



THE ALZHEIMER
SOCIETY *of* IRELAND

Human Rights and Older People in Ireland

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Appendix 1: Members of the Human Rights and Older People Working Group

Section 1: Background

1.1 What is the Human Rights and Older People (HROP) Working Group?

The Human Rights and Older People Working Group was established on the premise that the member organisations, although different in many ways, share a common focus on human rights and older people.

The members of the Group are The Alzheimer Society of Ireland; Irish Council for Civil Liberties; Age and Opportunity; Third Age; Public Interest Law Alliance; Age Action; Active Ageing in Partnership and Active Retirement Ireland.

The organisations initially met in March 2013 to hold an exploratory discussion about human rights and older people. At that meeting it was agreed to formally become a working group with a view to exploring a human rights based approach to older people's issues. A workshop was held on 21 June 2013 to bring together a range of perspectives and identify core issues.

The Alzheimer Society of Ireland (ASI) is resourcing and facilitating the working group for 2013.

1.2 The Human Rights and Older People Workshop

In June 2013, a human rights workshop was held involving key stakeholders from a variety of organisations and sectors.¹ In summary, the participants discussed inputs by three experts:

- **'Opening a conversation on human rights, equality and older people'** presented by Judy Walsh, Lecturer in Law and Head of the Equality Studies Centre in UCD.
- **'Applied human rights'** presented by Ann Leahy, Head of Policy at Age and Opportunity
- **'Progressing a human rights based approach'** presented by Mark Kelly, Director of the Irish Council for Civil Liberties

Some key points quickly emerged from the group discussions which have shaped the aims, objectives and structure of this report.

1. Stigma and ageism are major barriers which prevent older people realising their human rights

Older people are often seen as recipients of care rather than rights holders. Many older people have themselves internalised ageism and see themselves as burdens rather than people with rights and entitlements. Stigma is multiplied in the case of older people with a disability such as dementia.

Stigma

"A societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the person who possess them"

(Miles 1981:70)

Its components are "labelling, stereotyping, separation, status loss and discrimination"

(Link and Phelan, 2001:363)

*Perceptions of Stigma in Dementia
(The Alzheimer Society of Ireland, 2006).*

1 A full report of the workshop is available at www.alzheimer.ie

2. Lack of awareness and a perception of irrelevance must be addressed if older people are to engage more fully with human rights concepts and language

Many older people do not perceive human rights as something which is relevant to their day-to-day lives. The language used to speak about human rights can be alienating and can increase the perception that human rights are “something for lawyers.”

Participants expressed interest in the idea of human rights based approaches but found it difficult to imagine “how it would work in practice”. Accessible language and concrete examples are needed in order to enable wider engagement with human rights concepts and approaches.

3. Diversity among older people must be recognised

While it can be useful to speak of older people as a group in recognition of common issues faced by many older people, it is critical to recognise that older people are not a homogenous group. One of the effects of ageism is to view older people as homogenous, and likely to hold similar views, have similar needs and behave in similar ways, rather than seeing them as individuals. In addition it is important to recognise that many other factors interact with ageing to determine the experience of older people. These may include gender, economic disadvantage, educational disadvantage, disability or belonging to another minority (for example, older lesbian, gay, bisexual and transgender people have been described as an “invisible minority within a minority”).²

4. Key factors in the realisation of rights

Following on from the workshop the working group met to discuss the findings and identified five themes that had come up repeatedly when participants spoke of the experience of older people. These could be described as key determinants of whether human rights could be meaningfully realised in older people’s lives.

- (Lack of) access to appropriate and timely information
- (Not) having a voice
- (Lack of) access to redress
- (Inadequate) allocation of resources
- (Lack of) choice.

2 “LGBT Health: Towards meeting the health care needs of Lesbian, Gay, Bisexual and Transgendered people” (HSE, 2009)

1.3 Aims and Approach

This policy paper is part of a process aimed at creating dialogue around the relevance of human rights concepts and approaches for older people. It focuses on the issues identified at the HROP workshop in June 2013 with the aim of moving discussion towards concrete ways of using human rights, concepts, languages and approaches to improve the lived experience of older people in Ireland.

A key element of achieving this aim is to attempt to make human rights more accessible and relevant to older people. One of the common themes emerging from the workshop and working group discussions is that older people and organisations working with them do not see human rights concepts as relevant to them. There is often a sense of “that’s very nice, but what does it mean in practice?”

“Where, after all, do universal human rights begin? In small places, close to home.”

Eleanor Roosevelt, 1958.

This contrasts, for example, with the much more frequent use of human rights language and concepts by people with disabilities and organisation representing them.

In this policy paper, we will follow three stories based on typical cases encountered by members of the working group in order to see what difference a human rights based approach might make in common situations.

“Human rights did not begin on paper but in the daily struggles of disadvantaged people throughout history - human rights come about as a response to human wrongs”.

Judy Walsh, Lecturer in Law and Head of the Equality Studies Centre, UCD speaking at the HROP workshop, Dublin 21 June 2013.

1.4 Objectives

The objectives of this policy paper are to:

- Briefly outline the current situation relating to human rights and older people in Ireland
- Examine, through representative case studies, the relevance of human rights to older people’s experience and the impact of the key factors identified:
 - Access to appropriate and timely information
 - Having a voice
 - Access to redress
 - Allocation of Resources
 - Choice
- Outline what is meant by a Human Rights Based Approach (HRBA) and to illustrate what a HRBA might look like in the context of the case studies
- Identify examples of existing good practice
- Make recommendations for the progression of a human rights agenda in policy and practice in Ireland.

Section 2: Human Rights and Older People in Ireland: Overview

2.1 What are Human Rights?

Modern international human rights law is the product of a consensus reached by states as to the minimum standards they agree to be bound by, e.g. in the right to education and the right to health. The methods by which those standards are met are a matter of discretion for each state. For example, while the standards required to comply with the right to fair trial are clear and detailed (right to a defence, presumption of innocence, etc.), a wide variety of types of legal system (Civil Law, Common Law, etc.) meet those standards throughout the world.

Moreover, international human rights is an evolving body of law, as reflected in moves to make non-state actors accountable and to develop rights based approaches to new issues such as the environment.

By its participation in the international human rights framework Ireland has undertaken to ensure that its Constitution, laws, policies, budgets and practices reflect these legal obligations and achieve, rather than undermine, the minimum standards to which it has agreed.

“Our Rights, Our Future - Human Rights Based Approaches in Ireland” Amnesty International 2005.

In addition to the international treaties to which Ireland is a party, the Irish Constitution, Bunreacht na hÉireann, contains a range of fundamental rights in Articles 40-44, including rights to equality before the law, freedom of expression, freedom of religion and the right to education. The Constitution empowers the courts to declare legislation unconstitutional if it breaches these fundamental rights. In addition to the rights named in the Constitution, the Irish Courts over the years have held that the Constitution implies other rights, such as the right to bodily integrity, to marry, to privacy etc.

2.2 Are all Rights Created Equal?

Throughout the era of Cold War politics a distinction was drawn between civil and political versus economic and social rights. Increasingly proponents of human rights emphasise the linked nature of rights and reject the distinction. The Vienna Declaration and Programme of Action, adopted in 2003 by 170 states including Ireland in 1993, re-stated the legal principles that all internationally recognised human rights are universal, inalienable, interrelated and interdependent.

However a distinction remains within some of the international treaties in relation to the kind of obligation placed on states in relation to the different types of rights.

“The International Bill of Rights is comprised of two conventions adopted in 1966: The International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR). ...Since they are more likely to require government planning and the investment of resources, the ICESCR creates a requirement of “progressive realisation” of economic, social and cultural rights. The ICESCR imposes immediate obligations on governments “to take steps” (i.e. begin planning) to bring about the full enjoyment of the rights contained in the ICESCR, and “particularly the

adoption of legislative measures”.³

It is worth noting that many of the rights which impact most profoundly on the day-to-day lives of older people in Ireland such as the right to health and the right to housing would traditionally be seen as economic and social rights. Therefore the Irish government’s obligations in relation to these rights tend to be more obligations to take steps to bring the realisation of these rights –“obligations of conduct” - than stronger obligations to “respect” and “give effect” to them – “obligations of result”.

In addition, to date Irish Courts have consistently found that the separation of State powers enshrined in the Constitution means that the executive arm of government must make decisions about the allocation of resources without interference from the courts.⁴

A further relevant distinction exists between absolute rights and qualified rights. The right to life and the right to freedom from inhuman and degrading treatment are examples of absolute rights under the European Convention on Human Rights, which may not be infringed for any reason.

