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Coiste Comhairliúchán Poiblí an tSeanaid

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Seanad Public Consultation Committee

Report on The Rights of Older People

March 2012

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1. Executive summary

Medical advances of the past twenty years have extended life expectancy significantly across all first world countries. That extension brings with it an urgent requirement, not just to plan for the needs of older people, but to recognise that new needs will emerge because people will be living longer and because more people will live longer.

In the next three decades alone, the number of people in Ireland over 65 is expected to double. The challenges inherent in this great change are numerous and require that urgent, dedicated planning commences now to ensure that older people are not pushed to the margins of society.

2012 is the European Year for Active Ageing and International Solidarity between Generations and it also marks the 10th anniversary of the adoption of the Madrid International Plan of Action on Ageing (MIPAA). Seanad Éireann wanted to acknowledge and contribute to the national and international debate on the needs and rights of older people and to contribute to the ongoing work of the Department of Health's National Ageing Strategy.

Seanad Éireann's Public Consultation Committee (November 2011) invited submissions from relevant stakeholders on the Rights of Older People. Public hearings with senators on the floor of the Senate followed comprehensive written submissions. Expert briefings were also heard.

This report addresses the issues raised with and discussed by the Committee.

Stakeholders that took part include:

Ms. Caroline Lynch, The Irish Hospice Foundation

Mr. Jim Keegan, The National Federation of Pensioners Association

Dr. Roger O'Sullivan, Centre for Ageing Research and Development in Ireland (CARDI)

Mr. John Dunne, The Carers Association

Mr. Eamon Timmins, Age Action Ireland

Dr. Amanda Phelan, Institute of Community Health Nursing.

Ms. Patricia Conboy, Older and Bolder

Mr. Michael O'Halloran, Secretary of the Retired Workers, Irish Congress of Trade Unions

Mr. Liam Doran, Irish Nurses and Midwives Organisation

Professor Gerard Quinn, NUI Galway.

Dr Eilionoir Flynn, NUI Galway.

Professor Rose Anne Kenny of Trinity College Dublin.

Professor Alan Barrett, Director of Research TILDA

The transcripts of the public hearings by Stakeholders are available on the Oireachtas Committee web page at:

<http://debates.oireachtas.ie/PCJ/2011/11/24/>

<http://debates.oireachtas.ie/PCJ/2011/11/29/>

The Committee's recommendations are:

That we urge the Government to advance the case for drafting a new UN Treaty on the Rights of Older People.

The adoption of a new UN Treaty on the rights of Older Persons is needed to fully understand how existing human rights apply to older people and can be effectively enforced as part of the UN system.

That new Mental Capacity legislation be introduced as soon as possible to include the establishment of the Office of Public Guardian.

A Bill has been in preparation since 2006 to replace the archaic wardship procedure, which dates back to 1871. New legislation needs to be based on more up to date concepts of 'capacity' and introduce a system of guardianship.

That clarity of available entitlements for older people is made a priority and that those entitlements should be given a statutory footing

Eligibility criteria for home care services including home helps and home care packages are not currently published in a coherent way and the guidelines are unclear to those trying to understand them.

That HealthStat carries out an audit of all community care services for older people

HealthStat is the HSE's performance information system. The lack of such an audit makes it impossible to plan for future community-based care needs for older people aiming to stay at home.

That a format be found to pay the Carers' Allowance to those people who return to Ireland - and are not 'habitually resident' - to take on the role of caring at home for a family member

Family members who travel home to Ireland on a temporary basis to care for older relatives and lose their income in the process cannot currently apply for the Carers' Allowance because of the Habitual Residency Clause.

That the Health Act 2007 be amended to ensure that national quality standards are applied to private companies providing home-care packages

Commercial suppliers of home-care packages are not currently regulated and have no standards applied to their care systems. This leaves older people vulnerable to potential abuse and neglect.

That a portion of the Department of Social Protection's Free Travel Scheme budget be set aside to provide a rural taxi-voucher option for those who have no access to free travel

37% of older people eligible for the Free Travel scheme cannot avail of it because they have no access to rural transport.

That all patients receiving end-of-life care automatically are eligible for a medical card once the appropriate diagnosis is made

The vast majority of those with end-stage disease want to die at home. An automatic medical card would ease this decision and prove cost-effective.

Two major themes emerged 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 are offered in this light and they 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.

Each recommendation made here is backed by the submissions and briefings received by the Committee.

Each recommendation is examined in greater detail in the body of the report.

The SPCC would like to thank all those who made submissions – oral and written - to this Consultative Process and to the experts who provided briefings to the Committee. The SPCC would also like to acknowledge the invaluable work of the Oireachtas Library & Research Service.

2. The case for a United Nations (UN) Convention on the Rights of Older People

Amongst the witnesses who appeared before the SPCC were Professor Gerard Quinn and Dr. Eilionóir Flynn who briefed the SPCC on the merits of a possible UN treaty on the rights of older people.¹ The Irish Congress of Trade Unions (ICTU) and National Federation of Pensioners' Associations urged the Seanad and the government to adopt the Draft UN Convention.

A UN Working Group is, at present, considering proposals for the enhancement of the rights of older people. One of the main items on its agenda is whether to begin drafting a new United Nations thematic treaty on the rights of older people. Two sessions were held in 2011 and another crucial session will take place in 2012. The Global Alliance for the Rights of Older People, the main international federation of older persons' NGOs, is firmly in favour of a new treaty. At present, the European Union (including Ireland) appears to be firmly opposed – or at least remains to be convinced.

Professor Quinn told the SPCC that older people are seldom explicitly mentioned in existing international human rights treaties. This lack of any explicit mention of this specific group is unhelpful in trying to make universal rights equally effective for older persons as for other groups. While there are many soft law instruments (policy recommendations with no legal status) they are not generally judged to be effective.

Ireland has yet to publish its national strategy on ageing. It will be important that this national strategy should be framed not merely as an inward-looking policy instrument but also as one that is both conscious of international trends and contributes in its own way toward advancing those trends. In particular, it would be useful for the national strategy to reference and indeed anticipate the UN treaty. The two should be mutually reinforcing just as the National Disability Strategy is often portrayed as something that contributes to Ireland's implementation of the UN disability treaty. Having such a global instrument also helps keep the national policy narrative focused when there might be a tendency to respond only to political pressure points. While healthy in an open democracy this can have a distorting

¹ SPCC.Rights of Older People: committee discussion (resumed).Tuesday, 29 November 2011. Accessed at <http://debates.oireachtas.ie/PCJ/2011/11/29/00003.asp>

effect over time particularly when it comes to those with little or no voice. The convention could be seen in its own way as a corrective to this natural tendency in all democracies and thus underpin rational policy development in the broader public interest.

2.1. The context and purpose to any new UN thematic treaty

Professor Quinn asserted that the traditional focus of policy in the past was on the 'maintenance' of older people and the delivery of public services. However, when this becomes the sole focus it tends to reinforce dependence, passivity and negative stereotypes. The cultural assumptions that lie behind these policies are no longer valid if indeed they ever were.

But the inevitable question arises: What would a treaty do to reverse decades of previous cultural assumptions and the policies that were built on them?

According to Professor Quinn, the United Nations Working Group and most States seem to be mis-framing the core question. Instead of looking at the core barriers to the equal effective enjoyment of rights on the part of the elderly and the contribution a new treaty might make to their removal it has instead telescoped the relevant inquiry into whether there are 'normative gaps' in the existing treaties that must be filled. Their thinking is that it is only if such 'normative gaps' are found that a treaty drafting process should proceed. Professor Quinn explained his view that this approach is mistaken. Professor Quinn explained that there are no 'normative gaps' since the universal character of the existing rights ensures they have the potential to reach the situation of older persons. The real problem is not 'normative gaps.' It has to do with the fact that the universal norms are heavily distorted, discounted and diluted by decades of cultural assumptions about older people. He pointed out that there was no similar search for supposed 'normative gaps' in allowing the treaty drafting process to proceed on the ground of disability. Indeed, the disability treaty does not even purport to create 'new rights' or 'disability rights' – it simply professes to make the existing universal human rights rights 'real' in the context of disability. Something similar needs to happen for the elderly.

Triggering a debate about how those rights can be made 'real' should be the key challenge and focus of enquiry in any new treaty drafting process on the rights of old people. As to the potential content of such a treaty the Professor was of the view that some positive lessons could be learned from the drafting of the disability treaty – with the caveat of course that

most older people do not have a disability. Nevertheless he felt that some of the key conceptual building blocks of the disability treaty might have some traction in the context of a treaty on the rights of the elderly. This is not to preclude others. Among them might be the following.

Firstly, there should be a commitment to centring older persons to take charge and remain in charge of their own lives. He felt that the 'revolution' that is taking place around the world with respect to the key issue of legal capacity was particularly relevant. The key trend is away from laws and policies premised on deficits towards laws and policies based on a concept of supports to enable people to remain in charge of their own personal destiny.

Secondly, he felt that the right to live independently and be included in the community could also map over extremely well from the disability convention on to a convention for older people. Ireland is in fact innovating with respect to the achievement of this right for persons with disabilities. For example, some months ago the HSE published a report recommending the phasing out of all congregated settings on the ground of disability. This would include group homes of four people or more. Some eminent international commentators, for example Eric Rosenthal of Disability Rights International, have strongly suggested that the same logic should apply to institutions for the elderly. Indeed, there are interesting stories from the United States of America where nursing homes are being 'right-sized' to make them look and feel more like an ordinary domestic home. Should such an approach be adopted it would obviously have major implications for many institutions in Ireland.² A new UN treaty could underpin this dynamic of rightsizing.

Thirdly, any new treaty on the rights of the elderly will have to include a right to protection against violence, exploitation and abuse. He referred to a recent major report from the UK Equality and Human Rights Commission (EHRC) on the topic which graphically illustrates some of the risks and vulnerabilities.³ Perhaps the most important message from having

² See New York Times , 31 October 2011, *A nursing home shrinks until it feels like a home*. Accessed at: <http://www.nytimes.com/2011/11/01/health/shrinking-the-nursing-home-until-it-feels-like-a-home.html?pagewanted=all>

³ Equality and Human Rights Commission. *Close to home: An inquiry into older people and human rights in home care*. Accessed at: <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-home-care-of-older-people/close-to-home-report/>

such an article in the disability treaty is that it sends a very powerful signal that there can be no impunity if the rule of law is to have beneficial effects for all.

Fourthly, he was of the view that economic and social rights must be better harnessed to ensure the dignity, autonomy and connectedness of older people. People reflexively think that rights for older people equates to social welfare expenditure. The same used to be true in the field of disability. It would be better to think through what these social supports are **for** and reconfigure them to have the maximum impact in embedding people in their communities.

For example, the right to live independently, as expressed in the disability convention, includes a right to 'wrap' services around personal choice and preference. This is a trend throughout the world called the personalisation of social services, going so far as to take the form of personalised budgets. Indeed, some highly innovate entities are beginning to flourish in Ireland in the field of disability (e.g. *Áiseanna Tacaíochta*) which really place the person at the very heart of their own personalized services. He sees this as the future for older people too. It may be that this is the opportune time to make a start on the personalization of services in the context of older people.

