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Review of Legislation and Policy Guidance Relating to Adult Social Care in Northern Ireland

J Duffy

Subhajit Basu, *University of Leeds*

G Davidson

K Pearson, *Penn State University*



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REVIEW OF LEGISLATION AND POLICY GUIDANCE RELATING TO ADULT SOCIAL CARE IN NORTHERN IRELAND

REPORT AUTHORS

**JOE DUFFY, SUBHAJIT BASU, GAVIN DAVIDSON
KATHERINE C. PEARSON**

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Review of Legislation and Policy Guidance Relating to Adult Social Care in Northern Ireland

Defining Adult Social Care

It is important to commence this report by defining what is meant by adult social care. The following definition is used in *'Who Cares? The Future of Adult Care and Support in Northern Ireland'*:

Services provided or secured by HSC Trusts towards adults who need extra support, either to live their lives as independently as possible, who are vulnerable or who may need protection. Examples of services include day care, domiciliary care, nursing and residential home care, equipment and adaptations and the provision of meals.¹

The definition above is broadly similar to that used by the Department of Health in *Our health, Our care, Our say*² which defined adult social care as: 'the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships'.³ Gray and Birrell observe that adult social care definitions have tended to favour a focus on purpose-based statements rather than listing provision.⁴ The current definition used by the Department of Health aligns adult social care with promoting people's well-being, independence and choice.⁵ The Law Commission, in its important study of the legal status of adult social care, included in its definition a service orientated focus describing such care as: 'the care and support provided by local authority social services pursuant to their responsibilities to adults who need extra support'.⁶ Interestingly, the Law Commission concluded by defining the purpose of adult social care as: 'promoting or contributing to the well-being of the individual'.⁷

¹ Department of Health, Social Services and Public Safety (DHSSPS), *Who Cares? The Future of Adult Care and Support in Northern Ireland. A Discussion Document*, 37 (Belfast: DHSSPS, 2012).

² Department of Health, *Our Health, Our care, Our Say: A New Direction for Community Service*, para 1.29 (2006).

³ *Id.*, para 2.5.

⁴ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 2 (Bristol: Policy Press, 2013).

⁵ Department of Health, *Transparency in Outcomes: A Framework for Quality in Adult Social Care. The 2012/13 Adult Social Care Outcomes Framework*, 8 (London: Department of Health, 2012).

⁶ Law Commission, 2011, para 1.5 in Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 2 (Bristol: Policy Press, 2013).

⁷ *Id.*, para 2.1.

Introduction and Background

This project was undertaken by an international team of academics from Queen's University, Belfast, Leeds University and Pennsylvania State University (USA) who have examined models of adult social care provision across thirteen jurisdictions. The aim of this research is to present the Commissioner for Older People in Northern Ireland (COPNI) with possible options for legal reform to adult social care provision for older people in Northern Ireland.

Project Objectives

The agreed objectives of this research were to provide:

- Identification of gaps and issues surrounding the current legislative framework including policy provision for adult social care in Northern Ireland.
- Comparison of Northern Ireland with best practice in other jurisdictions to include (but not be limited to): England and Wales, Republic of Ireland, Scotland and at least two other international examples; Recommendations, based on the above, as to whether there is a need for legislative reform - provision of suggestions other than legislative change (if applicable).
- Recommendations or options based on the above, on how to best change the current framework in Northern Ireland to provide better support outcomes for older people.
- Stakeholder engagement via roundtable event to discuss outcomes/ recommendations.

Structure of Report

The findings from this research are based on an international review of adult social care in the local, national and international contexts. The report will, therefore, firstly present the key recommendations for Northern Ireland which have emerged from a systematic examination and review of adult social care in diverse jurisdictions. Each jurisdiction is then examined in the context of legislative and policy provision and examples of best practice are provided. The final section of the report then compares Northern Ireland to best practice from each of these aforementioned jurisdictions and the discussion entails the background to the report's final Recommendations. The recommendations in this report are thus directly linked in with the evidence we have gathered across different countries with contrasting systems of welfare.

Methodology

A Rapid Evidence Assessment (REA) method was used to identify, select and analyse the literature relevant to this review. REAs provide a rigorous, open and effective means of evaluating what is known and facilitating consideration of future developments and are particularly suited to projects where the potential literature is very broad but the themes from the evidence are needed to inform policy direction. The key stages of a REA are to: develop search strategies and identify appropriate databases; screen the results against agreed inclusion criteria; assess the quality of the included results; extract the key findings from the included results; and provide a synthesis of the key themes to inform the discussion and recommendations of the

review. The Government Social Research Centre and the Evidence for Policy and Practice Information and Co-ordinating Centre (2013) recommend a REA when there is a need to decide on a policy direction based on the best available evidence but despite there being a wide range of literature there are ongoing debates and questions. The methodology was informed by discussion with the research Advisory Group members. The key stages of the REA for this review are summarised below.

Search strategies

There were five main approaches used to search the literature. The broad search terms used were 'adult social care' and 'law' although these were adapted as needed for each search. The searches were limited to 2002-present and resources in English:

1. Searches of four general databases using 'adult social care' and 'law' to identify overview/policy/discussion resources. We searched Zetoc, the British Library's database (90 results); Social Care Online, the Social Care Institute of Excellence's database (76 results), Centre for Reviews and Dissemination (1 result) and the Cochrane Library (0 results).
2. Searches of Google Scholar using 'adult social care' and 'law' and the specific jurisdiction. This was to identify relevant research and policy documents. The results for each jurisdiction were: Northern Ireland (487); Scotland (715); England (1650); Wales (971); Republic of Ireland (42); Victoria (226); United States (including Maine (7), Florida (38), Pennsylvania (41); Ontario (65); British Columbia (34); Sweden (234); and Denmark (172).
3. More subject specific databases were then searched, again using 'adult social care' and 'law'. The results were Medline (20); Embase (25); Web of Science (74); Econlit (72) and Psycinfo (37).
4. Google Scholar searches were conducted using the names of the specific law: 'Social Services and Well-being (Wales) Bill' (6); Social Care (Self-Directed Support) (Scotland) Act (7); and 'Care Bill' and 'England' and 'adult social care' (195).
5. The final approach acknowledged that the terms used in the other approaches, especially 'adult social care', are not as relevant to jurisdictions beyond UK. This aspect of REA therefore consisted of more purposive, jurisdiction specific, searches based on the references identified in the main searches and the relevant team members' knowledge. For example searches within relevant voluntary organisations' websites and the use of 'seniors' in US and Canada rather than 'older people'.

Screening

All the search results were screened by two members of the research team. Results were included if they were assessed as being of direct relevance to one or more of the key aspects of the project as outlined below:

- Reviewing the current legislation, departmental guidance, regional guidance, codes of practice, policy and/ or other guidance relating to health and social care in Northern Ireland.

- Identifying and comparing best practice nationally to include: the draft Welsh Social Services and Well Being Bill; the Social Care (Self-directed Support) (Scotland) Act 2013; and the Care Bill in England.
- Comparing best practice internationally including the Republic of Ireland and specific jurisdictions within Scandinavia, Australia, United States, Canada and India.
- Identifying any financial, social, political or economic barriers and opportunities to reform as well as practical implications of any suggested types of reform.

Quality assessment

Each included publication was then assessed by two of the research team for quality and relevance to the review. The included publications were then reviewed in detail by the relevant member of the research team and the relevant data and themes extracted. For each jurisdiction a standard format was used to present the relevant findings as below:

- Introduction covering: demographic info, very brief overview of health and social care system, rationale for inclusion and key themes
- Legal framework
- Policy and guidance
- Definitions
- Scope: eligibility, assessment, care planning, services, funding, monitoring
- Research on implementation in practice (including political, social and economic factors)
- Practice examples
- Implications for Northern Ireland
- Implications for older people in Northern Ireland

Data synthesis

The main themes across jurisdictions were then identified to inform the discussion and recommendations of the review.

Advisory Group

The Team also established a Research Advisory Group whose role was to offer additional advice to the Research Team in their fulfilment of meeting the Tender requirements for this project. This Group therefore functioned to provide an additional level of quality assurance and robustness to the research approach adopted by this Team. This Group consisted of key stakeholders from service user, carer, policy and academic perspectives.

Note on Terminology used

The report uses the following terms interchangeably: older people, older persons, seniors, senior citizens, older adults, elder care, elders and the elderly. This reflects the terminology that is in usage in several of the jurisdictions we reviewed.

Comparing Northern Ireland with Practice in other Jurisdictions

The research team included the following international jurisdictions in this review: Northern Ireland, England, Scotland, Wales, Republic of Ireland, Denmark, Sweden, India, Canada (Ontario), Australia (Victoria) and the United States (including Pennsylvania, Florida and Maine as State examples). In addition to reviewing existing law and policy developments in the regions surrounding Northern Ireland (including England, Scotland, Wales and Republic of Ireland), the authors looked to European nations (Denmark and Sweden) well known for enlightened social policies as well as to other major world powers that, in theory, have responded to large financial and resource concerns connected to the demographics of population aging (Australia, Canada, India and United States). Thus, our research has sought to identify both best practice and implementation challenges in drafting our recommendations for Northern Ireland. In comparing Northern Ireland with best practice in other jurisdictions, we also selected countries with different systems of welfare provision. Scandinavian counties such as Sweden and Denmark would be described as having *universal* public services available to all of the public irrespective of ability to pay. On the other hand, countries such as England, Wales and the Republic of Ireland would be described as having more of a *residual* model of welfare whereby publicly-funded help is prioritised to those with the least financial means. Such a residual model of welfare is also associated with notions of subsidiarity where additional expectations are placed on the family to provide care and welfare for dependent relatives. The latter residual approach to welfare, for example, would be applicable to India, the US, Australia and Canada.⁸ The recommendations this report generates for Northern Ireland can, therefore, be contextualized within practice examples from other diverse welfare cultures, leading to recommendations based on best practices for Northern Ireland.

⁸ Mary Daly, *Welfare* (Cambridge: Polity Press, 2011).

Executive Summary

Our review of best practice both nationally and internationally leads us to conclude that legislative reform to adult social care in Northern Ireland is necessary. This is based on the findings that the current legislation and accompanying policy guidance is both confusing and fragmented. Our findings have also indicated that the legislation overlaps in key areas of social care provision and is both highly complex and inconsistent across Northern Ireland.

The current complexion of adult social care legislation in Northern Ireland is typified by disparate and dated pieces of law which are disconnected and without any sense of coherency in theme. The drafting of the Care and Support Bill in England was triggered by a similar concern from the Law Commission in 2011 that its legal system for adult social care was: ‘outdated, disparate, complex and fragmented.’⁹ Our report provides a case study/vignette to demonstrate the current application of law and policy in Northern Ireland and the problems we feel are inherent in this. The current legislation governing adult social care in Northern Ireland is provided through a myriad of laws dating back to 1978. Our research notes the absence of any overarching connecting themes or principles governing these and, more importantly, the absence of any sense of coherence in regard to directly locating the specific legal provisions governing social care for older people. Older people are, therefore, being treated differently in legislative terms than any other service user group. To address this issue, our key recommendation is the need to introduce a harmonizing piece of legislation to consolidate and bring together all of the current legislation governing older people’s social care needs in Northern Ireland. We have found examples on both Denmark and Sweden where this has occurred effectively. The latter would enable older people to have their citizenship rights and entitlements more meaningfully protected through the provision of consolidated legislation clearly outlining the duties of the State in regard to their welfare provision. The Report’s key recommendations are therefore drawn directly from our review of best practice across all of the jurisdictions we reviewed.

Our literature review has generated examples of where a consolidated law could be used as a mechanism whereby several existing pieces of legislation can be embodied within one as is the case in Denmark, Sweden, Wales, England and Scotland. Our findings would also support the view that adult social care law should be based on core principles such as equality, dignity, citizenship, choice, personalisation and human rights. We saw reference to such rights based principles in several countries we examined. We also note that the statutory duty to promote Personal and Public Involvement (PPI) is situated within the Health and Social Care Reform Act (2009) in Northern Ireland. Having this requirement enshrined within consolidated legislation for adult social care could potentially enhance the realization of PPI for older people. The emphasis placed on well-being, independence, choice and involvement are key principles evolving from the Law Commission’s report in 2011.¹⁰ These key principles are also evident in the legislative reforms in both

⁹ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 32 (Bristol: Policy Press, 2013).

¹⁰ Law Commission, *Adult Social Care*, (LAW COM No. 326) (London: The Stationery Office, 2011).

England and Wales. Referring to England's draft Care and Support Bill, 2012,¹¹ Long and Powell note its first key provision as 'the promotion of individual wellbeing as the driving force underpinning the provision of care and support'.¹² Gray and Birrell observe the partnership/involvement ethos that will evolve in adult social care in England where: 'the planning process will take place between the person, any carer and the local authority'.¹³ The 'statutory right to assessment' is a feature not only of England's legislative reform, but is also found in the changes heralded in the Welsh system. The Welsh government's Social Services Bill: 'gives a statutory right of assessment of need for people of all ages and provides a new legal framework for the management of care and support plans'.¹⁴

Prevention was a theme that was apparent in our review of adult social care in the United Kingdom and Scandinavia, in particular. The idea of introducing annual **Support Visits** for older people could be one important way in which older people's social care needs could be adequately addressed and responded to. Our review has also uncovered a notable shift away from institutional patterns of care for older people, again particularly evident in the Scandinavian countries we examined. In achieving the objectives for effective community care in Northern Ireland, we have also noted that services need to be better developed in order to support people to make their own decisions about care. We uncovered some creative and innovative methods whereby older people were empowered to have real choice and control over how access to social care was personalized and tailored to meet their individual needs. Our Review also reinforces the importance of needing to consider how services should be funded in the context of increasing demands for health and social care. We, therefore, recommend that future funding arrangements should be fair and not discriminate against groups including older people who may have higher levels of need.

The next section presents an overview of our findings in which Northern Ireland's adult social care system is compared with practices in other jurisdictions.

¹¹ Draft Care and Support Bill, Presented to Parliament by the Secretary of State for Health by Command of Her Majesty, Cm 8386 (July 2012).

¹² Robert Long and Thomas Powell, *Draft Care and Support Bill 2012-13*, 7 (London: House of Commons Library, Social Policy Section, 2013).

¹³ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 35 (Bristol: Policy Press, 2013).

¹⁴ *Id.*, 38.

Comparison of Northern Ireland with Other Jurisdictions to Identify “Best Practices”

This report presents an opportunity for comparing Northern Ireland’s adult social care system with other national and international contexts. This discussion will now summarize the key themes emerging from these country reviews and examine ways in which social care practice in Northern Ireland can be improved.

Our review of Northern Ireland has pointed to deficiencies in legal provision which is built around five different pieces of legislation all of which are central to the context for social care provision.

The annual Statistics on Community Care for Adults 2012-13¹⁵ provide an overview of the types and level of adult social care services in Northern Ireland. They report that:

- “Between 1 April 2012 and 31 March 2013, 42,310 persons were in contact with [Health and Social Care] Trusts, a 2% increase from the same period last year.
- Approximately a third of all contacts with HSC Trusts were by persons in the Mental Health [Programme of Care (POC)] (34%) and approximately a fifth of all contacts were by persons in each of the Elderly Care (20%), Learning Disability (22%) and Physical & Sensory Disability (22%) POC’s.
- Of those persons who had face to face contact with a HSC Trust and whose age was known, 12,162 (31%) were aged 65 and over.
- At 30 June 2013, of the 12,372 care packages in effect in Northern Ireland, approximately two thirds (68%) were nursing home care packages and just under one third (32%) were residential care packages.
- The proportion of residential and nursing home care packages in effect by POC has remained relatively constant from 30 June 2007 to 30 June 2013, with the vast majority (79%) of care packages in effect in the Elderly Care POC (approximately 9,800).
- Over four fifths (85%) of residential and nursing home care packages were provided by the private sector. The voluntary sector provided a much smaller proportion of residential and nursing home care packages (10%), whilst the statutory sector provided only residential care packages (6%).
- At 31 March 2013, 3,066 persons were in receipt of meals on wheels services. This was 203 (6%) less than the number in receipt at the end of the previous year and 2,105 (41%) less than the number in receipt five years ago.
- At 31 March 2013, over nine in ten (92%) persons receiving a meals on wheels service were aged 65 and over (16% were aged 65-74, 37% were aged 75-84, 39% were aged 85 & over).
- At 31 March 2013, the highest proportion (39%) of persons receiving meals on wheels services were aged 85 & over.
- At 30 June 2013, there were 5,347 residential places available. This comprised 4,399 places in 218 residential homes and 948 residential places in

¹⁵ Northern Ireland Statistics and Research Agency (NISRA), *Statistics on Community Care for Adults 2012-13*, 15-16 (Belfast: NISRA, 2013).

nursing homes. This was a 3% decrease in the number of residential care places available at 30 June 2012.

- At 30 June 2013, there were 10,872 available nursing care beds. This comprised 6,462 beds in 162 nursing homes and 4,410 nursing care beds in 106 dual registered homes. This was a very small decrease in the number of nursing home care beds available at 30 June 2012 (<1%)”.

Against this backdrop, our review indicates disparities in Northern Ireland’s integrated system of health and social care where some services are free whilst others are subject to a charge. Our report also observes the absence of clear direction in regard to how personalization, as a key principle in Transforming Your Care,¹⁶ will be developed in practice. Gray and Birrell observe that Northern Ireland ‘demonstrates a picture of relatively few strategies dedicated specifically to adult social care’.¹⁷ These authors also remark that Transforming Your Care failed to place the central emphasis on user involvement and personalisation which were so central to adult social care transformation in Great Britain.¹⁸ Gray and Birrell also note the absence in ‘Who cares: the future of adult care and support in Northern Ireland’¹⁹ of any reference to thinking towards reforming adult social care legislation ‘akin to that proposed in England, Scotland and Wales to put social care entitlements in a new statutory framework’.²⁰

The need for adult social care to prioritise needs over resources in regard to meeting older people’s social care needs is highlighted in our Report. The review of the current system in Northern Ireland also points to unevenness in emphasis in the integrated system, particularly where health seems to attract a more elevated focus than adult social care.²¹ Gray and Birrell commented that Transforming Your Care focused disproportionately on health issues, in particular the need to reconfigure acute hospitals given the shift in emphasis from hospital to care in the home/community.²² The perception of variation across Trusts in Northern Ireland is an issue that also should be explored and addressed through a more detailed policy blueprint for adult social care provision across Trust areas. A consolidated legislative framework would be a progressive step forward in addressing this inconsistency in service.

Our report identifies the cost aspects of social care as being fundamentally discriminatory. We suggest that to achieve the goal of uniform, high quality social care that means testing should be reviewed. Means testing can result in the service provision being tied to poverty, rather than as recognition of a fundamental right. Our Report also recommends that consideration should be given to reviewing the current costing structures for adult social care. This could represent a significant step towards avoiding the discrimination, anomalies and unfairness of the current

¹⁶ Department of Health, Social Services and Public Safety (DHSSPS), *Transforming Your Care: A Review of Health and Social Care in Northern Ireland* (Belfast: DHSSPS, 2011).

¹⁷ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 39 (Bristol: Policy Press, 2013).

¹⁸ *Id.*

¹⁹ DHSSPS, *Who Cares? The Future of Adult Care and Support in Northern Ireland. A Discussion Document* (Belfast: DHSSPS, 2012).

²⁰ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 40 (Bristol: Policy Press, 2013).

²¹ *Id.*

²² *Id.*, 39.

differences between the funding arrangements across health and social care which are often dependent on setting rather than need.

The identification of unmet need should be coordinated at the Trust and Regional levels and published as part of the relevant planning processes. Although this is already policy in Northern Ireland, the DHSSPS, in response to a Freedom of Information request, recently acknowledged that “The department do not hold Adult Services unmet need statistics but merely hold a number of statistical returns from HSC Trusts which attempted to collect data on unmet need. This information was incomplete, inconsistent across trusts and was not judged to be of sufficient quality by departmental statisticians to undertake any meaningful analysis. As such it was discontinued and was never analysed, or used for any purpose”.²³

England

The review of the proposals for adult social care in England has led us towards the view that a single statute for social care, which clearly sets out rights and responsibilities, could be considered as a way to provide a more coherent legal framework and social care system for Northern Ireland. We contend that this could also help promote awareness and understanding of rights to care and support services. The government in Northern Ireland in the recent times have favoured “collaboration” (proposal to establish integrated care partnerships (ICPs) instead of “competition”; hence, the proposed single statute would be a move in the right direction in achieving that goal. Although Northern Ireland has an integrated care system, it is yet to realise the potential benefit of an integrated health and social care system due to lack of coherent policies that promote and support integrated care. The structural integration of health and social care into a single service occurred over 40 years ago but it happened because of concerns about the ability of the local authorities to provide social care rather than concerns over fragmentation of care. However so far, we have seen domination of health care over social care as the focus of the public attention is on health.

Introducing a new piece of consolidated legislation could also reinforce the existing core principles of human rights and equality legislation to help ensure adult social care in Northern Ireland is accessible and responsive to the all the diverse needs of its population. A human rights-based approach thereby provides a framework of core values and principles upon which services can be based. There is a need for complete consistency and clarity in the application of the Human Rights Act and the public sector equality duty to all providers of healthcare and home care services. There are a number of common and recurring themes that should be applicable, such as positive obligations, proportionality, assessing and managing risk, user and public involvement, equality and good relations. Respecting and promoting human rights improves both the quality and effectiveness of health and social care, improves decision-making processes and enhances the health and well-being of all service users.

²³ Araon Ghiban, *Adult Services Unmet Need Statistical Survey*, Freedom of Information Request Correspondence, June 2013, available online at www.whatdotheyknow.com/request/adult_services_unmet_need_statist.

Wales

Our review of the adult social care system in Wales provided an interesting approach to streamlining services within a single piece of legislation which could be replicated in Northern Ireland. The Social Services and Well-being (Wales) Bill (2013) provides a good model for bringing most of the relevant aspects of a legal framework for adult social care together into one law. It also covers the provision of social care and adult safeguarding. The proposed duty to provide preventive services is another key and progressive aspect of the Welsh approach which could address a gap in similar provision in Northern Ireland. These preventive services are intended to delay or prevent people developing need for care. The following key elements will underpin the preventative approach:

- new duties on local authorities and local health boards to jointly assess population needs of people of all ages including carers and to assess the range and level of services required to meet those needs;
- new duties on local authorities and LHBs to assess the range and level of services needed to prevent, delay or reduce people's need for care and support;
- new duties on local authorities to provide a range of preventative services for people; and duties on local authorities to assess whether preventative services can meet identified need.²⁴

Our report addresses this issue in its Recommendation that Preventative Visits should occur for older people, similar to Sweden, once they reach the age of seventy-five. This is currently not structured in this way in Northern Ireland but could provide effective opportunities for joined up working between doctors and social workers, for example, in their involvement with older people.

Scotland

Our review of Scotland also led us to making key proposals in regard to the merits around having a consolidated piece of legislation to harmonize social care provisions. In Scotland the approach has been to have a range of separate laws addressing mental health, mental capacity, adult protection, social care and integrated working. Although this may provide clarity and focus within each individual law, it could be argued this creates a complex legislative framework with overlaps and tensions that may be difficult to understand for professionals, service users and carers.²⁵

The review of Scotland also influenced our Recommendation that personal care and nursing care should be provided free in Northern Ireland. The experience in Scotland suggests that this is popular, fair and possible. As Gray and Horgan have highlighted "The Northern Ireland Assembly voted in favour of providing free personal care in

²⁴ Gwenda Thomas, Deputy Minister for Social Services Written Statement - Social Services and Well-being (Wales) Bill: Prevention and Early Intervention, <http://wales.gov.uk/about/cabinet/cabinetstatements/2013/regulationinspection/?lang=en> accessed on 18 February, 2014.

²⁵ Tom Keenan, *Crossing The Acts: The Support and Protection of Adults at Risk with Mental Disorder; Across the Scottish Legislative Frameworks* (Birmingham: British Association of Social Workers and Venture Press, 2011).

2007, followed by a review of the costs and benefits of it. The review concluded that a relatively small number of people would benefit and that it would be therefore difficult to justify the cost".²⁶ It could be argued, however, that to not provide personal and nursing care free, is to discriminate against those groups more likely to need these services, particularly older people.

Republic of Ireland

The problems blighting adult social care provision in the Republic, for example, the geographical disparity and unevenness of service provision, should signal caution in Northern Ireland's intentions to consider legislative reform for adult social care. It is also important to recognize the difficulties associating with adult social care provision in the absence of clear legislative guidelines which stipulate rights and entitlements. The *Future Health* policy proposals should, however, go a considerable way to addressing these deficits. What is particularly plausible in the latter is the user orientated and rights focus in regard to the determination of social care needs within a wholly integrated health and social care system.

The Republic of Ireland system therefore places value on the following:

- Having a specialist position of advocate in disability services with a statutory remit to provide advice and guidance on service provision, assessment and entitlements.
- Basing proposed legislative reforms on the key principles of equality, rights, choice and person-centeredness.

Australia

Our review has evidenced some positive features of social care practice which could positively apply to Northern Ireland. The system in Victoria, in particular, places value on the following:

- Generic briefs for components of services which may help to ensure a consistent standard of adult social care across geographical areas
- Self-directed support which is aimed at promoting choice and independence but research from Australia highlights that care must be taken to ensure that these types of services are accessible to everyone who may wish to use them and that there are robust alternatives for those who decide they would prefer not to take more responsibility for managing their own care.²⁷

Canada

What emerges strongly from our review of Ontario (Canada) is the commitment at policy level to providing support at community level to enabling older people to live independently for as long as possible in their own homes. Having a policy strategy

²⁶ Ann Marie Gray and Goretti Horgan, *Social Care in Northern Ireland*, 2 (Belfast: Access Research Knowledge (ARK) Policy Brief, 2010).

²⁷ Karen R. Fisher, Ryan Gleeson et al., *Effectiveness of Individual Funding Approaches for Disability Support* (Canberra: Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, 2010).

for home renovations to support healthier and safer aging in the home is a manifestation of the value which demonstrates commitment to realising this. The latter therefore evidences a powerful commitment to Prevention which we feel has important implications for Northern Ireland.

Denmark

Denmark is a country not much bigger in population than Northern Ireland. It appears to have developed a progressive system of social welfare built on person centeredness and other humanistic principles such as choice, autonomy and empowerment. Several of its initiatives could read across to Northern Ireland but the funding question inevitably would have to be addressed. The system in Denmark places value on the following:

- Preventative Visit Scheme whereby older people (75+) receive a visit twice per annum to determine their need for social care services
- One overarching piece of legislation in the Consolidation Act on Social Services to holistically meet the needs of the adult social care population
- Adoption of the concept 'ageing in place' to concretely shift service provision to the 'home' environment for older people
- Including the concept of 'choice' in the fabric of legislation

India

Similar to Denmark, the system in India also places value on the concept "Ageing in Place" by ensuring housing, income security and homecare services. Institutional care is, thereby, seen only as the last resort. It recognises that care of senior citizens has to remain vested in the family, which would involve a collaborative approach between the community, government and the private sector. The idea of 'ageing in place' is a concept that could potentially undergird Northern Ireland's commitment to community care for older people. The need to avoid burdening the role of female carers, however, must be highlighted within this. The Indian government is also committed to addressing the concerns of poverty among older persons, particularly those living in rural areas and those who are victims of social and economic vulnerability. At provincial level, there is also a commitment to extending support for older people living below the poverty line in urban and rural areas and ensuring their social security, healthcare, shelter, welfare and protection from abuse and exploitation.