Qualified rights in the European Convention on Human Rights include the right to respect for private and family life, freedom of thought, conscience and religion, freedom of expression, freedom of assembly and association and the right to protection of property.

These rights can be restricted by government where the greater public interest requires it, provided it is done in accordance with law, for a legitimate aim and in the least restrictive manner way possible.

2.3 Human Rights and Social Policy

Current Irish social policy on ageing is set out primarily in the National Positive Ageing Strategy (2013) and the Healthy Ireland Strategy (2013). These documents are concerned with a strategic approach to healthy living and positive and active ageing in Ireland. For certain groups within the older population, disability policy is also relevant.

As people age, the likelihood of acquiring a disability (including dementia) increases. The CSO National Disability Survey (2006) showed that more than one third (36%) of all persons with a disability were aged 65 and over whereas this age group represented only 11% of the population.

Some disabilities affect some age groups more than others. The National Disability Strategy (2004) sets an ambitious and integrated agenda for the advancement of the mainstreaming agenda for people with disabilities in Ireland. The Disability Act (2005) and the provision for advocacy services in the Citizens Information Board Act (2007), were designed to create an integrated response for people with disabilities across all areas of the life cycle. For this reason, the integration of policy underpins the National Positive Ageing Strategy in order to live up to the stated aim of addressing ageing and disability issues within a lifecycle approach. However, older people, and more specifically older people with disabilities or additional health needs, continue to experience substantial unmet needs.

There is no explicit reference to human rights in the Healthy Ireland Strategy. The National Positive Ageing Strategy states that the UN Principles for Older Persons⁵ are the operating principles underpinning the Strategy. These principles are independence, participation, care, self-fulfilment and dignity.

3 “Our Rights, our Future - Human Rights Based Approaches in Ireland” Amnesty International 2005

4 O’Reilly v Limerick Corporation [1989] ILRM 181, T.D. v Ireland [2001] 4 I.R 259

5 <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>

The Strategy goes on to maintain that:

“As such, these Principles should guide any actions developed to progress Ireland towards an age-friendly society i.e. they should be used to assess the age-friendliness of policies, programmes and services for older people. By phrasing each principle as a policy question, a policy evaluation check-list can be developed, for example:

- How can the policy, programme or service under consideration be improved to better enhance the independence, participation, care, self-fulfilment or dignity of older people?
- Will a policy, programme or service under consideration have a negative impact on the independence, participation, care, self-fulfilment or dignity of older people?

Towards a UN Convention on the Rights of Older People?

The UN Principles do not currently have the status of a Convention which would create binding obligations on States Parties. There is ongoing debate at national and international level as to whether a UN Convention on the Rights of Older People would contribute to the realisation of rights. Proponents point to the positive effect of the UN Convention on the Rights of People with Disabilities (see section 2.4.1 below.) On the other hand, it can be argued that often the main barrier between older people and their rights is the absence of awareness, implementation, monitoring and enforcement, and that the focus should be on improving existing mechanisms of rights delivery.

In this way, these UN Principles can serve as a useful age-proofing tool for policy development and service delivery purposes.”⁶ This stops some way short of a Human Rights Based Approach (HRBA) as outlined in Section 4.

The National Positive Ageing Strategy refers to the Programme for Government commitment to the establishment of Older People Councils by local authorities, where members of the community can raise local concerns or issues of importance.⁷ It is envisaged that these Councils will have a ‘bottom-up’ role in monitoring the implementation of the Strategy. In establishing these Councils, local authorities are tasked with ensuring, among other things, that

- their composition is representative of the diversity of the older population at the local level;
- they are linked with local groups of older people;
- the participation of the most vulnerable is supported.

Again this is a move in the direction of a Human Rights Based Approach but stops short of adopting an explicit human rights framework.

6 National Positive Ageing Strategy 2013

7 Programme for Government 2007-2012

2.4 From Theory to Practice: The Delivery of Rights

National Constitutions and international Conventions are high level documents which guide state policy and legislation. In general, for the rights contained in high level documents to be accessible and meaningful to people in day-to-day life, it is necessary for a country to enact legislation spelling out what that right means in practice. If this is missing it can be very difficult to assert a right.

A person who believes that a Constitutional right has been breached can in theory bring a case to the High Court – as is also the case if the right is the subject of a Convention which has been incorporated into Irish law such as the European Convention on Human Rights - but in practice, there are many barriers. If someone needs a solution now, the long drawn out process of a court case may be of no use to them. If someone is in a vulnerable position they may have no access to a lawyer - they may not even know that what is happening is an abuse of rights, and that they need a lawyer. If they can access advice, the very substantial cost of a High Court action may well be a deterrent, particularly if the applicant is from a socially disadvantaged group.

Being able to look for a remedy when a right has been infringed is important, but in order for human rights principles to be influential in what happens every day on the ground without the constant need for recourse to the courts, there needs to be an implementation mechanism to bridge the gap between the high level Treaty or Constitution and the individual rights holder.

The primary way in which this happens is through legislation, where the Oireachtas spells out rights and entitlements in law.

Laws are usually given further detail by regulations, which are made by the relevant Minister and spell out the mechanics of how the law will operate in practice.

2.5 Legislation and the Rights of Older People

The rights of older people are more noticeable by their absence from Irish legislation than their presence. There are some exceptions.

The HIQA legislation (Health Act 2007) is a good example of an area where legislation, regulations, standards - and crucially, an inspection regime, has created better, though far from faultless, access to rights on the ground for older people in residential care.

The Equal Status Acts 2000-2010 and the Employment Equality Acts 1998-2010 include age as one of the nine grounds on which discrimination is outlawed in employment and in access to services. There have been a number of successful cases relating to dismissal from work on age grounds. In a recent case, two part-time civil defence instructors successfully challenged their dismissal on age grounds and were awarded just under two years salary.⁸ However, the Employment Equality Act currently allows for an upper age limit to be stipulated in a contract of employment⁹ or, in certain public service jobs, stipulated by law.¹⁰ (In the case of the Offaly Civil Defence, the age limit was not set out in a contract of employment).

8 Mr Patrick Dunican and Mr Thomas Spain -v- Offaly Civil Defence DEC-E2013-027

9 Paul Doyle v. ESB International DEC-E2012-086

10 Donnellan v. Minister for Justice, Equality and Law Reform and Ors. (Unreported, High Court, McKechnie J. 25 July 2008)

This is at odds with the EU Directive 2002/78 EC which only permits age discrimination where it can be objectively justified (eg. professions such as firefighter which require a very high level of physical fitness).¹¹

There are also limitations on the scope of the Equal Status legislation. Insurance is one of the areas in which older people frequently report discrimination. However, higher rates or refusal to insure can be justified on the basis of actuarial evidence that, on average, older people are a higher risk. (There is currently a move in Europe towards alternative methods of assessing risk in insurance which do not penalise an individual who may themselves pose a very low risk).¹² Active Retirement Ireland is currently working with Public Interest Law Alliance to pursue the experience of older people here in Ireland and identify a suitable test case to challenge age discrimination in insurance.

Outside of the equality legislation and the Health Act 2007 and regulations, there is no explicit mention of older people as rights holders in Irish legislation. There are, however, two pieces of legislation, one relatively recent and one hopefully imminent, which deal with issues impacting directly on many, though not all, older people, the Nursing Homes Support Scheme Act 2009 (and subsequent Regulations) and the Assisted Decision Making (Capacity) Bill 2013.

2.5.1 Decision Making: From 1871 to 2013

One of the critical gaps in Irish legislation in terms of rights which directly impact on older people is the absence to date of modern, human rights compliant capacity legislation. It is to be hoped that this is a gap which will shortly be filled by the enactment of the Assisted Decision Making (Capacity) Bill 2013 which at time of writing is about to begin its passage through the Oireachtas.

“Legal capacity means the ability to hold rights and duties and to exercise these rights and duties.” (Source: UN Committee on the Rights of Persons with Disabilities Draft General Comment on Article 12, para. 12).

In practice, having legal capacity means being recognised as a person who can make decisions. While age alone certainly does not mean that a person will have reduced decision-making ability, the effect of stigma and ageism often means that older people are assumed to have less capacity to make decisions for themselves. And while most older people will experience no decline in capacity, the risk of developing dementia does increase dramatically with age. People with dementia do experience a progressive decline in the ability to make and communicate decisions as the condition develops over time.