In sum, the main objective behind any new thematic UN treaty on the rights of the elderly would be to tailor general rights – which the elderly clearly enjoy in the abstract - in the context of this particular population group.

Some argue that the appointment of UN special rapporteur on the rights of older people should be given priority over the drafting of a new treaty. He felt that while mechanisms such as that can prove important provided they are adequately resourced, it is in fact no substitute for a legally binding instrument. However, there is no reason why the two cannot sit side by side as is in fact the case with the UN Special Rapporteur on disability and the UN Convention on disability.

The next session of the UN Working Group is due to be held in summer 2012. Ireland's position on such issues, when negotiated through a multilateral forum such as the UN, is forged in close alliance with our EU partners. Reportedly (see following section 3.3), the EU is adamantly opposed, or at least not yet fully convinced, of the added value of a treaty.

2.2. European opposition to a UN thematic treaty for older people

Dr. Eilíonóir Flynn attended the last UN working group meeting and briefed the SPCC on the reasons for the scepticism of the European Union and many of the countries regarding the need for a treaty at this point. It should be noted that EU negotiation positions are worked out by Member States in advance at COHOM and in Brussels.

It is important to note that the EU and other states who opposed the drafting of a new treaty emphasised that they were giving a judgement on this matter at this point in time rather than definitively. The following are some issues which the EU and others have raised in opposition to a treaty:

- Lack of evidence of normative gaps in existing international human rights law protections. As discussed above, many states feel that existing human rights treaties adequately protect the rights of older persons and want civil society to provide evidence of how current law fails to protect the rights of older people. They want to know what specific rights protections are required for older people and why they are not protected under the current human rights instruments before commencing any work on drafting. As Professor Quinn illustrated, it may be that that discussion mis-understands the fundamental case for a UN Treaty;
- Treaty fatigue. The EU and other countries discussed whether the addition of a new Convention to the existing UN human rights treaty system would lead to any increase in the protection of human rights of older people at grassroots levels. The growing number of UN human rights treaties was cited as a possible reason for growing delays in treaty monitoring and the failure of countries to report on their obligations under those conventions at present.
- Concern was expressed that the treaty monitoring bodies for the new human rights conventions, including the Convention on the Rights of Persons with Disabilities, are not given adequate time or resources to do their job. The addition of a new treaty on the rights of older people could put increased pressure on an already overburdened UN system and the expense of putting in place machinery to deal with a new treaty, monitor compliance and examine the relevant reports, would be significant.

Dr. Flynn reported to the SPCC that there was a view among some of the more developed countries that the equality of their elderly is secured, and that their elderly have a good standard of living. Many of the developing countries, however, especially the Latin American

states, appealed to their colleagues in developed countries to demonstrate solidarity with them in supporting the call for a new UN treaty – which they argued would lead to an improvement in human rights protection for older people at a global level.

3. Legal reform in the area of mental capacity

The Institute of Community Health Nursing, the Irish Hospice Foundation and Age Action Ireland briefed the SPCC on this subject.

Mental capacity refers to a person's ability to make decisions about important features of their lives, such as finance or healthcare.

In the year 2012 more than 41,000 Irish people have dementia, costing an estimated €1.7 billion in care every year, but the number of those with the disease is likely to rise to 147,000 by 2041. Therefore the number of people with dementia in Ireland is expected to triple over the next 30 years and they will be a "huge burden" on the State without a long-term care strategy, according to the Minister for Health.⁴

A person may lack mental capacity due to an injury or an illness and this may be a temporary or permanent loss. The proposed law will replace the wards of court system, under which those with one of the conditions above can have their decision-making rights taken away.

According to the Department of Justice and Equality:⁵

"The numbers of adults who are unable to make decisions for themselves is already significant and these numbers are predicted to steadily increase. The main categories of persons who are unable to make decisions for themselves of protections are (a) the elderly (b) persons with acquired brain injuries (c) persons with mental illness and (d) persons with intellectual disabilities. Each of these categories will grow as the Irish population continues to expand. In 2001 there were 430,000 persons over the age of 65. It is projected that this figure will rise to 840,000 by 2031.⁶ It is estimated that currently approximately 35,000 people in Ireland have dementia.

The Institute of Community Health Nursing in their submission to the Committee observed that certain legislation can create obstacles to older people's full enjoyment of rights. A particular barrier identified by them is the archaic Lunacy Regulation (Ireland) Act 1871. This

⁴ Irish Times, January 19, 2012. Accessed at:

<http://www.irishtimes.com/newspaper/ireland/2012/0119/1224310448130.html>

⁵ Mental Capacity Bill. Department of Justice and Equality Screening Regulatory Impact Assessment [http://www.justice.ie/en/JELR/Pages/Regulatory_Impact_Assessment.\[n.d. circa 2008\]](http://www.justice.ie/en/JELR/Pages/Regulatory_Impact_Assessment.[n.d. circa 2008])

⁶ Law Reform Commission Report Vulnerable adults and the law. (LRC 83 - 2006), 2006, Para 1.05

Act places restrictions on those thought to lack some or all capacity to make decisions for themselves, effectively rendering the older person with cognitive impairment voiceless. They hope that the proposed Mental Capacity Bill 2008, similar to the United Kingdom Mental Capacity Act (2005), will reframe the issue of mental capacity challenges:⁷

“The Mental Capacity Bill urgently requires to be debated and passed through the Oireachtas as it has the potential to reform current archaic legislation and promote a framework of engagement rights.”

The Irish Hospice Foundation supports the implementation of the Law Reform Commission’s proposal on mental capacity legislation and urges that legislation should be enacted as soon as possible.⁸ The issue of capacity affects people who are dying and their care providers when decisions have to be made about continuing or discontinuing treatment. They urge that every effort should be made to fulfil dying patients’ known last wishes, particularly when they no longer have the capacity to express their wishes.

3.1. Proposed Mental Capacity Bill

The proposed Bill defines mental capacity as “the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made.”

The proposed legislation is necessary to ratify the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and give effect to Article 12 of the UNCRPD, particularly regarding equal recognition before the law, regular review, adequate procedural safeguards, and access to support required to exercise legal capacity.⁹ Age Action Ireland recommended that this Convention be ratified.

In Ireland, decisions on general legal capacity are made by the High Court in the context of the Wards of Court system.¹⁰ The Lunacy Regulation (Ireland) Act 1871, and Orders 65 and

⁷ Discussion, Thursday, 24 November 2011. Accessed at: <http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

⁸ Ibid.

⁹ Department of Justice, Equality and Law Reform. (2008). *Mental Capacity Bill 2008: Screening Regulatory Impact Assessment*.

¹⁰ The Law Reform Commission. (2003). *Consultation Paper on Law and the Elderly*. See <http://www.lawreform.ie/files/Consultation%20Paper%20on%20Law%20and%20the%20Elderly%203-06-03.pdf>

67 of the Rules of the Superior Courts 1986 provide for an order making a person a ward of court. In order to be made a Ward of Court, the person must be of 'unsound mind' and incapable of managing his/her person or property.¹¹

The proposed mental capacity legislation will involve a major transformation of legal procedures dealing with incapacitated persons. The proposed Bill provides for:

- the removal of the current Wards of Court system and replacement of this system with Guardianship;
- a change in how incapacity is determined. Persons will now be assessed on each particular decision, at a single point in time;
- makes ill-treatment or wilful neglect of an incapacitated person an offence and subject to a fine or imprisonment;
- the establishment of the Office of Public Guardian; and
- gives jurisdiction to the Circuit Court to hear applications in respect of capacity decisions.

3.1.1. Assessing mental capacity

In 1995 the Law Commission of England and Wales identified three approaches to capacity: the status approach, the outcomes approach, and the functional approach.¹² These are explained thus:

(i) Status approach to mental capacity

The status approach considers a person who is deemed to lack legal capacity as being unable to make *any* decisions. This is the approach currently taken in Ireland, where an individual who is found to lack mental capacity is considered unfit to make any decisions or carry out any legal transactions.¹³ The Law Commission of England

¹¹ Keys, M. (2007). "Capacity – whose decision is it anyway?" Law and Mental Health Conference, NUI Galway. Retrieved 25th January 2010 from http://www.nuigalway.ie/law/documents/mental_health/Keys%20Talk.doc

¹² The Law Reform Commission. (2003). *Consultation Paper on Law and the Elderly*. See <http://www.lawreform.ie/files/Consultation%20Paper%20on%20Law%20and%20the%20Elderly%203-06-03.pdf>

¹³ Irish Human Rights Commission. (2008). *Observations on the Scheme of the mental Capacity Bill 2008*.

and Wales consider this approach contrary to the principal of treating people with autonomy by encouraging them to make decisions.¹⁴

(ii) Outcomes approach to mental capacity

The outcomes approach focuses on the merits of an individual's decision and uses this as a way of assessing capacity. The Law Commission of England and Wales argues that this approach penalises individuality at the cost of autonomy.¹⁵

(iii) Functional approach to mental capacity

The functional approach is issue specific and time specific.¹⁶ While a person may not be able to make a decision in one aspect of their life, such as finance, they may be able to make decisions in other areas, such as their living arrangements. Also, this ability to make decisions may change over time. This approach acknowledges that capacity can fluctuate and was favoured by the Law Commission of England and Wales, as well as the Law Reform Commission in Ireland.

The proposed Bill reflects the recommendations of the Irish Law Reform Commission to move towards a functional approach to capacity.¹⁷ The appropriateness of the functional approach to capacity is widely accepted.¹⁸ Under this approach, a new assessment of capacity is required for each new decision.¹⁹ However the Law Reform Commission recommends that common sense be applied where a person is unlikely to regain capacity, so that the need to carry out an assessment for every decision is reduced.²⁰ However, Donnelly (2007) argues that this 'common sense' approach could be abused and that any leniency in this regard should be legislated for.²¹

¹⁴ The Law Reform Commission. (2003). *Consultation Paper on Law and the Elderly*. See <http://www.lawreform.ie/files/Consultation%20Paper%20on%20Law%20and%20the%20Elderly%203-06-03.pdf>

¹⁵ The Law Reform Commission. (2003). *Consultation Paper on Law and the Elderly*. See <http://www.lawreform.ie/files/Consultation%20Paper%20on%20Law%20and%20the%20Elderly%203-06-03.pdf>

¹⁶ Irish Human Rights Commission. (2008). *Observations on the Scheme of the mental Capacity Bill 2008*.

¹⁷ Ibid.

¹⁸ Donnelly, M. (2007). 'Assessing Legal Capacity: Process and the Operation of the Functional Test'. *Judicial Studies Institute Journal*, 141-168.

¹⁹ Ibid.

²⁰ Ibid.

²¹ Ibid.

3.2 Effects of the proposed Bill

Up to 3,500 people are wards of court²². Once the Mental Capacity Act is implemented there is a possibility of a two-tier system where the rights of some people have been determined by the 1871 Act and those of others by a new Act. According to disability campaigners, this could be seen as unfair.²³The current lacuna in legislation not only affects the lives of thousands of people but also affects Ireland's ability to ratify the UN Convention on the Rights of People with Disabilities.