India also recognises that senior citizens are a valuable resource for the country and encourages their participation, both as individuals and groups, in social, economic, cultural and political spheres of life through appropriate incentives and programmes.

Sweden

Sweden's Universal system of welfare may pose problems in terms of applicability to Northern Ireland. The model of social care brings with it increased levels of taxation that are necessary for implementation. Having said that, the examples of good practice noted in the Swedish review, are laudable. This is particularly evident in regard to the emphasis on person-centeredness that underpins this country's system of welfare. There is thus a real sense that old age is valued in Sweden. There are,

however, emerging problems with the consequences of increased marketization. Nonetheless, there is a real sense that this is a country which is resisting any sense of embedding or officially recognising that informal care is an inevitability in the social care domain.

The Swedish system therefore places value on the following:

- A voucher system as a basis for enabling older people to exercise real choice in social care provision.
- A human rights based approach to working with older people, for example, the Social Services Act (2012).
- Having one piece of all embracing legislation governing older people's social care needs.

United States

In many countries, there are protections associated with older age as a matter of fundamental law, often tied to the concept of "human rights." In the U.S., while the rights and needs of older persons has often been recognized and protected by law, there is no fundamental set of rights nor any constitutional protection tied to older age and thus, in budget or political disputes, there is often no statutory basis for advocacy, including advocacy to pursue funding from social care. In regard to Northern Ireland, the absence of such a rights and entitlement framework has led us to recommend the adoption of a set of principles contained in law for older adults to permit a clear basis for advocating specific rights.

The U.S. also provided us with an innovative approach to assessing the living conditions of older people with a view to providing services. As demonstrated by shifts in funding for assistance from traditional nursing homes to home and community based services in the U.S. and Canada, there is a clear trend in consumer preference for in-home (or community) care services and supports. To assist the trend in "aging in place," we suggest that consideration be given to an early assessment of the home environment in Northern Ireland, with an eye towards physical adaptations of the home to assist in healthy, safe aging. The latter can occur within the Preventative Visit.

In some countries, such as the United States, a threshold level of free legal services is available to any older adult. While public awareness and implementation of free legal services to older adults has not been consistent across the states, despite funding and directions under the Older Americans Act, studies suggest that older adults find such services valuable and important to understanding the options, securing their rights, and preventing loss of services or quality care. We therefore suggest that consideration be given in Northern Ireland to a national program of threshold legal services, at low cost or without cost, for or for the benefit of older persons. The latter has already been recommended in previous research by Basu and Duffy²⁸ and Duffy, Basu and Pearson²⁹ but could represent an important vehicle to enable older people to exercise their legal rights in the context of social care.

²⁸ Subhajit Basu & Joseph Duffy, *Providing Legal Information and Advice to Older People: As Much a Question of Accessibility as Affordability*, European Journal of Law and Technology, 1(3), 1-32 (2010).

²⁹ Joseph Duffy, Subhajit Basu & Katherine C. Pearson, *Older People and Legal Advice: The Need for Joined Up and Creative Approaches*, Journal of Social Welfare and Family Law 34:1, 32-47 (2013).

The following section of our report includes key recommendations to guide the implementation of reform to Northern Ireland's adult social care system. Firstly, by way of context, we provide a case study example to demonstrate how the current legislative system in Northern Ireland, provides a context for addressing social care need.

Fictitious Case Example

Mrs. Brown is an 82 year old woman who lives alone in her privately owned dwelling. Her husband died a year ago following a heart attack. Mrs. Brown has always been an independent person who never before required social services. Six weeks ago Mrs. Brown fell down the stairs and fractured her right hip. She now has limited mobility and walks with the aid of a walking stick. Since admission to hospital, Mrs Brown has also been diagnosed with vascular dementia, she had been presenting as confused and forgetful, which triggered this assessment. Plans are now being made for admission to residential care in preparation for return home when Mrs. Brown is considered well enough.

Mrs. Brown's daughter, Mary (61), lives a few streets away and has a close relationship with her mother. She is separated from her husband and has no family. She is the manager of a local shop and had been calling with her mother in the mornings and at lunch time. Mary had been finding the ongoing task of caring for her mother very tiring and her own health is starting to worsen.

Application of Law to the above Scenario

	Law	Issues
Stage 1 Emergency Admission to hospital	Health and Personal Social Services (NI) Order 1972 and 1994 Health and Social Care Reform Act (2009)	Provision of free health care is enacted through the 1972 Order Overarching duty to provide health (and social care is found in the Reform Act) Health and social care provided free in hospital

<p>Stage 2</p> <p>Discharge Package</p>	Health and Personal Social Services (NI) Order 1972 and 1994	The 'duty to assess need' is legislated here. The 'duty to meet need' is, however, more of an anomaly and potentially dependent on available resources.
	Chronically Sick and Disabled Persons Act (1978)	The planned provision of community care services fall within Sections 1 and 2 of The CSDPA (1978)
	Mental Health (NI) Order 1986	The diagnosis of dementia is legally defined as a 'mental disorder' in Article 3(1) of the Mental Health Order.
	Disabled Persons Act (1989)	Section 4 of the DPA entitles the service user to an assessment. Such rights based language is, however, absent in all other legislation.
	Human Rights Act (1998)	<p>Key Articles of the ECHR contextualise the backcloth to planned social care provision:</p> <p>Article 6 - the right to a fair trial, in this instance implies the 'right to be heard/to be involved'</p> <p>Article 8 - the right to private and family' life is protected by the provision of community care services enabling Mrs. Brown to have 'family life' in her own home.</p> <p>If Mrs. Brown is looked after in some form of Intermediate Care to facilitate discharge this is not means tested.</p>
	Carers and Direct Payments Act (2002)	Mrs. Brown can receive direct payments to manage aspects of her care provision.
	Health and Social Care Reform Act (2009)	Department's general duties are now found in Sections 1 and 2 of the Reform Act.

<p>Stage 3</p> <p>Domiciliary Support and Family Support at Home</p>	<p>Health and Personal Social Services (NI) Order 1972</p> <p>Chronically Sick and Disabled Persons Act (1978)</p> <p>Disabled Persons Act (1989)</p>	<p>By virtue of this Order, the Trust undertakes a financial assessment to determine Mrs. Brown's ability to pay for her social care needs (such as home help, meals on wheels, day care).</p> <p>Community care services are legally defined in Sections 1 and 2 of this legislation. Language such as 'chronically sick' is outdated.</p> <p>Reference to assessment as 'entitlement, thereby rights based. Domiciliary support is not means tested but the threshold of need for funded services is set at a level which may mean that additional support provided by and/or funded by the family is necessary for Mrs. Brown to stay at home.</p>
<p>Stage 4</p> <p>Sheltered/Residential Accommodation</p>	<p>Health and Personal Social Services (NI) Order 1972</p>	<p>Means tested provision by virtue of the HPSO, in which trusts determine the service user's ability to finance their residential/nursing home care.</p>

Key Recommendations

1. There should be a single legislative framework underpinning adult social care in Northern Ireland with accompanying guidance for implementation. This could either be new or consolidated legislation, based on human rights principles, bringing existing social care law together into one coherent framework providing clarity on:
 - Eligibility
 - Entitlement, Rights to Services, Personal and Public Involvement (PPI)
 - Assessment of Need and Unmet Need
 - Health and Social Care Trust Duties
 - Existing frameworks for mental incapacity and adult protection
 - Other support services including housing and benefits entitlements.
2. All older people in Northern Ireland, once they reach the age of 75 years, should be offered a Support Visit by an appropriately trained HSC staff member. This will be based on principles of choice and self-determination and is aimed at helping older people to be aware of the support and preventative services that are available to them.
3. Increasing demands for health and social care reinforce the importance of considering how these services should be funded. All future funding arrangements must be equitable and must not discriminate against any group, including older people, who may have higher levels of need.

Implications for Northern Ireland

Rationale	Recommendation	Opportunities	Areas for Consideration
<p>Our review of best practice both nationally and internationally leads us to conclude that legislative reform to adult social care in Northern Ireland is necessary. This is based on the findings that the current legislation and accompanying policy guidance is confusing and fragmented. Our findings have also indicated that the legislation overlaps in key areas of social care provision and furthermore that this is highly complex and inconsistent across Northern Ireland.</p>	<p>1. There should be a single legislative framework underpinning adult social care in Northern Ireland with accompanying guidance for implementation. This could either be new or consolidated legislation, based on human rights principles, bringing existing social care law together into one coherent framework providing clarity on:</p> <ul style="list-style-type: none"> • Eligibility • Entitlement, Rights to Services, Personal and Public Involvement (PPI) • Assessment of Need and Unmet Need • Health and Social Care Trust Duties • Existing frameworks for mental incapacity and adult protection • Other support services including housing and benefits entitlements. 	<p>A more streamlined and accessible legislative framework which harmonizes and enhances the provisions currently existing in legislation relating to adult social care services for older people. This would meaningfully embody and enshrine the protections afforded to older people in the European Convention on Human Rights and in other relevant international rights based charters. This would also lessen the potential for older people to experience unfair and unequal treatment in regard to service provision.</p>	<p>Need to avoid creating further confusion and avoid duplication. Need to ensure that current legislative measures remain intact. Some aspects however would need to be updated and further developed, for example, the reference to 'chronically sick and disabled' found in the Chronically Sick and Disabled Persons Act (1978).</p> <p>This potentially could have implications in regard to the current gap concerning 'duty to assess need' and 'duty to meet need'. In a context of limited resources, the State would nonetheless be obliged to meet any assessed need irrespective of resource constraints. A legislative reform which is rights based will therefore have resource implications.</p>
<p>Services for older people in Northern Ireland are currently reactive in nature and decisions about social care are often made as a result of a crisis situation.</p>	<p>2. All older people in Northern Ireland, once they reach the age of 75 years, should be offered a Support Visit by an appropriately trained HSC staff member. This will be based on principles of choice and self-determination and is aimed at helping older people to be aware of the support and preventative services that are available</p>	<p>The development of the Mental Capacity Bill presents an excellent opportunity to explore how people whose decision making ability may be impaired, for example by dementia, can be supported to continue to make their own decisions and/or have their will and preferences represented. Intervening early would greatly facilitate this</p>	<p>Article 12 of the United Nations Convention of the Rights of Persons with Disabilities requires people's legal capacity to be respected and protected regardless of any form of disability they may be experiencing.</p> <p>There is a developing evidence base for the economic and effectiveness benefits of early intervention to</p>

	to them.	process. Support Visits would provide the opportunity for assessment of an older person's home environment with a view to determining if services were needed and/or adaptations to the home.	assess needs and support decision making.
To charge some or all people for social care services financially penalises people with social care needs. This is, therefore, discriminating against groups with higher social care needs including older and disabled people.	3. Increasing demands for health and social care reinforce the importance of considering how these services should be funded. All future funding arrangements must be equitable and must not discriminate against any group, including older people, who may have higher levels of need.	This Recommendation recognises the importance of funding considerations needing to be equitable and that people should not be additionally financially penalized because of their health and social care needs.	The inconsistencies characterising the current means testing approach for adult social care services should be reviewed given that people are means tested for some services and not for others.

Review of International Jurisdictions

This section of the Report provides a summative overview of adult social care across thirteen international jurisdictions. The research commissioner (COPNI) had stipulated the need to compare Northern Ireland with best practice in other jurisdictions to include (but not be limited to): England and Wales, Republic of Ireland, Scotland and at least two other international examples. Our review included India, Denmark, Sweden, U.S., Canada and Australia. Members of the research team had established links and familiarity with the socio-legal contexts of these countries and we, therefore, felt that the broader inclusion of these international contexts would augment the evidence base for the Report's recommendations.

A standardized structure was agreed for the jurisdiction reviews. Each country review would therefore broadly entail the following key areas: demographic information, overview of the health and social care system, legal framework, policy and guidance, research on implementation in practice, best practice examples and implications for older people in Northern Ireland. The team also concluded the review of each country by proposing recommendations from which the Report's six Key Recommendations are drawn. In this way, the Report's findings and recommendations are robustly evidence based.

The following review is further structured in the following way. We start firstly by examining the situation in Northern Ireland. Following this, the review then examines England, Wales, Scotland and the Republic of Ireland and, in alphabetical order, proceeds to examining other international contexts.

Northern Ireland

Introduction

This introductory section will provide a brief overview of the demography of Northern Ireland, the historical development of adult social care in this jurisdiction and a summary of the current types and level of services.

The population of Northern Ireland was 1.824 million in 2012 and it is projected to increase, by approximately 10,000 each year due to more births than death, reaching 1.9 million in 2020.³⁰ These projections suggest that there will be a large increase in the number of older people with those aged 65 and over increasing by a quarter between 2012-2022 (from 273,000 to 344,000) and those aged 85 and over increasing by almost 50% (from 33,000 to 48,000). In the same period it is also expected that the number of children will increase, by approximately 5%, and that there will be no increase in population due to migration. These demographic changes are one of the important drivers for ensuring that the legal and policy framework for adult social care is as fair, efficient and effective as possible.

An important characteristic of health and social care in Northern Ireland is that it is an integrated system. The sections on England, Scotland and Wales will demonstrate a current, general trend towards more integrated health and social services to provide adult social care but the system in Northern Ireland has been integrated since 1972. This was first formally proposed in a Green Paper published by the Northern Ireland Government in 1969 which suggested that “Nothing short of a fully integrated administrative system can provide an adequate framework for comprehensive care”. It is interesting to speculate whether this progressive proposal would have been implemented without the context of conflict. When Direct Rule was introduced in 1972, responsibilities that had been with local government, notably social services, education and housing, were transferred to new structures. The Health and Personal Social Services (NI) Order, 1972 established a new integrated organisational structure for health and social care provided through four health and social services boards. In the House of Lords debate on the Order, Lord Windlesham suggested that “In many fields the health of a community and its social needs are inter-related. The elderly, the handicapped and the mentally ill, for example, are particularly vulnerable groups in need of both medical and social care. The combined administrative structure will enable the health and social services for these groups to be fully co-ordinated”.³¹

In the 1990s the structures for adult social care were reviewed and changed through the policy document *People First: Community Care in Northern Ireland in the 1990s* (Department of Health and Social Services, 1990) and two laws (the Health and Personal Social Services (Northern Ireland) Orders 1991 and 1994) which enabled the associated organisational changes. These laws separated the commissioning of

³⁰ Northern Ireland Statistics and Research Agency (NISRA), *Statistical Report -2012-Based Population Projections* (Belfast: NISRA, 2013).

³¹ Hansard, volume 333 HL Deb 27 July 1972, cc1542-53 Available online at <http://hansard.millbanksystems.com/lords/1972/jul/27/health-and-personal-social-services> last accessed on 8th August 2014.

services by the four Boards from the provision of services by 19 Health and Social Services Trusts. These changes were part of a more general trend to both introduce a more market-based model to public services in the UK and encourage the transfer of the provision of care from hospital to community settings. *People First*³² suggested that the provision of care should be based on three principles: to help people lead as full and independent lives as possible; to respond flexibly and sensitively to the needs and wishes of service users and carers; and to concentrate resources on those who need them most.

Although this general policy direction has remained reasonably consistent, the structures for providing health and social care were again changed as a result of a wider Review of Public Administration launched in 2002, concluded in 2006 and implemented in 2007.³³ It resulted in the commissioning role being consolidated into one Health and Social Care Board and the provision of services into five geographical Health and Social Care Trusts and a regional Northern Ireland Ambulance Service Health and Social Care Trust. As will be discussed in further detail in the Legal framework section below, these new arrangements were further clarified and reinforced by the Health and Social Care (Reform) Act (Northern Ireland) 2009. As will be explored in the Research on implementation in practice section it is debatable whether the integrated system has achieved the intended seamless provision of services. As the most recent review of health and social care in Northern Ireland, *Transforming Your Care*, sometimes referred to as the Compton Review, reported: "Our system often does not deal with multiple conditions in an integrated way, which for the individual can mean having to engage with multiple clinicians and services which are not well joined up. The consequent personal experience is often very frustrating".³⁴ It is therefore currently proposed that 17 Integrated Care Partnerships should be created, at the local level, to facilitate the further integration of the planning and provision of health and social care in Northern Ireland.³⁵ The Compton Review also clarified the drivers for further change suggesting that it was necessary: "To be better at preventing ill health; To provide patient-centred care; To manage increasing demand across all programmes of care; To tackle health inequalities; To deliver a high-quality, evidence-based service; and To support our workforce in delivering the necessary change".³⁶

Legal Framework

The legal framework for adult social care in Northern Ireland is made up of a range of laws which have developed over the past 40 years and so provide a relatively fragmented framework which is therefore perhaps not as integrated, coherent and accessible as it could be. The following laws all provide different components of the current framework:

³² Department of Health and Social Services (DHSS), *People First: Community Care in Northern Ireland for the 1990s* (Belfast: DHSS, 1990).

³³ Department of Health, Social Services and Public Safety (DHSSPS), *Review of Public Administration*, online resources available at <http://www.dhsspsni.gov.uk/rpa-home> accessed on 9th May 2014.

³⁴ DHSSPS, *Transforming Your Care: A Review of Health and Social Care in Northern Ireland*, 23 (Belfast: DHSSPS, 2011).

³⁵ Jim Campbell, Gavin Davidson and Michael Donnelly, *The Integrated Service in Northern Ireland*, Tom O'Connor (ed.) Integrated Care for Ireland (Cork: Oak Tree Press, 2013).

³⁶ DHSSPS, *Transforming Your Care: A Review of Health and Social Care in Northern Ireland*, 4 (Belfast: DHSSPS, 2011).

- Health and Personal Social Services (NI) Order 1972, (as amended)
- Chronically Sick and Disabled Persons (NI) Act 1978
- Disabled Persons (NI) Act 1989
- Carers and Direct Payments Act (NI) 2002
- Health and Social Care (Reform) Act (NI) 2009

Some of the key Articles and sections of these laws are listed below.

- ***Health and Personal Social Services (NI) Order 1972***

This Order is the foundation of the legal framework. Article 4 (later repealed by Section 2 of the Health and Social Care Reform Act (2009)) sets out the general duty: “(a) to provide or secure the provision of integrated health services in Northern Ireland designed to promote the physical and mental health of the people of Northern Ireland through the prevention, diagnosis and treatment of illness; (b) to provide or secure the provision of personal social services in Northern Ireland designed to promote the social welfare of the people of Northern Ireland”.

Article 7(2) allows for these services, but not hospital services, to be charged for: “The Ministry [now the Department of Health, Social Services and public Safety (DHSSPS)] may recover from persons availing themselves of any service provided by the Ministry under this Article, otherwise than in a hospital, such charges (if any) in respect of the service as the Ministry considers appropriate”. Article 15 (1) of the 1972 Order imposes a duty to make available advice, guidance and assistance, to such extent as the DHSSPS considers necessary.

One of the gaps, however, in this legislation is the absence to any reference to assessment of need being rights based. Heenan and Birrell (2010) observe the fact that there is little reference to any set of guiding principles governing social care delivery in the context of this legislation.³⁷

- ***Chronically Sick and Disabled Persons (NI) Act 1978***

Sections 1 and 2 of the CSDPA (1978) outline the Trust’s duty to share information and make such arrangements as are necessary for the provision of social welfare services to meet the needs of any person coming within the definition of chronically sick and disabled. Language used is reflective of its time.

Section 1 (1) defines people covered by the Act as those persons who are “blind, deaf or dumb, and other persons who are substantially handicapped by illness, injury or congenital deformity and whose handicap is of a permanent or lasting nature or are suffering from a mental disorder within the meaning of the Mental Health (NI) Order 1986”.

Section 2 outlines the range of services which include: practical assistance in the home; the provision of or assistance in obtaining wireless, television, library or similar

³⁷ Deirdre Heenan and Derek Birrell, *Social Work in Northern Ireland: Conflict and Change* (Bristol: Policy Press, 2010).

recreational features; the provision of lectures, games, outings or other recreational facilities or assistance in taking advantage of educational facilities available; travel arrangements for the purposes of participating in services; assisting in arrangements for the carrying out of any works of adaptation to the home; facilitating the taking of holidays; the provision of meals; the provision of, or assistance in, obtaining a telephone.

The latter issue regarding home adaptations forms the basis for many community occupational therapy assessments. One of the weaknesses in this legislation is its outdated terminology which still characterises the definitions that social services staff still use. This, therefore, requires updating.

- ***Disabled Persons (NI) Act 1989***

Section 4 of the Disabled Persons (NI) Act 1989 creates a specific duty to consider the needs of people who come within the definition of chronically sick or disabled. An assessment must be carried out when requested by either a person with a disability, their representative or carer, to determine what services should be provided in accordance with Section 2 of the Chronically Sick and Disabled Persons (NI) Act 1978. An important element of this legislation is the inclusion of a legal right to an assessment of need.

- ***Carers and Direct Payments Act (NI) 2002***

Direct Payments are aimed at promoting independence, choice and partnership. They were first introduced to Northern Ireland in 1997 with the intention of enabling people to have more control over the services they require and the way in which those services are delivered. Payments can only be made in respect of personal social services which a person has been assessed as needing. Direct payments cannot be made in lieu of health services, including some community services such as community nursing or services provided by medical staff. The person needing assistance is given money to purchase his/her own service instead of having this arranged or provided by a Trust. The Act has 12 Sections, and builds on the Health and Personal Social Services (NI) Order 1972.

In Section 1 it also gives carers an independent statutory right to an assessment of their needs when requested. Section 2 empowers Trusts to provide services directly to a carer. Section 7 (2) requires that the Trust, when made aware of a carer, must notify that carer of their right to request an assessment and Section 8 specifies that Direct Payments can be made to carers to meet their own assessed needs.

There has, however, been variation across Trust areas in the uptake of Direct Payments. Reluctance to take on the organisational demands and tasks involved may be one reason why uptake is so low.³⁸

³⁸ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care*, 2 (Bristol: Policy Press, 2013).

- ***Health and Social Care (Reform) Act (NI) 2009***

This Act provides a legal framework for and clarification of the current structures for health and social care. The Explanatory Notes for this Act state that “The provision of health and social care in Northern Ireland is currently provided for by the Health and Personal Social Services (Northern Ireland) Order 1972 (the 1972 Order). The 1972 Order is now some 36 years old and has been significantly amended over the years. One option was to introduce a new single piece of primary legislation in order to consolidate all existing enactments as was the case in England and Wales. The timescale within which the new arrangements need to be in place, however, prevented such an all-embracing approach”.

Section 2(2) restates the DHSSPS’s general duty to “promote in Northern Ireland an integrated system of

- (a) health care designed to secure improvement
 - (i) in the physical and mental health of people in Northern Ireland, and
 - (ii) in the prevention, diagnosis and treatment of illness; and
- (b) social care designed to secure improvement in the social well-being of people in Northern Ireland”.

Section 19 requires Trusts to seek the views of service users and carers about the quality of services they provide. This is now referred to as the Trust’s duties to promote Personal and Public Involvement (PPI).

There are two further laws which, although they do not specifically address the provision of adult social care, are central to the legal framework. The Northern Ireland Act 1998 and the Human Rights Act 1998.

Arguably, this legislation continues the approach of addressing specific social care legislative issues in a piecemeal way, stating, generic duties and powers in the absence of concrete specific detail on implementation. This potentially can create a context within which services may develop which are disparate and geographically uneven. One of the positive features of this law however is the placing of Personal and Public Involvement on a legislative footing. There is also an absence of any reference to services being provided as of right.

- ***The Northern Ireland Act (1998)***

Section 75(1) imposes a statutory duty on public authorities, so including Health and Social Care Trusts, to “have due regard to the need to promote equality of opportunity

- (a) between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- (b) between men and women generally;
- (c) between persons with a disability and persons without; and
- (d) between persons with dependents and persons without”.

- ***The Human Rights Act (1998)***

Article 3 prohibits the subjecting of a person to torture, inhuman or degrading treatment or punishment. Although the threshold for infringing this right may be relatively high, it could be argued that not providing adult social care services to meet an assessed need could lead to a person being left in a condition(s) amounting to inhuman or degrading treatment. The Article 5 right to liberty may also be relevant if, for example, the failure to provide adequate social care services resulted in a person being detained in hospital. Article 8, the right to respect for her/his private and family life may also be relevant, if for example, a lack of effective domiciliary care in the person's own home meant they had no choice but to move to residential, nursing or hospital care.³⁹

Policy and Guidance

The policy and guidance which supports the implementation of the legal framework is also made up of a range of key documents listed below:

- People First: Community Care in the 1990s⁴⁰
- Range of DHSSPS circulars and guidance on eligibility and charging
- Transforming Your Care: A Review of Health and Social Care in Northern Ireland⁴¹
- Who cares? The future of adult care and support in Northern Ireland⁴²
- Service Framework for Older People⁴³

People First: Community Care in the 1990s (DHSS, 1990)

People First provides the policy context for the development of current adult social care services. It could be argued that had it been adequately resourced and implemented further substantial review and reform may not have been necessary. What was particularly innovative about this Policy was its focus on person-centred needs assessment. It also highlighted the entitlement to assessment of those in need: *'From 1 April 1993... health and social services boards will be required to assess the care needs of any person who appears to them to be in need of community care services and to decide, in the light of that assessment, whether they should provide or arrange for the provision of any services.'* This explicit right to assessment did not however appear in legislation.

³⁹ Law Centre NI, *Introduction to Community Care*, available online at <http://www.lawcentreni.org/EoR/community-care/introduction-to-community-care.html>, accessed on 9th May 2014.

⁴⁰ Department of Health and Social Services (DHSSPS), *People First: Community Care in Northern Ireland for the 1990s* (Belfast: DHSS, 1990).

⁴¹ DHSSPS, *Transforming Your Care: A Review of Health and Social Care in Northern Ireland* (Belfast: DHSSPS, 2011).

⁴² DHSSPS, *Who Cares? The Future of Adult Care and Support in Northern Ireland. A Discussion Document* (Belfast: DHSSPS, 2012).

⁴³ DHSSPS, *Service Framework for Older People* (Belfast: DHSSPS, 2013).

People First identified six central objectives:

1. "To promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever possible;
2. To ensure that service providers make practical support for carers a high priority;
3. To make proper assessment of need and good case management the cornerstone of high quality care;
4. To promote the development of a flourishing independent sector alongside good quality public services;
5. To clarify the responsibilities of agencies and so make it easier to hold them to account for their performance;
6. To secure better value for taxpayers' money by introducing a new funding structure for community care".⁴⁴

The main changes People First then introduced to attempt to achieve these objectives were: developing the role of the Boards as commissioners; individualising assessment; greater use of the independent sector; a new funding structure for residential and nursing care including for those eligible for welfare benefits; the registration and inspection of care services; and improved planning processes. The proposed improvements in care planning at the individual and community level were a key aspect of People First intended to both individualise care and also identify unmet need to inform the development of services. As will be discussed below, it is debatable how successful this policy has been in practice.