As a signatory to the UN Convention to the Rights of People with Disabilities (UNCRPD), Ireland is bound by Article 12 which deals with the issue of legal capacity.

However, Ireland cannot as yet ratify the Convention because Irish legislation dealing with capacity is completely outdated and at odds with the principles of the UNCRPD.

The 1871 Regulation of Lunacy Act created our current Wards of Court system. If for example, funds belonging to a person who has limited capacity need to be accessed to pay for their care, they have

11 Wolf v. Stadt Frankfurt am Main [Case C229-08]CEUJ

12 AGE Platform Europe background document for LIBE Hearing “Unblocking the Anti-Discrimination Directive” on age discrimination in access to financial services <http://age-platform.eu/age-policy-work/anti-discrimination/age-position-statements>

to be made a Ward of Court. The High Court then has ultimate responsibility for all decisions affecting them- they are in effect no longer a person in their own right for the purposes of the law. The only current alternative to Ward of Court is if a person has made an Enduring Power of Attorney prior to losing capacity. This is a legal document appointing a person or persons of their choice to make decisions on their behalf were to lose capacity in the future. While it at least allows the person to choose who will make decisions on their behalf, it does transfer all their decision making power to that person and as such is open to abuse.

The Assisted Decision Making (Capacity) Bill 2013 is intended to repeal the 1871 Act, replace the Wards of Court system, introduce a range of options for people with limited decision making ability and put Ireland into a position where it can finally ratify the UNCRPD.

Article 12:

Persons with disabilities have the right to recognition everywhere as persons before the law, on an equal basis with others. ...States Parties are obliged to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. ...Safeguards must be in place to ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

Assisted Decision Making (Capacity) Bill 2013 - Highlights¹³

Presumption of capacity:

Everyone, regardless of age or disability, must be presumed to have capacity until it is shown that they do not.

Definition of capacity

Capacity is to be assessed on the basis of the person's "ability to understand the nature and consequences of a decision to be made by him or her in the context of the available choices at the time the decision is made". This means that capacity always relates to a specific decision at a specific time, it is not "all or nothing". This definition recognises the reality that people's capacity may fluctuate and that a person who lacks capacity to make some kinds of decisions may be fully able to make other kinds of decisions.

Guiding principles

- The legislation will set out some important principles which must be applied in all situations where a person lacks or may lack capacity. These include:
- Nobody can be deemed to lack capacity unless all practicable steps have been taken to help them to make the decision
- A person cannot be deemed to lack capacity simply because the decision they make is unwise
- Intervention must be done in the way which is least restrictive of the person's freedom
- The person's will and preferences, so far as they can be established, must be given effect

New system

The Bill will replace the Office of the Wards of Court with the office of the Public Guardian.¹⁴ The Ward of Court system will be replaced with a range of options for people whose capacity is limited ranging from decision making assistance agreements to co-decision making to the appointment of a decision-making representative.

This is an example of how an international human rights convention has provided the impetus for Irish law to take a step forward in terms of protecting human rights – it also illustrates the fact that the convention by itself does not confer realisable rights without legislation to implement its principles. It is hoped that the legislation will have a significant effect on the involvement of older people and people with dementia in decisions affecting their lives. However, changing the law alone will not be enough without a significant cultural shift. Education for the public and professionals on the new approach to capacity and monitoring the impact of the legislation will be essential if real change is to happen in practice.

¹³ Please note that at time of writing the Bill has not passed through the parliamentary stages and is still subject to change, although substantial change to the core definitions and principles is unlikely.

¹⁴ The name of the office is still being debated and may change

2.5.2 Fair Deal? The Nursing Homes (Support Scheme) Act 2009 (NHSS)

The Nursing Homes (Support Scheme) Act 2009 gave a statutory footing to arrangements for financial support for people entering nursing home care, known as the “Fair Deal” Scheme. It replaced the scheme of Nursing Home Subvention which had been in existence since 1993, together with the system of contract beds and long-stay charges in public nursing homes. The stated intention of the scheme was to provide greater clarity and equality of access to state funding for long term residential care¹⁵. The previous system had been heavily criticised for inequity and inconsistency.¹⁶

In introducing standardised criteria and application procedures the NHSS has addressed some of those issues (although several submissions to the 2012 review of the Scheme stated that older people and their families experienced considerable difficulty in accessing appropriate information and navigating the application process).¹⁷

On the other hand, the legislation is not rights based in the sense that the Scheme is budget-capped and does not confer an actual entitlement to financial support for nursing home care. Thus, a person can fully complete the application process and meet all the criteria for eligibility but be left without a nursing home place due to lack of financial resources earmarked for the Scheme. In June 2011 the Scheme was temporarily suspended due to lack of funding causing significant hardship and distress to many older people and their families¹⁸ and at time of writing it is reported that the scheme is again under pressure with waiting times likely to increase, due in part to use of funding to free up acute hospital beds by prioritising these cases over admissions from the community.¹⁹

The Office of the Ombudsman has heavily criticised the NHSS as being poorly drafted and unclear, and disagrees with the Department of Health’s interpretation that it has amended the 1970 Health Act to give the State the discretion to provide long term residential care for those who cannot afford it, in place of the original obligation to provide care.²⁰

Submissions to the 2012 NHSS review also identify the detrimental effect of having a statutory footing for support for residential care but not for care in the community, with anecdotal accounts of people who would have been able to stay at home with some extra support being forced to opt for residential care, as the only option for which financial assistance was available.²¹

15 <http://www.dohc.ie/press/releases/2006/20061211.html>

16 E.g. see “Who Cares? - an Investigation into the Right to Nursing Home Care in Ireland (A Report to the Dáil and Seanad in accordance with section 6(7) of the Ombudsman Act 1980)” (Office of the Ombudsman 2010) esp. Section 4 for sample complaints from public

17 “Nursing Home Support Scheme, A Fair Deal: Summary of Submissions Received to Inform the Review of the Scheme” (DOHC, December 2012)

18 <http://www.thejournal.ie/nightmare-situation-as-fair-deal-applications-suspended-139659-May2011/http://debates.oireachtas.ie/dail/2011/06/09/00010.asp>

19 <http://www.irishtimes.com/news/health/waiting-list-for-nursing-homes-set-to-double-1.1477877>

20 “Who Cares? - an Investigation into the Right to Nursing Home Care in Ireland (A Report to the Dáil and Seanad in accordance with section 6(7) of the Ombudsman Act 1980)” (Office of the Ombudsman 2010)

21 “Nursing Home Support Scheme, A Fair Deal: Summary of Submissions Received to Inform the Review of the Scheme” (DoH, December 2012)

2.5.3 The Right to Health - falling through the gaps?

The guarantee in Article 40.1 of the Constitution that “all citizens are equal before the law” should in theory mean that older people have access to the means to have their rights vindicated. In practice, the gap between a Constitutional or Convention right and the person who needs to assert it can be too great to cross in the absence of some mechanism, such as specific legislation, to bring it within reach.

Perhaps the clearest and most common example of an area where older people struggle to realise their rights is in the area of access to community health services.

Ireland has ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) which recognises the right to health defined in relation to availability, access to, acceptability and quality of health facilities, goods and services. However, the right to health and personal social services is not defined in Irish legislation.

Many organisations dealing with older people have argued that, without legislation to underpin access to these services, access is discretionary, unequal and problematic. It is difficult to obtain information about services and reliable access to them at critical points e.g. discharge from hospital, onset of disability, diagnosis of long-term or life-limiting illness. The Ombudsman has observed that people do not know where they stand in terms of their entitlements and in terms of the HSE’s obligations to provide services.²²

Access to health services in the community has enormous knock-on importance for older people in that it is frequently the determinant of whether a person can remain living in their own home and community or must go into residential care. As outlined above, funding for residential care does have a statutory basis under the Nursing Homes (Support Scheme) Act 2009, and this imbalance may itself impact on the choices available to older people.