The Minister of State for Disability, Kathleen Lynch TD, told a conference that the enactment of this Bill would enable Ireland to ratify the UN Convention on the Rights of People with Disabilities as the State would then be in a position to comply with the legal obligations imposed by the Treaty.²⁴

These obligations are:²⁵

- (a) to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the Convention;
- (b) to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- (c) to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

²² *New mental capacity bill due in 2012. Insight: changing perspectives on disability.* Issue 1. Irish Times/Rehab, January 2012. See also Courts Service Annual Report 2010. Accessed at: [http://www.courts.ie/Courts.ie/library3.nsf/\(WebFiles\)/4523C03355124B90802578CC0033B0AF/\\$FILE/Courts%20Service%20Annual%20Report%202010.pdf](http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/4523C03355124B90802578CC0033B0AF/$FILE/Courts%20Service%20Annual%20Report%202010.pdf)

²³ *New mental capacity bill due in 2012. Insight: changing perspectives on disability.* Issue 1. Irish Times/Rehab, January 2012.

²⁴ Disabilities rights legislation due. Irish Times, 30 November 2011. Accessed at: <http://www.irishtimes.com/newspaper/breaking/2011/1130/breaking56.html>

²⁵ Convention on the Rights of Persons with Disabilities. Accessed at: <http://www2.ohchr.org/english/law/disabilities-convention.htm>

(d) to refrain from engaging in any act or practice that is inconsistent with the Convention and to ensure that public authorities and institutions act in conformity with the Convention;

(e) to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;

(f) to undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

(g) to undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(h) to provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

(i) to promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

The effects of the legislation were outlined to the Seanad in December 2010 by the then Minister of State with responsibility for Disability, John Moloney TD:²⁶

“The main provisions of the Bill include setting down guiding principles to assist both the courts and persons making decisions on behalf of adults who lack capacity. The statutory guiding principles will require that any act done or decision made on behalf of a person must be in that person’s best interests. The Bill will also provide that a person is entitled to supported or assisted decision-making.

Where it is not possible to support a person in exercising capacity or making a decision, the Bill will provide that the court or a personal guardian appointed thereby will act as the substitute decision-maker on his or her behalf. Under the Bill, an office

²⁶ Seanad Éireann. Mental Health Services. Wednesday, 1 December 2010. Accessed at: <http://debates.oireachtas.ie/seanad/2010/12/01/00012.asp>

of the public guardian which will be responsible for the supervision of personal guardians and donees of enduring powers of attorney will be established.

The Bill will also repeal and subsume the provisions of the Powers of Attorney Act 1996. The Bill's passage will give effect to the Hague Convention on the International Protection of Adults, as well as adding substantially to the overall progress made in implementation of the requirements towards ratification of the UN Convention on the Rights of Persons with Disabilities.”

The Bill is currently on the A List of the Government Legislation Programme. According to this list, publication of the Bill is scheduled for the spring session of 2012.²⁷

²⁷ See Government Legislation Programme. Accessed at:
http://www.taoiseach.gov.ie/eng/Taoiseach_and_Government/Government_Legislation_Programme/SECTION_A1.html

4. Staying at home , care services in the community and home care provision

The SPCC heard evidence on this topic from, among others, Older and Bolder, the National Federation of Pensioners Associations, the Irish Hospice Foundation ,the Institute of Community Health Nursing ,the Carers Association and The Irish Longitudinal Study on Ageing (TILDA)

Research by Older and Bolder provided to the SPCC found that the majority of people wished to remain at home in their older years.

Also of interest was recent evidence from The Irish Longitudinal Study on Ageing (TILDA) which was presented to the SPCC by Professor Rose Anne Kenny:²⁸

“The most striking finding from the TILDA analysis is the enormous contribution older people make to families and communities in Ireland. One third provide regular practical household help to children, such as shopping or household chores. One half provide care to grandchildren. In those components alone, they are releasing others to participate in labour markets.

One quarter are what is referred to as the sandwich generation, which means they are potentially caring for parents as well as children. One quarter have given gifts of €5,000 to one or more of their children over the past ten years. The median gift was €20,000 and the mean was €60,000. Conversely, 9% of older persons have received gifts from their children. Intergenerational transfer is, therefore, largely from older participants to their children.”

Professor Kenny informed the SPCC that disabilities are not uncommon among those aged 50 and older. Some 10% of those between the ages of 50 and 64 and 30% of those older than 75 have some level of disability. As TILDA is a study of those living in the community they have not yet involved people who are resident in nursing homes or other residential institutions but will be following participants over a ten year period or, hopefully, longer. Every two years they will follow up the participants, some of whom will probably enter institutional care.

She noted that the primary source of support for disabled recipients of care is the family and, by and large, the spouse. Only 3.5% of those aged over 50 are cared for by State-provided

²⁸ SPCC.Rights of Older People: Discussion (resumed).Tuesday, 29 November 2011. Accessed at <http://debates.oireachtas.ie/PCJ/2011/11/29/00003.asp>

home help services. The large majority of care for those with disabilities is provided by older adults.

She observed that mental illness, particularly depression, is quite prevalent in Ireland, with 10% of people over the age of 50 having significant symptoms of depression. Of those who are ascertained objectively as having significant depression, 80% have not been diagnosed. Therefore, there is a huge unmet need for diagnosis and treatment. Professor Kenny told of her surprise not so much at the prevalence rate of 10% of clinical depression but at the prevalence of sub-clinical depression amounting to a further 18%. That corresponds to a total of almost one third of people over the age of 50 years with depression, whether clinical or sub-clinical.²⁹

4.1. Community care services for Older People

Older and Bolder noted that Ireland has ratified the UN Covenant on Economic, Social and Cultural Rights which recognises the right to health defined in relation to availability, access to, acceptability and quality of health facilities, goods and services.³⁰ An issue highlighted by Older and Bolder in its submission to the SPCC is that the right to health and personal social services is not defined in Irish legislation.

Their contention is 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.

Older and Bolder illustrates this point with reference to the older people who need services to maintain them in their homes, e.g. Home Help, respite care, Home Care Packages, hospice home care services. The contention is 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.

²⁹ *ibid.*

³⁰ Submission to the SPCC

Older & Bolder endorses the Ombudsman's observation that "people do not know where they stand in terms of their entitlements and in terms of the HSE's obligations to provide services".³¹ Older & Bolder therefore calls for the introduction of legislation to establish a clear right to community care.

The National Federation of Pensioners Associations also recommend that community care should be underpinned by a clear legislative entitlement (among 18 recommendations covering the health requirements of older people.)³² It urges that older people and their organisations should be involved in the planning of services.

The Irish Hospice Foundation (IHF) also supports the introduction of legislation to establish a clear right to community care. This would enable people and professionals to plan and would reduce fear and stress for those requiring services.³³

These observations were supported by the authors of a research study on dementia:³⁴

"Family caregivers are the linchpin to the success of community care but only a small proportion of people with dementia are receiving critical services such as day care, public health nursing, home care packages and respite. Community care services for people with dementia and their carers remain under-developed, inequitable, and fragmented.....

One of the resounding weaknesses of Irish home care services is that these services are not underpinned by legislation nor are they provided on a statutory basis. In the absence of the required level of community support, people with dementia will continue to be placed in long-term care prematurely.....

This study has estimated the overall cost of dementia in Ireland to be just over €1.69 billion per annum, 48% of which is attributable to an opportunity cost valuation of informal care provided by family and friends to those living with dementia in the community. A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. The

³¹ Health Policy – An Ombudsman Perspective, Address by Emily O'Reilly at Mater University Hospital Conference, 9.09.2011, www.ombudsman.ie

³² Submission to the SPCC

³³ Discussion, Thursday, 24 November 2011. Accessed at: <http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

³⁴ Cahill, Suzanne, Eamon O'Shea & Maria Pierce. Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy A Research Review for Ireland's National Dementia Strategy. Trinity College, Dublin/National University of Ireland, Galway, 2012. Accessed at: https://www.tcd.ie/Communications/content/pdf/Creating_Excellence_in_Dementia_Care2012.pdf

average cost per person with dementia in Ireland is estimated at €40,500, which is consistent with per capita estimates from other countries.”³⁵

The authors say that improving care in the community and providing greater support for families will require additional public spending, including having to make difficult choices about the reallocation of some of the existing institutional resources to community care.

4.2 Personalisation of social services

According to the evidence given to the SPCC by Professor Quinn, personalisation of social services will become the norm within the next 20 years:³⁶

“We are at the very beginning of a revolution....For example, there are movements afoot towards handing out individualised and personalised budgets for persons to manage themselves such that they can purchase the services they need rather than those others believe they need. This will be advanced mightily by new technology over the next ten or 15 years.. ... My prediction, for what it is worth, is that our social protection will morph in that direction over the next 15 years.”

4.3. Government plans

The HSE National Service Plan 2012, which acts as its annual budget, outlines its attempt to offer increased value to the taxpayer.³⁷

In relation to services for older people nationally, the number of home help hours provided for older people will be cut by 4.5 per cent. A total of 500,000 home help hours are to be cut. The number of people who receive home help will be cut by 1.2 per cent; 621 fewer people will be in receipt of home help hours than in 2011.

However, the number of Home Care Packages³⁸ will remain at 2011 levels.

³⁵ Ibid.

³⁶ SPCC.Rights of Older People: Discussion (Resumed). Tuesday, 29 November 2011. Accessed at <http://debates.oireachtas.ie/PCJ/2011/11/29/00003.asp>

³⁷ HSE National Service Plan 2012. Accessed at <http://www.hse.ie/eng/services/Publications/corporate/nsp2012.pdf>

The HSE plans to close between 550 and 898 public nursing home beds next year. An additional 1,270 places are to be made available under the 'Fair Deal' Nursing Home Support Scheme. Under the scheme, which applies whether a nursing home is public, private or voluntary, those availing of the scheme must pay towards their long-term care while the state meets the balance.

A number of nursing homes will shut down, as will an unspecified number of public hospital beds. To offset such a loss of community beds, there will be greater emphasis on diverting older people to private nursing homes.

The mental health services will receive an extra 400 staff. There will also be funding for more medical cards and to replace primary posts. The disability service budget will be cut by 3.7%.³⁹

³⁸ A Home Care Package is a set of services provided by the HSE to help an older person to be cared for. The services, for example additional home help hours, nursing services, therapy services, might be needed due to illness, disability or after a stay in hospital or following rehabilitation in a nursing home. A Home Care Package includes extra services and supports that are over and above the normal community services that the HSE provides directly or through a HSE funded service. Community services, provided by the HSE, and HSE funded providers, include home help, nursing, physiotherapy, occupational therapy, speech & language therapy, day care services, respite care, etc. See http://www.hse.ie/eng/services/Find_a_Service/Older_People_Services/Benefits_and_Entitlements/Home_Care_Packages.html

³⁹ HSE National Service Plan 2012

Table 2. Home Care Packages and Home Help Hours available in 2012.