DHSSPS circulars and guidance on eligibility and charging

There are a range of circular and guidance documents that attempt to provide a standard, consistent approach to eligibility and charging. Regional access criteria for domiciliary care were issued in 2008.⁴⁵ It defined domiciliary care as "the provision of personal care and associated services that are necessary to maintain an individual person in a mutually agreed measure of health, hygiene, dignity, safety and ease in their home" and personal care was further defined as "undertaking any activity which requires a degree of close personal and physical contact with individuals who regardless of age, for reasons associated with disability, frailty, illness, mental health or personal physical capacity are unable to provide for themselves without assistance".⁴⁶ It then specifies banding of needs and risks into critical, substantial, moderate and low. It also specifies that "Where services cannot be provided a register of 'unmet need' should be collated by the Trust for use in future planning and service enhancement and development".⁴⁷

Updated general guidance on care management, the provision of services and charging was issued in 2010 in DHSSPS Circular HSC (ECCU) 1/2010.⁴⁸ It reinforced the principles of People First and specified that care management should "provide a holistic assessment of need which, where appropriate, takes account of

⁴⁴ Department of Health and Social Services (DHSS), *People First: Community Care in Northern Ireland for the 1990s*, 2 (Belfast: DHSS, 1990).

⁴⁵ DHSSPS, *Circular* (ECCU 2/2008).

⁴⁶ *Id.*, 3.

⁴⁷ *Id.*, 6.

⁴⁸ DHSSPS *Circular HSC* (ECCU 1/2010).

physical and mental health; emotional well-being; capacity for the activities of daily living and self-care; abilities (including attitudes toward any disability) and lifestyle (including how the day is spent); the contribution of informal carers (so long as they are able, willing and supported to carry on the caring role); social network and support; and housing, finance and environmental factors”.⁴⁹ It also highlighted that the Northern Ireland Single Assessment Tool had been developed to facilitate the assessment of service users’ and carers’ needs. The current capital limits, above which people are charged for residential and nursing home care are £14,250 up to £23,250, above which people must meet the costs of their own care. The Personal Expenses Allowance, people who are in funded care receive, is £23.90 per week.⁵⁰

Transforming Your Care: A Review of Health and Social Care in Northern Ireland (DHSSPS, 2011).

The most recent review of health and social care identified twelve principles which should underpin the development of services. They are:

1. “Placing the individual at the centre of any model by promoting a better outcome for the service user, carer and their family.
2. Using outcomes and quality evidence to shape services.
3. Providing the right care in the right place at the right time.
4. Population-based planning of services.
5. A focus on prevention and tackling inequalities.
6. Integrated care - working together.
7. Promoting independence and personalisation of care.
8. Safeguarding the most vulnerable.
9. Ensuring sustainability of service provision.
10. Realising value for money.
11. Maximising the use of technology.
12. Incentivizing innovation at a local level”.⁵¹

These principles appear very positive but it remains to be seen how they will be translated into practice. As mentioned above, a central component of this implementation process is to be the establishment of 17 Integrated Care Partnerships to improve integrated working at the local level.

Who Cares? The Future of Adult Care and Support in Northern Ireland (DHSSPS, 2012)

This consultation document set out the DHSSPS’s draft vision for adult social care with the following undergirding principles:

- “Every person should be treated with dignity and respect, and should, as far as possible, be supported to lead the life they freely choose, safeguarded against harm from abuse, exploitation or neglect;

⁴⁹ DHSSPS, *Circular HSC*, 3 (ECCU1/2010).

⁵⁰ DHSSPS, *Circular HSS* (ECCU1/2013).

⁵¹ Department of Health, Social Services and Public Safety (DHSSPS), *Transforming Your Care: A Review of Health and Social Care in Northern Ireland*, 5 (Belfast: DHSSPS, 2011).

- For all of us, care and support should recognise, foster and promote the preventative role we can all play as individuals in maintaining our own wellbeing and that of those around us;
- For people with a care need, care and support should be personalised to individual need, providing the right support at the right time in the right place, with a focus on early intervention to protect and restore independence wherever possible”.⁵²

Again, these principles seem very positive and Who Cares? Does seek views on a greater focus on earlier intervention, prevention and personalisation but again, there is little, concrete detail on which to base a meaningful response. Who Cares? Does however acknowledge a central issue with the funding of adult social care:

- People think it is unfair that they have to pay for a service such as residential and nursing home care which they believed had already been paid for through taxation;
- People with assets find it unfair that they often have to sell those assets to pay for their care, while those without assets receive financial support from government to ensure their care needs are met;
- While the vast majority of carers give their time willingly, they can nonetheless sometimes feel isolated, taken for granted and unsupported.

The central aim for a future funding system of care and support must therefore be a fair settlement between people who use services, carers and wider society who help fund care and support through taxation”.⁵³ The responses to Who Cares? Have now been published and a set of proposals is to follow.⁵⁴

Service Framework for Older People (DHSSPS, 2013)

The Service Frameworks are designed to provide standards for health and social care. The Service Framework for Older People includes several key standards which are relevant to the consideration of adult social care. The first is that it reinforces the People First emphasis on individualised or person-centred care. It also asserts that “All older people should expect the same opportunity of access to assessment, care and treatment as other users of health and social care services”. Standard 2 and Standard 5 states that “All older people should have access to independent advocacy that provides information, advice and support to enable them to make informed choices and be fully involved in decisions affecting them”.

Research on Implementation in Practice

Gray has identified a number of key issues which apply across the UK, including in Northern Ireland: “It is clear that there is substantive agreement across jurisdictions on a number of the main problems with current adult social care provision: entitlement to care and support; safeguarding and risk; the role of unpaid carers;

⁵² Department of Health, Social Services and Public Safety (DHSSPS), *Who Cares? The Future of Adult Care and Support in Northern Ireland. A Discussion Document*, 20 (Belfast: DHSSPS, 2012).

⁵³ *Id.*, 32.

⁵⁴ DHSSPS, *Who Cares? The Future of Adult Care and Support in Northern Ireland: Consultation Analysis Report* (Belfast: DHSSPS, 2013).

issues regarding the social care workforce and the need for workforce development, although the Northern Ireland documents do not say much about the social care workforce apart from social work; lack of integration between health and social care; and funding arrangements, including the commissioning of domiciliary care. A House of Commons Inquiry (2010) also found that many of the shortcomings in adult social care with regard to older people relate to a persistent ageism”.⁵⁵

There has been some research comparing the integrated system in Northern Ireland with the separate health and social care arrangements in England. Reilly et al. sought the views of consultants in the psychiatry of old age;⁵⁶ Challis et al. focused on care management for older people;⁵⁷ Reilly et al. on mental health services;⁵⁸ and Clarkson et al. analysed performance measurement systems for care for older people.⁵⁹ In general, the findings support the central idea that an integrated system does provide a better co-ordinated, multi-disciplinary approach to the assessment, planning, provision and review processes at the individual and service levels. On the other hand, the type and level of services were similar and it seems reasonable to conclude that integration may be necessary but far from sufficient for fair, effective and efficient adult social care services. Campbell et al., in a recent review of the integrated system in Northern Ireland, concluded that “appropriately-designed partnerships tend to deliver better targeted services to clients and to ensure that the interface between community and hospital services is managed efficiently. Other advantages include common systems of information, resource and personnel management and multi-disciplinary education and training opportunities. Limitations in the Northern Irish integrated health and social care service include the piecemeal nature of its coverage across different client groups and concerns about the excessive influence of medical discourses regarding service planning and delivery. Much of our understanding about the integrated service in Northern Ireland tends to be based on speculative views and practice wisdom; the evidence-base is partial and weak. Most of the studies focus on the views of professionals and have not given sufficient attention to other key stakeholders, such as service users, carers and communities. Also, in order to gain a more thorough understanding of the integrated service, there is a need to examine the important, but often poorly recognised, roles that the private, voluntary and community sectors play, alongside statutory

⁵⁵ Ann Marie Gray, *Transforming Adult Social Care in Northern Ireland: Personalisation*, Policy Briefing, 2, available online at http://www.niassembly.gov.uk/Documents/RalSe/knowledge_exchange/briefing_papers/gray020513.pdf, accessed on 9th May 2014.

⁵⁶ Siobhan Reilly, David Challis, Alistair Burns, and Jane Hughes, *Does Integration Really Make a Difference? A Comparison of Old Age Psychiatry Services in England and Northern Ireland*, 10 *International Journal of Geriatric Psychiatry* 18, 887-893 (2003).

⁵⁷ David Challis, Karen Stewart, Michael Donnelly, Kate Weiner, and Jane Hughes, *Care Management for Older People: Does Integration Make a Difference?* 4 *Journal of Interprofessional Care* 20, 335-348 (2006).

⁵⁸ Siobhan Reilly, David Challis, Michael Donnelly, Karen Stewart and Jane Hughes, *Care Management in Mental Health Services in England and Northern Ireland: Do Integrated Organisations Promote Integrated Practice?* 12 (4) *Journal of Health Services Research and Policy*, 236-241 (2007).

⁵⁹ Paul Clarkson, Sue Davies, David Challis, Michael Donnelly, and Roger Beech, *Has Social Care Performance in England Improved? An Analysis of Performance Ratings Across Social Services Organisations*, *Policy Studies* 30, 403-422 (2009), and Paul Clarkson, David Challis, Sue Davies, Michael Donnelly, Roger Beech, and Takayuki Hirano, *Comparing how to Compare: An Evaluation of Alternative Performance Measurement Systems in the Field of Social Care*, 1 *Evaluation* 16, 59-79 (2010).

organisations, particularly in a policy context that advocates a mixed economy of care”.⁶⁰

As acknowledged in *Who Cares?*, a major issue is the funding of adult social care. As Gray et al. explain: “In England, Wales and Northern Ireland, nursing care is free but personal care is means tested. The extremely popular decision to introduce both free nursing and personal care was taken in Scotland in 2002. While the Northern Ireland Assembly voted in favour of free nursing and personal care in 2007, this was later rejected by the DHSSPS Minister in 2009 on grounds of cost”.⁶¹ In England, if your needs are primarily health, the cost of your care may be funded through the National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care. Although this may benefit some people, introducing this system to Northern Ireland would not address the central issue of people being means-tested for social care but not health care. As the DHSSPS have reinforced “The Health and Personal Social Services (Northern Ireland) Order 1972 requires that a person is charged for personal social services provided in residential care or nursing home accommodation arranged by a HSC Trust. There is no such requirement, or authority, to charge for healthcare provided in the community, either in the service user’s own home or in a residential care or nursing home”.⁶² This further highlights the inconsistencies and potential discrimination involved in the current funding arrangements. So, a service user may receive free personal care in a hospital and domiciliary setting but will be means tested for this in a residential setting.

The DHSSPS has also outlined the range of services that should be provided: “In responding to assessed need, the HSC Board and HSC Trusts should explore and develop innovative services alongside the following key elements of community care provision and delivery: Self-care; Direct Payments; Domiciliary care; Day care; Respite care; Intermediate care; and Residential care and nursing home care”.⁶³ However, there is very little detail provided, in this guidance or in *Transforming Your Care*, about how these services should be provided, and crucially, the level of service provision that should be consistently available across Northern Ireland.

Gray suggests that although personalisation is identified within the principles of *Transforming Your Care*, detailed proposals on how it will be developed in practice have not yet been published.⁶⁴ Age (NI)’s survey of the views of older people on adult social care suggested we should “Centre first on the needs of the person and not on the finances” and “Provide a service which is based on needs and not means-tested”.⁶⁵

⁶⁰ Jim Campbell, Gavin Davidson and Michael Donnelly, *The Integrated Service in Northern Ireland*, n Tom O’Connor (ed.), *Integrated Care for Ireland*, 56 (Cork: Oak Tree Press, 2013).

⁶¹ Ann Marie Gray, Lizanne Dowds, and Paula Devine, *Attitudes to Social Care for Older People in Northern Ireland*, 12 (ARK, University of Ulster and Queen’s University Belfast, 2012).

⁶² DHSSPS, *Circular HSC*, Part 3, 18 (ECCU 1/2010). -.

⁶³ DHSSPS, *Circular HSC*, Part 2, 10 (ECCU 1/2010).

⁶⁴ Ann Marie Gray, *Transforming Adult Social Care in Northern Ireland: Personalisation*, Policy Briefing, 2, available online at

http://www.niassembly.gov.uk/Documents/RaISe/knowledge_exchange/briefing_papers/gray020513.pdf, accessed on 9th May 2014.

⁶⁵ Age NI, *‘Would You Have Sandwiches for Your Tea Every Night?’ Older People’s Views of Social Care in Northern Ireland*, 6 (Belfast: Age NI, 2011).

Practice Examples

A central aspect of good practice in Northern Ireland is the integrated system itself. Whilst there may be complexities with it, Heenan and Birrell identified a number of areas in which it has facilitated the provision of care: addressing delayed discharges from hospital; setting up integrated care teams; facilitating the resettlement of people from institutional to community care; and integrated working in general.⁶⁶ They suggest that “Integration of health and social care can be seen to improve access, referral and assessment processes while simultaneously reducing both waiting times and duplication of services”.⁶⁷ They also acknowledge there are still challenges with this system: the ongoing dominance of health; related to that is the relative priority attached to health agendas and targets; the relatively limited focus of integrated approaches to some areas of practice, such as adult social care. They suggest a number of changes would further develop services in Northern Ireland: “a higher profile for social care in modernisation initiatives; joint initial training sessions for health and social care professionals; a focus on outcomes for service users; renewed debate on social models of care; composition of new bodies to reflect a more equal status of health and social care; a systematic programme of research and evaluation in integrated working to provide a robust evidence base”.⁶⁸

The Northern Ireland Pensioners’ Parliament, organised by Age Sector Platform, and launched in February 2011, encourages people to get involved in policy issues across Northern Ireland and provides an example of how sustained, inclusive opportunities can engage and involve people in addressing issues that matter to them.

The Regulation Quality and Improvement Authority’s (RQIA) review of the Northern Ireland Single Assessment Tool reported that “there continues to be a lack of direct and reliable data available about current service provision and potential unmet need”.⁶⁹

The Northern Ireland Human Rights Commission has also raised some concerns about the basic quality of care available in nursing home settings and made a range of recommendations which include “ensuring that residents are enabled to access the outdoor environment of the home, that they receive appropriate and timely assistance with continence needs, and have adequate food and water accessible at all times of the day and night”.⁷⁰

⁶⁶ Deirdre Heenan and Derek Birrell, *Organizational Integration in Health and Social Care: Some Reflections on the Northern Ireland Experience*, 17 (5) *Journal of Integrated Care*, 3-12 (2009).

⁶⁷ *Id.*, 8.

⁶⁸ *Id.*, 11.

⁶⁹ RQIA, *Review by RQIA of Northern Ireland Single Assessment Tool Stage One Overview Report*, 24 (2011).

⁷⁰ Northern Ireland Human Rights Commission, *In Defence of Dignity: The Human Rights of Older People in Nursing Homes*, 7 (Belfast: Northern Ireland Human Rights Commission, 2012).

England

Introduction

The population of England is now around 53 million, up from 49.1 million people in 2001 (an increase of 7.9%), and on current projections will reach 61 million by 2032. The population is getting older and one in six people is aged 65 and over. Despite predictions to the contrary, the number of older people living alone has actually gone down, from 2.9 million people 65 and over in 2001 (14.4% of all households) to 2.7 million in 2011 (12.4%). This decrease is linked to the fact that people are living longer and there has been a fall in the proportions of people who are widowed.

Adult social care services have changed substantially in the past 25 years with successive governments trying hard to find a more sustainable and equitable way of funding adult social care but with limited success. The government is working to provide a social care system that provides care for those who need it, and which enables people to retain their independence and dignity. The government wants the users, not service providers or systems, to hold the choice and control about their care. The aim therefore is to make sure everyone can get the personalised support they deserve.

The current health and social care delivery system has, however, failed to keep pace with the needs of an ageing population, the changing burden of disease, and rising patient and public expectations. Unprecedented funding pressures affecting health and social care mean that incremental changes to current models of care will not be sufficient to address these and other challenges. A much bolder approach is needed involving a major shift in where care is delivered and how patients and service users relate to health and social care professionals. It has been argued, therefore, that the future health and social care delivery system needs to:

- See patients and service users as part of the care team.
- Focus on the development of effective health and social care teams in which staff work flexibly and full use is made of the range of skills available.
- Provide care in the right place at the right time by reducing overreliance on hospitals and care homes.
- Use information and communication technologies to revolutionize patients' and users' experiences.
- Harness the potential of new medical technologies more effectively.
- Make intelligent use of data and information to empower patients and support professionals to deliver high-quality care.

Although integration of health and social care has been on the agenda for England for a number of years, it was not until recently the policy makers in England made a serious commitment in this direction.

Legal Framework

According to the Law Commission report published in 2011, 'adult social care law, including how it relates to other legislation, has been described at various times by judges as "piecemeal", "numerous", "exceptionally tortuous", "labyrinthine" and as including some of the "worst drafted" subordinate legislation ever encountered'. The general legal framework for adult social welfare provision is still based on the National Assistance Act 1948 although this has been updated in recent years. Key legislation is identified and described below:

- ***The Health and Social Care Act 2012***

Integrated care lies at the heart of the new health and care system that was implemented in England in April 2013 with the enactment of the Health and Social Care Act 2012. This legislation embodies the aim to make the NHS more "responsive, efficient and accountable". The Act intends to put clinicians in charge of shaping services and will enable patients to be able to choose services which best meet their needs, including from charity or independent sector providers, as long as they meet NHS costs. The new "Healthwatch" is designed to ensure patient involvement across the NHS. The Act provides the underpinnings for Public Health England and removes unnecessary tiers of management, releasing resources to the frontline.

- ***The Care and Support Bill (Care Bill (HL Bill 1))***

Is aimed at providing protection and support to the people who need it most and to take forward elements of the government's initial response to the Francis Inquiry. The Bill brings together existing care and support legislation into a new, modern set of laws and builds the system around people's wellbeing, needs and goals. It sets out new rights for carers, emphasises the need to prevent and reduce care and support needs, and introduces a national eligibility threshold for care and support. It introduces a cap on the costs that people will have to pay for care and sets out a universal deferred payment scheme so that people will not have to sell their home in their lifetime to pay for residential care.

- ***Mental Health Act 2007***

The Mental Health Act (2007) made several key changes to the Mental Health Act (1983) which laid down provision for the compulsory detention and treatment of people with mental health problems in England and Wales. Whereas the 1983 Act focused on strengthening patients' rights to seek independent reviews of their treatment, the 2007 Act introduced Community Treatment Orders and was more focused on public protection and risk management.

- ***Carers (Equal Opportunities) Act 2004***

In 2004, the government introduced the Carers (Equal Opportunities) Act 2004 designed to facilitate independent living and maximize potential. It was integral to wider proposals for the reform of health and social care at the time (it is said that the legislation is strongly influenced by the Northern Ireland Equal Opportunities

legislation). The Act seeks to ensure that carers are identified and informed of their rights, that their needs for education, training, employment and leisure are taken into consideration and that public bodies recognise and support carers. The Act is an acknowledgement that carers are entitled to the same life chances as others and should not be socially excluded as a result of their caring role but it poses challenges and will require active strategic partnerships between local authorities, family carers and the people they support.

Policy and guidance

Adult social care policy is part of the Government's wider public service reform agenda. The government wants services to be personalized according to the needs and preferences of users. In adult social care, there are two central and inter-linked policy pillars - "reform of the delivery of social care" and "reform of social care funding". The government looked at the first policy framework through the Putting People First transformation programme, and reform of the funding of care and support as described in the Green Paper Shaping the Future of Care Together. The transformation of social care was initially signalled in the Green Paper, Independence, Well-being and Choice, reinforced in the White Paper, Our health, Our Care, Our Say: A New Direction for Community Services and confirmed in the Putting People First Concordat. The government aimed to achieve a 'system-wide transformation' in which people using services have 'maximum choice, control and power over the support services they receive'. The second major pillar of adult social care policy has developed in response to the future demographic, financial pressures. The Coalition government has since adopted similar principles, which reiterated its commitment to this agenda as part of its Vision for Adult Social Care.

In 2011, the Law Commission and the Dilnot Commission's report signposted key public responsibilities in relation to caring for adults. The Law Commission's proposals provide the normative foundations for new legislation so that public responsibilities in relation to such care can be understood and the law relating to need assessment and the allocation of public resources is fit for purpose in the twenty-first century'. Furthermore, it was stressed that a neutral legal framework needed to be created and the 'Dilnot Enquiry seeks to provide a firmer, fairer foundation for the allocation of responsibility for funding the cost of providing care to meet such expectations'.

The Care and Support White Paper, published in July 2012, set out the Government's vision for a reformed care and support system, building on the 2010 Vision for Adult Social Care and framework for transparency and quality in adult social care. The White paper is based on two principles:

1. The focus of care and support should be to promote people's independence, connections and wellbeing by enabling them to prevent and postpone the need for care and support.
2. People should be in control of their own care and support, and that services should ensure that they respond to what people want

Humphries argued that the Caring for our Future White Paper and the Care Bill will promote a new model that:

- is driven by promoting independence rather than reacting to crisis
- reduces the need for formal services by promoting wellbeing and strengthening the capacity of individuals, families and communities to self-care
- addresses mounting concerns about the quality of care and how dignity and safety can be assured and safeguarded
- gives priority to enabling people's recovery after illness or accident (including re-ablement, intermediate care and telecare)
- offers people choice and control through personalised approaches and access to personal budgets
- offers good advice, information and assessment to all, irrespective of their financial means.⁷¹

The whole structure of the new health and care system is based on the government mantra of “no decision about you without you”. The NHS Future Forum stated that ‘we need to move beyond arguing for integration to making it happen’. “It is clear the health service now needs to drive integration in a way that has simply never happened to date. In practice, current contracting processes, funding streams and financial pressures can actually discourage integration. There needs to be a service that both encourages innovation and supports collaboration. We also believe competition will play an important role driving change”. It also recommended that “local commissioners explore the potential benefits of joint commissioning and pooled budgets in health and social care for key populations requiring integrated approaches”. The government responded through the enactment of the Health and Social Care Act 2012 which is now placed at the heart of government's plan regarding the integration of health and social care. “The Act contains a number of provisions to encourage and enable the NHS, local government and other sectors, to improve patient outcomes through far more effective and co-ordinated working. The Act provides the basis for better collaboration, partnership working and integration across local government and the NHS at all levels. The drivers of integration in the modernised NHS will be clinical commissioning groups (CCGs) and the NHS Commissioning Board. Both have new duties to promote integrated workings by taking specific action to secure integration”. The local health and wellbeing boards are at the centre of this approach. Integration is not primarily about structures, organisations or pathways; it is about better outcomes for patients. Hence, how different services work together around patient needs will be a key part of the strategy. “The Act places a duty on Boards to consider the partnership arrangements under the NHS Act while developing their strategy”.

The Care Bill further takes forward the recommendations of the Law Commission to consolidate existing care and support law into a single, unified, modern statute to improve the quality of the care following the findings of the Francis Inquiry and to establish Health Education England and the Health Research Authority as non-departmental public bodies. The purpose of the Bill is to simplify the current legal framework for care and support. It aims to refocus the law around the person not the service. The Bill is seen as the crucial step in delivering the vision that promotes

⁷¹ Richard Humphries, *Paying for Social Care Beyond Dilnot*, 13 (Kings Fund, 2013).

“people’s well-being by enabling them to prevent and postpone the need for care and support, and puts them in control of their lives so that they can pursue opportunities, including education and employment, to realise their potential”. The draft Bill will:

- Modernise care and support law so that the system is built around people’s needs and what they want to achieve in their lives;
- Clarify entitlements to care and support to give people a better understanding of what is on offer, help them plan for the future and ensure they know where to go for help when they need it;
- Support the broader needs of local communities as a whole, by giving them access to information and advice, and promoting prevention and earlier intervention to reduce dependency, rather than just meeting existing needs;
- Simplify the care and support system and processes to provide the freedom and flexibility needed by local authorities and care professionals to innovate and achieve better results for people; and
- Consolidate existing legislation, replacing law in a dozen Acts, which still date back to the 1940’s with a single, clear statute, supported by new regulations and a single bank of statutory guidance.

The Institute for Public Policy Research has said that the Patients in England must have a single point of contact for all their care needs, as part of a move towards a “whole person approach” to care. The report says “that everyone benefits from a system that meets the physical health, mental health, and social care needs of patients holistically”. The “clause 3 of the Care Bill places a duty on local authorities to carry out their care and support functions with the aim of integrating services with those provided by the NHS or other health-related services, such as housing. It is the counterpart to the duty on the NHS in the Health and Social Care Act 2012, to ensure that organisations work together to improve outcomes for people”.

Definitions

Adult social care

The care and support provided by local social services authorities pursuant to their responsibilities towards adults who need extra support. This includes older people, people with learning disabilities, physically disabled people, people with mental health problems, drug and alcohol misusers and carers. The scope of adult social care is defined as:

- universal services; and
- services provided for individuals following an assessment

The extent of the duty to provide services for individuals is then defined by:

- An assessment of a person’s needs and the outcomes they wish to achieve.
- Identifying eligible needs by reference to an eligibility framework set out in regulations, and locally determined eligibility criteria ; and
- The provision of community care services, as defined by a list of services and outcomes and subject to a number of prohibitions on the types of services that can be provided.

Scope: Eligibility, Assessment, Care Planning, Services, Funding, Monitoring

Social care involves a wide range of services designed to support people to maintain their independence, thereby enabling them to play a fuller part in society. Successive governments have tried to find a way in which social care is funded and how the costs of these services are shared between the individual and the state, the latest development being the “Dilnot Enquiry”. Its terms of reference had a particular focus on:

- How best to meet the costs of care and support as a partnership between individuals and the state
- How people could choose to protect their assets, especially their homes, against the cost of care
- How, both now and in the future, public funding for the care and support system can be best used to meet care and support needs
- How its preferred options can be delivered.

The Law Commission report focused on promoting the single principle that adult social care must ‘promote or contribute to the wellbeing of the individual’ and the decision makers therefore have to:

- Assume that the person is the best judge of their own wellbeing.
- Follow the individual’s views, wishes and feelings wherever practicable and appropriate.
- Ensure that decisions are based upon the individual circumstances of the person (rather than assumptions relating to, for example, age or appearance).
- Give individuals the opportunity to be involved as far as is practicable in assessments, planning, developing and reviewing their care and support
- Achieve a balance with the wellbeing of others if this is relevant and practicable.
- Safeguard adults wherever practicable from abuse and neglect.
- Use the least restrictive solution where it is necessary to interfere with the individual’s rights and freedom of action.