In 2011, Seanad Éireann’s Public Consultation Committee invited relevant stakeholders to make submissions on the Rights of Older People. Older & Bolder called for the introduction of legislation to establish a clear right to community care.²³ The National Federation of Pensioners Associations also recommended that community care should be underpinned by a clear legislative entitlement (among 18 recommendations covering the health requirements of older people). It urged that older people and their organisations should be involved in the planning of services.²⁴ The Irish Hospice Foundation (IHF) also supports the introduction of legislation to establish a clear right to community care in order to enable people and professionals to plan and reduce fear and stress for those requiring services.²⁵

The Report of the Seanad Public Consultation Committee (March 2012)²⁶ reflected these concerns. The report identified two major themes emerging from across the submissions heard; the need for the rights for older people to be enshrined in a formal way and recognised and the need to support and encourage independent living at home for as long as possible. The Committee’s recommendations “support fully the idea that future policies relating to older people must move away from the ‘maintenance’ model to the ‘rights’ model and that future policies should be in step with international best practice and indeed contribute to such best practice.” The Committee recommended “that clarity of available entitlements

22 Address at launch of “Caught in the Web” (Older and Bolder, 2012) 8 February 2012
<http://www.irishexaminer.com/ireland/ombudsman-make-it-easier-for-older-people-to-access-services-183018.html>

23 Older and Bolder Submission to the Seanad Public Consultation Committee on the Rights Of Older People November 9 2011

24 National Federation of Pensioners Associations Submission To The Seanad Public Consultation Committee on the Rights Of Older People November 2011

25 Irish Hospice Foundation Submission To The Seanad Public Consultation Committee on the Rights Of Older People November 2011

26 <http://www.tcd.ie/tilda/assets/pdf/Seanad%20Report.pdf>

for older people is made a priority and that those entitlements should be given a statutory footing”.

What would the difference be if there were a right to community health services defined in legislation? It would not magically make more resources available, but it would place an obligation on the state to make certain choices about the use of existing resources. Equally importantly, it would mean that there was a way to challenge withdrawal of services, and a right of redress - a way of ensuring things are put right if wrong has been done.

Olive and Joe in our case study (page 15) are dependent on community services to stay living together in the community. In the absence of community services, Joe will have to go into a nursing home. Their situation is similar to the real-life situation of Esther Darling, who is 74 and depends on day services. But Ms. Darling lives in California, and in California the MediCal programme which funds services to older people and people with disabilities is governed by legislation. When the state tried to reduce funding, Esther Darling and other service users took a class action²⁷ to prevent them.²⁸

Esther Darling et. al. v. Toby Douglas, Director of California Department of Health Care Services (C:09-03798 SBA)

Esther has been going to Woodland Healthcare Yolo Adult Day Health Center in Woodland, California five days a week since 1997. She has diabetes, post-stroke paralysis, atrial fibrillation, incontinence, oedema, depression, hearing loss, haemorrhoids and gout. Everyday, a nurse at the center manages Esther’s 19 medications, monitors her blood sugar and water retention, and checks her for signs of heart failure. She also receives physical therapy which has been critical in progressing her from using a wheelchair to using a walker and being able to dress and feed herself again.

If the State had gone ahead with cuts to the MediCal programme which funds the Day Health centres, Esther and many other users of the service would have had an option but to go into residential care.

However, as the scheme is based in legislation, Esther and the other service users were able to bring a class action objecting to the withdrawal of services on the basis that the State had an obligation in law to provide community health services. They were represented pro bono by lawyers from the Disability Rights Center and National Senior Citizens’ Law Center.

The action was settled in March 2012 with an agreement that the State would terminate that programme but immediately start another programme with identical services and eligibility criteria but a different funding source.

It should be noted that even where a legal solution exists things will not be perfect. The Darling v. Douglas settlement has been problematic in practice. Many people who should be eligible have been refused the service and there is a backlog of appeals against these refusals, meaning that in the interim some people have lost services.²⁹

However, the existence of a legislative basis for the service in questions gave the plaintiffs in Darling v. Douglas a way of challenging a situation that affected them, a right of redress, which does not exist for a person in Ireland whose community health services are withdrawn due to cutbacks.

27 A class action is a type of legal case in which a number of named plaintiffs take the case on behalf of everyone whose circumstances are similar to theirs. Class actions are not also possible under Irish law, except in very limited circumstances

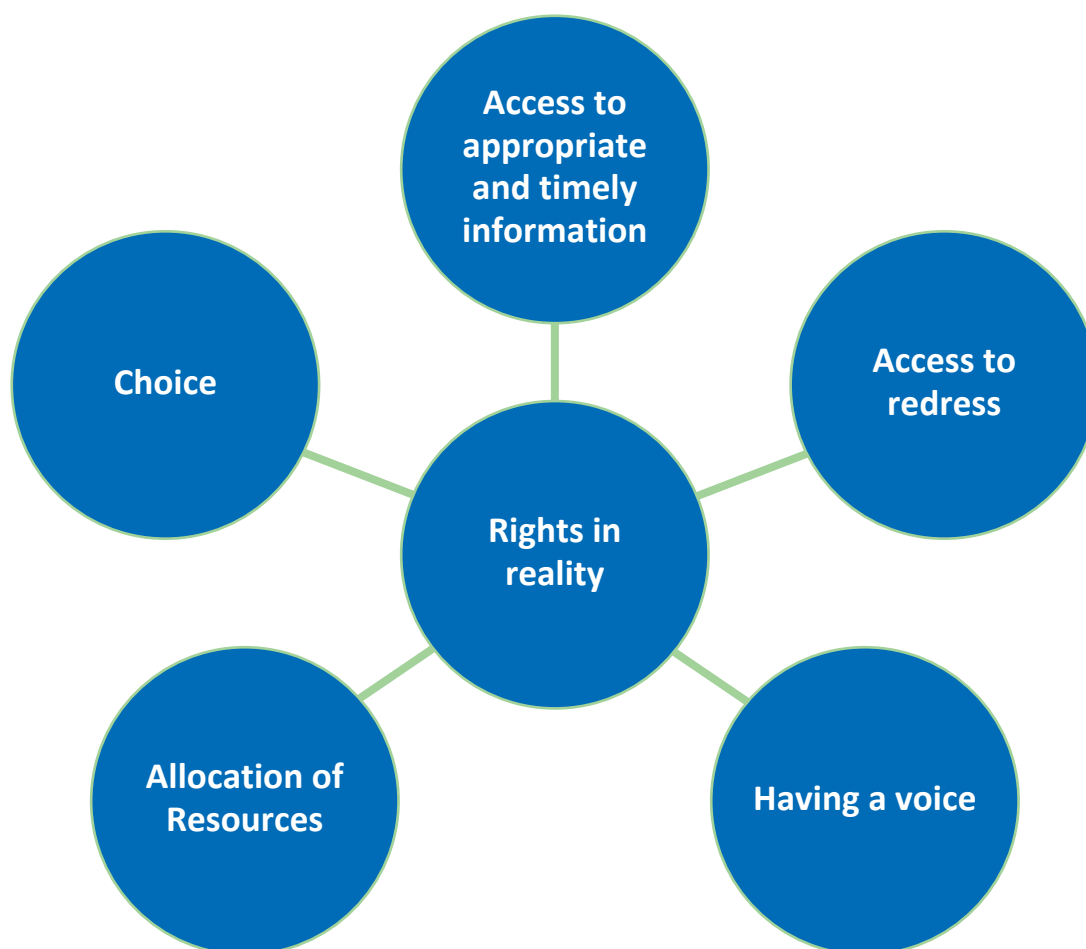
28 Esther Darling et. al. v. Toby Douglas, Director of California Department of Health Care Services (C:09-03798 SBA)

29 Radio Interview with Elissa Gershon, Senior Attorney, Disability Rights California
<http://radioalice.cbslocal.com/2012/08/12/disability-rights-california-and-adult-day-health-care-center-funding/>

Section 3: Human Rights and Older People in Ireland: Lived Experience

3.1 The Key Factors

The previous section identified issues such as access to redress and allocation of resources as key determinants of whether abstract rights become concrete. Members of the HROP Working Group confirmed that this is reflected in the experience of their constituents, and identified a further three key factors in terms of how abstract rights become concrete: access to appropriate and timely information, the ability to exercise choice, and having a voice. The factors are heavily interdependent, e.g. access to redress depends on having a voice and access to the right information.



In this section we follow these themes through three case studies which are composites of real cases reported by member organisations. (The **blue** boxes suggest alternative versions of the story if barriers to realising rights had been removed or a human rights approach adopted).

We then look at some current examples of initiatives in each of the five areas identified as key to the realisation of rights.