Standardised Assessment in Community and Acute Settings	Single Assessment Tool (SAT)															
	Conclude pilot SAT and analyse findings										Q1					
	Prepare business case for consideration										Q2					
Performance Activity and Performance Indicators																
	Expected Activity / Target 2011					Projected Outturn 2011					Expected Activity / Target 2012					
	DML	DNE	South	West	Total	DML	DNE	South	West	Total	DML	DNE	South	West	Total	
Home Care Packages*																
Total no. of persons in receipt of a HCP	2,355	3,385	2,345	2,145	10,230	2,662	3,545	2,425	2,238	10,870	2,662	3,545	2,425	2,238	10,870	
No. of HCPs provided	1,460	1,253	1,304	1,283	5,300	1,460	1,253	1,304	1,283	5,300	1,460	1,253	1,304	1,283	5,300	
No. of new HCP clients	1,000	1,150	1,000	1,250	4,400	1,497	1,771	1,184	1,177	5,629	1,250	1,100	1,100	1,350	4,800	
Home Help Hours																
No. of home help hours provided for all care groups (excluding provision of hours from HCPs)	2.16m	2.41m	3.9m	3.5m	11.98m	2.00m	2.15m	3.79m	3.26m	11.20m	1.91m	2.06m	3.62m	3.11m	10.70m	
No. of people in receipt of home help hours (excluding provision of hours from HCPs)	12,000	12,900	14,700	14,400	54,000	12,003	9,486	15,681	13,453	50,623	12,003	9,486	15,053	13,460	50,002	
Day Care																
No. of day care places for older people	Baseline to be set					National survey undertaken Q4 to inform 2012 targets					Targets to be determined					
NHSS																
No. of people being funded	Baseline to be set					6,223	4,246	6,157	5,715	22,341	Centralised scheme in 2012					23,611

National Service Plan 2012 Page 46

Source: HSE National Service Plan 2012

Eamon Timmins of Age Action Ireland had made a submission to the SPCC, before the HSE National Service Plan 2012 was published, advocating community services for older people. He was reported as saying that the reductions would impact on the sickest people:⁴⁰

"The loss of so many public beds and the scale of the cuts in the home help service provided by the HSE will undoubtedly be felt by the sickest of older people. Without home help service frail older people will struggle, and those requiring round the clock nursing home care will end up being admitted to acute hospitals for their care if a nursing home bed is not available."

Seán Moynihan, chief executive of ALONE, said that if the number of nursing home beds was to be cut, the Health Minister should make good on his commitment to providing care in the community for older people in need:⁴¹

⁴⁰ Groups protest plan to cut hundreds of nursing home beds. The Irish Examiner, 17 January 2012

"The cost of home care provision is significantly less than that of nursing home care provision, and we would like to see any savings reinvested into home care services, not a reduction in both. We're calling on the Government to ensure that these cuts will not affect service provision for the most vulnerable in society, and to outline how they intend to protect the welfare of older people in need of these services."

Tadhg Daly, chief executive of Nursing Homes Ireland, welcomed the commitment in the HSE Service Plan to provide financial support through the Fair Deal for an additional 1,270 long-term residential care places this year as "a step in the right direction":⁴²

"Nursing Homes Ireland has consistently highlighted the continual growing demand for long-term residential care and today's commitment to provide an additional net 1,270 places goes some way towards acknowledging the demand there is for such specialised care."

The SPCC is concerned at the trend towards reducing the supports available to enable people to remain at home, which are more cost-effective than institutional care and which runs counter to the wishes of the majority.

Senators noted that home care services would become even more important after February 2012 when large numbers of hospital staff retired from the health service.

"Mr. Doran [Irish Nurses and Midwives Organisation] referred to what would happen at the end of February [2012] and the shortages that might develop in terms of front-line staff. We need to consider how we will deal with this issue. It is clear that home care services will be even more important then and that we will be more reliant on them. These are all issues with which we need to grapple."⁴³

⁴¹ Ibid.

⁴² Ibid.

⁴³ Discussion, Thursday, 24 November 2011. Accessed at: <http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

5. Introduction of an audit of community care services

Older and Bolder explained to the SPCC their view that an audit is required of community care services to establish clearly what services are available for older people and what are not.⁴⁴ They pointed out that in HSE National Service Plans, among others, the amount of money being spent on home help services is published. However, they have found that the small print reveals that this relates to home help services across the care groups and not solely to older people. Consequently, in their experience, finding out what are the services to which people have access is highly difficult. They advocate the HSE making more use of its HealthStat performance information system to audit the existing services and to provide more information about the HSE services that are available in the community. HealthStat is useful on the acute hospital sector and this is a measure that could be added to enable mapping of the available services, identify the deficits and plan for the future of community care.

⁴⁴ <http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

6. The Regulation of Home Care Provision: application of national quality standards to commercial home care

Evidence on this subject was provided to the SPCC by the Institute of Community Health Nursing, Carers Association and Irish Hospice Foundation

In the absence of safeguards, recipients of home care services – older people living in their own homes – are vulnerable to inhumane treatment and abuse.

The Institute of Community Health Nursing told the SPCC that legislative quality standards combined with inspection by the Health Information and Quality Authority (HIQA) are a necessary safeguard of the safety and welfare of older people in residential nursing home care.⁴⁵ However, they pointed out that there is no comparable system regarding quality, regulation, inspection of providers of home care services to older people, despite the growth in commercial home care services.

The Carers Association too recommends that HIQA should oversee home care packages within a regulatory framework.⁴⁶

The Irish Hospice Foundation also supports the extension of the role of HIQA to oversee home care packages, if it was allocated sufficient resources to develop the implementation of these standards.⁴⁷ They believe it is important that end-of-life care is included in any home care standards. Standard 16 of HIQA's national quality standards for residential care settings for older people in Ireland covers end-of-life care.

6.1 Analysis

At the end of 2010 it was reported that the HSE was to review the standard of care being provided to 65,000 older people in their own homes.⁴⁸

⁴⁵ Submission to the SPCC

⁴⁶ Discussion, Thursday, 24 November 2011. Accessed at:
<http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

⁴⁷ Review to follow home care revelations, 14 December, 2010. Accessed at
<http://www.irishhealth.com/article.html?id=18353>

⁴⁸ Ibid.

“This followed a four-month undercover investigation by the RTE *Prime Time Investigates* programme, broadcast on 13 December 2010, which found appalling standards of care by a number of private home care providers paid by the HSE.

The programme found there are an estimated 150 companies providing home care in Ireland yet the area remains unregulated with no standards and no legal obligation on the home care provider companies to vet staff. Around 10% of this home care is provided by private companies and is a lucrative industry.

The investigation uncovered companies hiring workers with no training, no Garda vetting and no checking of references. The programme filmed an elderly woman being force-fed by a care worker employed by one company....It cited evidence of staff not being properly trained to lift care recipients or to deal with pressure sores, and of the "dumping" of medications. One elderly man alleged he had a considerable sum of money stolen from him by a staff member working for one private firm.”

The then Minister for Older People, Áine Brady, was reported as saying it was clear that in the cases shown on Prime Time, the behaviour and practices highlighted breached trust in an unacceptable way. However, the HIQA told the Prime Time programme that it was not aware of any imminent plans for regulation of the home care sector.⁴⁹

In February 2011 it was reported that the HSE said it had put in place alternative arrangements for carers where appropriate, following the RTÉ exposé of abuse of some elderly people by their home care providers:⁵⁰

“Furthermore, the HSE stated, a national review into all home care and home help service provision.... had now commenced.

The HSE said it had made direct contact with a large number of clients who were in receipt of services from the organisations featured in the *Prime Time* programme. The vast majority of these had indicated that they were satisfied with the care being provided.

In addition, services nationwide had been alerted to the issues raised in the programme and arrangements were being reviewed with service providers for those in receipt of home help or home care packages, to ensure that they were appropriate to the clients’ needs, as per the national review.

All providers of home help and home care packages featured on the RTÉ programme had also been asked to confirm compliance with training, qualification and vetting

⁴⁹ Ibid.

⁵⁰ *Review of home care underway*, Irish Medical Times, 9 February 2011.

Accessed at <http://www.imt.ie/news/latest-news/2011/02/review-of-home-care-underway.html>

requirements. These matters would be addressed with all other agencies as part of the national review...”

The need for regulation was again publicised in December 2011 when information released to The Irish Times under the Freedom of Information Act revealed the types of problem which can arise with home help services, judging by complaints submitted to the Health Service Executive (HSE) by families.⁵¹

In one case, an elderly woman’s daughter complained that when the home help arrived for work, the complainant could smell alcohol from the home help and knew she had been drinking. A HSE disciplinary investigation was carried out. While the HSE said disciplinary action was taken against the home help in question, it would not specify what form this took.

6.2. Regulation

The Health Act 2007 introduced a change to how residential care settings for older people are inspected and registered. This Act requires that all ‘designated centres’, including residential care settings for older people, must be inspected and registered, whether run by the HSE, private providers or voluntary organisations.⁵²

Under the Act, the Health Information and Quality Authority (HIQA) is the regulatory and standard-setting body for the residential nursing home setting. In 2009, HIQA published national standards for the residential care setting. These standards cover 5% of the over-65 category. The Health Act 2007 does not, however, empower HIQA to set comparable standards for the provision of health care in the home setting, which would cover the remaining 95% of the over 65 category (though, of course, not all this group require home care).

On 30 January 2012, the Law Reform Commission published a Report on Professional Home Care.⁵³ The report recommends that HIQA should be given additional regulatory and

⁵¹ *Home help admitted being 'half cut' before starting work.* Irish Times, 15 December 2011. Accessed at: <http://www.irishtimes.com/newspaper/frontpage/2011/1215/1224309100113.html>

⁵² HIQA. *National Quality Standards for Residential Care Settings for Older People in Ireland.* Accessed at http://www.hiqa.ie/system/files/HIQA_Residential_Care_Standards_2008.pdf

⁵³ Law Reform Commission. *Legal Aspects of Professional Home Care.* (LRC 105 - 2011), December 2011. Accessed at: http://www.lawreform.ie/_fileupload/Reports/r105Carers.pdf

inspection powers to ensure that appropriate legal standards are in place for undertakings providing professional home care (the report does not propose that the HIQA regulatory and inspection system would apply to informal carers, such as family members). The Report makes twenty nine recommendations for reform of the law and also includes a draft Health (Professional Home Care) Bill to implement them. Among the Law Reform Commission's recommendations are that:

- HIQA should be empowered to regulate and monitor undertakings that provide professional home care (whether public sector or private sector, and whether for-profit or not-for-profit). While the main beneficiaries of the proposed new HIQA regulation would be likely to be those over 65, the proposed system should apply to professional home care provided to any adult over the age of 18 in their own home. HIQA national standards for professional home carers should be specifically tailored for the home care setting, building on 2008 draft HSE home care guidelines and existing HIQA standards for nursing homes. The proposed standards should have regard to specific principles, including the right of the care recipient to independent living, privacy, dignity, quality of care and protection from abuse. There should be a specific register of professional home carers, which would set out specific requirements in relation to the registration and monitoring of professional home carers.

7. Carer's Allowance and the Habitual Residence Condition

The Carers Association gave evidence to the SPCC on this topic.

7.1 Background

The Carers Association submitted to the SPCC⁵⁴ that Family Carers provide over 3.7 million hours of care each week and save the State almost €4 billion a year⁵⁵. On average, they say, a full-time Family Carer saves the State more than €62,000 per year. The Carers Association points out that the savings made by carers' work are even more apparent when comparisons are made to the cost of nursing home care which is in the region of €800-€1,000 per week, and the cost of acute hospital care which is in the region of €5,000 per week⁵⁶.