Although the frame of reference for both reports is that of adult social care, the position of the elderly is clearly of central concern to both. The proposed legal framework recognises that social care is closely connected with family caring. The Dilnot Commission argued the case for a changed approach to social care assessment through the development of a new assessment measure, and (consistent with the recommendations of the Law Commission) portability of assessments between local authorities. The assessment measure should be ‘more objective and more easily understood’. However, Henwood’s scoping report argued that ‘there are considerable challenges with such reform, and there is a long history in social care of endeavour to achieve greater consistency and better integration in assessment’.

The Health and Social Care Act 2012 aims to put clinicians at the centre of commissioning, frees up providers to innovate, empowers patients and gives a new focus to public health. The government wants compassion to be a part of all health

and social care services. The Act establishes “Healthwatch” England, an independent organisation that will make sure that the public has a say in health and social care services. The Act provides the underpinnings for “Public Health England”, a new body to drive improvements in the public’s health. On the other hand, the government sees the Care and Support Bill as a critical step in reforming care and support in order to achieve the aspirations of the white paper, *Caring for Our Future* .

The Care Quality Commission (CQC) is the independent regulator of health care and adult social care services in England and protects the interests of people whose rights are restricted under the Mental Health Act 2007. Linked in with the latter, the government has committed to continuing to publish the Adult Social Care Outcomes Framework which explains:

- People’s experience of integrated care (for people who need both health and care services at the same time).
- The proportion of patients who would recommend their hospital to a friend or family member (the friends and family test).
- The number of vulnerable people who are referred for care to protect them from harm and who say they feel safe in care.

Research on Implementation in Practice

Recent research reveals a lack of public awareness about social care. The Law Commission found that the current legal framework is “paternalistic and narrow and built around state defined services rather than meeting and responding to the needs and goals of individuals by personalised care and support”. It recommended that adult social care should be regulated through a three level structure of statute, regulations and guidance issued under the statute and further recommends the creation of one single statute. It noted the difficulty of disentangling the law from politics in this area.

The government expects the Health and Social Care Act 2012 to address the longer-term underlying trends and pressures affecting health and social care services. The Act sets out clear roles and responsibilities, whilst keeping Ministers’ ultimately responsibility for the NHS. It limits political micro-management and gives local authorities a new role to join up local services. However, it fails to recognize that the reforms are mainly concerned with how the NHS is organized, rather than how care is delivered. The Nuffield Trust has recently argued that the Act resulted in a more fragmented governance system for the NHS, with signs of increasing power moving towards the Secretary of State.

In social care, the standards of provision are too variable and there are continuing concerns about the quality of care provided in people’s homes and in residential settings. In particular, the care of older people has highlighted the challenge of providing health and social care with dignity and respect to vulnerable people. This includes ensuring effective co-ordination of care and integration between the many organisations and services concerned with the needs of older people who are today the main users of hospitals and care homes. Although the Care Quality Commission report (CQC 2012/13) found that there have been real improvements in health care

and adult social care, the care many people receive was still poor throughout 2012/13.⁷²

The growing gap between needs and resources has led to a tighter rationing of care by local authorities. There are also concerns about the quality of care that is offered both within residential care homes and in people's own homes. The specialist housing on offer does not always reflect older people's preferences. The health and social care system gives too little priority to preventing illness and actively supporting people to live independent and healthy lives. "Support for the elderly is considered to fall within the realm of the public rather than private intergenerational transfer",⁷³ and there is no general duty owed by adult children to parents and very limited and specific duties owed by parents to adult children.

Economic circumstances are also likely to have a mixture of different impacts on the future development of social care. It is argued that "despite the Bill's best intentions, further cost cutting will reduce the quality of care for vulnerable older people". Although the new "cap and a higher upper means test threshold for social care are a major step forwards, the funding which will support the new cap and means test threshold will not fully bridge the growing gap between funding and demand for social care".⁷⁴ It may leave "out people whose needs may be serious but are not classed as 'substantial'".⁷⁵ The Care Quality Commission warned in its first report on the state of health and adult social care "...as the population ages and financial pressures grow, we expect that access to publicly-funded care will become further restricted".⁷⁶ The "Dilnot Enquiry" aims to provide a fairer, more secure funding regime for social care. However, the Joint Committee on the Draft Care and Support Bill has warned of disputes and legal challenges regarding the level of cap and eligibility threshold.

It is being hoped, however, that the Care Bill will provide greater fairness, personalized care and services but potential risks have been identified for local authorities:

- "Councils may be challenged in courts or by the ombudsman when they give advice about care.
- Increased demand for deferred payments.
- Councils need a long run in to change eligibility to ensure compliance with European Human Rights i.e. there is a requirement to consult widely and conduct impact assessments.
- The sequencing of implementation and that local authorities may not be involved soon enough in the development of the guidance and regulations.
- Regulations and guidance are not tested sufficiently.
- Implementing the technical complexities will be time consuming.
- The additional costs to local authorities of these reforms, in a context of challenging cuts to the revenue support grant as a whole. Funding for social care will not be ring-fenced.

⁷² Care Quality Commission (2012/13).

⁷³ J. Herring, *Caregivers in Medical Law and Ethics*, 25 Journal of Contemporary Health Law and Policy 12, 1-37 (2008).

⁷⁴ Nuffield Trust (2013).

⁷⁵ Nuffield Trust (2013).

⁷⁶ Care Quality Commission (2010).

- The financial modelling and the distribution across the country may lead to a shift in resources”.

There is no single ‘best practice’ model of integrated care. “Despite having the longest history of integrated care, Northern Ireland has been the slowest to exploit the potential benefits”.⁷⁷ Ham et al. argues that a structural integration between social care and health care is only one of the many factors responsible for implementing an effective integrated care. Northern Ireland needs to look beyond England perhaps towards Scotland for developing coherent policies designed to promote and support integrated care. Scotland, and in more recent times Wales, has shown a commitment to integrated care as a policy priority for their respective governments. Northern Ireland needs to find a way to remove the barriers that inhibit progress, establish a policy context that is fully aligned with the aims of integrated care, and through enabling policies and actions demonstrate that integrated care is a core objective for government.

Practice Examples

- National minimum eligibility threshold will be established from April 2015 for adults who need care, and carers.
- Entitlement will be portable if users/carers move to another council area, with councils required to maintain services until a re-assessment is completed.
- Carer’s rights to an assessment have been extended, and there will be a clear entitlement to support.
- Dignity and respect are placed at the heart of new recommended minimum training standards and a code of conduct for those working in care.
- A framework in which choice and competition (on quality, not price) can operate, including appropriate safeguards (Health and Social Care Act, 2012 provides necessary the framework).
- Integration along with competition- focuses on what benefits patients - to ensure that the benefits to patients outweigh any negative effects to competition.
- Legal initiative through Health and Social Care Act, 2012 to reduce inequalities in the benefits, which can be obtained from health services.
- “Healthwatch” England the new independent consumer watchdog for health and social care in England.
- Implementation of a duty to incorporate preventative practice and early intervention into commissioning, and new requirement for cooperation between the local authority and relevant partners, in relation to adults with needs for care and support, and carers.
- New provision to ensure adult social care and housing work together, and an expectation that NHS will work with the local authorities to consider developing housing for older and disabled people.

⁷⁷ C. Ham et al., *Integrated Care in Northern Ireland, Scotland, and Wales*, 78 (The King’s Fund, 2013).

Wales

Introduction

In 2003, the Welsh Government launched the first Strategy to address the issues and aspirations of people aged 50 and over, living in Wales. The overall proportion of older people is increasing across the United Kingdom, however, this demographic trend is even more pronounced in Wales. People over 50 in Wales currently account for 35.9% of the total population, whilst those over 60 constitute 22.7% and the number is set to rise further in less than 20 years' time.

Since devolution, the social care legislation and guidance in Wales and England has been diverging. The Government of Wales Act 2006 and the referendum on law-making powers ensures that the process of reform of adult social care law falls within the context of the devolved legislative powers. The reform of adult social care law has been a legislative priority, and it features in the post referendum Government legislative programme. Importantly, it intends to integrate health and social services.

Up to September 2009, there were 22 Local Health Boards (LHBs) and 22 Social Services authorities in Wales with shared boundaries and so, in theory at least, this should have made joint working easier. In practice, however, this was not always obvious to service users and their families and carers. In October 2009, the NHS in Wales implemented a major reorganisation and there are now 7 LHBs, but still 22 Social Services authorities. The Institute of Public Policy Research (IPPR) in its report "Policies for Peace of Mind? - Devolution and older age in the UK" found that: 'The Welsh approach seems to be the most coherent long term commitment to improving the position of older people of any administration in the UK in the last decade...the Welsh Strategy appears the most likely of any to ensure a continuing high profile for older people's issues across many policy areas and at a local level'.

Legal framework

- ***Social Services and Well-being (Wales) Bill, 2013***

Aims to facilitate the implementation of the Welsh Government's social services policies and to consolidate and provide a legal framework for the policy aims of the Welsh Government in relation to social services. Although the Bill is about social care generally, including children, it would also repeal most of Part 3 of the Children Act (1989) in relation to Wales (local authority services for children).

- ***National Health Service (Wales) Act 2006***

The NHS (Wales) Act 2006 consolidates a range of regulatory requirements relating to the promotion and provision of the health service in Wales, and to separate them from those relating to England. It is designed to secure improvement in: (i) the physical and mental health of the people of Wales and (ii) the prevention, diagnosis and treatment of illness. It also describes how to set up and manage partnership arrangements to support cross sectorial partnerships to help transform delivery of integrated, citizen focused services.

- ***Government of Wales Act 2006***

The Government of Wales Act 2006 is seen as significant step in Wales's constitutional development. The Act increases the scope of Wales's autonomy and gave more power to the devolved institutions. It made a number of significant changes, such as: creating powers for the Assembly to seek permission to create legislation on devolved issues. It separated the executive and legislature by establishing the Welsh government as an executive body-whose work affects areas such as health, education, transport and local government. The Act also made provision for further referendums on extending the powers of the Welsh Assembly.

The following legislations are applicable to some extent:

- Part III of the National Assistance Act 1948
- Section 45 of the Health Services and Public Health Act 1968
- Section 21 of and Schedule 8 to the National Health Service Act 1977
- Section 117 of the Mental Health Act 1983

A person may access social care by way of the Chronically Sick and Disabled Persons Act 1970 (CSDPA 1970) and the Disabled Persons (Services, consultation, and Representation) Act 1986. The Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000, and the Carers (Equal Opportunities) Act 2004; Community Care (Delayed Discharges) Act 2003 are also of relevance.

Policy and Guidance

In November 2009, the "Independent Commission on Social Services" in Wales was established to explore how best social services and social care can meet the needs of the citizens of Wales over the next decade. It published its findings in its report, *From Vision to Action*. In 2010, the Care and Social Services Inspectorate Wales (CSSIW) reviewed access to care services and reported that it is difficult to ascertain whether the system is fair and consistent across Wales. Furthermore, the government's vision for social services in the context of increasing demand and expectation was published in "Sustainable Social Services: A Framework for Action". Subsequently in 2012, the government published the Consultation Paper on the future shape of adult social care in Wales through 'Social Services (Wales) Bill: Our plans to change and improve social services in Wales'. The Consultation Paper draws not only upon the independent Commission's work but also on a number of Welsh initiatives as mentioned.

The Law Commission proposed a three-level model – a single statute, secondary legislation, and a statutory Code of Practice. 'The Welsh Government's consultation supports the idea of a statutory "Code of Practice" that will be subject to the National Assembly's negative resolution procedure. It anticipates single, comprehensive and consolidated guidance; however, it aims to achieve this on a phased basis'. The Welsh Government Consultation paper argues that 'there should be a general duty to "maintain and enhance" the well-being of "people in need" '.

The objective behind the proposed new legislation is to protect vulnerable adults. The Bill will promote equality, improve the quality of services and the provision of information people receive. The accompanying explanatory memorandum calls for:

- Maintaining integrated social services;
- Increasing consistency of services;
- Consolidating Welsh social care legislation;
- Empowering service users;
- Strengthening the safeguarding and protection of adults and children;
- Promoting partnership working in social care;
- And enhancing the preventative role of local authority and health services and setting out overarching well-being duties for them and their partners

In order to achieve the above-mentioned objectives, the Welsh Bill aims to:

- Create a single statute encompassing all councils' duties and functions in adult social care.
- Impose a general duty to promote well-being on bodies exercising functions under the legislation.
- Impose duties on councils to provide and arrange preventive services; provide information and advice; assess people who appear that they may need care and support; assess carers who may need support; meet needs of service users and carers if eligibility thresholds are met; provide care and support plans for eligible service users and support plans for eligible carers.
- Establish a minimum eligibility threshold for care and support.
- Impose a duty on councils to investigate cases where they suspect an adult with care and support needs (whether met or not) is at risk of abuse and unable to protect themselves because of their needs.
- Provide service users with portable eligibility, meaning they would continue to receive equivalent services if they moved areas, pending reassessment.
- Establish statutory adult safeguarding boards.

The Bill provides the legal framework for policy implementation through regulations and the Code of Practice which will themselves be developed in partnership with stakeholders and citizens, and subject to consultation in spring 2014. The focus has been on being preventive and maximising opportunities to intervene earlier to offer people proportionate help in meeting or reducing need. It will “enshrine the notion of ‘well-being’ in law, and requires the government to establish a framework for the measurement of the performance of statutory authorities in improving well-being”.⁷⁸ “It gives the government powers to speed up the provision of direct payment schemes.” The Bill also requires the local authorities to “promote the integration of care and support with health and health-related provision, with a view to improving well-being, prevention and raising quality”.⁷⁹ The approach is to encourage such cooperation, but the Bill gives ministers the power to force the pace if they are not satisfied with progress.⁸⁰

⁷⁸ Ham et al., 66 (2013).

⁷⁹ Welsh Government, para 84 (2013).

⁸⁰ Ham et al., 66 (2013).

Definitions

The definition of 'in need' is found in s.17 (10) Children Act 1989; there is no corresponding definition for adults however. Wales intends to create a holistic approach to the delivery of social care that will lead to an easier and better-planned transition from childhood to adulthood. A person will be considered to be 'in need' if:

- i. They are unlikely to achieve or maintain or have the opportunity of achieving or maintaining a reasonable standard of health or well - being, (and, in the case of a child, development) without the provision for them of social care services;
- ii. Their health, well - being (and, in the case of a child, their development) is likely to be significantly impaired, or further impaired, without the provision for them of social care services;
- iii. They are a disabled child;
- iv. They are in need of safeguarding or protection. If they are an adult, they are an adult in need who has been harmed or is at risk of harm by virtue of that need.

Scope: Eligibility, Assessment, Care Planning, Services, Funding, Monitoring

The Welsh government has called the Bill a "game changer" in transforming the provision of social care in Wales, claiming that the current legal framework is not capable of supporting the service change required to deal with a growing, ageing population.

As mentioned before, the Social Services and Well-being (Wales) Bill, 2013 will make local authorities responsible for making inquiries and deciding if action needs to be taken to protect an at-risk adult. The "Adult Protection and Support Order" to be issued by a "Justice of the Peace", would permit entry onto private premises to investigate whether a person is at risk. The Bill will also establish local and national safeguarding boards, however, the Welsh ministers can order the amalgamation of an adults' board with a children's board to create a single safeguarding board. It allows ministers to require local authorities and NHS bodies in Wales to enter into formal partnership arrangements, or even require different local authorities to enter into formal partnership arrangements with each other. It will further allow the extension of services available by direct payments and introduce a national eligibility criteria and national outcomes framework in Wales.

Research on Implementation in Practice

A series of Welsh Assembly Government papers endorse the need for social care services to be based on available evidence and aim for efficiency and effectiveness in producing the best outcomes for service users. Glasby et al. note that: despite a tendency to focus on structural "solutions", evidence and experience suggests a series of more important processes, approaches and concepts that might help to promote more effective inter-agency working – including a focus on outcomes,

consideration of the depth and breadth of relationship required and the need to work together on different levels.⁸¹

Although the Bill will have the potential to deliver transformational change in enabling people to live independent lives, “the successful implementation of the Bill will depend heavily on the interplay between well-being, prevention, assessment, eligibility and information and guidance if it is to achieve its aims”.⁸² A report by a committee of the National Assembly for Wales which examined the Bill, although welcoming its general underlying principles and the need for legislation, it expressed concern that the policy objectives of the Bill might not be realized in practice.

Practice Examples

- Development of the idea and legal classification of “person in need” based on children’s legislation.
- Portable assessments - where service users do not need to be reassessed if they move from one authority to another.
- Integrated health and social care services.
- Plans to give carers equal legal rights to those they look after.
- Delivery of services in an integrated way to people of all ages, not in separate ways to children and to adults.

Advantages of the Wales Model

Wales has followed the example of Scotland since 2009 with the creation of unified local health boards and again local authorities continue to have responsibility for social care. The government of Wales is proposing that:

- People are assessed according to their needs, regardless of where they live.
- "Portable assessments", meaning people will not have to be re-assessed if they move to a different local authority.
- Assessments of carers' needs to find out if they are eligible for help from social services

Comparison to England and Scotland

The Social Services and Well-being (Wales) Bill and the Care and Support Bill (HC Bill 168) are based on the recommendations of the Law Commission⁸³ for a statute and code of practice that would pave the way for a coherent social care system. Since the devolution of powers in 1999, health and social care policy in Wales has moved away from the quasi-market approach in England.⁸⁴ The Wales approach has

⁸¹ Jon Glasby et al., *Partnership Working in England—Where We Are Now and Where We’ve Come From*, 11 International Journal of Integrated Care 6, 1-8 (2011).

Glasby et al. note that: “despite a tendency to focus on structural “solutions”, evidence and experience suggests a series of more important processes, approaches and concepts that might help to promote more effective inter-agency working – including a focus on outcomes, consideration of the depth and breadth of relationship required and the need to work together on different levels”.

⁸² Welsh Local Government Association and NHS Confederation, 70 (2013).

⁸³ Law Commission, Adult Social Care No. 326 HC 941 May (London: HMG, 2011).

⁸⁴ C. Ham et al., *Integrated Care in Northern Ireland, Scotland and Wales*, 58 (The King’s Fund, 2013).

placed emphasis on public health and tackling health inequalities. It is focused on ensuring collaboration between public services, particularly the NHS and local government.⁸⁵

The Care and Support Bill (HC Bill 168) of England is only concerned about adults. However, the Welsh Bill is about social care generally, including children and it intends to ‘promote the integration of care and support with health and health-related provision, with a view to improving well-being, prevention and raising quality’.⁸⁶ In fact, the Welsh Bill would repeal most of Part 3 of the Children Act 1989 in relation to Wales and would create a decision-making structure for children’s services which mirrors that for adult social care.

The Welsh Bill is far more ambitious in its aim as it creates a new legal tool for protecting adults, the “adult protection and support order”. These orders would permit entry onto private premises to investigate whether a person is an adult at risk. However, both Bills provide for the establishment of local safeguarding adults boards, although the Welsh Bill allows for Welsh Ministers to order the amalgamation of an adults’ board with a children’s board to create a single safeguarding board. The Welsh Bill also provides for a National Safeguarding Board with oversight of all local safeguarding boards in Wales. Even though both Bills contain provisions to promote the integration of services. However, the Welsh Bill creates stronger powers for the government to intervene to enforce integration. It allows Welsh ministers to require local authorities and NHS bodies in Wales to enter into formal partnership arrangements, or even require different local authorities to enter into formal partnership arrangements with each other.

The Welsh Bill also proposed to create a code of practice specifying how councils should implement their social services duties and such codes would be subject to Welsh Assembly approval. By contrast, the draft Care and Support Bill in England would specify how duties should be implemented in multiple pieces of statutory guidance but would not be subjected to parliamentary approval. The draft Care and Support Bill, however, contains provisions that its Welsh Bill does not such as, duty on councils to promote a diverse and high-quality market; duty to provide service users or their carers with a personal budget and provisions for portable eligibility for support to apply for carers as well as service users.

⁸⁵ C. Ham et al., *Integrated Care in Northern Ireland, Scotland and Wales*, 58-59 (The King’s Fund, 2013).

⁸⁶ Welsh Government *Social Services and Well-being (Wales) Bill Explanatory Memorandum*, para 84 (Cardiff: Welsh Government, 2013).

Scotland

Introduction

Scotland provides an interesting comparison with Northern Ireland, not only because of its proximity but, since devolution, Scotland has managed to create a relatively comprehensive series of laws relevant to adult social care. It has also managed, under the Community Care and Health (Scotland) Act 2002, to provide free nursing care to all and free personal care to everyone aged 65 or over. *"In 2002, charges for personal care for older people living in their own homes or in care homes in Scotland were abolished, and local authorities prohibited from charging for such services. In this measure Scotland differed from the rest of the UK, where charging continued to be permitted. Scotland alone of the jurisdictions of the United Kingdom thus implemented the recommendation of the Royal Commission on Long Term Care for Older People (1999) that personal care should be free for all who needed it. Free personal care was represented as a 'flagship' policy by the new Scottish Parliament (formed at devolution in 1999) and thus invested with ideological significance".*⁸⁷

The National Health Service in Scotland has traditionally been managed separately from Social Work Departments in Councils but this is currently changing as will be discussed below. The Registrar General for Scotland (2013) reported that in 2012 Scotland's population was estimated to be 5,313,600, the highest ever. In general Scotland's population has tended to be fairly stable over the past 50 years. The last peak was at 5.24 million in 1974 and dipped to 5.05 million in 2002. The recent increase has been mainly due to more people moving to Scotland than leaving. Approximately 17% of the population are aged 65 and over. Between 2010 and 2035 it is estimated that the number of people aged 65 and over will increase by 63%, from 0.88 million to 1.43 million.

Legal framework

As mentioned in the introduction, Scotland has a relatively long list of laws relevant to adult social care (Institute for Research and Innovation in Social Services, 2013). The Social Work (Scotland) Act 1968 provides the main foundation for social services provided through the local authorities to provide information, assess need and provide services, but a range of subsequent laws has introduced amendments and/or additions. The Chronically Sick and Disabled Persons (Scotland) Act 1972 requires that the need of disabled people be assessed and service provided. The Disabled Persons (Services, Consultation and Representatives) Act 1986 enables a representative to be appointed for a disabled person and it also requires the needs of someone who has been in psychiatric in-patient care for six months to be assessed by the health and local authority. The NHS and Community Care Act 1990 inserted, into the 1968 Act, a duty to assess anyone who may need community care services. The Carers (Recognition of Services) Act 1995 established a duty to consider the needs of carers and the Community Care (Direct Payments) Act 1996 introduced

⁸⁷ Alison Bowes and David Bell, *Free Personal Care for Older People in Scotland: Issues and Implications*, 6.03, Social Policy and Society, 435-445 (2007).

direct payments as an alternative to direct service provision. The Adults with Incapacity (Scotland) Act 2000 provides a legal framework for those whose decision making ability may be impaired. The Regulation of Care (Scotland) Act 2001 established the Scottish Commission for the Regulation of Care and the Scottish Social Services Council. The Community Care and Health (Scotland) Act 2002 introduced regulations about the charging and not charging for social care. The Mental Health (Care and Treatment) (Scotland) Act 2003 also requires local authorities to provide care and support services. The Adult Support and Protection (Scotland) Act 2007 provides a legal framework for adult safeguarding.

Two more recent laws are central to the provision of adult social care. The first is the Social Care (Self-directed Support) (Scotland) Act 2013 which will come into force in 2014 and is a consolidating Act, in other words, it brings together provisions from a range of laws in a more coherent and integrated way. The Act sets out general principles and a range of options for how self-directed support can be provided. The other relevant legislative development is the Public Bodies (Joint Working) (Scotland) Bill which is intended to provide increased integration between health and social services either by establishing a joint Board or agreeing which agency will take the lead on certain functions.

Policy and Guidance

As Gray and Birrell (2013) report, Changing lives: Report of the 21st century social work review (Scottish Executive, 2006) had set out the major policy directions for social care which included personalisation, co-production, integration, early intervention and the mixed economy of care.⁸⁸ Reshaping care for older people (Scottish Government, 2010) is an initiative which aims to continue to shift the balance of services from hospital to community by further developing anticipatory care and prevention.⁸⁹ The Self-directed Support (Scotland) Strategy (2010) had set out a 10 year plan for increasing choice and control and the subsequent Act is an important part of that process.⁹⁰

Research on Implementation in Practice

A review of social care in Scotland had concluded that services had become too focused on risk and that “Social care in Scotland should be organised around the idea of personalisation: people as active participants in shaping, creating and delivering their care, in conjunction with their paid and unpaid carers, so that it meets their distinctive needs and their hopes for themselves”.⁹¹

As part of the development of self-directed support, three test sites were identified and evaluated. In each of these areas, this approach was promoted through: leadership and training; reducing bureaucracy; and providing bridging finance. The evaluation reported that previously direct payments had not been working well and, although the test sites increased the availability of self-directed support, some of the

⁸⁸ Ann Marie Gray and Derek Birrell, *Transforming Adult Social Care* (Bristol: Policy Press, 2013).

⁸⁹ Scottish Government, *Reshaping Care for Older People* (Edinburgh: Scottish Government, 2010).

⁹⁰ Scottish Government, *Self-Directed Support: A National Strategy for Scotland* (Edinburgh: Scottish Government, 2010).

⁹¹ Charles Leadbeater and Hannah Lownsbrough, *Personalisation and Participation: The Future of Social Care in Scotland*, 4 (Demos, 2005).

difficulties with a lack of choice in service provision and local variations seemed to continue.⁹²

An independent review of the provision of free personal and nursing care by Lord Sutherland in 2008 concluded that “despite some practical difficulties in its formative years, the Free Personal and Nursing Care policy remains popular and has worked well in the largest part, delivering better outcomes for Scotland’s older people”.⁹³

The most recent statistics from the Scottish Government (2014: 2-3) report that:

- *78,000 people in Scotland benefit from Free Personal Care, just over 30,000 people in Care Homes and nearly 48,000 people living in their own home;*
- *The overall number of older people in care homes has reduced slightly since the Free Personal and Nursing Care policy was introduced, from around 32,000 in 2003-04 to just over 30,000 in 2012-13;*
- *The number of older people receiving personal care services in their own homes has increased from 33,000 in 2003-04 to nearly 48,000 in 2012-13.*

*The amount spent by Local Authorities on providing personal care services to older people in their own home has risen from £133 million in 2003-04 to £349 million in 2012-13. Large increases in expenditure in the early years of the policy have gradually diminished and recent years show much smaller rises with an increase of only 0.7% in 2012-13. The overall increase in expenditure over the last 8 years reflects the fact that an increasing proportion of older people are cared for at home, rather than in hospital or care homes; that increasingly Home Care workers are providing personal care services rather than domestic services; and that people living at home have increasing levels of need.*⁹⁴

Practice Examples

- The Social Care (Self-directed Support) (Scotland) Act 2013 provides a good example of the potential of a consolidating law to bring together a range of provisions from a number of laws which have developed over time.
- The provision of free personal and nursing care would also seem an excellent example of a fair and non-discriminatory system of funding and providing social care.
- There are also some good examples of involvement in Scotland, such as the annual Scottish Older People’s Assembly and Edinburgh’s A City for All Ages reports which include Working Together: The participation of older people in the development of policies and services in Edinburgh (Employment Research Institute, 2012).