3.2 Case Studies

Joe and Olive

Olive and Joe got married in 1940. They were a very close couple - they hardly ever had a cross word between them. They have one son who lives in England. Joe worked all his life in An Post. When he retired, Olive was afraid he would miss the work but initially it worked out well. Joe loved his garden, and he loved to go for long walks with the dog in all weathers. He loved the bit of chat with the neighbours and seeing what building was going on and what people were doing with their gardens. They enjoyed going on bus tours together and they would go to England every year to see their grandchildren. Neither of them was really a drinker but Joe liked his pint on a Friday and they enjoyed the odd night out in their local.

Around the time Joe turned 70, things began to change. He would frequently misplace things or forget what he had been about to do, and he stopped going for his pint and took less interest in the garden. Olive was worried and eventually managed to get him to the G.P., under protest. He insisted he was fine and the doctor just went along with him and said "it's normal as you're getting older to be a bit less sharp."

Joe's doctor takes Olive's concerns seriously and refers him to a Memory Clinic, where a consultant meets with them both individually and together, and diagnoses early stage Alzheimer's disease. The social worker sits down with Joe and Olive and explains what this means. At first Joe is angry and upset and refuses to admit that anything is wrong. The social worker gives Olive lots of information leaflets and a contact number for the Alzheimer Society, where she is able to get support and advice from Dementia Advisor who visits them in their home.

Olive was still concerned but they just got on with things. She started going for walks with Joe to be sure he did not get lost. She would be exhausted afterwards as her own health wasn't great, but if he had to stay in the house it would be worse. He had always been such a gentle man but now he could get very frustrated and aggressive. After a year, Joe's symptoms were worsening all the time and Olive's own health was deteriorating. They went back to the G.P. and this time she referred him to a specialist who told Olive that Joe had Alzheimer's. Olive was terribly upset and didn't know what to do. Eventually a neighbour put her in touch with the Public Health Nurse and a home care package was put in place for two mornings a week. The nurse suggested Joe might go to the day care centre one or two mornings, but he hated it and wouldn't go - "too many women yakking".

Eventually Olive is able to persuade Joe to see a solicitor and he makes an Enduring Power of Attorney which allows her to make decisions about their finances and day-to-day welfare. She applies for a home care package and gets a carer for three mornings a week. The carer spends a lot of time getting to know Joe and what he likes. They go for walks around the neighbourhood and sometimes they even go for a pint. Joe has some bad days but mostly he enjoys the carers' visits, especially the chance to get out and about and is much more cheerful. After some time Olive manages to persuade him to try the local Alzheimer Society Day Centre. The Centre's bus picks him up and drops him back. There are a few other men there the days he goes and he enjoys their company. The staff try to make sure people get to do activities they enjoy such as bowling and gardening.

Olive would have like to pay for more help privately and Joe had a few thousand in a savings account, but it was in his name and though the bank staff were very nice to Olive, they told her she couldn't get it out unless she had an Enduring Power of Attorney. It was too late now to get one as Joe wouldn't be able to understand what he was doing. To get at the money she'd have to have Joe made a Ward of Court and that would probably cost more than was in the bank in the first place.

Olive reluctantly had to admit she couldn't cope anymore. Joe needed constant round-the-clock care and the stress and lack of sleep was taking its toll on her own health. Her biggest fear that she would collapse and leave Joe without anyone to look after him. She applied for the Fair Deal Scheme.

As Joe's condition progresses, Olive wants to draw on their savings to pay for extra care privately. She gets the EPA registered and is able to use the money in Joe's account. It is still hard work but it feels manageable to keep Joe at home for a bit longer.

Olive wanted a nursing home close by so she can visit often and maybe take Joe for his regular walk around their neighbourhood. The two local nursing homes couldn't cope with Joe's level of dementia. The only bed that was available was in a home some distance away.

Joe became very agitated and distressed when he went into the home. He walked non-stop around the corridors, banging on the doors and demanding to be let out. He was put on medication "to calm him down" and now he mostly sits in his chair dozing, but he sometimes gets agitated and tries to get up out of the chair. The Director of Nursing explained to Olive that this is dangerous and he could fall and injure himself badly, so Olive signed a consent form to say that the staff can use a lap belt to keep him in his chair. It seemed like the best thing to do to keep Joe safe. It breaks her heart to see him "like a zombie" and she feels terrible guilt that she was not able to keep him at home, but at least he is being looked after. She would prefer him to be closer to home and somewhere smaller and cosier but she had to take what was available. This is not how they hoped their retirement would be.

When Joe entered the nursing home a lot of time and effort went in to developing his care plan and it is reviewed regularly in consultation with Olive. Joe's care plan specifies that he likes to walk a lot and that this reduces his agitation. There is a safe enclosed garden and he is able to go out himself and walk around. There are raised beds where the residents can plant and weed with assistance from the staff. The residents regularly walk down to the local shops and park with staff members and staff make sure that Joe gets the chance to go on these outings. They have also looked at other ways of distracting him when he gets upset. Knowing that he was a postman, they tried giving him the post to "sort" into piles and he enjoys this. He still gets agitated sometimes but is much calmer and more content than when he arrived.

The home operates to best practice standards in relation to restraint and does not use lap belts. Staffing ratios are adequate to make sure that is a resident is distressed or wants to get out of their chair, a staff member can give them attention. Medication is not used to control behaviour.

Tony

Tony is 65 and recently retired from his job in a large hardware and builder's supplies shop in a small town. He didn't have a choice, everyone goes at 65.

Tony is aware that it may not be legal to dismiss him on the basis of age. He calls into the local one-stop-shop information service for older people where he is advised that he may have a case under the Employment Equality Legislation as there is no age clause in his contract. He is able to get assistance through the Citizens information Centre with preparing his case for the Tribunal.

To be honest he would have been delighted to keep going. He's always worked hard and enjoyed his work. He enjoyed the craic with colleagues and customers and he didn't have that many interests outside work to be honest, apart from a bit of DIY maybe and following the GAA. He used to enjoy the odd drink in his local but he hasn't been going out so much lately. Now he mostly sits in front of the television.

His daughter says he is depressed and should go to the doctor, but he's not going to pay €50 to be told what he knows already.

Tony has received advice on whether he is eligible for the medical card or GP visit card and assistance with the application if he is. He may still decide not to go to the doctor but cost should not be the main barrier.

One of the neighbours suggested he should come down to the "club" where her mother goes. He was insulted. He may be past it but he is not ready to sit round drinking tea.

Tony lives near a Men's Shed where he enjoys meeting other men, working with other men of his age group on a variety of projects. The environment is relaxed and supportive and there are a number of options for accredited training.

He would like to learn something new, but most of the courses are not geared for him. He's no good at computers and he doesn't want to be making a fool of himself.

Tony has access to a Getting Started³⁰ course, a free IT course run specifically by Age Action and its partners for older people as part of their campaign to combat digital exclusion.

30 <http://www.ageaction.ie/getting-started/about-getting-started>

Eileen

Eileen is 84. Her husband Michael died 10 years ago. She lives on the family farm eight miles from the nearest town. She signed over the house to her son Mick some years ago. He brought her into his solicitor and it was done in a hurry. It made sense, as he was taking over the farm. He has it remortgaged and lives in a big house across the field.

Eileen was aware that she should have independent advice on the transfer of her house and was able to access free legal advice through the Citizen's Information Centre/FLAC. She was advised about the risks of signing over her home. She had support from the CIC in deciding what to do and making her decision known to her son.

They keep a good eye on her. She can look after herself fairly well but she's fallen a few times and her heart is not good. She has a home help one morning a week but Mick's wife Theresa helps out a lot with cleaning and laundry and the like. She can be a bit sharp but she has a lot on her plate.

Mick collects Eileen's pension for her, does the shopping and gives her "pocket money". She doesn't need much, but it feels strange not to know what she has in the post office. Her husband Michael always took care of the money but he'd discuss everything with her, he trusted her judgment. She'd like to have a bit more just to be able to buy a mass card or something for the children.

Agency arrangements are carefully monitored by post office or bank staff to reduce risk of abuse. Eileen has support to take more control of her own finances.

But Mick and Theresa are very good to her really. She couldn't manage without them. She is only a burden to them at his stage. She hates to be dependent. She hates to be always asking them to take her appointments. The doctor does give out to her sometimes for missing appointments but it is difficult when you've no way of getting there and everyone is so busy. She couldn't afford to be getting a taxi all the time.

She used to love dancing with the neighbours but she doesn't see many people these days. The neighbours don't call as much. The bus comes for her once a week to go to the day centre in town and she enjoys that. Majella the centre manager has said she could come another day or two but the bus isn't available and Mick can't drop her.