The witnesses explained that the Carers Allowance is classified as a Social Assistance Payment. Therefore, Family Carers must satisfy a means test and the Habitual Residence Condition to be eligible to receive it. The Carers Association contends that classifying Carers in this way is not rational.

According to Mr. John Dunne, chief executive of The Carers Association:⁵⁷

"The habitual residence condition was introduced in 2004 to combat welfare tourism.....There is a small number of problem cases. Approximately 18,000 people apply for carer's allowance each year and 600 are tested using the habitual residence condition. Approximately 40% of foreigners....are declined, while 8% of Irish people are declined... How did we get to this position? The habitual residence condition was included in law in the Social Welfare (Consolidation) Act 2005, with new regulations becoming effective in 2007. Section 180 of the 2005 Act relates to carer's allowance, with subsection (2) noting that the allowance shall be subject to the habitual residence condition."

The Carers Association point out that carers are the only social welfare recipients who are required to work fulltime for their payment and are providing a service that Government is unable to provide at this cost. They contend that rather than placing restrictions on carers,

⁵⁴ Carers Association submission to the SPCC

⁵⁵ Carers Association calculations are based on the hourly rate of €20 per hour which is the average cost of HSE home helps.

⁵⁶ Age Action Ireland: *A Fair Price for Care* (2006)

⁵⁷ Discussion, Thursday, 24 November 2011. Accessed at:
<http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

Government should recognize that money spent on the Carers Allowance is money saved, i.e. if these Carers were not available, it would cost the State a great deal more to provide this care.

The Carers Association recounted cases of returning emigrants, refused the Carer's Allowance on grounds of the HRC, who were then obliged to live on the pension of the older person for whom they were caring.

7.2 State Policy on Carers

During 2008, an interdepartmental group, chaired by the Department of the Taoiseach undertook work, including a public consultation process, to develop a National Carers' Strategy.⁵⁸ However, because of the prevailing economic situation, it was not possible to set targets or time limits which could be achieved.

In that context, rather than publishing a document which did not include any significant plans for the future, the Government decided not to publish a strategy. This position remains unchanged.

On behalf of the Minister for Social Protection, Minister of State Perry outlined the position to the Dáil in July 2011:⁵⁹

“The Department of Social Protection ... will have a role in developing and implementing a strategy.

Currently, more than 51,000 people get a carer's allowance payment from the Department. That includes more than 21,000 who receive a half-rate carer's allowance in addition to another [social protection] payment.

There are approximately 1,700 people in receipt of carer's benefit.

In addition, more than 17,000 people who are not in receipt of a carer's allowance or benefit payment received the annual respite care grant of €1,700 this month.

The estimated expenditure for carers in 2011, including carer's allowance, carer's benefit and the respite care grant is approximately €658 million. That does not include the household benefits package or free travel which carers also receive. It is

⁵⁸ Dáil Éireann. Written Answers.29/09/2010 Question 1256

⁵⁹ Adjournment Debate: National Carers Strategy. Dáil debates, 14 July 2011.

not possible at this time to outline the contents of the strategy as it has not been drafted, but the commitment to develop a strategy during the lifetime of the Government is an important one.”

The policy document, *Towards 2016 partnership agreement*, contained a commitment to ensure those on average industrial earnings continue to qualify for a full carer’s allowance.⁶⁰

Financial analysis

A carer aged over 66 caring for 1 person would receive €12,525 per annum, according to the 2012 rates for Carer’s Allowance.

Table 1. Carer’s Allowance rates in 2012

Carer	Maximum weekly rate
Aged under 66, caring for 1 person	€204
Aged under 66, caring for 2 or more	€306
Aged 66 or over and caring for 1 person	€239
Aged 66 , caring for 2 person	€358.50
Increase for a Qualified Child	€29.80 (full-rate)
	€14.90 (half-rate)

Source: Department of Social Protection⁶¹

As outlined by the Carer’s Association above, a full-time Family Carer saves the State on average €62,000 per annum

Mr. John Dunne explained the Carers Association calculations to the SPCC:

“On differential costings, in fairness, one must compare like with like. Our figures suggest that the cost of providing family care within the family in the home compared to public provision of the same care if one factors in the carer’s allowance, as distinct

⁶⁰ http://www.taoiseach.gov.ie/attached_files/Pdf%20files/Towards2016PartnershipAgreement.pdf

⁶¹ <http://www.welfare.ie/en/schemes/illnessdisabilityandcaring/carers/carersallowance/Pages/ca.aspx>

from what the Health Service Executive might pay someone to do the same work, is a multiple of four in that case.

Sometimes care at home involves a high level of medical treatment. We are not just talking about keeping a person company. The difference in cost between this and keeping a patient in an acute hospital bed is a multiple of between 25 and 30. There is a significant difference, but one is not comparing like with like.⁶²

If the 600 people per annum (Irish and foreign nationals) who were declined the payment every year received the rate for a carer (aged over 66 caring for 1 person), that would cost the State €7,316,800.⁶³ If, instead, those needing care were obliged to enter State care for lack of such a carer, the cost to the State of caring for 600 people, based on the amount outlined above of €62,000 (at a minimum), would be €37,200,000. The SPCC suggests therefore that this scenario would seem to favour exempting Irish citizens and EU nationals from the Habitual Residency Condition.

7.3 The legal background to the Habitual Residence Condition

The criteria for determining whether a person is habitually resident are contained in Section 246 of the Social Welfare Consolidation Act 2005, as amended by Section 30 of the Social Welfare and Pensions Act 2007.⁶⁴ The five criteria have been taken from a decision of the European Court of Justice Case C 90/97 Swaddling v UK, in which habitual residence was based on five factors:

- a) the length and continuity of residence in the State or in any other particular country;
- b) the length and purpose of any absence from the State;
- c) the nature and pattern of the person's employment;
- d) the person's main centre of interest, and
- e) the future intentions of the person concerned as they appear from all the circumstances.

⁶² Discussion, Thursday, 24 November 2011. Accessed at:

<http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

⁶³ Oireachtas Library & Research Service calculations based on figures above.

⁶⁴ <http://www.flac.ie/news/2008/08/13/flac-concerns-on-application-of-habitual-residence-requirement/>

These criteria have been transposed into Irish law.⁶⁵

7.4 The Carer's Allowance and EU law

A spokeswoman for the Department of Social Protection was reported as saying that the purpose of the habitual residence condition is to safeguard the social welfare system from abuse by restricting access for people who are not economically active and who have little or no established connection with Ireland.⁶⁶

“Exempting Irish nationals from satisfying the habitual residence condition would be contrary to the equality principles that Ireland has adopted in equality legislation. It would also be contrary to EU law to exempt Irish nationals from the HRC and not exempt other EU nationals on the same basis.”

It is not possible to exempt a particular category of Irish citizens, such as returning Irish emigrants, from the habitual residence condition (either in general or for Carer's Allowance) without extending the same treatment to all EU nationals. The guidelines on determination of habitual residence address the issue of returning emigrants. The guidelines state that:⁶⁷

“A person who had previously been habitually resident in the State and who moved to live and work in another country and then resumes his/her **long-term** residence in the State may be regarded as being habitually resident immediately on his/her return to the State.”

The Irish Carers Association says the HRC, as applied to carers, is unfair. Many may return home on a temporary basis to provide care to an elderly relative, before returning to the country in which they were living previously, but if they do not intend to settle here permanently they do not meet the condition.⁶⁸

According to the then Minister for Social Protection, Éamon Ó Cuív, TD:⁶⁹

“Irish people returning permanently to Ireland should generally be able to show that they satisfy the HRC whether they return as carers, or are intending to resume work

⁶⁵ See Social Welfare and Pensions Act 2007 s.30. Accessed at: <http://www.irishstatutebook.ie/2007/en/act/pub/0008/print.html>

⁶⁶ Number of Irish refused carer's allowance over residency quadruples. Irish Times, 28 July 2010

⁶⁷ Habitual Residence Condition - Guidelines for Deciding Officers on the determination of Habitual Residence. Accessed at: <http://www.welfare.ie/en/operationalguidelines/pages/habres.aspx>

⁶⁸ Number of Irish refused carer's allowance over residency. Irish Times, 28 July 2010

⁶⁹ Éamon Ó Cuív, TD, Minister for Social Protection. *Government is helping carers*, Irish Examiner, 2 August 2010

here, or to retire here. However, a person returning temporarily who does not satisfy the HRC will not be entitled to the assistance payments or child benefit, which are subject to that condition...Exempting only Irish nationals from satisfying the habitual residence condition would be contrary to EU law and to the equality principles that Ireland has adopted in equality legislation. This could therefore be open to a legal challenge and we would be obliged to extend the same entitlements at least to all EU citizens. This Government recognises the huge commitment given by carers and, for this reason, protected last year the half rate carer's allowance for people who are already in receipt of other state payments."

The Irish Hospice Foundation (IHF) recommends that the Government recognise and support family carers and their needs in caring for those with life limiting conditions with measures such as the introduction of a Compassionate Care Leave Benefit Scheme.

8. Rural Transport

The importance of rural transport for the wellbeing of older people living at home was raised in the Committee hearings by witnesses from the Centre for Ageing Research and Development in Ireland (CARDI). The National Federation of Pensioners Associations also gave evidence on this topic.

8.1 Background

In 2007, the Department of Transport and the Department for Regional Development (Northern Ireland) undertook joint research into the provision of rural transport services (Department of Transport, 2007).⁷⁰ The audits of existing services showed that many people in rural counties have no access to any scheduled public transport services. Projections indicate that an estimated 450,000 rural dwellers could have unmet transport needs by 2021, including 250,000 people in key target groups such as older people. (Pobal 2008)

Older people and those with a disability tend to be among the group who rarely or never have car availability.

8.2 Rural Transport Programme

The Rural Transport Programme (RTP) was launched in 2006.⁷¹ It was initiated as a response to the economic and social impacts of inadequate transport in rural areas and the interest amongst community groups in implementing local solutions. The RTP is funded by the Department of Transport and managed on its behalf by Pobal. The Programme, which has expanded to provide national coverage, is delivered locally through 35 community based groups, all of whom operate on a not-for-profit basis.

⁷⁰ See The new ageing agenda. Accessed at <http://www.ageingwellnetwork.com/The-New-Ageing-Agenda/age-friendly-communities/mobility-and-transport/rural-transport>

⁷¹ Rural Transport Programme 'Rural transport connecting rural Ireland': performance & impact report, 2008/2009.

Accessed at <https://www.pobal.ie/Funding%20Programmes/RTP/Documents/RTP%20Performance%20%20Impact%20Report%202009%20Final%20-%20oct.pdf>

Funded by €10.6 million per annum under the National Development Plan 2007-2013, the aim of the RTP is to provide a quality nationwide public transport system in rural Ireland which responds to local needs. Funding is projected to reduce to €9.1m. in 2013 and to €8.5m. in 2014.⁷² In addition, the Department of Social Protection contributes €1.5m to the Free Travel Scheme of the RTP.

Four models or a combination of them have been adopted by RTP Groups:⁷³

- Groups that own and operate their own vehicles – community buses.
- Groups that subcontract the provision of services to other local transport operators.
- Groups that utilise spare capacity of vehicles owned by other voluntary organisations.
- Car sharing schemes - either a) co-ordinated hackney services-where journeys are coordinated in advance and shared, thus bringing down the cost of travel or b) community car schemes - where volunteers provide transport in their own vehicles for a set number of hours per week.

