach broadens the scope of advocacy to include a wider range of services, issues and groups of older people as citizens as well as service users.

- Advocacy is a means of operationalising or putting into practice the citizenship of older people.

- The objective of a comprehensive advocacy services strategy within the Welsh Assembly Government Third Dimension strategy action plan has not been delivered.

- Older people are doubly disadvantaged as there is no comprehensive national advocacy strategy to include them and no stand alone national strategy for advocacy for older people (in contrast with children and young people and other groups).

- Second tier advocacy organisations in Wales lack organisational capacity to fully engage with the development of policy and practice development.

- Advocacy organisations in England and Wales have developed a manifesto calling for a national framework for advocacy.

- Advocacy was not included in the Strategy for Older People in Wales, despite apparent synergies. However, some local authorities have developed advocacy strategies or services under its auspices.
Section 5: Human Rights and Equalities

- Human rights and equalities are a crucial part of the context for advocacy and broaden its concerns beyond the health and social care of older people.

- The UN Principles for Older Persons do not explicitly mention advocacy, but can be drawn upon by advocates in supporting older persons with regards to the promotion and protection of independence, participation, care, self fulfilment and dignity.

- Advocates are drawing upon the Human Rights Act 1998 in representing the older person in letter, decision making meetings and other situations.

- A human rights approach in advocacy with older people has been encouraged by the House of Lords and House of Commons Joint Committee on Human Rights and is supported by training materials and opportunities for advocates.

- Advocates will be able to draw upon the Equality Act 2010 which extends the circumstances in which people are protected against discrimination and places an equality duty on a range of public bodies and related organisations. This also allows for a wider consideration of protected characteristics including the position of gay and lesbian older people and black and minority ethnic elders.

- The Equality and Human Rights Commission includes independent advocacy within its strategic priorities and is committed to ensure that such advocacy is available as part of a social care system based on equality and human rights – particularly with regard to older people and other protected groups.

- The Older People's Commissioner for Wales is widely welcomed but respondents suggest that more work is needed to raise awareness and clarify the nature of the advocacy role of the Commissioner and to develop relationships with advocacy organisations across Wales.
The broad strategic framework for health and social care supports the engagement and empowerment of older people as service users and citizens, and can be complemented by the provision of advocacy.

The National Service Framework for Older People includes the availability and use of advocacy within Standard 1 regarding rooting out age discrimination, but does not require or resource local provision.

As yet, advocacy has not been formally linked to the Dignity in Care agenda, but has received support from the Dignified Revolution campaign group.

Older people with mental health problems might be denied advocacy support if they fall outside the terms of statutory provision, including those seeking access to mental health services in the first place.

Similarly, older people with dementia might be unable to access advocacy if they do not meet the criteria for IMCA and other statutory provision, including those needing such support on an ongoing, long term basis.

Whilst the National Dementia Plan for Wales and establishment of dementia advisers might improve awareness of advocacy services, such provision has to be available and capable of meeting demand.

The Welsh Assembly Government Statement on Policy and Practice for Adults with a Learning Disability (2007) recognises the significant ageing of the population of people with learning disabilities and highlights the importance of advocacy in supporting people in making their needs known.

Despite the Welsh Assembly Government Advocacy Grant Scheme for advocacy groups working with people with learning disabilities, the availability and sustainability of such groups remains uncertain.

There is no statutory right to advocacy on the basis of physical or sensory impairment - the prevalence of which increases with age - and there is a dearth of provision in these areas.
Section 6: Health and Social Care (cont.)

- The Welsh Vision Strategy Implementation Plan 2010-13 includes advocacy in its objectives and some local authorities have sought to take account of the advocacy needs of older people with physical and sensory impairments within their commissioning, wellbeing and advocacy strategies.

- Older people comprise a significant proportion of carers. Despite legislation and policy developments to support carers in assessment and the provision of information and advice, there is no entitlement to advocacy to ensure that their voices are heard.

- Some advocacy schemes working with older people more generally do represent issues raised by older people who are carers and the carers’ movement has developed advocacy skills training and other initiatives.

- Advocacy can be crucial in making a decision about entering a care home, whilst living in a care home or in the event of leaving a care home due to its closure or change of circumstances.

- The National Minimum Standards for Care Homes for Older People in Wales (2002) require that service users are assisted in accessing advocacy services, but the availability of such services is variable and inspection reports by CCSIW do not always include reference to their use.

- Independent living has been promoted by the disability movement and Welsh Assembly Government has developed citizen centred support through direct payments and other means. Advocacy can help to support older people living in the community to exercise choice and control.
Section 7: Adult Protection and Safeguarding

- Advocacy in relation to adult protection is an under-researched area.
- Advocacy can be a vital component in the prevention of and protection from abuse.
- The current review of In Safe Hands and consultation on the creation of unified policy and procedures for adult protection provides a significant opportunity to promote the development of advocacy for older people in Wales.
- The CSSIW national overview of adult protection gives little reference to advocacy and coverage in local inspection reports is variable.
- There is no legislation on adult protection in Wales (or in England or Northern Ireland), whereas in Scotland there is such legislation which also includes provision of advocacy.
Section 8: Complaints and the Public Services Ombudsman

- Advocacy can provide a means of support for older people in making a complaint and in negotiating the complaints process.

- Advocacy may be preventative in supporting an older person to achieve a positive outcome before a complaint has to be made or finding resolution early in the complaints process.

- The Social Services Complaints Procedures (Wales) Regulations (2005) places a duty on the authority to make available to any complainant information on how to contact an advocacy scheme, but not a duty to arrange such provision.