Eileen has access to a rural transport scheme to allow her to get to town more regularly and also to a specific scheme for attending medical appointments.

The Public Health Nurse called out the other week. Eileen thought she was a nice enough girl but asked too many questions. Majella in the centre is easier to talk to now, but she hates to be complaining when she has little to complain about really compared to some.

Mick's under a lot of pressure at the minute. There's no money in the farm and the bit of building he was doing hasn't worked out now everything's gone to the dogs. He can be very irritable sometimes and raise his voice to her, which is not like him at all.

Recently he said they might have to give her house back to the bank and put her in the “home”. That’s her worst fear. She hates the shouting and just tries to keep quiet and keep to herself.

Eileen is able to speak to someone she trusts about her situation at home. If there is a suggestion of abuse, the person she speaks to is well informed about elder abuse and is able to handle it sensitively and appropriately, respecting Eileen’s wishes, addressing her fears and building her capacity to decide what she wants to do.

Eileen is used to always being busy with the farm and the children and it’s hard sitting around all day. She knows she is lucky not to be put away in a nursing home but sometimes she thinks maybe she’s lived past her time.

3.3 Good Practice Examples

Appropriate and Timely Information: Louth Age Friendly Website and Parlours

In Co. Louth, consultation with older people revealed a clear demand for a one-stop shop for information on services and entitlements.

An easy-to-use information booklet on all services available to older people in the county was designed by the Citizens Information Centre, working directly with older people.

Louth Age Friendly Communications Group was set up to adapt the data from the booklet and develop a website and communications model that would assist older people in accessing information more easily and from their own homes.

A website was designed in consultation with older people. It is easy to use and engaging, with lots of photos and case studies. The website was tested in two IT classes by Louth Leader Partnership/Age Action/DkIT involving over 70 older people. It now forms part of the curriculum of all Louth Leader and Age Action IT classes for older people in Louth.

The website was designed to be used by older people, their families, frontline services and public services for older people (a “no wrong door” approach). The service was promoted through the distribution of posters and business cards with the Louth Age Friendly Lo-Call number. Posters were displayed in GP waiting rooms, HSE outlets, Garda stations and churches. The use of photographs was very influential in engaging older people and in encouraging them to access the website.

The Parlours also use the website to access information in a one-stop-shop format. The Parlours are innovative new drop in centres, developed by Louth Older People’s Forum. Older people’s frontline services, such as Drogheda and District Support 4 Older People, Drogheda Senior Citizen’s Interest Group and Cuidigh Linn work together to provide a variety of services. Older people can call into the parlour to access information on services, care and repair, security pendants and care to drive services.³¹

31 www.louthagefriendlycounty.ie

Appropriate and Timely Information: The Alzheimer Café, Donnybrook

The Alzheimer Café model, while worldwide, originates in the Netherlands and is very well established there, with more 180 Alzheimer Cafés throughout the country. In June 2011, a group of healthcare professionals got together to set up Ireland's first Alzheimer Café.³² They choose the Avila Centre in Donnybrook as the location. There are now many more Alzheimer Cafés around the country.

The Alzheimer Café is designed to complement current services for people who are affected by dementia. People with dementia, friends and family members, health and social care professionals mix together in a relaxed, informal atmosphere. It offers support, information and an environment in which there is an openness about dementia. There is an emphasis on the emotional and psychosocial rather than the medical aspects of dementia.

The Donnybrook Café happens once a month on a Thursday evening. When people arrive they sit at tables and have a chat over a cup of tea and a slice of cake with others. After about half an hour, there is a short talk on some topic related to dementia and an opportunity after for discussion. Just like any café, people can come and go whenever suits them.

Dermod Slevin heard about the Donnybrook Alzheimer Café by chance when he bumped into an organiser of the café in the park. He had been diagnosed with Lewy Body dementia two years previously but had received very little information or sign-posting at the time. "My G.P. told me the best thing I could do was to go home and forget about it." He immediately found in the Alzheimer Café a supportive, positive and open environment. **"It is a refuge. I feel I belong here."**

Attending the Café also opened up a whole range of connections and opportunities for Dermod who is now a dedicated activist on behalf of people with dementia. He has been instrumental in setting up the first Irish National Working Group of People with Dementia, a self-advocacy group for people with dementia.

Appropriate and Timely Information/Having a Voice: The Think Ahead Project

The Think Ahead Project³³ highlights the links between appropriate and timely information and having a voice.

Active Retirement Ireland have partnered with The Irish Hospice Foundation to create a greater awareness among their members of the importance of planning ahead to make sure that an individual's right to make decisions for themselves and to be heard are honoured.

The purpose of Think Ahead is to guide members of the public in discussing and recording their preferences in the event of emergency, serious illness or death. Think Ahead is an idea that came to life through feedback from people from all walks of life, all ages and all levels of health across the country. The idea developed over a series of public meetings held throughout Ireland between 2009 and 2010.

Together, members of the public, emergency services, medical, legal and financial professionals recognised the importance of planning ahead to make sure that an individual's right to make decisions for themselves and to be heard are honoured. Input from all groups helped to craft the Think Ahead form – a document that will assist anyone on planning for end of life and help protect those close to them from anxiety that comes with the illness or death of a loved one.

32 www.alzheimercafe.ie

33 www.thinkahead.ie

Having a Voice: Cavan Older People's Council

Older people in Cavan were not formally represented on local planning or decision making structures and had no representative voice at local level.

The Cavan 050 Network secured nominations for older people onto the Cavan Social Inclusion Measures (SIM) Group and the 050 Chair is also now represented on Cavan Community Forum. This now means that older people are formally represented at policy level, via the SIM Group for example, and at community level, through Cavan Community Forum.

The 050 Network and the Cavan Age Friendly County Programme have also been successful in establishing the Cavan Older People's Council, the first meeting of which was held in April 2013. This new Council will be a network for older people, representative organisations, service providers, and community and voluntary groups to be represented and develop activities to support Cavan Age Friendly County.

Having a Voice/Access to Redress: Third Age National Advocacy Programme and The Office of the Ombudsman

The function of the Ombudsman is to investigate complaints from members of the public who believe that they have been unfairly treated by certain public bodies. At present, the public bodies whose actions may be investigated by the Ombudsman are: all Government Departments, the Health Service Executive (HSE) (and public hospitals and health agencies providing services on behalf of the HSE), and Local Authorities.

The Ombudsman does not deal exclusively with older people but many of the users of the office are older people. The former Ombudsman, Emily O'Reilly, has frequently spoken out and published reports on issues affecting older people, as well as being a frequent speaker at older people's events.

In an address³⁴ to volunteer advocates on the rights of older people, Emily O'Reilly outlined some cases her office had handled and also emphasised the role of advocacy in assisting vulnerable older people to access redress.

"A letter received from an advocate represented an issue that I had received a number of other complaints about. Complainants told me that despite them having a medical card and despite them having a need for therapy services, solely due to the fact that they were residing in a private nursing home, they were being denied essential therapy services. My staff had some success in specific cases referred to us, to have therapy services provided, where there was an identified medical need established..."

(Another) case concerned the provision of home help services. A man (now deceased) lived on his own in a rural area and contacted the Office himself. However, he had suffered a stroke and it was quite difficult to understand him or the nature of his complaint. It took many phone calls with the HSE to fully understand his situation. Although his case was eventually resolved, I believe that an advocate would have helped to communicate his concerns to the HSE and my Office at a much earlier stage, thus reducing the distress caused to him. I am aware that NAPA is currently limited to residential services, but it is clear that older people in hospitals and the community also need access to advocacy services."

34 <http://www.ombudsman.gov.ie/en/news/speeches-articles/2011/the-rights-of-older-people.html>

The Third Age National Advocacy Programme, (TANAP) was originally launched in 2008 by the HSE as an Advocacy Programme for Older People in Residential Care in response to recommendations made by the Forum on Services for Older People (set up following an inquiry into the abuse of older people in Leas Cross Nursing Home in North Dublin). In 2010 the Programme was externally evaluated with the recommendation that its governance should be out-sourced to an independent agency. The programme was handed over to Third Age in September 2011, and it has adopted as its motto “An ear to listen, a voice to speak”.

Within TANAP the trained and Garda-vetted volunteer advocate meets regularly with the resident and develops a mutually trusting relationship. The volunteer listens to and represents the resident’s views, providing one-to-one support and helping the older person express their wishes, access their entitlements, and assert their rights.