The RTP has self-drive initiatives for community groups and is also now exploring car pooling as a cheaper community focused alternative to the community car/hackney scheme.

The RTP is considered by some stakeholders to be a success in the areas where it operates, but there are many parts of the country where the service is not available.

⁷² <http://per.gov.ie/wp-content/uploads/2011/12/209-COMPREHENSIVE-EXPENDITURE-REVIEW-CURRENT-EXPENDITURE.pdf>

⁷³ Rural Transport Programme 'Rural transport connecting rural Ireland': performance & impact report, 2008/2009.

Figure 1 - Coverage of the RTP Groups' Services



Source: Pobal, November 2011

Older people and people with disabilities form the core customer base of the RTP.

In 2008, over 1.24 million passenger journeys were recorded, a substantial increase from 650,000 passenger journeys in 2005.⁷⁴ Over 76% of these journeys were provided on a door to door basis and free travel pass holders accounted for an average of 64% of passengers. Of these journeys 13% were made by passengers who required assistance in order for them to travel. Some 1,400 volunteers support the day to day management and delivery of the

⁷⁴ <http://www.ageingwellnetwork.com/The-New-Ageing-Agenda/age-friendly-communities/mobility-and-transport/rural-transport>

programme, contributing in the region of 40,000 hours of voluntary expertise and skills each year. Over 6.2 million km of services were provided in 2008 alone, using a combination of community owned buses, voluntary cars and private local providers.

8.3 Rural transport and older people

Rural transport is important for health appointments, access to key services and avoiding social exclusion, according to witnesses from the Centre for Ageing Research and Development in Ireland, CARDI:⁷⁵

“In the [Republic of – sic] Ireland....37% of older people living in a rural area had a transport need that is not being met by public or private transport means. Transport needs relate to shopping, personal issues such as hospital appointments and visiting friends. Transport in rural areas is an important issue for remaining connected and is important for the health of people living in rural areas.

...Research indicates the provision of rural transport is not sufficient for older people who do not drive, do not have access to public transport, cannot afford to keep a car or need to make regular hospital appointments. High quality integrated rural transport can help to combat social exclusion among older people, thereby improving their lives. The provision of adequate rural transport for older people is a key aspect of positive ageing and policy decisions should recognise that.”

To address the unmet need it was suggested by Mr. Jim Keegan, vice president of the National Federation of Pensioners Associations, that instead of having the free travel pass, rural people could be given vouchers for taxis so they can go into town to do their shopping and meet people, as the free travel pass is no good to them.⁷⁶ This suggestion was supported by Dr. O’Sullivan and by members of the Seanad Public Consultation Committee.

Their observations are endorsed by research carried out by the Society of St. Vincent de Paul.⁷⁷

“Those who had access to local rural transport schemes also valued them highly, ‘a lifesaver’, particularly because of their flexibility. You could for example phone

⁷⁵ Dr. Roger O’Sullivan, director of the Centre for Ageing Research and Development in Ireland, CARDI. Rights of Older People: SPCC Discussion, Thursday, 24 November 2011. Accessed at: <http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

⁷⁶ Ibid.

⁷⁷ Kathy Walsh and Brian Harvey. Report of the Commission of Older People. Older people: experiences and issues. Society of St Vincent de Paul, September 2011. Accessed at http://www.rte.ie/news/2011/0907/svp_report.pdf

the local transport in advance to ask them to call and because their buses were small, they could go up boreens and turn in farmyards. They were seen as a great way to check that people were all right and a support that enabled people to continue living in their homes. The drivers of these services were commended for the way in which they helped old people on and off the bus, carried their belongings, saw them inside and raised the alarm if there was a problem. Others welcomed the new ramps which helped people with diminished mobility. These bus services were generally thought to be very well run, efficiently organized and delivered huge benefits at low cost, but there were too few of them. It was annoying to see some buses (school buses may have been alluded to here) lying idle around the countryside when they could be in use.

The research also found that public transport in many villages and small towns was a myth and 'to survive and get about you need a car'. In many towns and villages, there were buses only once or twice a week and often they were poorly scheduled ('they give you only 90 minutes in town and then you've to come back') with inadequate routings ('a lot of places they don't go to')."

Some consultees commented that the free travel pass was useless in these situations and they would prefer a bigger pension instead. Where people did not have access to a car and in the absence of public transport, they had to resort to the use of taxis, which was relatively expensive.⁷⁸

The lack of more availability of RTP services is related to funding. The proposed RTP budget reductions could most likely result in an increase in the 37% of rural dwellers identified by CARDI as having an unmet transport need. .

8.4 Taxi Voucher Schemes

The provision of vouchers was discussed by the Minister of Social and Family Affairs in response to a parliamentary question in June 2009:⁷⁹

"The issue of access to public transport in rural areas is being addressed at present through the Rural Transport Programme, which is being managed by Pobal, on behalf of the Department of Transport. My Department is contributing €1.5 million to the initiative this year to ensure that free travel pass holders continue to have access to community based transport services. I am aware of the difficulties that some free travel pass holders

⁷⁸ Ibid.

⁷⁹ Written Answers - Rural Transport Programme, 23 June 2009. Accessed at: <http://debates.oireachtas.ie/dail/2009/06/23/00262.asp>

have in accessing public transport and my officials have discussed this issue with the Commission for Taxi Regulation.⁸⁰

Various alternatives to the existing system, including the use of vouchers, have been examined. A study, "A Review of the Free Schemes", published in 2000 by the Policy Institute, Trinity College Dublin, concluded that a voucher type system, which would be open to a wide range of transport providers including taxis and hackneys, would be extremely difficult to administer, open to abuse and unlikely to be sufficient to afford an acceptable amount of travel. This position remains unchanged."

However, the study quoted by the Minister was commenting on the option of the abolition of the Free Travel scheme and its replacement with a voucher type system. Since 2000, when the study was published, sophisticated technology and software have been developed which make such schemes more feasible and less costly.

The study quoted above by the Minister also stated that:⁸¹

"The abolition of Free Travel and its replacement with a voucher type system, which would be open to a wide range of transport providers including taxis and hackneys, would be complicated and less feasible than the current system. Voucher schemes, by their nature, introduce stigma into a scheme. In addition, they are administratively unfeasible, particularly if issued annually, as the number of vouchers and potential operators would be enormous.

For example, if people were issued with only four vouchers per month, allowing two return journeys, this amounts to 25 million vouchers to be processed annually, based on the current number of Free Travel Passes issued. The experience of the Department operating a voucher based scheme, such as the Free Bottled Gas scheme, which is claimed by only 414 recipients, suggests that the difficulties inherent in this type of scheme make it most unsuitable for a Central Government Department to operate.

There are huge payment and accounting difficulties, which in the case of the Free Bottled Gas scheme, have resulted from vouchers being presented which are more than two years old. In addition, vouchers are easily lost and there is much greater fraud potential, requiring more involved administrative and control procedures. Finally,

⁸⁰ The Minister for Transport dissolved the Commission for Taxi Regulation on the 1st January 2011. With effect from that dissolution date, the National Transport Authority started to carry out the principal functions of the Commission under the 2003 Taxi Regulation Act. The Board of the Authority now decides the key taxi regulation decisions

⁸¹ Quinn, Orlaigh. A review of the free schemes operated by the Department of Social, Community and Family Affairs. Dublin, The Policy Institute (TCD) in association with the Department of Social, Community and Family Affairs, 2000. Accessed at: http://www.tcd.ie/policy-institute/publications/bluepaper_05.php

the current value of the Free Travel Pass would not be sufficient to provide an acceptable amount of travel and would inevitably lead to demands for increases.”

However, in January 2010, the Oireachtas Joint Committee on Community, Rural and Gaeltacht Affairs recommended the establishment of a new statutory transport authority with responsibility for the delivery of rural transport. Among the proposals made by the Committee were to provide vouchers to allow the elderly to more easily avail of private taxi services; extend the free travel pass and provide a special service for the elderly on pension payment day.⁸²

According to Deputy Michael Ring, a member of that Joint Committee:⁸³

“There is no reason why a scheme cannot be put in place to provide an option for rural transport. People will get so many vouchers for the week and give them to the taxi driver who will collect his money at the end of the week.... We need the voluntary aspect of a community to get involved or else it will not work but I have no doubt that if a pilot scheme was put in place it will work.”

One model is the Rural Transport Fund Voucher Scheme funded by the Northern Ireland Department for Regional Development.⁸⁴ This scheme is aimed at rural non-profit making community groups wishing to transport upwards of 17 passengers at a time. The scheme provides a £100 voucher per quarter towards the cost of transport for successful applicants(i.e.£400 per annum to successful applicants).

The Voucher Scheme was rolled out across Northern Ireland during 2009/10. Supported by the Rural Transport Fund, the scheme works in partnership with private transport operators who deliver transport for the scheme. The scheme incorporates all rural areas in Northern Ireland. 25 vouchers are available for each of the 13 Rural Community Partnerships. To fund

⁸² Joint Committee on Arts, Sport, Tourism, Community, Rural and Gaeltacht Affairs. *Report on Rural Transport Provision*, January 2010. Accessed at

http://www.oireachtas.ie/documents/committees30thdail/j-artssportstcrqa/reports_2009/20100224.pdf

⁸³ Mayo News, 2 March 2010. Accessed

at:http://www.mayonews.ie/index.php?option=com_content&view=article&id=9071:taxi-vouchers-proposed-for-rural-transport&catid=23:news&Itemid=46

⁸⁴ See <http://www.communityni.org/news/rural-transport-fund-voucher-scheme-5>

those community organisations that help the most vulnerable there is a selection process. The trip records show that the majority of the vouchers are used for recreational purposes.⁸⁵

Another model is the Rural Transport Voucher scheme introduced in England by Suffolk County Council.⁸⁶ Those who qualify for this Rural Transport Voucher scheme are:

- Anyone with a disability/blindness or injury which has a substantial and long-term effect on their ability to walk. This being of such severity that they are unable to use conventional public transport services at any time (whether or not those services are available).
- For residents who would qualify for a Free Travel Bus Pass but are unable to use the pass as there are insufficient bus services to and from the parish they live in with no more than 3 return bus journeys per week to a town with shops and other services (e.g. healthcare, banking, etc.).

The value to the individuals of the vouchers issued is £50 per annum. Residents being issued with Travel Vouchers will not be entitled to a free bus pass and give up their right to have one by accepting vouchers instead. They receive a booklet of vouchers which are in £1 denominations, which can be used to pay for their journeys by community transport, taxi or private hire vehicles. Vouchers are accepted on participating community transport, taxis or private hire vehicles.