⁹² Julie Ridley, Helen Spandler et al., *Evaluation of Self-Directed Support Test Sites in Scotland* (Edinburgh: Scottish Government Social Research, 2011).

⁹³ Lord Sutherland, *Independent Review of Free Personal and Nursing Care in Scotland*, 3 (Edinburgh: Scottish Government, 2008).

⁹⁴ Scottish Government, *Free Personal And Nursing Care, Scotland, 2012-13*, 2-3 (Edinburgh: Scottish Government, 2014).

Republic of Ireland

Introduction

The Republic of Ireland is described as a liberal welfare state with a subsidiary and residual approach to welfare provision influenced by Catholic conservatism.⁹⁵ This is a particularly important aspect of how the state has viewed its responsibilities in regard to social care provision towards older people in particular.

Legislation, Policy and Guidance

Timonen et al. point out that little developed in regard to policy activity since 1968 when community care as official government policy was outlined in the Report of the Inter-Departmental Committee on the Care of the Aged. The latter policy is noteworthy in its reference to maintaining “elderly people in dignity and independence in their own home” as being a public policy objective of the State”.⁹⁶ Ahern et al. considered this to be particularly important as it resonates with Article 8 of the European Convention on Human Rights as supported by European case law, see below.⁹⁷ The current policy in regard to social care for older people in Ireland is shaped by the Working Party on Services for the Elderly, 1988, and this remains intact despite the significant social and demographic changes that have occurred in Ireland. Ahern et al. in reference to the latter policy reports point out that: “The State has long placed a heavy rhetorical emphasis on the importance of community care over institutional care. Among the reasons forwarded for this is that community care is a cheaper alternative to institutional care and it is the preference of the majority of older people”.⁹⁸

The National Development Plan for 2007-2013 ring-fenced 4.7 billion Euros for community-based services to older people.⁹⁹ This marked a significant commitment to expanding social care services for older people, what was still absent however was any legislative or policy instruments for monitoring and regulating such services in terms of access, eligibility and quality monitoring. The 2001 health strategy Quality and Fairness - A Health System for You signalled the government’s continuing commitment to community care social care services which would have a shaping influence over the coming 10 years.

Home-care Support Schemes was the official term used at the start of the new millennium to describe the range of social care provision available to older people in the Republic. This is the scheme that was rolled out nationally in 2006 and administered by the Health Service Executive (HSE), the official body with responsibility for providing social care services to Republic of Ireland’s population.

⁹⁵ Virpi Timonen, Martha Doyle and Ciara O’Dwyer, *Expanded, But Not Regulated: Ambiguity in Home-Care Policy in Ireland*, 20(3) Health and Social Care in the Community, 310-318 (2012).

⁹⁶ D. Ahern, M. Doyle and V. Timonen, *Regulating Home Care of Older People: the Inevitable Poor Relation?*, 29 Dublin University Law Journal, 375 (2007).

⁹⁷ “Personal Autonomy and Dignity were Regarded by the European Court of Human Rights as Aspects of the Right to Respect for Private Life in *Pretty v United Kingdom* [2002] 2 FLR 45” (cited in Ahern et al., 376 (2007)).

⁹⁸ *Id.*, 375.

⁹⁹ Virpi Timonen, Martha Doyle and Ciara O’Dwyer, *Expanded, but Not Regulated: Ambiguity in Home-Care Policy in Ireland*, 20(3) Health and Social Care in the Community, 310-318 (2012).

Nonetheless, older people do not have a 'right' to these home-care packages. There has been inconsistency also noted in refining eligibility criteria for these home care services in the absence of any standardised set of criteria which has culminated in provision being disparate across the country.

It is noted however that whilst the Irish government pumped in significant expenditure to develop home-care services in particular, this occurred within a legislative and policy vacuum, so nothing still existed in terms of either governance or regulation. The introduction of the Health Act (2007) established the Health Information and Quality Authority (HIQA) whose function would be to inspect and regulate institutional/residential (public and private) care. An on-going serious problem, however, relates to the gross geographical disparities and inconsistencies in regard to both accessibility and availability of social care services. An added problem to social care provision relates to its existence and delivery in the absence of any regulatory framework to monitor its delivery and quality. With reference to home care provision, within which 'social care' provision is largely found, there is thus the inherent ambiguity associated with increased service provision outside of a corresponding legislative and policy environment.

Research on Implementation

Evidence has shown that the expansion of home care services and expenditure is also directly related to the problems associating with older people having unnecessarily prolonged stays in hospital.¹⁰⁰ The government in the Republic of Ireland, therefore, had to be seen to be responding to this crisis. Some commentators have also concluded that policy making in Ireland occurs in the absence of any guiding principles¹⁰¹ and is prone to political manipulation and exploitation.¹⁰² Arguably as a result of Ireland's political system of proportional representation, candidates seeking election can engage in localised initiatives promotion that are short term and linked to benefitting their own constituencies.¹⁰³ Policy making at a macro/national level is inevitably, therefore, faced by obstacles in a system that cultivates localism. Timonen et al. conclude that "remnants of the clientilistic system ...may still be impeding the development of an overarching vision of care for older people" in the Republic of Ireland in spite of the reforms associating with the 2001 National Health Strategy (Department of Health and Children, 2001).¹⁰⁴

The Republic of Ireland has a system of social protection characterised by 'low tax-low spend'.¹⁰⁵ As a result, means-testing is applied to the context of service provision in adult social care. It is a country, whilst claiming to be wedded to community care as a policy priority, which has invested more resources into residential care than to home care services, which the state has no legal obligation to

¹⁰⁰ Virpi Timonen, Martha Doyle and Ciara O'Dwyer, *Expanded, But Not Regulated: Ambiguity in Home-Care Policy in Ireland*, 20(3) Health and Social Care in the Community, 310-318 (2012).

¹⁰¹ OECD (2008) Ireland: Towards an Integrated Public Service. OECD, Paris.

George Taylor G. *Negotiated Governance and Public Policy in Ireland* (Manchester University Press, Manchester, 2008).

Pat Nolan, *Dynamics of Regulation in Ireland: Advocacy, Power and Institutional Interests* (IPA, Dublin, 2005).

¹⁰² Taylor, *Negotiated Governance and Public Policy in Ireland* (Manchester University Press, Manchester, 2005).

¹⁰³ Timonen et al. (2012).

¹⁰⁴ *Id.*, 315.

¹⁰⁵ *Id.*

provide. Timonen et al. succinctly summarise the problem as follows: “The continuing absence of legislation, which would provide citizens with a statutory entitlement to domiciliary care services based on care needs, evinces a lack of aspirations to shift the allocation of resources from institutional care to domiciliary care”.¹⁰⁶ It is argued also by Alber that, in the absence of a regulatory framework, inadequately resourcing and cutting back on domiciliary services is inconsequential in a context of economic austerity. Politicians are therefore ‘let off the hook’ whilst uncertainty and lack of clarity inevitably remain in regard to issues around entitlement to and eligibility for domiciliary services.¹⁰⁷

It is also noted that the overwhelming majority of older people in the Republic wish to stay at home in preference to institutional care.¹⁰⁸ This, however, is not mirrored in legislation, namely the Health Act (1970). This legislation is, therefore, not specific about who is entitled to community care services.¹⁰⁹ Eligibility to health care services is, instead, dependent upon the recipient having a medical card and is given priority by virtue of this. The 1970 legislation is also discretionary in the State’s responsibilities to maintain and support people with high levels of dependency and infirmity in their own homes (Section 61 of the Act). Hamilton therefore concludes: “there is no legal framework in place for the delivery of such care”¹¹⁰ in reference to domiciliary care for older people. Hamilton also observes that there is no legislative basis or requirement to assess older people’s needs who are living at home.¹¹¹

Section 7 of the Nursing Homes Support Scheme Act (2009) does, however, provide for an assessment where a person is making an application for state support in respect of residential care. A proper needs assessment is therefore occurring through an applicant applying for funding for institutional based care, which does present as something of an anomaly. Policy development has however occurred.

The Long Term-Term Care Report (2008) set down the basis for introducing Home Care Packages (HCP) whereby older people at risk of being admitted to institutional care would receive community care services at home. This scheme has not, however, enjoyed much success due to assessments being quite fragmented with different means tests being applied and arbitrariness evidenced across regions. The key criticism of this scheme is, ultimately, that it was not based on any legislation. Absence of fair and equitable eligibility criteria regarding admission to nursing homes has also been noted by the Irish Human Rights Commission (2003). The Health (Amendment) Act (2005) introduced a system of payment by older people for maintenance charges in publicly provided nursing homes. The Nursing Homes Support Scheme Act (2009) established the *Fair Deal* scheme through which residents applying for nursing home care in either the public or private sectors would be required to pay based on their income and assets with the State then making up any shortfall.¹¹²

¹⁰⁶ Timonen et al., 316.

¹⁰⁷ Jens Alber, *A Framework for the Comparative Study of Social Services*, 5(2) Journal of European Social Policy, 131-149 (1995).

¹⁰⁸ Irish Human Rights Commission (2003).

¹⁰⁹ Claire Hamilton, *Irish Social Care Law* (Dublin: Gill & Macmillan, 2012).

¹¹⁰ *Id.*, 204.

¹¹¹ *Id.*

¹¹² *Id.*, 208.

The Equal Status Acts (2000-2004) protect older people with disabilities from discrimination in regard to provision of goods and services and accommodation. The Citizens Information Acts (2000-2007) introduced a formal system of advocacy to “support people with disabilities in identifying their needs and accessing social services”.¹¹³ The Disability Act (2005) stipulates the legal right to assessment of need, however, this does not apply to adults and only applies to children under the age of five.¹¹⁴ The Health Act (2004) imposes a statutory duty on the Health Service Executive (HSE) to manage and deliver health and personal social services and also underscores mandatory provision of inpatient and outpatient services free of charge to those with full or partial eligibility.¹¹⁵ People with disabilities do not retain an individualised right to community care services instead a “generalised obligation is imposed on the HSE to make such services available within the limits of available resources”.¹¹⁶ Section 61 of the Health Act (1970) uses the term ‘may’ in regard to any obligation towards service provision for people who are sick and infirm and living in their own homes. Again, this distances the State from having any statutory duties; instead this is discretionary in status.

Mental health provision in the Republic is governed by the Mental Health Act (2001). This was significantly influenced by the 1984 policy document: The Psychiatric Services - Planning for the Future which underscored the importance of providing mental health services in the community. The Mental Health Act was introduced in 2006 and replaced the Mental Treatment Act (1945), which was considered very draconian and inadequate in the protection of civil liberties.¹¹⁷ The introduction of new legislation was regarded as significantly improving things for people with mental health problems. “Severe dementia” is defined in Section 3 of the 2001 Act as a form of mental disorder. People with mental ill-health in Ireland do not have a statutory right to treatment; they do, however, have such a right to an individualised care plan if they are living in an institution that is registered by the Mental Health Commission. The existence of such a care plan affords significant protections and ensures that needs are met in an organised and multi-disciplinary manner.

Future Policy Directions

The Republic has set out its vision for health and social care in its Strategic Framework.¹¹⁸ This document states that that this is the most significant reform in the history of the State. Central to financing these reforms is a system of Universal Health Insurance (UHI) based on principles of social solidarity. At the core of this will be equality in access to healthcare based on need and not income. Social care services will be ‘outside of this UHI system but integrated around the user’.¹¹⁹ Within this, the government is removing its long-standing commitment to residential care as a form of community care and envisions instead that older people and people with disabilities should be helped to live in their own homes for as long as possible. Within this Strategy also, the Fair Deal Scheme is to be extended to both disability and mental health sectors. Interestingly, given the deficits already alluded to on

¹¹³ Hamilton, 221 (2012).

¹¹⁴ *Id.*, 223.

¹¹⁵ *Id.*, 224.

¹¹⁶ *Id.*, 225.

¹¹⁷ *Id.*

¹¹⁸ Department of Health (DOH) Future Health, *Strategic Framework for Reform of the Health Service 2012-2015*, (DOH: Dublin, 2012).

¹¹⁹ *Id.*, i.

regulation, the policy commits to having a "robust "regulatory scheme to ensure quality and safety".¹²⁰ The thrust of the new proposed arrangements sees social care and *continuing care* placed together assessed via a single assessment framework in terms of service delivery to: people with disabilities, people with mental health issues, older people and palliative care. Robust arrangements for quality assurance and regulation are proposed with an emphasis and recognition of person-centeredness as a core principle undergirding service provision.

In regard to the generic principles proposed for underpinning this new system of social and continuing care, the Republic is committing itself to: "a focus on the rights and dignity of the person concerned with care guided by the person's own views and wishes".¹²¹ A standardised care assessment framework will be the main tool for assessment of social and continuing care needs. This framework will use a scoring system to determine the extent of funding provided by the state to support an individual's assessed social care needs. Pro-rata funding is proposed for those with lower scores in this framework. Nonetheless, there are important caveats referred to in this strategy: "taking into account the overall level of funding available and the anticipated level of demand".¹²² The latter implies that the State will be able to defend its inability to provide services based on inadequacy of resources. Individualised budgeting will also be a central plank to how the State will attempt to achieve person-centeredness as a core principle. A system of direct payments has, therefore, been proposed as a way of delivering on the latter.

In regard to modernising disability services, the Strategy also recommends a person-centred model as the basis for future direction focusing on individualism and community care as priorities. Legislative change is also recommended in regard to both regulation and inspection in regard to social care provision by 2016.

Practice Examples

The appointment of an advocate in the Citizens Information Acts (2000-2007) is a positive development. This enables a service user to receive direct assistance in navigating access to social care services. The legal right to an assessment of need as stipulated in the Disability Act (2005) is also an example of good practice conceptually even though this does not apply to adult social care. Nonetheless, it is important to have such a requirement fore fronted in legislation.

¹²⁰ Id., v.

¹²¹ Id., 38.

¹²² Id., 39.

Australia (Victoria)

Introduction

Australia is also experiencing the demographic changes that are happening in most developed countries. In the past ten years the proportion of Australia's population aged 15-64 years has remained stable and the proportion of people aged 65 years and over has increased from 11.6% to 14.4%. During the same period, the proportion of population aged 85 years and over has almost doubled from 1.0% to 1.9% of the population.¹²³ Victoria was included in this review mainly because it had a relatively fast transition from institutional to community care in the 1980s and so has perhaps had a longer experience of community care than most jurisdictions.

In Australia, assessments for adult social care for older people are carried out by Aged Care Assessment Teams (ACATs) to identify need and eligibility for care. There are national guidelines but this doesn't extend to nationally agreed assessment tools or criteria and, in addition to Federal laws and policies, each state develops its own legal and policy framework.

Legal framework

The Commonwealth Home and Community Care Act 1985 was an early example of a law to facilitate people to move from institutional care and to be supported in their own homes. It aimed to "to promote the provision of a comprehensive and integrated range of home and community care designed to provide basic maintenance and support services, both directly and through their carers, to persons within the target population and thereby to assist them to enhance their independence in the community and avoid their premature or inappropriate admission to long term residential care".¹²⁴ The legal framework for adult social care in Victoria is made up of a range of laws including the Aged Care Act 1997, the Carers Recognition Act 2012, the Health Services Act 1988 and the Disability Act 2006 which facilitated the use of more individualised funding models.

Policy and Guidance

Victoria provides a range of generic briefs for the different components of services so, for example, below is the introduction to the brief for Aged Care Assessment Services:

"Aged Care Assessment Services (ACAS) are an integral part of the wider aged care system. They provide assessment, information advice and assistance to older people who are becoming frail and wish to remain at home or who are thinking about moving into residential care. Younger people with a disability may also be eligible for assessment services. The generic brief has been developed

¹²³ Australian Bureau of Statistics, *Australian Demographic Statistics*, (2013) available online at <http://www.abs.gov.au/>, accessed on 9th May 2014.

¹²⁴ Commonwealth Home and Community Care Act 1985, Section 5.1.a.

to ensure that ACAS facilities are designed to create a quality environment that meets the service needs of the community.

The aim of this generic brief is to:

- Outline the guidelines for the development of project specific briefs for individual State funded Aged Care Assessment Services in Victoria, Australia.
- Provide a consistent and clear framework within which regions develop and negotiate health service delivery strategies with potential service providers.
- Provide general principles for quality design outcomes for ACAS.
- Provide an overview of the services and activities that ACAS will commonly provide.
- Describe in generic terms the spaces required to conduct those services and activities”.

Given concerns about regional variation in service provision, these generic briefs could be one way of promoting standardised, consistent service provision. Victoria has also had a form of self-directed support programme called Support and Choice since 2003. It aims to allow people to create their own service plans. The state has also implemented supported decision making, which refers to the process of facilitating someone who has impaired decision making ability to make their own decisions. The Department of Human Services has proposed seven decision making principles to frame this process:

1. “I have the right to make decisions;
2. I can make decisions;
3. I might sometimes need help to make decisions;
4. I might be able to make decisions about some things but not others;
5. I can learn from trying things out;
6. I might want to change my mind;
7. I might make decisions other might not agree with”.¹²⁵

The provision of support based on clear, accessible principles like these may be an important way of ensuring that people can engage with their own social care.

Research on Implementation in Practice

An Australian evaluation of the effectiveness of self-directed support identified the different ways people could employ their own support workers.¹²⁶ These included recruiting directly or through a company, association or cooperative. It concluded that a range of models are needed to respond to people’s needs and preferences that may also develop and change over time. It reported that there is a clear need for information and support to facilitate people to make decisions about how and what they want to do, in terms of the process, provision and content of care. The evaluation also highlighted that individual funding is more likely to be used by people of working age with low support needs, by male and non-Indigenous service users,

¹²⁵ Department of Human Services, *Supported Decision Making: A Guide to Supporting People with a Disability to Make Their Own Decisions* (Melbourne: State Government of Victoria, 2012).

¹²⁶ Karen R. Fisher, Ryan Gleeson et al., *Effectiveness of Individual Funding Approaches for Disability Support* (Canberra: Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, 2010).

by people with a single impairment, and by people across all disabilities without informal care networks.¹²⁷ This would suggest that specific attention would be needed to consider issues of access and support to ensure people are aware and supported to engage with these models of social care.

¹²⁷ Karen R. Fisher, Ryan Gleeson et al., *Effectiveness of Individual Funding Approaches for Disability Support* (Canberra: Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, 2010).

Canada (Province of Ontario)

Introduction

Ontario is one of ten provinces in Canada, and with approximately 13 million in population (as of 2011), it has more than 40% of the total population of Canada. The median age of Ontario's population is projected to rise from 40 years in 2012 to 43 years in 2036. Median age for women will climb from 41 to 44 years over the projection period while for men it is projected to increase from 39 to 43 years.¹²⁸

The number of seniors aged 65 and over is currently about two million, which is 14.6 percent of population in 2012. The senior population is project to more than double, and to increase its total share of the total population to approximately 24.0 percent by 2036. The Ontario Ministry of Finance observes, "By 2016, for the first time, seniors will account for a larger share of population than children aged 0-14."¹²⁹

Further, the Ministry projects that the "older" seniors will experience the fastest growth. The Ministry projects that number of people aged 75 and over will rise from 910,000 in 2012 to over 2.2 million by 2036. "The 90+ group will more than triple in size, from 96,000 to 291,000".¹³⁰

Law, Policy and Guidance

Recognizing the link between health and healthy aging, Ontario has a single Ministry for "Health and Long-Term Care." The Ministry has also pursued a phased "Senior Care Strategy." For example, in 2012, the Ministry announced that its strategy would include:

- Expansion of doctor's house calls;
- Increase in access to home care for seniors in need;
- Establishing care coordinators to work with health care providers so seniors receive the right care, particularly as they recover from a hospital stay;
- Allowing seniors to adapt their home to meet their needs as they age with the assistance of the Healthy Homes Renovation Tax Credit;
- Helping seniors stay healthy by eating well and exercising regularly so they can manage their own care and stay mobile.

A major component of the Senior Care Strategy was developed by a team lead by Dr. Samir Sinha, described by the Ministry as passionate in pursuit of a senior care policy, with a background as Director of Geriatrics at Mount Sinai and the University

¹²⁸ Ontario Ministry of Finance, Population Overview at <http://www.fin.gov.on.ca/en/economy/demographics/projections/#s3b>.

¹²⁹ Ontario Population Projections Update, Spring 2013 at <http://www.fin.gov.on.ca/en/economy/demographics/projections/#s3b>.

¹³⁰ Ontario Population Projections Update, Spring 2013 at <http://www.fin.gov.on.ca/en/economy/demographics/projections/#s3b>.

Health Network Hospitals in Toronto.¹³¹ The team report, titled “Living Longer and Living Well”, was released in March 2013, and provides a detailed blueprint of analysis and recommendations for government support, oversight and funding for an integrated strategy to health and social care in Ontario.¹³²

As in the U.S. and other countries, the strategy recognizes the increased importance of care in the home and community settings, outside of hospitals and traditional nursing homes. However, the Ontario Senior Care Strategy also emphasizes the need for better integration between acute care in hospitals and long-term care for older adults. Examples of this integrated care approach include a theory of “right care,” focusing on “timing,” as well as on quality of health care and in the right places for care. One of the steps taken to implement the Ontario Senior Care Strategy has been a “Healthy Home Renovation Tax Credit” available to persons 65 and over to improve the home to better assure safety and healthy aging. The existence of the credit would appear to encourage retiring individuals, who have sufficient income to benefit from a tax credit, to plan up to \$10,000 in renovations that will enable them to stay in their home for a longer period, with the incentive being the receipt of a credit of \$1,500.¹³³

Another example of the recommendations supporting the integrated approach to health and social care was enhancement of standards for “Personal Support Workers,” represented by a new PSW Registry by requiring mandatory registration, requiring a common educational standard for all future registrants, and developing a complaints process that can protect the public and the profession. In addition, the Strategy emphasizes an enhanced role for senior-specific “para-medicine,” especially as response to senior care emergencies of all descriptions is often handled by paramedics as the first responders.¹³⁴

¹³¹ “Ontario Helping More Seniors Live At Home Longer: McGuinty Government Moving Forward With Seniors Care Strategy,” News Release from Ministry of Health and Long-Term Care, May 24, 2012, available at

<http://news.ontario.ca/mohltc/en/2012/05/ontario-helping-more-seniors-live-at-home-longer.htm>.

¹³² Living Longer and Living Well, at

http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf.

¹³³ Details on Ontario Healthy Home Renovation Tax Credit at <http://www.ontario.ca/taxes-and-benefits/healthy-homes-renovation-tax-credit>.

¹³⁴ Living Longer and Living Well, at

http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf.

Denmark

Introduction

Denmark has a current population of 5.5 million people, 15% of whom are 65 years and older and 4% are 80 years and older. Similar to other EU countries, these trends will continue to rise over the next thirty years with one quarter of the population estimated to be over 65 by 2050 and 9.7% of the population will be over 80 years of age.¹³⁵

Legislation, Policy and Guidance

Denmark also has a system of social welfare best described as universal, within which it is the responsibility of the State to provide welfare service to all of its citizens. Within this, adult social care is financed through local taxes and block grants from the State based on the core principle of free and equal access. All types of personal care are therefore viewed as being the responsibility of the municipality (State). Denmark's National Action Plan (2003), in reference to older people, calls for all services to older people to be based upon their "wants and needs".¹³⁶ Denmark's National Strategy Plan (2006) highlights the importance of empowerment as a context to service provision for older people in particular. The end objective in government provided assistance is therefore always aimed at enabling "the recipient to the widest extent possible to help perform as many tasks as possible".¹³⁷

Rostgaard observes that: "Elder care in Denmark is driven by the principle of 'ageing in place', that is, to provide help and care in the community so that seniors can remain in their own homes as long as possible".¹³⁸ Provision of *home care* is this country's primary way of delivering on this objective. Denmark's priority to home care in preference to institutional care is higher than in any other EU country. This is very much seen as a reflection of its commitment to espousing the key principles of normalisation and continuity of care as being core to its system of social care provision. The voluntary sector and informal sector (family carers) have a subsidiary part to play in social care provision and there is no expectation that families will become part of the helping system. Women also participate in the labour market in a large scale. Home care provision is provided free of charge and home help is the main form of in-home social care provision reaching a significant number of Denmark's citizens.

Marketization is also, however, a prevalent feature of the adult social care system in Denmark, having taken hold significantly in 2003: "with the introduction of the 'Frit valg' (Free Choice of Provider) scheme, which requires local authorities to encourage

¹³⁵Erika Schulz, *The Long-Term Care System in Denmark*, 6 (German Institute for Economic Research: Berlin, 2010).

¹³⁶ National Action Plan (NAP)(Denmark, 2003).

¹³⁷ National Strategy Plan (NSP), 41 (Denmark, 2006) (Cited in Schulz, 1 (2010)).

¹³⁸ Tine Rostgaard, *Quality Reforms in Danish Home Care-Balancing Between Standardisation and Individualisation*, 20(3) Health and Social Care in the Community, 248 (2012).

alternative service provision from for-profit providers”.¹³⁹ As a result, private for profit providers of home care are also very much part of the social care delivery system. This is felt to be consistent with increasing “productivity, improving quality and adhering to user choice”.¹⁴⁰ The concept of quality has arguably been the golden thread that has been at the heart of welfare reform in Denmark, especially in the context of older people. Unsuccessful and subsequently unpopular attempts to reduce welfare costs resulted in strong public opposition to the Danish government in the late 1980’s. This, in turn, fuelled the focus on quality at policy level.¹⁴¹ Within the latter, user involvement, choice, meeting needs and preferences, would become predominant features of adult social care, particularly for older people. Denmark’s Ministry of Social Affairs underscores this commitment through the following statement on its official website: “Social welfare development aims to secure innovation and development of the public welfare service. The goal is to gain better quality in the effort towards vulnerable children and young people, in the eldercare and all the other parts of the welfare service. Important elements in the professional development of the welfare sector are enhanced focus on best practices, documentation and effects and user involvement”.¹⁴²

Denmark’s manifest commitment to ‘ageing in place’ was demonstrated by the enactment of the 1987 Act on Housing for Older and Disabled People. Within the latter, the government stipulated that nursing homes should no longer be built with shared living facilities. Instead, these would have to incorporate design entailing independent living units for older residents. Rostgaard comments that: “provision of care for elderly and disabled in Denmark is based on principles of 1) continuity, 2) autonomy and empowerment, and 3) help-to-self-care”.¹⁴³ Significant emphasis is therefore placed on older people having choice and influence over any services they might need. Denmark’s National Commission on Ageing (1981) was significant in developing this person centred orientation to social care. This was also significant in the development of the annual Preventative Visit to older people over 75 and is also linked in directly with Denmark’s integrated health and social care system.