TANAP today represents a partnership between Third Age, the HSE and Nursing Homes Ireland. At present 120 volunteers are working in 90 nursing homes in Ireland.

Allocation of Resources

Given its potential to increase the quality and quantity of data available on the experience of ageing in Ireland, the Department of Health (with the Atlantic Philanthropies and Irish Life) agreed to co-fund the Irish Longitudinal Study on Ageing (TILDA; www.tilda.ie). This is a 10 year longitudinal study of the health, social and economic circumstances of a representative sample of 8,000 people aged 50 years and over on a periodic basis. TILDA’s objectives are to investigate;

- the health status and needs of older people;
- the social and economic status and needs of older people;
- the health and social status and needs of families and carers of older people;
- the biological and environmental components of successful ageing;
- the contributions that older people are making to society and economy;
- how each of these main life domains (health, wealth, happiness) interact.

The data gathered by TILDA has the potential to form the basis for policy direction and resource allocation decisions which are accurate and fair responses to the real experience of older people in Ireland.

Choice: Men's Sheds – Co. Louth

Through consultation with older people, men were highlighted as a key group at risk of being vulnerable or isolated. The Louth Men's Sheds project was initiated under the Louth Age Friendly Initiative to target men at risk of isolation or experiencing major life changes. The project is very simple and has one focus – men and the need to engage with them in ways that are meaningful and relevant for them.

The 'shed' environment encourages men to share skills and learn new ones, for example, skills in wood turning, mechanical work and horticulture, to name but a few.

Socialising is a large part of the project too, providing opportunities to develop new friendships, as well as renew old ones.

Three Sheds across Louth have been developed to date with the support of a full-time coordinator.

The Dundalk Shed is frequented by a close-knit group, ranging in age from 60 to 87 years. Although these men tend to be less physically active, they find great enjoyment in spending time together and working alongside each other. There are a number of social entrepreneurial activities going on in this shed, with the men generating a regular income from the sale of their goods.

Each Shed also runs FETAC accredited courses in partnership with the Vocational Educational Committee (VEC). In total, approximately 200 older men are attending sheds across the County.

Section Four: Human Rights Based Approaches (HRBA)

4.1 What is a HRBA?

HRBA is a way of putting human rights into practice by applying five key principles (PANEL)³⁵ to any process:

Participation

Who are the people affected? Are they involved in the process? Are there any barriers to their involvement identified and addressed?

Accountability

Who is responsible for the process? Is there a way of assessing whether they have carried out their responsibilities? Is there a mechanism to hold them accountable?

Non-discrimination/equality

Is the process designed in such a way as not to exclude any individual or group who may be at a disadvantage? Will the end result of the process impact on all groups equally?

Empowerment

Does the manner in which the process is carried out empower the people who are affected as opposed to putting them in the position of recipients of charity?

Legality

Is the approach explicitly grounded in human rights law?

Does it follow the relevant principles of human rights law?

If there is relevant legislation does it comply?

Is it explicitly stated what the legal framework is so that rights holders can use this to bolster their claims?

35 <http://www.scottishhumanrights.com/ourresources/promotinghrba>

4.2 Application of HRBA

HRBA are often talked about in the context of developing countries. However, it must be remembered that development is an ongoing process within any society. HRBA can be applied in many circumstances including:

- The development of government policy, including budgetary policy (see below)
- The allocation of funding by state agencies
- The development of a piece of legislation
- How a piece of research is conducted (see below)
- How services are designed and delivered (see below).

“In each situation we confront, a rights-based approach requires us to ask: What is the content of the right? Who are the human rights claim-holders? Who are the corresponding duty-bearers? Are claim-holders and duty-bearers able to claim their rights and fulfil their responsibilities? If not, how can we help them to do so? This is the heart of a human rights based approach.”

Mary Robinson, former UN High Commissioner for Human Rights, comments at 2nd Interagency Workshop on Implementing a Rights-Based Approach in the Context of UN Reform, May 2003.

4.3 Moving towards HRBA in Practice: Case Studies

Policy: Equality Budgeting – the Scottish Model

In Scotland, an independent advisory group, the Equality and Budget Advisory Group (EBAG), works together with the Scottish Government to:

- Provide advice and support for the mainstreaming of equality in policy with the appropriate allocation of resources
- Contribute to mapping the pathway between evidence, policy and spend
- Improve the presentation of equality information in the Scottish budget documents
- Contribute to improved commitment to and awareness of mainstreaming equality in to policy and budget processes.

The advisory group is made up of government and civil society actors, such as the Women’s Budget Group, the Equality and Human Rights Commission, the Scottish Government Finance Directorate and the Office of the Chief Economic Adviser.

The Scottish budgetary process involves the publication of a draft budget, which allows for public consultation and debate on the particulars of the budget before it is finalised. The publication of an “equality statement” alongside the draft budget clearly outlines the equality implications of the budget. The statement is arranged under key themes of the budget, such as “health and wellbeing”, “culture and external affairs”, and “finance, employment and sustainable growth”. Additionally, the statement provides an overview of the equality implications by “equality characteristic”, that is, by gender, age, disability, and other categories. Hence, it includes a detailed analysis of the impact of specific policy measures on women, on young people, on people with disabilities, and others, while providing a detailed view of the equality outcomes for members of the public.

In addition to this, the Scottish government has undertaken in-depth research on the effects of the economic crisis in a report entitled “Coping with Change and Uncertainty: Scotland’s Equality Groups and the Recession (2010)”, and a further updated analysis in the report “The Position of Scotland’s Equality Groups: Revisiting Resilience (2011)”. Both reports and the Equality Statement on the draft budget are publicly available on the Scottish government’s website, as are the minutes of meetings held with EBAG.³⁶

Research: Older People’s Perspectives on Elder Abuse

“A Total Indifference to our Dignity - Older People’s Understanding of Elder Abuse” is a report by Age Action with the Social Policy and Ageing Research Centre, Trinity College Dublin, University of Ulster, South Eastern Health and Social Care Trust, NI and Queen’s University Belfast.

The report revealed that older people’s understanding of the issue was quite different from government and service provider models and focussed on the idea of the erosion of personhood and the need for a preventative approach, interweaving informal sources of support (family, friends, peers etc.) with formal services (health, welfare, advocacy and legal services).

The report was the first Irish research to directly canvass older people’s views on the issue of elder abuse.

The project was also innovative in its use of peer researchers. Four volunteers ranging in age from their mid-60s to mid-80s received training and participated in the research design, data collection, analysis and dissemination. The peer researchers led eight focus groups of older people across the Republic and Northern Ireland.

The researchers were explicit about the human rights rationale behind the chosen method and the other PANEL values of participation and empowerment:

“Walker (2007) argued that the engagement of older people in research is warranted for a number of reasons. Firstly, on grounds of human rights older people have a right to be part of a process where they are the subject or object of research. Providing older people with the skills necessary to carry out research builds capacity and confidence enabling older people to exercise control over the process.

Secondly, if findings are to be relevant they need to reflect older people’s understanding of issues, which may be far removed from those of social scientists. Thirdly, engagement is a means of challenging ageism and enabling self-representation by older people. We also recognised that people have different expertise; older people are experts in the field of ageing, they have the advantage of life experience and the topic of elder abuse has particular salience within their realm.”³⁷

Accountability was demonstrated by the ethical approval process and by careful attention to the provision of information prior to obtaining consent to participate and follow up support after each focus group session.

The PANEL principle of non-discrimination/equality was, by the report’s own admission, the weakest area of the study in respect of a human rights approach. The fact that participants were selected through a range of community groups meant that there was a gender bias towards women and that the experiences of older people who are marginalised (e.g. cognitively impaired, unwell) or socially excluded were not recorded as a result.

36 www.equalitybudgeting.ie

37 A Total Indifference to our Dignity- Older People’s Understandings of Elder Abuse (Age Action 2011) p26

Service Design and Delivery: Irish National Working Group of People with Dementia

The Alzheimer Society of Ireland (ASI) is committed to hearing the voice of people living with dementia. ASI established the Irish National Working Group of People with Dementia (INWGPD) to ensure that it directly engages with people with dementia in order to improve how we meet the needs of people with dementia and deliver ASI services going forward.

The meetings offer a space for people with dementia to talk about their experiences and to highlight specific issues or areas that are important to them. The meetings may also have a specific focus or topic where those who attend are asked to reflect on the topic and express their thoughts and views.

Members of the working group have also actively engaged in work of the ASI Dementia Friendly Community (DFC) Project. A number of people with dementia assisted the DFC Project Leader in the process of selecting successful DFC grant applications.