Age Action is pressing the Government to adopt a more flexible approach in areas where there is no rural transport by providing older people with a book of vouchers. These could then be used as payment for a range of potential transport providers in a community. For example, they suggest that, with some flexibility, it should be possible to use school buses - when they are not being used for students - to provide rural transport services for older people.⁸⁷

⁸⁵ Personal communication, Department for Regional Development

⁸⁶ See Suffolk on Board. Accessed at www.suffolkonboard.com/content/download/.../Travel%20Vouchers.pdf

⁸⁷ Greater flexibility needed for rural transport scheme. Waterford News and Star, 19 January 2007. Accessed at <http://www.waterford-news.ie/news/cweyeycwau/>

8.5 UK and other European taxi schemes

The UK Commission for Integrated Transport (CfIT) assessed shared taxi schemes - or what it christened 'TaxiPlus' services - from across Europe and the UK.⁸⁸ Research undertaken by Mott MacDonald on behalf of CfIT assessed these schemes which operate on a large scale in many rural areas of mainland Europe, and are particularly successful in the Netherlands and Switzerland where sophisticated journey matching software is used to match people's trips. Because 'TaxiPlus' services only run when requested, they are more cost-effective than conventional bus services in remote areas and at off-peak times, providing services seven days a week from early in the morning until late at night in places where a conventional bus service would not be viable.

CfIT found schemes in mainland Europe provided from five to fifty times as many passenger trips as typical schemes in England, and achieved significant economies of scale. CfIT believes the economies of scale achieved on mainland Europe should also be possible in England.

CfIT recommended a pilot 'TaxiPlus' scheme, running at least at county level and over seven years. It could offer subsidised, on-demand, door-to-door services linking in to other transport modes plus bookable services at off-peak times on core bus routes. The pilot would evaluate how shared taxis could improve accessibility, raise social inclusion, and offer other social benefits. It would also test the potential to achieve modal shift away from the private car, bringing with it climate change benefits that would justify additional subsidy.

CfIT's research identified that whilst there are no insurmountable regulatory or legislative obstacles to the development of 'TaxiPlus' schemes in the UK, their framework is complicated. In the medium term reforms to the licensing system for taxis and to the funding for public transport would help stimulate services in rural areas.

⁸⁸ CfIT. Flexible taxi services hold the key to halting rural stagnation, 27 November 2008. Accessed at <http://webarchive.nationalarchives.gov.uk/20110304132839/http://cfit.independent.gov.uk/pn/081127/index.htm>

The origin of this work was a study commissioned by CfIT in 2002 (LEK Consultancy, 2002) which suggested taxi services could be a more cost-effective alternative to bus services in deep rural areas.⁸⁹

Patterns of movement in rural communities are often too dispersed to be handled efficiently by conventional public transport and, as a result, these kinds of transport tend to require high subsidies to remain in operation.

The types of schemes operating in the Netherlands and Switzerland typically use a fleet of small vehicles to provide shared transport to passengers who pre-book. In some cases, the service operates on a fixed route and at a fixed time but in a location or at a time of day when conventional bus services would not be viable. In other cases, the service is door-to-door. Pre-booking can generally be made up to an hour before travel. Hours of operation are commonly from early in the morning until late in the evening, seven days a week. Ticketing is integrated with conventional public transport, and services are designed to connect with buses and trains.

While they operate within a national framework, the Dutch and Swiss schemes are generally managed at a regional or sub-regional level. For example, the licensing system for providers of what is known as 'small-scale collective transport' in the Netherlands is national, so that providers need only register once in order to be able to operate anywhere in the country. A single provider operates a small number of call centres that take bookings from passengers anywhere in the country. Contracts for small-scale collective transport services are then let by the various provincial administrations.

Within the UK, the Government's Local Transport Bill (enacted as the Local Transport Act 2008 No 26/2008⁹⁰) sets out a framework for sub-regional co-ordination of transport planning that may make it easier to manage demand-responsive transport services on a regional or sub-regional scale - for example across several counties. This would help achieve the economies of scale shown by the mainland European schemes.

⁸⁹ Commission for Integrated Transport. *A New Approach to Rural Public Transport*. Accessed at: <http://webarchive.nationalarchives.gov.uk/20110304132839/http://cfit.independent.gov.uk/pubs/2008/rpt/report/index.htm#exec>

⁹⁰ Accessed at <http://www.legislation.gov.uk/ukpga/2008/26/contents>

In the UK, taxi and private hire vehicle (PHV) licensing outside London is the responsibility of district and unitary councils. This is seen as working against the development of large firms with the capacity to run sizable operations of the type seen in mainland Europe.

However, the National Transport Authority manages the regulation of the Small Public Service Vehicle sector in Ireland.⁹¹

Prompted by the research above, the Commission for Rural Communities (CRC) and Commission for Integrated Transport (CfIT) supported the Rural Wheels initiative in the English county of Cumbria, a shared taxi scheme providing subsidised travel for rural communities.

Rural Wheels in Cumbria is a shared taxi scheme that is integrated into the wider transport network. Operated by Cumbria County Council, it provides door-to-door transport when people want it and at reasonable cost, using smart card technology for ease of payment. The scheme covers the county and in 2008 carried over 12,000 people, charging 30p per mile. It is run and managed by the Council's passenger transport team.⁹²

The UK Parliament's House of Commons Transport Committee was in favour of similar schemes, such as 'taxi-buses':⁹³

Clause 26: Use of private hire vehicles to provide local services

73. At present, taxi owners are eligible to apply for a "special restricted" PSV operator's licence, specifically to enable them to register and operate local bus services ("taxi-buses"). As a measure to assist community-based transport, the draft Bill includes a provision to extend similar eligibility to holders of a private hire vehicle (PHV) licence in England and Wales.....74. We welcome the extension of taxi-bus licenses to private hire vehicles, which is likely to enhance the provision of community-based transport. Since they will be operating a bus service, we recommend that drivers of these vehicles should be subject to the same safety standards as other bus drivers; rather than the locally-applied standards for PHV drivers.

⁹¹ National Transport Authority Taxi Regulation. Accessed at

<http://taxiregulation.nationaltransport.ie/for-everyone/about-taxi-regulation/>

⁹² See <http://crc.staging.headshift.com/files/rural%20wheels%20news%20release1.pdf>

⁹³ House of Commons. Transport Committee. The draft Local Transport Bill and the Transport Innovation Fund. Volume I. Report, 25 July 2007.HC 692-I,Incorporating HC 564-i.Published, 3 August 2007. Accessed at:

<http://www.publications.parliament.uk/pa/cm200607/cmselect/cmtran/692/692i.pdf>

Examples of taxi-buses are to be found in the Northern Irish and Scottish cities of Belfast, Edinburgh and Fife.⁹⁴

8.6 Current position

The free travel budget has been frozen at 2010 levels--€1.5million- while the number of eligible customers and the cost of fares continues to rise each year. For this reason the Department of Social Protection says there is no possibility of a taxi voucher scheme.⁹⁵

8.7 Integrated rural transport

A question which may be posed in a time of budgetary pressure is whether the introduction in Ireland of schemes similar to 'TaxiPlus' might run the risk of diverting money from other schemes and thereby reducing access to transport for other recipients.

An alternative would be the development the existing services in order to expand the high quality integrated rural transport commended by Dr. O'Sullivan of CARDI (above).

RTP policy is to take an integrated approach in order to maximise the transport access for all users. Integration gives synergy, which will give rise to savings, which can then be used to expand services (and thereby reach more potential passengers) while remaining universal in character.

To this end, the RTP is piloting Local and Rural Transport Integrated Services (LARITS). The characteristics of the LARITS are:

- Social inclusion. Better transport services reduce transport-related social exclusion
- Economic and financial benefits. Integration can help deliver more/better transport with the same/less resources.

In an integrated partnership approach Pobal, Bus Éireann, HSE, the Irish Wheelchair Association, the Department of Transport, Tourism and Sport and the Department of Education and Skills are represented on the on the Steering Committee of the LARITS. Its purpose is to test and evaluate:

⁹⁴ See Cooper, James, Ray Mundy and John Nelson. *Taxi! Urban economies and the social and transport impacts of the taxicab*. Farnham, Ashgate (Surrey), 2010.

⁹⁵ Personal communication, Department of Social Protection, 12 January 2012.

- how needs are identified;
- opportunities for better connectivity and integration; physical, ticketing, information, schedules;
- fleet and service optimisation; and
- benefits of pooling skills, knowledge and systems.

8.8 Integrating healthcare with other transport services

The embryonic partnership and integration approach is exemplified by the engagement of the RTP with the HSE in recent years.

The HSE avails of taxi services to transport patients for appointments. The taxi/hackney services are chosen by tender; patients must choose their provider from this list. Patients are allocated taxi services according to two criteria, medical need and financial need. The HSE does not have a budget for transport, but pays for this service from different budgets. As a result, coverage varies hugely across the country. In some areas access to taxis is available while others have none at all.

The HSE is now moving away from the costly provision of taxis towards using the Local and Rural Integrated Transport Services(LARITS), in order to avoid duplication and achieve economies of scale with better value for money. They co-ordinate with the RTP in Co. Donegal by booking places for patients on their buses. This co-operation between the Rural Transport Scheme with the HSE offers synergies. For example, timetables for services offered by RTP Groups could be printed on the back of medical appointment cards.

Collect and Connect

Another result of partnership is the collaboration between Bus Éireann and an RTP Group, Sligo Rural Transport, in their 'Collect and Connect' services in the Curry and Tubbercurry region.⁹⁶ On Thursdays the rural transport bus operates a door to door pick up service connecting with the Bus Éireann service to Sligo in Curry at 10.50a.m. On Friday mornings the rural transport bus collects and connects with Bus Éireann in Tubbercurry at 10.53a.m

⁹⁶ See <http://www.sligotoday.ie/details.php?id=6486>

for Sligo. The return Bus Éireann service leaves Sligo at 3.00p.m and the rural transport bus will be waiting in Curry and Tubbercurry to bring passengers to their own doors.

Bus Éireann links to Galway can also be made. Booking a seat on these rural transport services, from home, costs €2.00.

In another collaboration, the RTP timetables are added to the Bus Éireann timetables in certain areas, e.g. Waterford, Wexford and Kerry.

Car-based schemes—paid or voluntary

A further possibility is the expansion of RTP community car schemes, either

- a) co-ordinated hackney services-where journeys are coordinated in advance and shared, thus bringing down the cost of travel; or
- b) community car schemes - where volunteers provide transport in their own vehicles for a set number of hours per week.

Eight RTP Companies are operating a Community Car/ Co-ordinated Hackney scheme.

They are West Sligo,CLASP (Co. Sligo),Rural Roadrunner(Wexford),Rural Lift (West Cavan), Westmeath Rural Transport, West Cork, Avondhu and Cavan Area Rural Transport (CART). One of these, Avondhu,operates a Taxi Voucher Scheme .

West Sligo Rural Transport and CLASP (Community of Lough Arrow Social Project) serve rural communities in the south east of County Sligo through a Community Car Scheme, while Avondhu in Co.Cork runs a Taxi Voucher Scheme.

CLASP was the first community car- based scheme, set up in 2003. It has 15 voluntary cars and 3 mini-buses.

Both projects provide community based door-to-door, flexible transport services, scheduled to link with public and private transport services locally. Other services such as a separate 'evening services' scheme are being piloted by Pobal in seven different projects nationwide.

Avondhu Taxi Voucher Scheme

This scheme was established in 2003. Avondhu operate a taxi voucher scheme similar to that in operation in the UK. The scheme is only open to people with disabilities. Passengers

must be members of the scheme. Approximately 150 members are entitled to 2-3 trips per month. 3 local private operators provide the services. The scheme is mainly used for accessing training courses and GP visits. Approximately 10% of total trips are used for health appointments. Trips are booked directly through the operator. The service is not delivered in partnership/consultation with the HSE. 6,374 passenger trips were provided in 2008.