- Local authority complaints officers and NHS complaints officers acknowledge that access to advocacy would make complaints procedures more accessible.

- Older people aged 60 years and over comprise 50% of all complaints supported by CHC’s. However, less than 40% of the total number of complaints to the NHS were supported by CHC’s.

- Uniquely, in Powys the CHC has been commissioned to provide IMCA and IMHA services as well as CHC Complaints Advocacy services.

- There have been variations in the way in which issues involving the abuse of older people have been subject to complaints or adult protection procedures. Advocates can have a role in helping to ensure that the appropriate channels are pursued on behalf of the older person.

- Housing agencies have developed complaints procedures and mechanisms for tenant participation and representation. However, such representation tends to be on a collective rather than individual level and there is little evidence of arrangements to facilitate access to independent advocacy.

- The PSOW has identified a number of concerns regarding advocacy for older people in Wales, including the patchiness of provision; lack of access within a range of settings and situations; lack of resources and capacity of some advocacy services; as well as the need to raise awareness.
Section 9: Funding and Commissioning

- There is a general view that advocacy with older people is under resourced and that funding for non-statutory advocacy in particular is insufficient.

- Most non-statutory advocacy schemes working with older people receive funding from more than one source. Whilst this can protect independence and bring flexibilities in provision, it also entails more time spent in securing funding and adhering to funding requirements.

- Reliance upon short term funding arrangements can place advocacy schemes in a vulnerable position.

- The funding and commissioning of advocacy for older people by Welsh Assembly Government, local authorities and health boards has been subject to varying degrees of attention and prioritisation.

- Advocacy organisations have raised concerns about funding based upon “number mapping” of the population and caseload statistics without consideration of rurality, geography and language.

- There is a marked contrast between the legislative and policy position, funding status and level of service provision of advocacy with older people and that of other groups, particularly children and young people.

- An overarching advocacy strategy across all groups would highlight gaps and inconsistencies in the funding and provision of advocacy throughout the life-course of all citizens.

- The current economic climate, public service cuts and end of funding through the Strategy for Older People in Wales, has heightened concerns that advocacy outside statutory obligation, or outside very tight prioritisation set by statutory bodies, will not be commissioned.

- Wider benefits of advocacy could be highlighted, including its role in helping to meet Welsh Assembly Government objectives of citizenship, empowerment and inclusion; supporting improvements in person centred care and service quality; and providing consumer feedback.
Section 9: Funding and Commissioning (cont.)

- There has been a lack of funding for second tier advocacy organisations to support the development of advocacy in general and with older people in particular. In contrast, the Scottish Government directly funds the Scottish Independent Advocacy Alliance.

- AdvantAGE, the Big Lottery Fund Cymru programme provides a generous and unprecedented funding opportunity for the development of advocacy with older people in Wales. However, there are concerns that the initiative should not become a substitute for a substantive advocacy strategy or funding from statutory sources.

Section 10: Standards and Outcomes

- The Advocacy Counts 2 survey (Age Concern Cymru 2008) showed that 56% of advocacy schemes used standards developed by Action for Advocacy, whilst the remaining 44% used a variety of frameworks including those developed by Welsh Assembly Government and host organisations.

- Some advocacy schemes have sought external quality marks such as Investors in People, the Community Legal Service Quality Mark and Practical Quality Assurance System for Small Organisations Quality Mark (PQASSO).

- Statutory advocacy providers have quality standards set down by Government. These quality standards were largely developed in consultation and engagement with the advocacy movement.

- The Action for Advocacy Quality Performance Mark (QPM) has attained widespread recognition and has so far been awarded to six advocacy providers working in Wales.

- Advocacy schemes are variously monitored and reviewed using frameworks they themselves put in place, by their host organisations or by funders and commissioners.
Advocacy schemes can be evaluated in a variety of ways, including the Action for Advocacy Quality Performance Mark, evaluative research by academics and consultants, as well as user engagement and feedback initiatives.

In the evaluation of advocacy, it is important to maintain core principles, to consider process as well as outcomes and to avoid overly simplistic or mechanistic measures of results.

A national advocacy qualification was launched in 2009, aiming to ensure quality and consistency in the training of advocates. The qualification was developed by the Department of Health in partnership with Welsh Assembly Government and involving advocacy organisations in the process.

Whilst there has been growing recognition of the need for such training and engagement by the advocacy movement, there have been concerns about the professionalisation of advocacy, replicating traditional forms of service provision and becoming removed from its more radical roots.

Advocates and those running advocacy schemes need supervision, support and opportunities for development in order to deal with the substantial ethical, legal and practical challenges and dilemmas they frequently face.

Independence

1. Older persons should have access to adequate food, water, shelter, clothing and health care through the provision of income, family and community support and self-help.

2. Older persons should have the opportunity to work or to have access to other income-generating opportunities.

3. Older persons should be able to participate in determining when and at what pace withdrawal from the labour force takes place.

4. Older persons should have access to appropriate educational and training programmes.

5. Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.

6. Older persons should be able to form movements or associations of older persons.

Participation

7. Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.

8. Older persons should be able to seek and develop opportunities for service to the community and to serve as volunteers in positions appropriate to their interests and capabilities.

9. Older persons should be able to form movements or associations of older persons.
Care

10. Older persons should benefit from family and community care and protection in accordance with each society’s system of cultural values.

11. Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.

12. Older persons should have access to social and legal services to enhance their autonomy, protection and care.

13. Older persons should be able to utilise appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.

14. Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

Self-fulfillment

15. Older persons should be able to pursue opportunities for the full development of their potential.

16. Older persons should have access to the educational, cultural, spiritual and recreational resources of society.

Dignity

17. Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.

18. Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.