The Preventative Visit is legally mandated through the Consolidation Act on Social Services. This is described in Section 79a of this Act as follows: “The municipal council shall offer preventive home visits to all citizens who have attained the age of 75 and are residents of the municipality. The municipal council shall offer at least one annual preventive home visit.”¹⁴⁴ “The Preventive Visit has been introduced after several randomised controlled trial studies proved this service cost-efficient in that it reduces the risk of becoming hospitalised or admitted to a nursing home, and proved to have a positive effect on mortality”.¹⁴⁵ The focus of this visit is on needs assessment and helping continue planning for sustained independent living.¹⁴⁶ The

¹³⁹ Tilde Marie Bertelsen and Tine Rostgaard, *Marketisation in Eldercare in Denmark: Free Choice and the Quest for Quality and Efficiency*, Gabrielle Meagher and Marta Szebehely (eds), *Marketisation in Nordic Eldercare: A Research Report on Legislation, Oversight, Extent and Consequences*, 127 (Department of Social Work: Stockholm University, 2013).

¹⁴⁰ Rostgaard, 74 (2012).

¹⁴¹ Preben Melander, *Det fortraengte offentlige lederskab-Offentlig ledelse efter New Public Management* (Copenhagen: DJOF Publishing, 2008).

¹⁴² <http://english.sm.dk/welfare-development/Sider/Start.aspx>.

¹⁴³ Rostgaard, 76 (2012).

¹⁴⁴ Part 14, Section 79a, Consolidation Act no.1093 of 5 September 2013.

¹⁴⁵ Rostgaard, 78 (2012).

¹⁴⁶ Erika Schulz, *The Long-Term Care System in Denmark* (German Institute for Economic Research: Berlin, 2010).

statement below is an extract from Denmark's Ministry of Social Affairs on the initiative:

Preventive Home Visits

"Every municipality has the obligation to offer each citizen, who has turned 75 years old and live in their own home without personal or practical help, at least two preventive home visits every year. The purpose of the preventive home visits is to enable both the elderly citizen and the municipality to make use of those offers available that can help the elderly sustain physical and social skills and prevent loneliness, loss of feeling of security etc. The elderly citizen has the right to say no to a visit, but still the number of preventive home visits continues to rise." <http://english.sm.dk/social-issues/Elderly-people/preventive-home/Sider/Start.aspx>

Research on Implementation

Vass et al. report that these visits have however been blighted by inconsistencies in how they have been managed and implemented as standardised guidelines were not issued.¹⁴⁷ Schulz also reports that: "in 2007, 30% of preventive home visits were refused (117,000) and in 45% of the cases completed, preventive home visits were carried out (178,000)".¹⁴⁸

The Consolidation Act on Social Services (2013) is the key legislation governing the delivery of public social services in Denmark and applies to the broad range of social welfare recipients (older people, children and families, palliative care, mental illness and learning disability). Municipalities, however, can individually develop their own particular policies in regard to provision of services to such groups. There is, however, evidence of regional disparities in spending and lower levels of service provision in a context of fiscal restraint and fewer resources.¹⁴⁹

Service provision is funded by the municipalities in Denmark through taxation which is agreed with central government. Social care services are mostly funded through local taxes and municipalities receive block grants and subsidies from central government to fund and expand service provision. "Any person lawfully living in Denmark who is in need of care is entitled to receive such care, irrespective of age, financial means, income or family situation".¹⁵⁰ Assessment of need is conducted by a 'special corps of assessors' from the municipalities. A standardised assessment tool known as *Common Language* is used to assess and determine the need for social care services. Assessment of need is described as being holistic and multi-dimensional, covering all aspects of an individual's health and social care needs.¹⁵¹

¹⁴⁷ Vass, M., Avlund, K., Hendriksen, C., Philipson, L., Riis, P., *Preventive Home Visits to Older People*, 40 Denmark - Why, how, by whom, and when? Zeitschrift für Gerontologie und Geriatrie, 209-216 (2007).

¹⁴⁸ Schulz, 6 (2010).

¹⁴⁹ Per H. Jensen. & Henrik Lolte, *Dynamics Behind Local Variations in Elderly Care*. Paper prepared for the 8th ESPAnet Conference, Budapest, 2-4 September 2010, Stream 12.2. Local Care Policies and Care Work in Times of Global Crisis.

¹⁵⁰ Rostgaard, 87 (2012).

¹⁵¹ Schulz, 2 (2010).

Denmark commits itself to the notion of free and equal access to its welfare services as Schulz highlights in the following quote: “There are no minimum requirements in impairments to receive personal and practical help. After an individual assessment the help needed will be provided, even if the required time for help is less than 2 hours per week”.¹⁵² Service users are expected to make only minimal contributions to care costs, particularly in regard to temporary home help. Permanent personal assistance however is free. Service users living in nursing homes are expected to pay rents which are income based and generally not considered to be high.

The Law on Free Choice of Provider of Practical Assistance and Personal Care (2003) is an important manifestation of Denmark’s commitment to promoting consumer choice. It is also, however, a reflection of the presence of market forces in its social care system. When first introduced, this legislation related to the country’s home care system and requires municipalities to include private for-profit providers alongside public providers in the context of home care provision. The older person can therefore choose between providers at no extra cost, the deciding factor is the quality of care on offer.¹⁵³ Schulz observed that this initiative has proven popular with: “user satisfaction slightly higher among those using private suppliers”.¹⁵⁴ In 2007, with the introduction of the Law on Independent Nursing Homes, this concept of user choice was extended to nursing home care provision. Research also evidences however that older people did find it challenging to determine and judge quality measures in regard to the choice of home care providers they were being presented with.¹⁵⁵ Furthermore, many users were still unaware of the fact that they could choose between public and private for profit providers.¹⁵⁶ Nonetheless, among those older people who knew about choice, “68% reported that having a choice of provider was either important or very important to them”.¹⁵⁷

Denmark, therefore, has a culture of and policy commitment to community care and advocates the need for people to live in their homes more so than any other EU country according to Schulz.¹⁵⁸ Similar to Sweden, sustaining this level of universalism and public commitment to funding care provision will, nonetheless, be a challenge to Denmark looking forward given the implications of an ageing population. Some commentators therefore suggest that cost cutting social welfare measures will in future tend to more increasingly characterise Denmark’s system.¹⁵⁹

Practice Examples

- Emphasis on choice, empowerment and user engagement in policy
- One piece of legislation dealing with adult social care generally

¹⁵² *Id.*

¹⁵³ Tilde Marie Bertelsen and Tine Rostgaard, *Marketisation in Eldercare in Denmark: Free Choice and the Quest for Quality and Efficiency*, Gabrielle Meagher and Marta Szebehely (eds.) *Marketisation in Nordic Eldercare: A Research Report on Legislation, Oversight, Extent and Consequences*, 127-158 (Department of Social Work: Stockholm University, 2013).

¹⁵⁴ Schulz, 11 (2010).

¹⁵⁵ Bertelsen and Rostgaard (2012).

¹⁵⁶ Epinion Brugerundersøgelse om hjemmehjælp til borgere i eget hjem og i plejebolig/ plejehjem [*User survey on home care for citizens in their own home and in nursing homes*] (Aarhus: Social - og integrationsministeriet 2012).

¹⁵⁷ Bertelsen and Rostgaard (2012) (Citing Epinion, 2011).

¹⁵⁸ Schulz, 3 (2010).

¹⁵⁹ M Strandberg-Larsen, M.B. Nielsen, S. Vallgarda, A. Krasnik, A and K. Vrangbaek, *Denmark - Health System Review*, 9(6) *Health Systems in Transition* (Copenhagen, 2007).

- Preventative Visit scheme
- Strength of emphasis on community care and 'ageing in place' as a concept
- Existence of a law promoting choice
- Move away from nursing home construction in favour of more specialist type dwellings for older people.

India

Introduction

India's evolving social structure has throughout recorded history allowed extremes of poverty and wealth. The demographic profile predicts that between 2000-2050, the overall population in India will grow by 55%, whereas the population of people aged 60 years and above will increase by 326%; those in the age group of 80+ by 700% - the fastest growing group.¹⁶⁰ Of the 100 million (current estimate) older persons, 33% live below the poverty line.¹⁶¹

In India, presently most of the healthcare is provided through the private sector; however, because of a lack of affordable insurance protection, it is principally funded by the individuals or family members. Although a majority of Indians believe they have adequate access to services, evidence suggests that the current system often fails to meet medically defined need and is ill-suited to meeting the requirements of communities characterised by increasing chronic/non-communicable disease burdens.¹⁶² The government of India only recently took serious any initiatives related to welfare policy for older people¹⁶³ as traditionally the family always played the greatest role in the welfare of older people (Senior Citizens).¹⁶⁴

The "National Policy on Older Persons"¹⁶⁵ was announced by the Government of India in 1999.¹⁶⁶ It was the first broad policy guidelines at the national level related to the welfare of older people. It covered the following aspects: financial security, healthcare and nutrition, shelter, education, welfare and protection of life and property. India currently only spends 1.2 per cent of its GDP on publicly funded healthcare. This is considerably less than most other comparable countries. The country's 12th Five Year Plan projected an increase in public health spending to 2.5 per cent of GDP by 2017. The large sections of the Indian population do not as yet have reliable and affordable access to good quality healthcare.¹⁶⁷ Although the public healthcare system has been strengthened since the start of the 21st century through

¹⁶⁰ US Census Bureau Report (2009). It is estimated that of the 33% living below poverty line 90% are from the unorganized sector with no social security, and 73% are illiterate and dependent on physical labour.

¹⁶¹ In terms of economic dependence while there is not much difference between rural and urban population but it is apparent the female population is more dependent than the male population. Male older people tend to live with their spouse while for women close to 50% live with their children as they live longer. Indian women because of social custom usually remain single after they have been widowed or separated from their husbands. The percentage of women at work is also lot less than the men which means they have less old age savings compared to men.

¹⁶² IMS (2012) Increasing healthcare access: Market survey findings.

¹⁶³ H. Ota, *Senior Citizens and the old age: Social and Income Security in India* K. Usami (ed.) Old Age Social and Income Security in the Emerging Economics, 81-98 (Chiba: Institute of Developing Economics, 2009).

¹⁶⁴ V. Kumar, *Health Status and Health Care Services among Older Persons in India*, 15 (2-3) Journal of Aging Society Policy, 67-83 (2003).

¹⁶⁵ NPOP.

¹⁶⁶ The National Policy for Older Persons, Ministry of Social Justice & Empowerment, (1999).

¹⁶⁷ High Level Expert Group on Universal Health Coverage , *High Level Expert Group report on Universal Health Coverage for India*, New Delhi: Planning Commission of India (2011).

initiatives such as the “National Rural Health Mission” (NRHM),¹⁶⁸ it still suffers from significant limitations in areas such as the free provision of essential medicines to the poorest Indians.¹⁶⁹ The effect of aging and welfare policies are not only important for developed countries where aging has taken place rapidly but also in developing countries. The reason we choose India among the developing countries is to highlight the alternate understanding to aging and care from point of view of a “collectivist society” which seems to embrace a socio-centric conception of the relationship of individual to society in contrast to that of Northern Ireland, an “individualistic society”.

Legal Framework

- ***The Maintenance and Welfare of Parents and Senior Citizens Act, 2007***

This Act provides for:

- Maintenance of Parents/ senior citizens by children/ relatives made obligatory and justiciable through Tribunals;
 - Revocation of transfer of property by senior citizens in case of negligence by relatives;
 - Penal provision for abandonment of senior citizens;
 - Establishment of Old Age Homes for Indigent Senior Citizens;
 - And adequate medical facilities and security for Senior Citizens.
- ***The Hindu Adoptions and Maintenance Act, 1956*** (Recognizes duty of the children to maintain their aged parents and the right of the parents to maintenance).
 - ***The Rights of Persons with Disabilities Bill, 2012***

Article 41 of the Constitution of India provides that the State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want; Article 47 of the Constitution of India provides that the State shall regard the raising of the level of nutrition and the standard of living of its people and the improvement of public health as among its primary duties.

Policy and guidance

The government of India generally through the Ministry of Social Justice & Empowerment¹⁷⁰ ensures empowerment of the disadvantaged and marginalized sections of the society. The target groups of the Ministry are:

- Scheduled Castes;
- Other Backward Classes;

¹⁶⁸ Prime Minister of India also wants to extend to scope of this programme to the urban poor under the umbrella of National health Mission (NHM); J, Gill and D, Taylor, *Health and Health Care in India: National Opportunities, Global Impacts* (UCL School of Pharmacy, 2013).

¹⁶⁹ J, Gill and D, Taylor, *Health and Health Care in India: National Opportunities, Global Impacts* (UCL School of Pharmacy, 2013).

¹⁷⁰ In this respect Ministry of Social Justice & Empowerment works in close collaboration with State governments, Non-Governmental Organisations and civil society.

- Persons with Disabilities;
- And senior Citizens and Victims of Substance Abuse.

The well-being of older people is mandated in the Constitution of India under Article 41, which states that “the state shall, within the limits of its economic capacity and development, make effective provision for securing the right to public assistance in cases of old age”. As mentioned before, the “National Policy on Older Persons” (NPOP) was announced by the Government of India in 1999.¹⁷¹ The policy envisages State support to ensure financial and food security, health care, shelter and other needs of older persons, equitable share in development, protection against abuse and exploitation, and availability of services to improve the quality of their lives. The primary objectives are:¹⁷²

- To encourage individuals to make provision for their own as well as their spouse’s old age;
- To encourage families to take care of their older family members;
- To enable and support voluntary and non-governmental organizations to supplement the care provided by the family;
- To provide care and protection to the vulnerable elderly people;
- To provide adequate healthcare facilities to the elderly;
- To promote research and training facilities to train geriatric care givers and organizers of services for the elderly; and
- To create awareness regarding elderly persons to help them lead productive and independent live.

In 2011, the Government of India produced a “Revised National Policy for Senior Citizens”.¹⁷³ One of the main objectives of this new policy is to create an “age integrated society” by strengthening integration between generations, facilitate interaction between the old and the young as well as strengthening bonds between different age groups. The policy promoted development of a formal and informal social support system so that the capacity of the family to take care of senior citizens is strengthened and they continue to live in the family. This new policy also focused on bringing the concerns of older women into the national development debate.

The other key objectives of the new policy:

- Promote the concept of “Ageing in Place” by ensuring housing, income security and homecare services, old age pension and access to healthcare insurance schemes and other services to facilitate and sustain dignity in old age. The thrust of the policy is therefore on prevention rather than cure.

¹⁷¹ It was a step in the right direction in pursuance of the UN General Assembly Resolution 47/5 to observe 1999 as International Year of Older Persons and in keeping with the assurances to older persons contained in the Constitution.

¹⁷² Situation Analysis of the Elderly in India, Central Statistics Office, Ministry of Statistics & Programme Implementation, Government of India, June 2011.

¹⁷³ National Policy on Senior Citizens (Ministry of Social Justice and Empowerment, 2011). The government wanted to implement the Madrid Plan of Action and the United Nations Principles for Senior Citizens adopted by the UN General Assembly in 2002, the Shanghai Plan of Action 2002 and the Macau Outcome document 2007 adopted by UNESCAP.

- Institutional care as the last resort and that care of senior citizens has to remain vested in the family in partnership with the community, government and the private sector.
- Recognise that senior citizens are a valuable resource for the country.
- Employment in income generating activities after superannuation.
- Long term savings instruments and credit activities.
- Support and assist organizations that provide counselling, career guidance and training services.

Definitions

“Senior citizen” is any citizen of India of 60 years and above whether living in India or not.

Scope: Eligibility, Assessment, Care Planning, Services, Funding, Monitoring

It needs to be noted that the family, neighbourhood, community, the civil society, and philanthropy-led initiatives by the corporate sector and individuals in India have traditionally continued to remain the largest resource providers for supporting the welfare and development of older people (senior citizens). Many religious and social institutions have periodically organized food security initiatives for vulnerable persons, including older persons; some of these initiatives have also been aimed at ensuring shelter security and support for subsistence living.

A survey conducted by ILC India¹⁷⁴ showed most older people prefer to remain living with their son, or failing this, with their daughter. Otherwise, they prefer to live on their own. People in their sixties expressed preference to live on their own or in a retirement community complex, if possible. They also prefer to live close to children, to enable them to interact regularly with children and grandchildren, and to feel assured they will be looked after in times of medical emergency and to monitor their well-being. The survey also found that they prefer to have a paid caregiver to look after their daily needs.

As mentioned before, the Ministry of Social Justice and Empowerment has been providing financial support for Old Age Homes, Day Care Centres, Respite Care Centres, Mobile Medical Vans, and HelpLines. The Ministry of Finance provides Income tax rebate and higher rates of interest on saving schemes for Senior Citizens. The Department of Telecommunications gives priority to faults/complaints of Senior Citizens by registering them under Senior Citizens category. Most of the courts in the country accord priority to cases involving older persons and ensure their expeditious disposal. The “National Old Age Pension Scheme” (NOAPS) provides a pension to people above the age of 65 with no source of income or financial support. This has now been revised as “Indira Gandhi National Old Age Pension Scheme” (IGNOAPS)¹⁷⁵ which now includes Indira Gandhi National Widow Pension Scheme

¹⁷⁴ International Longevity Centre-India, Housing Needs of the Elderly (ILC-I and Tata Housing, Survey Report, 2012).

¹⁷⁵ The IGNOAPS is one of the major social welfare schemes under the Unorganised Sector Workers’ Social Security Act 2008 specifically for the benefit of the workers in the unorganised/low income sector.

(IGNWPS) and Indira Gandhi National Disability Pension Scheme (IGNDPS). Employees are also afforded further protections under the Employees Provident Funds and Miscellaneous Provisions Act 1952.¹⁷⁶ The eligibility criteria for beneficiaries for most of the government sponsored projects are:

- Old Age Homes - for destitute older persons.
- Mobile Medicare Units - for older persons living in slums, rural and inaccessible areas where proper health facilities are not available.
- Respite Care Homes and Continuous Care Homes - for older persons seriously ill requiring continuous nursing care and respite.

Research on Implementation in Practice

It is difficult to comprehensively examine the policy related to older people in India, however, a number of research studies have managed to identify the problems and made recommendations.¹⁷⁷ Older people in India can be categorized in two sections according to their financial condition: first, those who were below the poverty line during their economically active ages; second, and those who were above the poverty line. This disparity made it difficult for the government of India to provide effective support under a single scheme. Any welfare measure is further controlled by the financial constraints of the government along with the magnitude of poverty in the society. It was not until 1980s, following the World Assembly on Aging held at Vienna 1982 which formulated a package of recommendations which gives high priority to research related to the developmental and humanitarian aspects of ageing¹⁷⁸ that any significant attention was paid towards the welfare of older people.¹⁷⁹ In 1987-88 an Inter-Ministerial Committee was setup for the purpose of addressing the concerns of older people.¹⁸⁰

In August 1998, the Old Age Social and Income Security (OASIS) Project was set up by the Minister for Social Justice and Empowerment to research and devise a sustainable pension system. As stated before, the National Policy on Older Persons (NPOP) was announced in January 1999. In pursuance of the NPOP, a “National Council for Older Persons” (NCOP) was constituted in 1999 under the Chairpersonship of the Minister for Social Justice and Empowerment to oversee

¹⁷⁶ The Act was enacted with the main objective of making some provisions for the future of industrial workers after their retirement and for their dependents in case of death. It provides insurance to workers and their dependents against risks of old age, retirement, discharge, retrenchment or death of the workers. Employees' Provident Fund Organisation (established by the Act) is a statutory body of the Government of India under the Ministry of Labour and Employment. It administers a compulsory contributory Provident Fund Scheme, Pension Scheme and an Insurance Scheme.

¹⁷⁷ See S. I. Rajan and E.T. Mathew, *India*, S.I. Rajan (ed.) *Social Security for the Elderly: Experiences from South Asia* (New Delhi: Routledge) 39-106; A.K. Joshi, *Older Persons in India* (New Delhi: Serial Publications, 2006); D. Hatton et al., *Facing the Future: Indian Pension Systems* (New Delhi: Tata McGraw-Hill Publishing Company Ltd, 2007); M. Alam, *Aging in India: Socio-Economic and Health Dimension* (New Delhi: Academic Foundation, 2006); A. B. Bose, *Social Security for the Old: Myth and Reality* (New Delhi: Concept Publishing Company, 2006).

¹⁷⁸ H. Ota, *India's Senior Citizens' Policy and Examination of the Life of Senior Citizens*, 402 North Delhi IDE Discussion Paper (South Asian Studies Group, Area Studies Centre, IDE, 2013).

¹⁷⁹ H. Ota, *India's Senior Citizens' Policy and Examination of the Life of Senior Citizens*, 402 North Delhi IDE Discussion Paper (South Asian Studies Group, Area Studies Centre, IDE, 2013).

¹⁸⁰ C.P. Sujaya *National Policy on Older Persons* in *Aging: A Symposium on the Greying of our Society* (2000).

implementation of the Policy. The NCOP¹⁸¹ was the highest body to advise the Government in the formulation and implementation of policy and programmes for the aged. The Council was re-constituted in 2005 with members comprising Central and State government representatives, representatives of NGOs, citizen's groups, retired person's associations, and experts in the field of law, social welfare, and medicine.¹⁸²

The Implementation Strategy for this National Policy envisages the following:

- Preparation of Plan of Action for operation of the National policy
- Setting up of separate Bureau for Older Persons in Ministry of Social Justice & Empowerment
- Setting up of Directorates of Older Persons in the States
- Three Yearly Public Review of implementation of policy
- Setting up of a National Council for Older Persons headed by Ministry of Social Justice & Empowerment from Central Ministry, states, Non-Official members representing NGOs, Academic bodies, Media and experts as members
- Establishment of Autonomous National Association of Older Persons
- Encouraging the participation of local self-government

Since 1992, the government of India also ran an “Integrated Programme for Older Persons” (IPOP) with the objective of improving the quality of life of senior citizens by providing basic amenities like shelter, food, medical care and entertainment opportunities and by encouraging productive and active ageing through providing support for capacity building of Government/ Non-Governmental Organizations/ local bodies and the community at large. Under the Scheme, financial assistance up to 90% of the project cost is provided to nongovernmental organizations for establishing and maintaining old age homes, day care centres and mobile Medicare units. Several projects have been funded through the Scheme. Some of these are:

- Maintenance of Respite Care Homes and Continuous Care Homes;
- Running of Day Care Centres for Alzheimer's Disease/Dementia Patients,
- Physiotherapy Clinics for older persons;
- Help-lines and Counselling Centres for older persons;
- Sensitizing programmes for children particularly in Schools and Colleges;
- Regional Resource and Training Centres of Caregivers to the older persons;
- Awareness Generation Programmes for Older Persons and Care Givers;
- Formation of Senior Citizens Associations.

The “National Council for Senior Citizens”¹⁸³ was constituted in 2012 to advise the Central and State governments generally for the welfare but specifically on physics and financial security, health, and independent living of older people. Most personal laws, including the Hindu Adoptions and Maintenance Act (1956), recognize the duty of children to maintain their aged parents and the right of the parents to

¹⁸¹ Until replaced by the “National Council for Senior Citizens” in 2012.

¹⁸² Situation Analysis of the Elderly in India, Central Statistics Office, Ministry of Statistics & Programme Implementation, Government of India, June 2011.

¹⁸³ This council was constituted based on the recommendations of the Revised National Policy for Senior Citizens 2011.

maintenance.¹⁸⁴ Section 125 of the Criminal Procedure Code (1973) specifically provides for maintenance from children if parents are unable to maintain themselves but cases are rarely filed by parents due to love and affection, fear of stigma and time and money required for the legal proceedings.

India does not have any policy on housing for older persons, although reference was made to housing in the first “National Policy on Older Persons” (1999) and also in the revised “National Policy on Senior Citizens of India” (2011), but the focus has always been providing basic housing, not specialist housing. The concept of specialist housing and “ageing-in-place” for older people in India is also comparatively new. Traditionally, older people lived in an extended family system comprising their own family and the families of siblings. Although there are government funded old age homes for people of low socio-economic means, the homes often do not meet minimum living standards. In the private sector, by contrast, developers and builders seize opportunities to provide specialist housing - driven by a commercial motive; however, such elder-friendly housing projects only target high-end clientele, or affluent older consumers.

The revised “National Policy on Senior Citizens” also contained the following proposals for implementation:

- Income security in old age: Old age pension scheme to cover all senior citizens living below the poverty line. Additional pension in case of disability, loss of adult children and concomitant responsibility for grandchildren and women.
- Public distribution system would reach out to cover all senior citizens living below the poverty line.
- Liberal taxation policies to reflect sensitivity to the financial problems of senior citizens which accelerate due to very high costs of medical and nursing care, transportation and support services needed at homes.
- High priority given to healthcare needs of senior citizens with the aim to provide good, affordable health service, heavily subsidized for the poor and a graded system of user charges for others. It would be a mix of public health services, health insurance, health services provided by not-for-profit charities and private medical care.
- Stringent punishment for abuse of older people including establishment of protective services linked to help lines, legal aid and other measures
- Promote measures to create avenues for continuity in employment and/or post retirement opportunities.
- A welfare fund for senior citizens.
- Promoting bonding of generations and multigenerational support by incorporating relevant educational material in school curriculum and promoting value education.
- Involving mass media as well as informal and traditional communication channels on ageing issues.¹⁸⁵

¹⁸⁴ Maintenance includes provision for food, clothing, residence, medical attendance and treatment.

¹⁸⁵ National Policy on Senior Citizens (2011).

Practice Examples

- High Level Working Group on Universal Health Coverage instituted by the Planning Commission of India prescribed a single theoretically 'optimal' national model.
- Ten percent of housing schemes for urban and rural lower income segments will be earmarked for senior citizens.
- Non-segregation of older people in housing.
- Taxation policies to reflect sensitivity to the financial problems.

Sweden

Introduction

“Health and social care for the elderly are important parts of Swedish welfare policy. Of Sweden’s 9.6 million inhabitants, 18 percent have passed the retirement age of 65. This number is projected to rise to 23 percent by 2030, partly because of the large number of Swedes born in the 1940s.”¹⁸⁶

Legislation, Policy and Guidance

The Swedish welfare system is described as ‘universal’ in terms of adult social care service delivery: “available to all citizens according to need rather than ability to pay”.¹⁸⁷ Sweden, therefore, has a reputation as being one of the most generous countries in the world in regard to its public spending levels for older people.¹⁸⁸ Nonetheless, it has not sustained this commitment in line with the ageing population in Sweden, in fact, spending has decreased.¹⁸⁹ With the emerging influence of marketization, Sweden has now moved towards an increasing tendency for home care services being provided by the private sector. Social welfare policy is the responsibility of Sweden’s municipalities which have the powers to raise taxes to fund these. Such high levels of welfare service provision consequently entail Swedes having to pay high income and corporation taxes.¹⁹⁰

The legislation governing the provision of health and medical services in Sweden is found in the Health and Medical Services Act.¹⁹¹ “This legislation is constructed as a ‘defined-duties legislation’ (*skyldighetslagstiftning*), i.e. it lays down different duties for the local and regional authorities, together with the basic principles to observe in their field of activities”.¹⁹² Responsibility for the organisation and delivery of health care falls to regional and local authorities, the county councils and the municipalities (*landstingskommuner* and *primärkommuner*).¹⁹³ The provision of social care to “elderly people, the chronically ill, the disabled and other persons living in special types of accommodation” is governed by the Social Services Act.¹⁹⁴ The needs of adults with mental health issues are also met within this legislation. Mattsson states

¹⁸⁶ <http://sweden.se/society/elderly-care-in-sweden/>.