Members were also involved in a focus group and workshops on the dementia design guidelines being prepared for homes. They used this opportunity to speak openly about experiences of the dementia friendliness of their homes and some of the challenges they face and how they overcome these and what would help.

Having a say on information leaflets and informing content and design is also another piece of work that ASI has engaged the working group in. For example, the “Know Your Rights” and “I Have Dementia... How do I plan for the future?” booklets were both produced in consultation with working group members.

ASI has also facilitated members of the working group to be actively engaged in consultation with the members of the National Dementia Strategy Working Group. In addition, members have participated in media events and ASI policy and advocacy events. Further development of this type of advocacy work means that the voice of the person with dementia could be a critical tool in dementia specific policy development.

Section Five: Recommendations

The recommendations are structured around the five factors identified as critical to the realisation of rights. This policy paper is limited in scope and in terms of the evidence that it draws on so therefore, the recommendations are a reflection of this reality. There is a need for much more data gathering and analysis of the landscape in relation to human rights and older people in order to have a complete picture and make concrete and evidenced based recommendations.



5.1 Access to Appropriate and Timely Information

5.1.1 There is a need to address the information gap in relation to human rights and older people in Ireland. This cannot be done without taking into consideration older peoples’ expressed preferences for the format and manner in which they receive information, and the need to provide information in ways which are meaningful and accessible to people with cognitive impairment or other disabilities.

Recommendations

- **An information guide on Human Rights and Older People that is easily accessible and in plain English is needed as an essential first step.³⁸**
- **Growing and sustaining dissemination models such as the parlours, Alzheimer Cafés, and one-to-one advocacy programmes are critical in ensuring that older people get the information they need in the way that they need it.**
- **Tailored information technology training programmes such as “Getting Started” are essential in giving older people access to information through the internet.**

5.1.2 There is a need to educate key stakeholders on the concept and practice of human rights, including older people themselves, organisations representing older people and service providers.

Recommendations

- **The HROP Working Group should explore the possibility of delivering a number of HRBA sessions to relevant NGOs and statutory organisations to build awareness and capacity.**
- **Older people NGOs who are committed to realising the human rights of older people need to educate their internal stakeholders including older people themselves on the issues and how their work programme can reflect the principles of human rights in practice.**

38 The Alzheimer Society of Ireland, in conjunction with the Equality Authority, has produced a booklet for people with dementia and their carers: “I have Dementia – I Have Rights: Know Your Rights” (The Alzheimer Society of Ireland, 2012) available at www.alzheimer.ie

5.2 Choice

5.2.1 Older people are not a homogenous group and there is no one-size-fits-all solution to any of the issues they experience. The only way to meet the diversity of need in terms of service provision is to consult directly, inclusively and meaningfully with older people on a local basis at the planning stage and offer a range of services based on identified need.

Recommendation

- **Service planning for older people should always involve consultation with older people (supported by capacity building and outreach to marginalised older people). The HROP Working Group should look at identifying and assembling good practice models for consultation with older people.**

5.2.2 Within services older people often experience a lack of choice as to the types of activity they engage in, the manner of service provision, the timing of activities etc.

Recommendations

- **Organisations which fund and deliver services to older people should adopt a HRBA and operating according to the PANEL principles with emphasis on participation by service users in design and delivery of services.**
- **Service Level Agreements and monitoring of spend with the HSE could require services to demonstrate that the PANEL principles are applied.**
- **The HROP working group should explore developing a dialogue with HIQA around human rights and older people.**

5.2.3 An opportunity exists with the advent of the Assisted Decision Making (Capacity) legislation to bring about cultural change in relation to the perception of older people and people with disabilities as agents of choice. The extent of the challenge should not be underestimated however, as long established attitudes are difficult to change.

Recommendation

- **A programme of awareness raising and education for the public and professionals on the impact and application of the new approach to capacity is essential if being consistently supported to exercise choice is to become a reality for older people with cognitive impairment.**

5.2.4 One of the most critical areas for older people to have choice is in where they live. Currently for many older people entering residential care, this is experienced as an absence of choice.

Recommendations

- **Further research and policy exploration is needed to understand the limitations of choice of places for older people in terms of where they want to live. The recommendation of the Seanad Public Consultation Committee (2012) on the Rights of Older People that rights to community health care services should be put on a statutory footing needs to be fully explored.**
- **Older people and relevant human rights NGOs need to prioritise this issue within their advocacy agendas.**

5.3 Allocation of Resources

5.3.1 Accurate information is essential for planning resource allocation. Current data sets, and in particular the TILDA data needs to be mined to produce evidence to support evidenced based policy making and resource allocation from a human rights perspective.

Recommendation

- **The HROP Working Group should actively promote research into human rights and older people. The working group should aim to recruit a member of the working group from a research body with a remit around older people research.**

5.3.2 It is necessary to recognise that resource allocation decisions which affect communities as a whole may have an disproportionately adverse effect on older people (eg. public transport restructuring).

Recommendations

- **Work towards having impact assessments with specific focus on disadvantaged groups including older people as a core part of the resource allocation process.**
- **Older People's Councils could play an important role in rolling out impact assessment locally.**

5.4 Having a Voice

5.4.1 Organisations working with and representing older people need to build their capacity to understand and respond in a human rights based way and integrate this approach in their organisations in a strategic way.

Recommendation

- **The HROP Working Group should play a lead role in facilitating the sharing of knowledge and skills around human rights and older people among older people NGOs and human rights experts.**

5.4.2 Older Peoples' Councils as recognised in the National Positive Ageing Strategy (NPAS) have the potential to become a valuable voice for older people. To date, NPAS has not been developed using a HRBA with consequent deficits in terms of participation, non-discrimination and accountability.³⁹

Recommendation

- **A HRBA should be explicitly adopted to the development of Older People's Councils with emphasis on capacity building and outreach to ensure representation of more marginalised older people.**

39 Presentation by Anne Leahy, Age and Opportunity at HROP workshop, Dublin, June 2013

5.4.3 The Assisted Decision Making (Capacity) legislation has the potential to significantly improve the ability of people with cognitive impairment and other disabilities to have their voices heard and recognised. However, it must be recognised that it represents a significant change in thinking and practice. The double stigma attached to ageing and disability has to be continuously challenged in order for the legislation to have the desired effect in practice.

Recommendations

- **There needs to be comprehensive monitoring and review of practice in different settings to identify areas where implementation can be improved. NGOs have a role to play in this regard.**
- **The new options for assisted decision making and legal mechanisms created by the Bill must be monitored and regularly reviewed specifically in respect of their impact on the ability of older people with disabilities to have their voices heard.**

5.5 Access to Redress

5.5.1 Older people as well as being aware of their rights need to be able to utilise the mechanisms that are currently in place in relation to the vindication of their rights. The Office of the Ombudsman, The Irish Human Rights and Equality Commission and the Health Information and Equality Authority (HIQA) are all highly relevant actors in this regard.

Older people's organisations in particular have a role to play in supporting people to seek redress when and where it is needed. In many cases, where the person is marginalised, has a disability or cognitive impairment, they need the support of an independent advocate to have their rights upheld. The Citizens Information Board National Advocacy Service for People with Disabilities and the Third Age National Advocacy Programme (TANAP) have the potential to address this need.

Recommendations

- **Relevant NGOs that are engaged in policy and political advocacy need to ensure that policy developments (NPAS/Healthy Ireland (HI) and the National Dementia Strategy (NDS) and others) are responsive to include the human rights agenda and that the statutory mechanisms to seek redress are robust.**
- **Relevant NGOs could also play a monitoring/watchdog role in this regard.**
- **The role of independent advocacy in assisting marginalised older people to access redress needs to be recognised and resourced.**

Section Six: References

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- Whyte, Gerry (2001) Social Inclusion and the Legal System: Public Interest Law in Ireland Institute for Public Administration

Appendix 1:

Membership of the Human Rights and Older People Working Group

- **The Alzheimer Society of Ireland** (Lead) Gerry Martin
Gráinne McGettrick
Mags Crean
- **Third Age** Cathleen Mulholland
- **Age and Opportunity** Ann Leahy
- **Active Retirement Ireland** Susan Shaw
- **Age Action** Lianne Murphy
- **Active Ageing in Partnership** Maurice O'Connell
- **Irish Council for Civil Liberties** Mark Kelly
- **Public Interest Law Alliance** Mairead Healy
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