¹⁸⁷ Marta Szebehely and Gun-Britt Trydegård, *Home Care for Older People in Sweden: A Universal Model in Transition*, 20(3) Health and Social Care in the Community, 300 (2012).

¹⁸⁸ M. Huber, R. Rodrigues, F. Hoffmann, K. Gasior & B. Mari, *Facts and Figures on Long-Term Care. Europe and North America* (Vienna: European Centre, 2009).

¹⁸⁹ M. Szebehely M. *Insatser for aldre och funktionshindrade i privat regi [Privately provided care services for older and disabled persons]*. L. Hartman (ed.) Konkurrensens Konsekvenser [The Consequences of Competition], Stockholm: SNS Centre for Business and Policy Studies 219 (2011).

¹⁹⁰ Michael J. Holosko, Deborah Ann Holosko & Katherine Spencer, *Social Services in Sweden: An Overview of Policy Issues, Devolution, and Collaboration*, 24 Social Work in Public Health, 210-234 (2009).

¹⁹¹ The Health and Medical Services Act, 763 (1982).

¹⁹² Titti Mattsson, *Social and Welfare Law*, Michael Bogdan (ed.) Swedish Legal Systems, 119 (Elanders Sverige AB: Sweden, 2010).

¹⁹³ Id., 120.

¹⁹⁴ The Social Services Act, 453 (2001).

the goals of this legislation are: “to promote people’s economic and social security, equality in living conditions and active participation in the life of the community”.¹⁹⁵

Health and Social care legislation in Sweden consistently makes reference to grounding principles of *self-determination, privacy and integrity*. Annually, the maximum costs associated with payments for: “special accommodation, home-based services, daily activities and health and medical care” for people with disabilities and older people are set by the National Board of Health and Welfare.¹⁹⁶ In so doing: “a certain amount is left for normal living expenditures for the person”.¹⁹⁷ The Social Services Act is also described as: “a goal-oriented framework law ensuring a general right to assistance if needs cannot be met in any other way, but without detailed regulations or specific rights. Everybody has a right to claim public service and support at all stages of life, and local authorities have a mandatory responsibility to see to that these needs are met. The assistance should be of good quality and given in ways that ensure a ‘reasonable level of living’”.¹⁹⁸ A process of needs assessment is carried out by a care manager, mandated by locally elected politicians”.¹⁹⁹

The Social Services Act also stipulates that any services provided within its remit must be prefaced on *free choice and autonomy*. Expenditure on social care services for older people is funded through a combination of municipal and national taxation. Services are, however, not entirely free and users have to pay a small proportion of the costs. There is, nonetheless, fragmentation in terms of service delivery between central and local government. It has been argued that services to older people in particular have suffered as a result of this chasm. Resourcing the social care needs of older people in Sweden has also been impacted by the increase in expenditure needed to resource the needs of other groups. For example, the Disability Act 1994 brought about improved rights to services for people with disabilities and, as a result, resources in this area increased by 65% between 2000 and 2009.²⁰⁰ Similar increased expenditure was incurred by the introduction of free childcare to all children from 1-12 years through the School Act 1995. Szebehely and Trydegård therefore conclude that: ‘Older people’s need for care has been sacrificed for other groups’ need for support’.²⁰¹

Similar to the Republic of Ireland, the emphasis on community care as the preferred site for social care services has been significantly shaped by the problems Sweden was experiencing with older people staying in hospital for lengthy periods. As a result: “Sweden today has significantly fewer hospital beds and shorter lengths of stay than all other EU-countries”.²⁰² These numbers were reduced by half in the period between 1992 and 2005.

Social care in Sweden is, therefore, now targeted towards those with greatest need amidst a context of limited resources. The guidelines around provision of care services have become more stringent irrespective of “the individual older person’s

¹⁹⁵ Mattsson, 128 (2010).

¹⁹⁶ *Id.*, 129.

¹⁹⁷ *Id.*

¹⁹⁸ The Social Services Act, 453 (2001).

¹⁹⁹ Szebehely and Trydegård, 301 (2012).

²⁰⁰ Szebehely, 218 (2011).

²⁰¹ NBHW (2010) *Lagesrapport 2010* [Status Report 2010], Stockholm: Socialstyrelsen, 23 (cited by Szebehely and Trydegård, 302 (2012)).

²⁰² OECD, *Health at a Glance 2009: OECD Indicators*, 94-98 (OECD Publishing, 2009).

situation and needs as prescribed by the legislation”.²⁰³ Commentators would argue that this does not represent a distancing of the government from a commitment to provide services but instead should be seen more in view of a global trend towards marketization in social welfare. The Local Government Act of 1991 gave rise to a purchaser-provider split enabling Swedish municipalities to have their publicly funded services provided by private for-profit companies.²⁰⁴ This is particularly evidenced by Sweden’s introduction of the Act on Free Choice Systems which strongly introduced consumerism into the social care system.²⁰⁵

Through the introduction of a voucher system, older people would be offered choice as to which providers they would select to provide care services. Providers in both the public and private sector had to compete for such vouchers on ‘quality’ only; reimbursement for both sectors was exactly the same, the user therefore paying exactly the same fee to each. Disabled people’s organisations in Sweden had long called for such empowerment and choice based models of service delivery, so this development was especially welcomed in that sector. It is argued, however, that older people and their organisations had not been campaigning for this in Sweden and instead this was seen as more of an ideological decision.²⁰⁶ Municipalities in Sweden will all have to introduce these choice based models of provision and are being financially incentivised to do so. If failing to comply, legislation requiring this will be introduced by 2014. Choices in social care are however quite challenging for older people: “Several scholars have stressed the difficulties in making well-informed choices when it comes to care services, in particular at the stage of life when eldercare is on the agenda”.²⁰⁷ Others highlight that highly educated and resourced older people will be better placed to judge and access higher quality care. Szebehely and Trydegård therefore suggest that: “the increased focus on consumerism and choice in Sweden... constitutes a challenge to universalism”.²⁰⁸

The rights of persons with disabilities in Sweden are catered for by the Services to Certain Disabled Persons Act (1993) through which: “disabled persons have a number of well-defined rights, including the right to a personal assistant or the financial means to engage such an assistant him - or herself. The services are provided and financed by the municipality, except for the costs of a personal assistant exceeding 20 hours of work per week”.²⁰⁹ The Attendance Allowance Act (1993) can be used to finance personal care in excess of 20 hours per week. The latter however is not applicable to people over 65; in these instances the municipality will provide such attendance services. 17% of Sweden’s population of nine million are over the age of 65. Sweden is also one of the countries with the highest number of older people over the age of 80. The municipality shoulders much of the responsibility for fees, and this is covered through taxes and government support

²⁰³ A. Duner & M. Nordstrom (2006) *The Discretion and Power of Street-Level Bureaucrats: An Example from Swedish Municipal Eldercare*, 9 (4) European Journal of Social Work, 425-444 (2006), (Cited in Szebehely and Trydegård, 302 (2012)).

²⁰⁴ Szebehely and Trydegård, 307 (2012).

²⁰⁵ The Act on Free Choice Systems, 962 (2008).

²⁰⁶ P.G. Edebalk & M. Svensson, *Kundval för äldre och funktionshindrade i Norden. Konsumentperspektivet [Customer Choice for Elderly and Disabled Persons in Scandinavia. The Consumer Perspective]*, 19 (2005), TemaNord, 507 (2005) (Copenhagen: Nordic Council of Ministers).

²⁰⁷ Szebehely and Trydegård, 307 (2012).

²⁰⁸ *Id.*

²⁰⁹ Mattsson, 134 (2010).

leaving the fees to be paid by older people as small. The trend in Sweden is for most older people to live well and live in their own homes for as long as possible, as Mattsson highlights: “Most of the elderly people live in their own home and many are in good health.”²¹⁰ Municipalities will only set fees for adult social care that protect the individual from incurring excessive amounts. The maximum fee that a municipal authority can: “charge for home help services, care in sheltered accommodation, day care services and municipal health care services is 1,516 SEK/£149 per month”.²¹¹

The Social Services Act was further amended in 2012 to afford elderly spouses the right to live together in special housing irrespective if one of the spouses did not have particular needs for this. Nonetheless, a progressive measure consistent with promoting ECHR family life rights under Article 8: “This provision reflects an emphasis on worthy and good family living conditions for active aging. Elderly care should aim to support older people in living their lives on their own terms and conditions”.²¹²

Research in Implementation

The Official Statistics of Sweden (Oct, 2012) provides an up to date picture of care and social services usage among the country’s elderly population. The summary of the published data concludes the following:

- 14% of Sweden’s over 65 age group either lived permanently in special forms of housing or were in receipt of home help services in ordinary housing. 38% of people 80 and older were in receipt of similar services.
- 5% of those over 65 and 14% of people older than 80 were living in special forms of housing.
- Home help services were provided to 9% of the 65+ population and to 24% of the 80+ population.
- For 31% of older people the home help allocation over a month was between 1-9 hours. For around 20% this allocation was between 10-25 hours.

Szebehely and Trydegård report the findings from a large scale survey they conducted examining home care usage among Sweden’s older people.²¹³ They observed a notable decrease in the use of home care and an increase of reliance among older people on family and friends for help: “Between 1988-1989 and 2004-2005, fewer older people with an impairment and self-reported care needs were receiving needs assessed home care (a decrease from 46.2-39.8%; $P = 0.043$). Instead the proportion reporting that they received care from family or friends outside their own household increased from 40.8-50.6% ($P = 0.002$)”.²¹⁴ These authors therefore conclude that Sweden’s universalist model of welfare has shifted towards what they describe as *re-familialisation of care*. They argue that this very much is inconsistent with Swedes’ preference for public care over family care.²¹⁵ In further interrogation of their findings, it was also noted that older people with lower levels of

²¹⁰ *Id.*, 135 (2010).

²¹¹ Artikelnr, 22 (2002).

²¹² Mattsson, 94 (2010).

²¹³ Szebehely and Trydegård, 2012.

²¹⁴ *Id.*, 304.

²¹⁵ Eurobarometer , *Health and Long-Term Care in the European Union*, 283 Special Eurobarometer, 67 (Brussels: European Commission, 2007).

education were more likely to rely increasingly on family/informal care. The introduction of an enhanced tax incentive scheme through the (Government Bill 2006 /2007:94) also enabled older people to benefit from tax deductions in their receipt of personal care services from private for-profit providers.²¹⁶ Szebehely and Trydegård note that: “in 2004-2005, 16.7% of older people with higher education and self-reported care needs reported that they purchased help at the private market (paid out of pocket) compared to 6.9% in the group with lower level of education (P = 0.004)”.²¹⁷ These authors conclude that a dual system has now emerged in Sweden’s adult social care system where older people who are better educated are more likely to turn towards the private sector, whereas less well educated people are more likely to rely on their families for help

Concluding Observations

Sweden is still committed to its universalist principles in regard to providing state funded welfare services. There is no official move towards the government encouraging or expecting families to assume increased levels of caring responsibility. Nonetheless, Sweden has not been unaffected by the global recession and, as a consequence, marketization has gradually crept into its system of welfare provision and thresholds for eligibility to state funded provision have been tightened.²¹⁸ The latter authors also argue that increasing notions of choice and consumerism do represent a threat to Sweden’s system of welfare. Exercising choice in regard to quality has been found to be much less complex for better educated older people. The system of tax deduction for household and care services introduced in 2007 has also created a two tier system of social care in Sweden where better off older people are purchasing additional care from private sector providers whereas poorer older people receive the basic levels of public care. Szebehely and Trydegård believe that Sweden’s system is now facing a real threat of becoming seriously diminished in quality as a result of the chasm that has been increasingly generated by marketization.²¹⁹

Practice Examples

- Key governing legislation based on principles of *self-determination, privacy and integrity, equality and participation*.
- One single key piece of legislation (The Social Services Act) embracing the breadth of adult social care needs.
- Act on Free Choice Systems as a piece of legislation espousing key principles such as choice and autonomy and the accompanying use of vouchers which older people can use in determining their choice of social care provider.²²⁰
- ECHR friendly legislation enabling older couples to continue living together irrespective of needs but recognising the importance of family life and relationships.
- Municipal provision of ‘personal assistant’ to directly assist adults with disabilities through the Services to Certain Disabled Persons Act (1993).

²¹⁶ Government Bill, 94 (2006 / 2007) Skattelättnader for hushallstjanster, m.m. [Tax deductions on household services etc.].

²¹⁷ Szebehely and Trydegård, 305 (2012).

²¹⁸ *Id.*

²¹⁹ *Id.*

²²⁰ Act on Free Choice Systems, 968 (2008).

United States (including Pennsylvania, Florida and Maine)

Introduction

In the United States, there are both national and state laws and policies affecting social care. In effect, the national laws set a starting point or threshold, supplemented or made more specific in application by the states. As a starting point, under national law in the U.S., age 65 is most often used as the starting age for laws and policies addressing “Older Adults”. The percentage of the total population that is “older” in the U.S. is 13.3%.²²¹ Several features of the older population in the U.S. are significant in framing laws and policies regarding “social care”, although as explained below, that phrase is not widely used in the U.S.

Increasing Potential for Isolation: An increasing number of older adults live alone, increasing the potential for isolation. Approximately 28% of older Americans who are not institutionalized (i.e., living in nursing homes or other residential care settings) are living alone. The percentage is even higher for those aged 75+. Isolation poses a particular potential for problems, especially in a nation such as the U.S. where “individualism” is deemed important, and neighbours, friend, or even extended family, may be hesitant to step in or call public authorities for assistance. “Self-neglect” by older adults is a serious question in the U.S.²²²

Growing Numbers of Elders Potentially Affect Dependency Ratio: The population of older adults, both in absolute numbers and in terms of percentage of the total population is increasing, as baby boomers (in the U.S., those born between 1946 and 1964) retire, which in turn affects the “dependency ratio”, of non-workers to workers.²²³ As one study observes, “The aging of the older population is noteworthy, as those in the oldest ages often require additional care giving and support”.²²⁴ Immigration is, however, considered to be an important potential mitigating factor on the dependency ratio.²²⁵

Lower Rates of Retirement Income Predicted, both from Public and Private Sources: Several factors are resulting in lower income and savings for the next generation of retirees, including changes in public funding (Social Security and government employee pensions) and private sources for retirement funding. Some sources

²²¹ U.S. Administration on Aging (hereafter U.S. AoA), Profile of Older Americans 2012, drawing from government data sources, including the U.S. Census Bureau, the National Center for Health Statistics, and the U.S. Bureau of Labor Statistics, all as summarized on U.S. AoA. http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2012/2.aspx.

²²² Xinqi Dong, M.D. et al., *Elder Self-Neglect and Abuse & Mortality Risk in a Community-Dwelling Population*, 302(5), Journal of American Medical Association (JAMA), 517-526 (2009, August 5).

²²³ U.S. Census Bureau, The Next Four Decades: The Older Population in the U.S. 2010-2050, issued May 2010, at <http://www.census.gov/prod/2010pubs/p25-1138.pdf>. The population aged 65 and older is projected to increase to 79.7 million in 2040. Within this increase, the population of the “very old,” those aged 85+, is predicted to more than double, from 5.7 million in 2011, to 14.1 million. *Id.*, 4.

²²⁴ U.S. Census Bureau, The Next Four Decades: The Older Population in the U.S. 2010-2050, issued May 2010, at <http://www.census.gov/prod/2010pubs/p25-1138.pdf>, 4.

²²⁵ U.S. Census Bureau, The Next Four Decades: The Older Population in the U.S. 2010-2050, issued May 2010, at <http://www.census.gov/prod/2010pubs/p25-1138.pdf>, 3.

predict a significant percentage of current retirees will not have adequate private financial sources to cover predicted needs, even though on average their annual retirement incomes may be higher than in previous generations. Currently, economic security of older adults in the U.S. depends on a combination of Social Security payments (currently received by 86% of older persons), income from assets (currently reported to be received by 52% of older persons), private employee pensions (27%), government employee pensions (15%), and earnings from continued work (26%). As of 2010, Social Security constitutes 90% or more of the income received by 36% of beneficiaries.²²⁶

Significant Numbers of Elders Live in Poverty: In 2011, almost 3.6 million older persons in the U.S. were below the official level of poverty, representing 8.7% of older adults. However, in 2011, the U.S. Census Bureau also released a new “Supplemental Poverty Measure”, (SPM) which analyzes additional factors contributing to economic insecurity. The SPM showed a revised poverty level for older persons of 15.1%. This higher figure is deemed to be heavily affected by out-of-pocket medical expenses.²²⁷

Legal Framework

In the United States, “social care” is not a widely used phrase, and is rarely used to define federal or state laws or policies. Historically, the phrase “public welfare”, rather than “social care”, has more often been used to describe U.S. efforts to provide services to defined segments of the U.S. population. The tension between more conservative and more liberal political groups in the U.S., a tension which has increased in recent years, has resulted in “public welfare” often being viewed as a negative label, rather than a term for an agreed or widely-shared set of principles of government commitment. In the U.S., for example, there are political arguments made against viewing age-related or disability-related benefits as “entitlements”.

Offsetting this negative perception of “public welfare” (or publically funded “social care”), are renewed efforts to change labels and consolidate programs to make them appear more cost efficient. Newer labels and consolidation efforts are discussed below. With respect to older Americans, there are arguably four broad categories of long-standing federal laws that address key social care concerns:

1. **“Social Security”**, with a key focus on a national system of income benefits for most retired individuals (Title II on Old Age, Survivors and Disability Insurance, or OASDI), as well as other benefits, such as support payments for the unemployed, widows and dependents, and supplemental income supports for the very poor (Title XVI on Supplement Security Income or SSI), and funded in part by payroll taxes;²²⁸

²²⁶ U.S. AoA, Profile of Older Americans 2012, http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2012/2.aspx.

²²⁷ U.S. AoA, Profile of Older Americans 2012, http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2012/2.aspx.

²²⁸ The Social Security Act, Pub. L. 74-271, 49 Stat. 620, was originally enacted in 1935, and is codified in Chapter 7 of Title 42 of the United States Code.

2. **“Medicare”**, providing a national system of health insurance for older adults, funded in part by work-based premiums;²²⁹
3. **“Medicaid”**, focusing on health-related benefits for low-income/poor older adults, with state/federal funding components that have provided a key source of “long-term care benefits” which can fund care in facilities or the home;²³⁰
4. **“Older Americans Act”** providing a basic framework for social service agencies, legal services, and additional supports to be provided at the state or community level, often through block-grant funding from the federal government to state governments. An example of a popular program under the Older Americans Act is “Meals on Wheels”, one of several approaches to improving senior nutrition. States in turn often provide additional funding, and most of the federal and state funding comes from general tax revenues.²³¹ The Older Americans Act required states to create both State Units on Aging and local offices to implement social services, often called Area Agencies on Aging (AAAs). In some instances, additional condition-specific social services are authorized by separate legislation, such as provisions of the Public Health Service Act that govern the Alzheimer’s Disease Supportive Services Program of 1990,²³² or the Lifespan Respite Care Program of 2006.²³³

Until recently, the U.S. Administration on Aging (AoA, operating under the U.S. Department of Health and Human Services) was in charge of administration of policies and a myriad of programs falling under the Older Americans Act or related social services legislation. The AoA policies are administered at the state level by State departments of aging and at the local level, usually through county offices called Area Agencies on Aging or AAAs. In 2012, however, the U.S. Administration for Community Living (ACL) was created to “bring together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities into a single agency that supports both cross-cutting initiatives and efforts focused on the unique needs of individual groups, such as children with developmental disabilities or seniors with dementia”.²³⁴ The change in identity is still under way, and the full implications of the change may not yet be clear, with the Administration on Aging (AoA) now appearing as one of four sub-units of the ACL. Arguably, this new identity is a move away from seeing “age” as a single factored reason for services, and a move toward consolidation of services based on cross-age group factors that include physical or mental disability. This consolidation could leave older

²²⁹ In 1965, Congress passed key legislation amending the Social Security Act of 1935, creating Medicare and Medicaid. What is sometimes referred to as Title XVIII, is known as “Medicare,” with Part A providing hospital insurance for older adults, and Part B providing supplemental health insurance.

²³⁰ Title XIX of the Social Security Act, also adopted in 1965, created “Medicaid,” which creates a federal/state funding system for health care to low-income or poor individuals, including the elderly.

²³¹ The Older Americans Act, Pub. L. 89-73, 79 Stat. 218, 42 U.S.C. § 3001, was first enacted in 1965.

²³² Section 398 of the Public Health Service Act, P.L. 78-410, 42 U.S.C. § 280c-3.

²³³ Title XXIX of the Public Health Service Act, 42 U.S.C. § 201.

²³⁴ The U.S. Administration for Community Living has a website, linked to the Administration on Aging’s website, at www.acl.gov. The ACL also operates under the U.S. Department of Health and Human Services, but on organization charts the ACL is “over” the Administration on Aging. See e.g., the ACL Organizational Chart at http://acl.gov/About_ACL/Organization/acl_org.aspx.

adults who have no specific “disability”, but who are isolated, frail, or simply unable to fully manage their daily needs “out in the cold”.

Policy and Guidance

The Older Americans Act, which had stable funding through 2010, has not been fully reauthorized or funded since 2011. An example of the impact from underfunding is Area Agencies on Aging (the agencies charged with implementation of most state and federal social services at the local level) report that nearly 60% of all Older Americans Act programs have significant waiting lists for services, with home-delivered meals (often called “Meals on Wheels,”) being a particularly urgent concern.²³⁵

The new U.S. Administration for Community Living (ACL) issued its first strategic plan, covering 2013-2018. As indicated earlier, the creation of the new agency appears to signal a consolidation of services for older people and people with disabilities. The stated mission of the ACL is to “maximize the independence, well-being, and health of older adults, people with disabilities, and their families and caregivers”.²³⁶ The strategic plan identifies five “goals”, focusing on “Advocacy”, “Protect Rights and Prevent Abuse”, “Individual Self-Determination & Control”, “Long-Term Services and Supports”, and “Effective and Responsive Management”.²³⁷ The label “Long-Term Services and Supports”, often abbreviated to LTSS, is an intentional shift in language, moving away from the past use of “Long-Term Care” as a goal. Under each of these five headings, the ACL sets forth multiple objectives intended to serve the goals. For example, in support of “Long-Term Services and Supports”, the agency identifies the following four objectives:

1. “Administer and continue to modernize the Older Americans Act and the Developmental Disabilities Act”.
2. **“Assist states to develop high quality, person-centered, and integrative systems that seamlessly address the health and long-term services and supports needs of people with disabilities and older adults”.**
3. “Assist the aging and disability networks to continue to play a meaningful role in support of the Affordable Care Act transformations in health and long-term care”.
4. **“Promote the development and adoption of national standards for home and community-based services, including quality standards that reflect consumer experience with long-term services and supports programs”.**²³⁸

The second and fourth points (in **bold** above) from the ACL Strategic Plan seem particularly relevant to social care policy, as there has been a great deal of criticism in the U.S. about the fragmented and confusing approaches to provision of publically-funded services for people who need them most, including frail elders. Further, it is

²³⁵ Trudy Lieberman, “The Real Hunger Games,” The Nation, October 14, 2013, at <http://tinyurl.com/kqmr2c7>.

²³⁶ Administration for Community Living, ACL Strategic Plan 2013-2018, available as a PDF document through the ACL website at http://acl.gov/About_ACL/StrategicPlan/Index.aspx.

²³⁷ Administration for Community Living, ACL Strategic Plan 2013-2018, at pages 3-4, available as a PDF document through the ACL website at http://acl.gov/About_ACL/StrategicPlan/Index.aspx.

²³⁸ Administration for Community Living, ACL Strategic Plan 2013-2018, at pages 10-12, available as a PDF document through the ACL website at http://acl.gov/About_ACL/StrategicPlan/Index.aspx.

generally acknowledged that older persons increasingly prefer to avoid traditional “nursing homes” for long-term care and wish to stay “at home” as long as possible. Indeed, government agencies frequently use “home care” preferences as an argument for de-funding traditional nursing homes, also pointing to the “high cost” of nursing home care.

For the purposes of this report, we have selected three American states, all with significant senior populations: **Pennsylvania** (a large state, with many services, but where implementation of services is not yet fully integrated); **Florida** (a large state with a historic identity as a “retirement” destination); and **Maine** (a smaller state with a smaller population, with greater integration of services).

Definitions & Scope of Services (including Funding Sources)

Pennsylvania

Population

Pennsylvania has a relatively high number of older adult residents in the state, currently approximately two million persons who are age 65 or older, which means that approximately 16% of the state’s population is “older”, as compared to the national average of approximately 13%. In recent years, Pennsylvania has ranked approximately 4th in the nation, both in absolute number of older adults and proportion of the population deemed older.²³⁹

Care Needs Assessment

Until relatively recently, most publically funded long-term care was available only if the individual was admitted to a nursing home for skilled care, and was found to be medically and financially eligible for Medical Assistance (MA). As will be discussed, there are several recent programs that provide better funding for “long-term services and supports” or LTSS, the latest acronym, used to describe public benefits provided for assistance outside of nursing homes. Every individual who is seeking (or who may seek) public funding for care must complete a detailed form, including five years of records about financial transactions and assets, and the applicant must be assessed both medically (functionally) and financially as eligible, triggering review by the local AAA and the local County Assistance Office, as the representative of the Department of Public Welfare. This review is often the first time that U.S. elders are assessed by public authorities for “need”.

Nursing Home Care

A significant number of older Pennsylvanians continue to reside in nursing homes. The State has approximately 710 nursing homes with nearly 89,000 beds, with approximately 90% occupied. Currently, approximately 65% of all care provided in nursing homes is funded by MA, while Medicare provides funding for approximately 13% of this, and the remaining costs are paid privately. While the exact figures are not easily available in Pennsylvania, it is likely that care in nursing homes is

²³⁹ Pennsylvania Long-Term Care Statistics, Pennsylvania Health Care Association website at <http://www.phca.org/research/long-term-care-statistics.htm>.

“underfunded” by MA. For example, a 2012 study indicates that “the cost to nursing homes for care for Medicaid patients exceeds their actual Medicaid reimbursement by \$26.26 per day” or “an average of \$9,500 per Medicaid resident per year”.²⁴⁰ Even with the underfunding, Pennsylvania actively seeks to reduce the nursing home population, through programs such as “Money-Follows- the-Person” and “waiver” programs.

Alternatives to Nursing Home Care

Pennsylvanians have a range of good alternatives to nursing home care, such as small group homes (either Personal Care Homes or Domiciliary Care Homes), Assisted Living facilities, and Continuing Care Retirement Communities (that may include supported Independent Living, Assisted Living, Memory Care and Skilled Care units). Most of these are selected and paid for privately by the residents or the residents’ families. If, however, a resident needs additional funding and seeks funding with public dollars, the resident will need to apply for a publically funded “waiver” program. The access for waiver programs is usually the local Area Agency on Aging (AAAs),²⁴¹ although County Assistance Offices (CAOs) may also be involved in determining financial eligibility. Thus, AAAs can be seen as a key point of access for social services, particularly as the case workers in AAAs often have social work training and experience, with an orientation towards “service” rather than “cost containment”, which in some instances is the bias of the CAO office.

Home & Community Based Care

In Pennsylvania, there is a number of publicly funded or partially funded programs for assistance in the home (or non-nursing home settings, such as Personal Care, Domiciliary Care, or Assisted Living) that can be described as part of the “social care” network, including but not limited to, “Home and Community-Based Services (HCBS) for Individuals Aged 60 and Older; and the Pennsylvania Caregiver Support Program (providing stipends to eligible caregivers in the ranges of \$200 to \$500).

Pennsylvania has also moved in the direction of consolidating some or all “access” points for social care services for persons with disabilities and older persons. Thus, some county AAAs have new labels reflecting consolidation, such as “Aging and Disability Resource Centers” or Aging and Community Living” offices, or simply “Community Care”.²⁴² There is also a telephonic “SeniorLaw Helpline” in

²⁴⁰ Pennsylvania Long-Term Care Statistics, Pennsylvania Health Care Association website at <http://www.phca.org/research/long-term-care-statistics.htm>.

²⁴¹ AAAs are also permitted to “contract out” with servicer providers or oversight providers; indeed, counties may choose to “contract” with a private entity for all aging social care services. The Center for Advocacy for the Rights and Interest of the Elderly (CARIE), a nonprofit corporation, operating in the large Pennsylvania city of Philadelphia, operates as a contractor for AAA services. See <http://www.carie.org/about/about/>.

²⁴² For example, Cumberland County, Pennsylvania received an early pilot grant to create an “Aging and Disability Resource Center”, a concept which was later adopted in whole or in part by other counties in the state. However, when grant money terminated for the ADRCs as separate operations, Cumberland County merged that program into its AAA, which is now called “Aging and Community Services”. See the County’s website at: <http://www.ccpa.net/index.aspx?nid=119>. This county agency is also a “government fiscal/employer agent”, and as such is authorized to provide “financial management services” to residents in the community, including providing assistance in paying taxes, managing public welfare funds, assisting with consumer-directed budgets”. See description at the Cumberland County website at: <http://www.ccpa.net/index.aspx?NID=3311>.

Pennsylvania that is toll-free and offers free, confidential, limited legal advice and referrals for persons 60 and over.²⁴³

Legal Services

Legal Services are an additional component of services that may be provided to older Pennsylvanians without charge, although the amount of service may be limited and the type of service may be basic, supported by the national Older Americans Act.²⁴⁴ States are given flexibility to design a delivery system, and in some states, the counties have additional discretion in how to use the “legal services” money. In Pennsylvania, the 52 local Area Agencies on Aging typically enter into multi-year, renewable (but re-biddable) “contracts” with private lawyers, law school clinics (providing free legal services by students certified to practice law under the guidance of a licensed lawyer), or with non-profit Legal Aid offices to provide legal services in their immediate area, usually paying the provider a flat fee to handle all referrals from the AAA.

Significance of “Medicaid Planning” for Long-Term Care Benefits and Elder Law Attorneys

It should be noted that the question of eligibility for Medicaid/Medical Assistance has triggered specialization among a segment of attorneys across the U.S., who have expertise on how to negotiate eligibility rules and the complexities of planning options.²⁴⁵ “Elder Law” specialists may work in legal aid offices providing free legal representation to poverty-level clients,²⁴⁶ or with higher income clients who are seeking to preserve assets within the family while qualifying a care-needing elder for public funding.²⁴⁷ Medicaid/Medical Assistance now usually requires the state to examine the previous five years of financial records for the person seeking benefits, to determine whether there were transfers or gifts that create “ineligibility” or whether any transfers fall within recently tightened eligibility rules that have been interpreted as still permitting some “planning”.²⁴⁸ The question of “Medicaid Planning” can be controversial or viewed as artificially creating eligibility for public benefits. The rules that govern planning are complex; families or the community spouse may be able to avoid spending assets through legal strategies or techniques, such as converting “countable” resources into “uncountable” community spouse income through the purchase of annuities.²⁴⁹

²⁴³ The SeniorLaw Helpline is operated under a grant, and based in the Philadelphia area SeniorLaw Center. See <http://seniorlawcenter.org/projects-and-clinics/pennsylvania-seniorlaw-helpline-1-877-pa-sr-law/>.

²⁴⁴ 42 U.S.C. § 3026(a)((2)(c).

²⁴⁵ Richard L. Kaplan, *Elder Law as Proactive Planning and Informed Empowerment During Extended Life*, 40 Stetson Law Review 15 (Fall 2010).

²⁴⁶ See, for example, “CARIE,” the Center for Advocacy for the Rights and Interests of the Elderly in Philadelphia, at <http://www.carie.org/about/about/>; see also the Aging and Disabilities Unit at Community Legal Services, also in Philadelphia, at <http://clsphila.org/about-cls>.

²⁴⁷ See, for example, the Law firm of Marshall, Parker & Weber, LLC., with principal offices in Williamsport, Pennsylvania at <http://www.paelderlaw.com/firm-overview/>.

²⁴⁸ Robert C. Gerhard III, *Pennsylvania Medicaid: Long Term Care* (Bisel Co., 2013).

²⁴⁹ See e.g., *James v. Richman*, 547 F.3d 214 (3d Cir. 2008) (Under Pennsylvania Medicaid/Medical Assistance rules, wife was permitted to treat annuity payments funded by \$250,000 of the couple’s resources, as uncountable income, thereby immediately qualifying her husband for Medicaid payments for nursing home).

Protection, Agency and Guardianship Services

All states are obligated, under the Older Americans Act, to offer “protective services” to older adults beginning at age 60, and Pennsylvania adopted the Older Adults Protective Services Act in 1988.²⁵⁰ In addition, Pennsylvania has recently expanded its “protective services” to all adults, aged 19-59, through passage of an Adult Protective Services Act, and is currently in the process of creating a coordinated system of reporting, investigation and action that will be available to assist any adult who is a potential victim of suspected abuse, neglect, self-neglect, exploitation, or abandonment.²⁵¹ Protective Service units within the AAAs are currently the point of receipt for reports of suspected abuse, with a state-wide, toll-free telephone number for confidential reports to be made on a 24-hour per day basis.²⁵²

A key component of social care may be “financial management services”, where an agent is appointed by the individual to have authority to handle such matters. Most often this is accomplished by the individual signing a durable power of attorney. In Pennsylvania, AAAs frequently assist older adults in finding or selecting an appropriate agent. In some instances the county AAA can itself be appointed as the agent. For example, Cumberland County’s Office of Aging and Community Services is an authorized “Government Fiscal/Employer Agent” and is certified to provide “Financial Management Services”.²⁵³ In other counties, the AAA may suggest a nonprofit organization to serve as an agent, and that agency or individual may work for a small fee paid by the county or may be paid a modest amount, on a sliding scale based on income, by the individual. In many states, including Pennsylvania, one potential concern is that “agents” serving under the authority of powers of attorney are not subject to any systematic oversight.²⁵⁴

Where the individual no longer has the capacity to select or designate an agent, a state “guardianship” may be necessary. In some states, there is a state or “public” guardian (a formal public office, and similar in administrative creation, to the Commissioner of Older People in Northern Ireland) who can be appointed as the official representative for the incapacitated person.²⁵⁵ Pennsylvania does not have such a system. In Pennsylvania, as in all states, the process and rules for guardians, both for the person and the estate (sometimes called a conservatorship), are set by law, with enforcement and oversight vested in state courts.²⁵⁶ AAAs frequently are involved in assessment of need for guardianships, especially for individuals who have no immediate family members. For example, in 2013, Dauphin County’s AAA

²⁵⁰ Pennsylvania Older Adults Protective Service Act, 35 P.S. §§ 10225.101 through 10225.5102, with regulations at Title 6, Pennsylvania Code §§ 15.5 through 15.161.

²⁵¹ Pennsylvania Adult Protective Services Act, 35 P.S. §§ 10210.101 to 10210.704 (effective on April 7, 2011).

²⁵² The toll-free numbers for elder abuse reporting in all states is widely available on the internet. See e.g., http://www.nccafv.org/state_elder_abuse_hotlines.htm.

²⁵³ See e.g., Cumberland County website describing the FEA/FMS roles <http://www.ccpa.net/index.aspx?NID=3311>.

²⁵⁴ See e.g., Shay Jacobson, The Perils and Pitfalls of Powers of Attorney Designations, for ElderCare Matters Bulletin, available at <http://www.eldercarematters.com/eldercarearticles/2013/07/the-perils-and-pitfalls-of-power-of-attorney-designations/>.

²⁵⁵ See e.g., Pamela B. Teaster, et al., *Public Guardianship: In the Best Interests of Incapacitated People?* (ABC-CLIO 2010).

²⁵⁶ 20 Pa.C.S. A §§ 5501-5555.

had \$100,000 allocated for legal expenses associated with the county's role in guardians for older adults.²⁵⁷

Questions about lack of consistent practices in appointment and oversight for guardianships across the state of Pennsylvania are the subject of a report recently released to the public. The recommendations by the researchers from their evaluation have not yet been released.²⁵⁸

Filial Support Laws

Finally, Pennsylvania is one of approximately 20 States in the U.S. with "filial support laws", but it is also one of only three States that actively enforce such laws.²⁵⁹ In Pennsylvania, the filial support law requires adult children to "care for and maintain, or financially assist" a parent if "indigent".²⁶⁰ The law is rarely triggered by a parent seeking financial assistance from the child;²⁶¹ rather, the law has become a major tool for hospitals, nursing homes, or other entities providing care to older adults to seek "third-party" payment, usually because of an unpaid bill occurring because of a failure of the resident to qualify for Medicaid/Medical Assistance.²⁶² The law is, at best, not well known by the general public in Pennsylvania, and therefore, standing alone, Pennsylvania's filial support law, even though in existence since colonial times, is unlikely to influence behavior of families, except in response to a collection suit for unpaid debts at care centers.²⁶³

Florida

Population

Florida has more than 4.6 million residents age 60 and over, and is currently the State with the highest percentage of elders. In Florida, 24% of the population is 60+. Further, as a "sunshine" state, it attracts residents from elsewhere in the U.S. for winter accommodations and as a long-term retirement destination.

²⁵⁷ Dauphin County AAA budget for 2012-13, copy provided by Dauphin County AAA Executive Director Robert Burns, copy on file with authors.

²⁵⁸ See Center for Advocacy for the Rights and Interests of the Elderly (CARIE), The State of Guardianship in Pennsylvania: Result from the 2012 CARIE Study of Guardianship in the Commonwealth of Pennsylvania, commissioned by the Pennsylvania Department of Aging, November 2013, available at http://www.aging.state.pa.us/portal/server.pt/community/pennsylvania%27s_aging_initiatives/17891.

²⁵⁹ For a detailed analysis of filial support laws, see Katherine C. Pearson, *Filial Support Laws in the Modern Era: Domestic and International Comparison of Enforcement Practices for Laws Requiring Adult Children to Support Indigent Parents*, 20 Elder Law Journal (No. 2) 269-314 (2013).

²⁶⁰ 23 Pa. C.S.A. §§ 4601-6406, especially §4603 (as amended 2005).

²⁶¹ During the last 25 years, only one reported appellate case in Pennsylvania is by a parent directly. See *Savoy v. Savoy*, 641 A.2d 596 (Pa. Super. Ct. 1994) (holding son liable for \$150 per month to pay mother's debt to hospital).

²⁶² See e.g., *Health Care & Retirement Corp. of America v. Pittas*, 46 A.3d 719 (Pa. Super. Ct. 2012) (holding son liable to nursing home for \$93,000 for mother's six months of care in a nursing home).

²⁶³ See e.g., Katherine C. Pearson, *Rethinking Filial Support Laws in a Time of Medicaid Cutbacks*, 76 Pa. Bar. Q. 162-70 (2005).

Aging Network

The Florida Department of Elder Affairs (DOEA), established in 1992, is the primary state agency for planning, policy-making, coordinating, and administering programs of human services programs for older adults in Florida, and works in coordination with eleven Area Agencies on Aging (AAAs) in the state, linked to local offices at the county level.²⁶⁴ As in Pennsylvania, there are a large number of programs, often funded through individual legislation, that offer services such as assistance with food or care in the home, or funding support for poorer elderly people for residential living. Indeed, the menu of programs can be bewildering in length, as demonstrated by the DOEA website.²⁶⁵ The DOEA makes heavy use of on-line internet resource guides for individuals or their families to identify local services.²⁶⁶

Transition from Focus on “Aging” to focus on “Aging & Disability” for Service Centers

In April 2004, Florida received a national grant to establish one or more “pilot” Aging and Disability Resource Centers.²⁶⁷ Florida is now in the middle of a five-year plan for expanding, to transition from AAAs or Aging Resource Centers (ARC), to Aging and Disability Resource Centers (ADRC).²⁶⁸ The goal is to establish at least one coordinated ADRC in each of the 11 “areas” of the state, with the hope of creating streamlined access to home and community based supports and long-term care options for both older adults and those with developmental disabilities. Cost saving is also a goal of the consolidation.

Unique Issues in Florida

One of the unique aspects of aging policy in Florida is its location in a region vulnerable to devastating weather events, such as hurricanes. In 2013, the DOEA issued its latest “Disaster Preparedness Guide for Elders”, encouraging both individuals, families and communities to adopt “disaster plans”.²⁶⁹

In many ways, Florida’s reputation as a retirement destination has resulted in communities marketed specifically to retirees, often advertised as capable of meeting the needs for care and services. However, in an article titled “‘Peter Pan’ as Public Policy: Should Fifty-Five Plus Age-Restricted Communities Continue to be Exempt from Civil Rights Law and Substantive Federal Regulation, Stetson University College of Law Professor Mark D. Bauer, is critical of states, including Florida, that have permitted developers to create age-limited communities, but without truly meeting the needs for older adults. For example, he points to the absence of

²⁶⁴ Florida Department of Elder Affairs website, at <http://elderaffairs.state.fl.us/index.php>.

²⁶⁵ <http://elderaffairs.state.fl.us/doea/programs.php>.

²⁶⁶ For example, the Florida Department of Elder Affairs has “Consumer Resource Guide,” using a colored map where an interested person can “click” to access a list of services within any of the 67 counties in the state. See http://elderaffairs.state.fl.us/doea/resource_county.php.

²⁶⁷ <http://elderaffairs.state.fl.us/doea/adrc.php>.

²⁶⁸ See Florida Department of Elder Affairs Report, “Aging and Disability Resource Centers: Five-Year Plan for Expanding ADRs Statewide,” April 1, 2011, available at http://elderaffairs.state.fl.us/doea/ARC/ADRC_5_Year_Plan_final.pdf.

²⁶⁹ <http://elderaffairs.state.fl.us/doea/disaster.php>

construction legal standards that require such communities to be accessible for people with disabilities.²⁷⁰

Maine

Population

Maine is a comparatively small state, ranking 41st of the 50 U.S. states in population, with an estimated total population in 2012 of just 1.3 million, with many of its citizens in rural settings. In terms of the proportion of population deemed “older”, Maine is one of the “oldest” states, with 17% of the population over the age of 65.²⁷¹ Maine recognized that the state’s demographic trends were combining to create a serious public policy challenge and therefore reported in 2008: “[Maine’s] has a higher rate of poverty than the U.S. and New England average, ranking as the 18th highest state in the nation for persons aged 65+ at or below the Federal Poverty Level (FPL). The 2000 Census reports that 54% of Mainers 65+ below the FPL also reported a disability, compared to 40% of the same age group reporting a disability if incomes were higher than the FPL. This leaves those most in need of assistance least able to pay for it. Maine’s population is also aging at a faster rate than most other states, because the percent of Maine’s older adults is increasing, but also because the percent of Maine’s younger persons is decreasing”.²⁷²

Aging Network

By comparison to Pennsylvania, which still has a stand-alone State Department of Aging, Maine has fully implemented steps to consolidate services for seniors and disabled persons. As of August, 2012, Maine’s Office of Elderly Services no longer exists; instead the “Office of Aging and Disability Services” (OADS) is a single unit within the state’s Department of Health and Human Services,²⁷³ with local offices that were called Area Agencies on Aging (AAAs). The state appears to be creating new names for those access points, further reflecting the combined service for older and disabled adults. For example, the OADS website describes new steps to improve services over the next two years, including a plan for “every person served” to have an “individualized assessment of their support needs using the Support Intensity Scale (SIS)”, and noting that to the extent permitted by budget and Medicaid rules, “individuals will be able to choose their own services”.²⁷⁴

Transitions from Nursing Homes to Home and Community Care

Maine has also been aggressive in seeking to move individuals out of traditional nursing homes. For example, in 2008 Maine reported: “Perhaps the greatest trend

²⁷⁰ Mark D. Bauer, *Peter Pan as Public Policy: Should 55-Plus Age Restricted Communities Continue to be Exempt from Civil Rights Laws and Substantive Federal Regulation*, 21 University of Illinois Elder Law Journal 33 (2013), accessible at <http://ssrn.com/abstract=2131816>.

²⁷¹ U.S. Census Bureau, State and County Quick Facts, at <http://quickfacts.census.gov/qfd/states/23000.html>.

²⁷² Maine State Plan for Aging (2008-2012), prepared by the then Office of Elderly Services, page 3, available at <http://www.maine.gov/dhhs/oads/aging/policy/index.shtml>.

²⁷³ Maine State Plan for Aging, covering 2012-2016, prepared by the Office of Aging and Disability Services, available at <http://www.maine.gov/dhhs/oads/aging/policy/index.shtml>.

²⁷⁴ How we Move Forward - 2014/2015, on Maine OADS website at <http://www.maine.gov/dhhs/oads/disability/planning.shtml>.

in services has been the progress made toward reducing the use of nursing facilities. In 2001, Maine had 52 nursing facility beds per 1,000 people, ranking Maine 19th in the nation for the most beds per capita. By 2005 Maine ranked 36th with 39 beds per 1,000 people”.²⁷⁵ Maine describes the trend to avoid or delay nursing home placement as both a measure of cost savings and striving to meet consumer preference. “Homeward Bound” was the name for Maine’s “demonstration project” with CMS funding to “help elderly and disabled adults move from institutional to community settings”.²⁷⁶

As part of that trend, Maine has pursued what it calls “Long Term Care Services and Supports”, a move to integrate several programs that provide supportive services. Long Term Care Services and Supports are funded through MaineCare (Maine’s version of Medicaid comparable to Pennsylvania’s Medical Assistance program) or state funds. Services are organized into different programs, often sounding similar to the consumer, including:

- State-funded In-Home and Community- Home-Based Care;²⁷⁷
- Medicaid Waiver Program for Elderly and Adults with Disabilities;
- Assisted Living Facilities (including one of 7 state-funded facilities, with individual apartments and assistance in medication, meals, homemaking and other activities);
- Independent Housing with Services (5 facilities, similar to above, but without assistance in medication);²⁷⁸
- Residential Care Services;²⁷⁹
- Alzheimer’s Respite;
- Homemaker Services, through “Catholic Charities of Maine”;²⁸⁰
- Adult Day Services, funded jointly by state and federal funds at licensed locations.²⁸¹

Eligibility for most of the above Long Term Care Services and Supports is determined by a functional/health and financial assessment.²⁸² The functional/health component of the assessment appears to be outsourced.

²⁷⁵ Maine State Plan for Aging, covering 2008-2012, prepared by the then-existing Office for Elderly Services, available at <http://www.maine.gov/dhhs/oads/aging/policy/index.shtml>.

²⁷⁶ Maine Homeward Bound Program, for “Money-Follows-the-Person” demonstration project, with details (including an “operational protocol”) at <http://www.maine.gov/dhhs/oads/aging/mfp/mfp.shtml>.

²⁷⁷ See website for in home care options at Maine Office of Aging & Disability Services at <http://www.maine.gov/dhhs/oads/aging/long-term/in-home-care.shtml>.

²⁷⁸ See website for in Assisted Living options at Maine Office of Aging & Disability Services at <http://www.maine.gov/dhhs/oads/aging/long-term/assisted-housing.shtml>.

²⁷⁹ See website for Residential Care Services, including shelter and personal care at Maine Office of Aging & Disability Services at <http://www.maine.gov/dhhs/oads/aging/long-term/residential-care.shtml>

²⁸⁰ See website for Homemaker Services at Maine Office of Aging and Disability Services at <http://www.maine.gov/dhhs/oads/aging/long-term/residential-care.shtml>.

²⁸¹ See website for Adult Day Services, at Maine Office of Aging and Disability Services at <http://www.maine.gov/dhhs/oads/aging/long-term/residential-care.shtml>.

²⁸² See website for Maine Office of Aging and Disability Services at <http://www.maine.gov/dhhs/oads/aging/long-term/assessment.shtml>.

Legal Services

Maine offers free legal services to individuals 60 and over through “Legal Services for the Elderly”, (LSE) a private, non-profit agency. LSE, established in 1974, is the single agency identified in the state to receive funding under the federal Older American Act. It also is funded through state dollars and through private, charitable (tax exempt) fundraising. It has offices in five locations around the state, and also has a state-wide toll-free hotline.²⁸³

Long-Term Care Ombudsman

Maine’s Long-Term Care Ombudsman program is a private, non-profit agency designated to serve as an “advocate and mediator for consumers receiving long-term care through nursing homes and home and community based services”. The agency “receives and investigates complaints from individuals and agencies regarding issues that affect the care, health, safety or rights of recipients of long-term care”.²⁸⁴ The program is another of the mandates by the Older Americans Act, with enabling state legislation.²⁸⁵

Protection, Agency, Guardianship Services

As with Pennsylvania, Maine has laws and programs for adult protective services (including an Adult Protective Services hotline),²⁸⁶ guardianships, and alternatives to guardians, including use of agents.²⁸⁷ All of the information on this area is well organized and described on the website for the Maine Office of Aging and Disability Services, including a very useful section of “Questions and Answers” about guardianships, conservators, and alternatives. There is also an on-line “tutorial”, including an easy to load video of a judge describing the way that the court process and alternatives work, with a nice section called “Myth Busting”, where the judge reminds people that guardianships, standing alone, cannot solve problems such as lack of money, dysfunctional families, and similar personal problems, and thus the need to be realistic about what guardianships can accomplish.²⁸⁸

Filial Support Laws

Maine does not have a filial support law obligating adult children to support parents. Maine does, however, have an “improvident transfer” law that entitles an “elderly dependent person” to void a transfer or gift of real estate, personal property or money, if the transfer was accomplished through someone with whom the elder has a confidential or fiduciary relationship, unless the “elderly dependent person” was represented during the transaction by “independent” counsel. An elderly dependent person is defined as someone who is 60 or over and “who is wholly or partially

²⁸³ Maine Legal Services for the Elderly, website at http://mainelse.org/content/about_us.

²⁸⁴ Maine State Plan on Aging, 2012-2015, page 10, available at <http://www.maine.gov/dhhs/oads/aging/policy/index.shtml>.

²⁸⁵ 22 Maine Rev. Stat. §§ 5106 and 5107-A.

²⁸⁶ See website description adult protective services in Maine at <http://www.maine.gov/dhhs/oads/aging/aps/index.shtml>.

²⁸⁷ See website on Adult Guardianship and Alternatives in Maine at <http://www.maine.gov/dhhs/oads/guardianship/index.shtml>.

²⁸⁸ See “Guardianship Tutorial” on Maine website at <http://www.maine.gov/dhhs/oads/guardianship/wbt/index.html>.

dependent upon one or more persons for care or support, either emotional or physical”.²⁸⁹ The statutory cause of action is deemed to expire upon the elder’s death.²⁹⁰

Concluding Observations on Best Practice

Having examined adult social care in the context of the United States, we can conclude with the following observations in regard to the issues that the U.S. places value on:

- The U.S.A. is moving in the direction of coordinated access for adults in need of social services or benefits, without regard to “age” alone. In some instances, this coordination is also moving in the direction of single point access to services, as demonstrated by the recent creation of “Aging and Disability Resource Centers”. The implementation concern that accompanies this movement, however, comes from U.S. advocates for older persons, who are concerned that this may result in a reduction of services made available for older adults or a prioritization of services based on level of disability, thus favoring younger physically or learning disabled individuals over older adults who are reluctant to self-identify as disabled. Example: Availability of Meals on Wheels (home delivered meals) and free legal services has not been tied to disability for older adults.
- The U.S. increasingly values home care as the expressed preference of most older adults, and in support of this preference has implemented additional public support for education, training, and some funding of home care workers, including family members to provide care in the home. The implementation concern is the potential for the emphasis on home care to increase the burdens on family members, without providing family members with adequate funding or resources to provide quality of care.
- The U.S. values clear standards for assessment of quality of care by third-party carers, both in the home and in facility-based care. The implementation concern is that data about quality of care, and deviations from quality of care is not being collected or monitored on a uniform basis.
- The U.S. historically has valued access to free or low cost legal services for older adults through grants specifically funding such services at the state and local level. The implementation concern is that the public funding is being cut.

²⁸⁹ 33 Maine Rev. Stat. §§ 1021-1025.

²⁹⁰ *Sylvester v. Benjamin*, 767 A.3d 297 (Maine 2001).

Conclusion

Our review of adult social care in Northern Ireland in comparison to other jurisdictions leads us to conclude that the legal system for social care provision needs to be amended. We have provided examples in several countries in our review where this has occurred and is effective as a mechanism for addressing the needs of older people in a clear and consistent manner. Our review has also uncovered consistency in several countries in the value that is placed on preventative services and the importance of service provision against a legislative backdrop built on human rights based principles. An integrated health and social system has served Northern Ireland well for over forty years, particularly during a troubled period of our history, but here we have noted inconsistencies in regard to disparities in service provision across the domains of health and social care.

Thus, as set forth in numbered items in the Executive Summary and Key Recommendations, we believe that Northern Ireland should use the opportunity provided by devolution to enact a modern legislative framework that addresses social care needs for “adults rather than separate frameworks for “older persons” and “disabled persons”. We recommend a continued allegiance to explicit human rights principles to secure a social care framework that permits individual decision making, based on need and preferences, with early opportunities for assessment and intervention to reduce the possibility of crisis and otherwise preventable institutionalization.

We have also observed inconsistencies in regard to cost issues. Increasing demands for health and social care reinforce the importance of considering how these services should be funded. Our Report therefore recommends that future funding arrangements should be fair and not discriminate against groups, including older people, who may have higher levels of need.

Finally, we recognize that the recommended consolidated piece of legislation will need to include not just adult social care, but also mental capacity, developmental disabilities and adult protection concerns. We believe this is a ripe opportunity for Northern Ireland to be seen as the leader in the world for a clear, comprehensive and coherent strategy to address the core human rights of adults, who because of age or disability need assistance.

We firmly believe that adopting the Recommendations in this report will lead to a more streamlined and clearer system of social care services for older people which will fundamentally address the discriminatory and unequal aspects of current service delivery.