The total cost of the scheme in 2008 was €46,400. €1.80 per mile is paid to operators. The cost of the service per passenger is €5.00 per trip.

Challenges faced in taxi voucher scheme

Some passengers are unwilling to travel with other passengers or by bus. Passengers have become accustomed to this type of service and are now unwilling to travel on a bus with other passengers, even though it would prove more cost effective for the RTP company

Future prospects

The issue of using the School Bus fleet to provide additional services is under consideration in the LARITS. However, it is not as simple as just using the buses as they currently function. There is an acceptance that an integrated approach can only make this option cost effective.

RTP groups under the LARITS concept could administer the carsharing/ridesharing schemes at local level and indeed coordinate any additional funds channelled through vouchers schemes.

It is important to note that any change to the RTP allocation of Free Travel Pass funding would significantly affect the availability of transport provision to larger numbers of people than the 37% of rural dwellers unable to access transport. The crux is that this 37% are not able to access RTP services due to the limited resources available at present.

As noted above, continued cuts to the RTP vote until 2014 are envisaged so one can extrapolate that the figure of 37% will increase as a result⁹⁷.

However the RTP groups will strive to reduce this increase through various supply options like reduced service levels as opposed to cutting full services. It would be their contention that the services currently provided by the RTP including predominantly door to door public transport services are best placed to provide for a social inclusion agenda as opposed to services provided on an individual basis through taxi vouchers given to some at the exclusion of others.

There is a possible role for vouchers with taxis but it could be argued that this is where there is a safety and or health issue necessitating such service provision and that dialogue must be made with the relevant authorities (i.e. doctors or Gardaí).

Government Plans

On 29 February 2012, it was reported that Minister of State with responsibility for Rural Transport, Alan Kelly, announced that six pilot schemes will be set up to examine how the rural transport programme, school transport and Health Service Executive non-acute transport can be integrated.⁹⁸

One option under consideration is that school buses could be used during the day as part of a realignment of rural transport services. The Minister said that it did not make sense to have school buses parked for six hours every day.

A new high-level committee involving representatives from the Department of Transport, Tourism and Sport, the National Transport Authority, the Department of Education, the Department of Health, Bus Éireann, the HSE, local authorities and rural transportation groups will all oversee the pilots and the future integration of the services

⁹⁷ Personal communication with Pobal.

⁹⁸ School buses may be used by public. Irish Times 28 February 2012. Accessed at: <http://www.irishtimes.com/newspaper/breaking/2012/0228/breaking54.html>

9. End-of-life patients

The Irish Hospice Foundation addressed the SPCC on this topic.

The Irish Hospice Foundation (IHF) told the SPCC that more than 6,000 people use hospice services annually. It is estimated that up to 13,000 patients will require access to hospice and specialist palliative care in 2016.⁹⁹

They note that all those with advancing life-limiting disease require a palliative approach to their care. Specialist palliative care services respond to those with complex needs and provide advice for those caring for people dying at home, as well as in residential and acute settings.¹⁰⁰

“The first Irish survey of death and dying in 2004 was commissioned by the Irish Hospice Foundation and found that two thirds (66%) of people wished to die at home. Some 10% expressed a preference to die in hospital or a hospice. The reality is that only 25% of people die at home; more than seven out of ten die outside their own homes and 48% die in busy acute hospitals. Therefore, the majority of older people die in acute and long-stay settings.”

According to the IHF, 90% of care provided in the last year of life is provided by a GP and a primary care team.¹⁰¹ The average GP practice will care for up to 20 dying patients every year.

9.1 Formal framework for the delivery of palliative care

The IHF informed the SPCC that Ireland, unlike some other countries, lacks a formal framework to support the delivery of palliative care services by primary care teams. Such a framework would assist in people being cared for in their homes for longer. It would also be of assistance in planning the transition for patients and facilitate the involvement of family and carers. With better communications and mapping of the available services, professionals would understand each other's roles and what services are available for their

⁹⁹ SPCC Discussion, Thursday, 24 November 2011. Accessed at: <http://debates.oireachtas.ie/PCJ/2011/11/24/00003.asp>

¹⁰⁰ Ibid.

¹⁰¹ Ibid.

patients. One such service might be 24-hour access to advice from the local specialist palliative care service.

Some resources would be required for the provision of training, after-hours nursing services, communications systems between care providers and up-to-date and flexible responses. The IHF says that many of these measures will be cost neutral as it is cheaper ultimately to have people well cared for at home than dying in an acute hospital.

They also suggest that people diagnosed with a life-limiting condition should automatically be entitled to a medical card and full range of community services. Financial stability is often lost after such a diagnosis. As a patient or carer can no longer work, they have less income but greater expenditure. The medical card would allow them to access a range of services. Those without a medical card who would qualify on the basis of their new diagnosis would be using it for a limited time:¹⁰²

“A study conducted in nine counties in 2009 and 2010 by hospice and palliative care social workers of the Irish Association for Palliative Care found that processing requests for medical cards varied from one to 85 days, with 23% of applications taking more than 20 days to process. As a result, 13% of patients died before the process was completed, while 24% of applicants had been refused a medical card. Obviously, this is unacceptable.”

The IHF also informed Senators that, in 2011, the Minister established a more centralised system for the administration of discretionary medical cards. These are given to patients who would not normally be entitled to a medical card but are given one on the basis of hardship or illness. That is the only progress that has been made. The IHF wants to do more research in this regard, particularly into the economic costs. They are of the opinion that ensuring people have access to a medical card and all the services that go with it enables people to stay at home for as long as possible, which is a cheaper option overall for the State than admitting people to an acute hospital, where the cost is estimated to be €1,000 per night.

In the same month as the SPCC hearings (November 2011) the IHF published *Primary Palliative Care in Ireland. Identifying Improvements in Primary Care to Support the Care of*

¹⁰² Ibid.

Those in Their Last Year of Life – a collaboration between the IHF, the HSE and the Irish College of General Practitioners (ICGP).

At the launch Dr. Paul Gregan, Chairperson of the Primary Palliative Care National Steering Group, stated:¹⁰³

“Research has found that 80% of people with end-stage disease in Ireland want to die at home. To facilitate this, there is a great need to improve the generalist palliative care that is available in the community.

Implementing the recommended initiatives in this report will help to keep more patients with life-limiting disease in the community... It is feasible to improve this aspect of care delivery within the current fiscal restrictions... .”

The HSE had published *Palliative Care Services - Five Year Medium Term Development Framework (2009 - 2013)* in July 2009. It had been developed using a holistic, system-wide, approach to addressing the level of need identified by both the Baseline Study on the Provision of Hospice / Specialist Palliative Care Services in Ireland (2006) as well as the HSE Audit of Palliative Care Service Provision (2007).

The HSE Audit was conducted in the context of the recommendations of the Report of the National Advisory Committee on Palliative Care 2001 (the NACPC Report).

This Framework document is grounded in the recommendations of the NACPC Report, (e.g. palliative care definition, palliative care service areas, staffing and bed number ratios), and informed by the findings of the HSE Audit.

It details the required actions and initiatives necessary to address the gaps in palliative care service provision, against the recommendations set out in the NACPC Report.

This report concludes that:¹⁰⁴

¹⁰³ See http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=679:report-announces-measures&catid=2:general-news&Itemid=11

¹⁰⁴ See <http://www.hse.ie/eng/services/Publications/corporate/palcareframework.pdf>

“Government support is central to ensure the successful delivery and implementation of national palliative care framework 2009 – 2013. Appropriate funding will need to be made available to support the national priorities for palliative care detailed in this report..... Identification of appropriate funding may be achieved through a combination of the following:

- Reorientation and reconfiguration of existing resources, to be undertaken in partnership with all relevant stakeholders, including both the statutory and voluntary sectors;
- Identification of additional resource requirements when further funding comes on-stream.”

Appendix 1

Members of the Seanad Public Consultation Committee

Senator Denis O'Donovan
Chairman



Senator Ivana Bacik



Senator Paul Bradford



Senator Paul Coghlan



Senator Maurice Cummins



Senator Mark Daly



Senator Lorraine Higgins



Senator Rónán Mullen



Senator Susan O'Keeffe



Senator Diarmuid Wilson



Senator Katherine Zappone



Appendix 2

Téarmaí Tagartha Terms of Reference

“D’ainneoin aon ní sna Buan-Orduithe, go ndéanfar Orduithe an 19 Iúil, 2011 agus an 26 Iúil, 2011 ón Seanad i dtaobh Choiste Achainí Poiblí an tSeanaid agus Choiste Comhairliúchán Poiblí an tSeanaid a urscaoileadh agus go gcuirfear an tairiscint seo a leanas ina n-ionad:

‘Beidh Roghchoiste arna bhunú ar feadh ré an 24ú Seanad ar a dtabharfar Coiste Comhairliúchán Poiblí an tSeanaid (CCPS) ar a mbeidh 11 chomhalta. Cúig chomhalta is córam don Choiste.

Is é is cuspóir don CCPS socrú a dhéanamh le haghaidh idirphlé agus comhairliúcháin dhírigh idir daoine den phobal agus an Seanad, trí phróiseas ina n-iarrfaidh Seanad Éireann aighneachtaí tríd an CCPS ó dhaoine den phobal faoi shaincheist leasa phoiblí (arb é an míniú atá air saincheist shonrach a bhaineann le cumhachtaí reachtacha an tSeanaid nó saincheist bheartais phoiblí). Déanfaidh an CCPS breithniú ar na haigneachtaí a dhéanfar, féadfaidh sé éisteachtaí poiblí a thionól agus eiseoidh sé tuarascáil ina mbeidh moltaí a ndéanfar díospóireacht orthu i Seanad Éireann nó a tharchuirfear chuig an gComhchoiste iomchuí.

1. Sonróidh an CCPS agus poibleoidh sé réimse áirithe a bhaineann le cumhachtaí reachtacha an tSeanaid nó le saincheist bheartais phoiblí a n-iarrfar aighneachtaí ón bpobal ina thaobh nó ina taobh.

2. Sonrófar agus poibleofar freisin

“That, notwithstanding anything in Standing Orders, the Orders of the Seanad of 19 July 2011 and 26 July 2011 concerning the Seanad Petitions Committee and the Seanad Public Consultation Committee be discharged and the following motion be substituted therefor:

‘There shall stand established for the duration of the 24th Seanad a Select Committee which shall be called the Seanad Public Consultation Committee (SPCC), which shall consist of 11 members and the quorum of the Committee shall be five members.

The purpose of the SPCC is to provide for direct engagement and consultation between members of the public and the Seanad, through a process where Seanad Éireann through its SPCC invites submissions from members of the public on an issue of public interest (defined as a specific issue related to its legislative powers or an issue of public policy). The SPCC will consider the submissions made, may hold public hearings on the issues, and will issue a report with recommendations which will be debated in Seanad Éireann or referred to the relevant Joint Committee.

1. The SPCC shall specify and publicise a particular area related to the legislative powers of the Seanad or to an issue of public policy on which submissions from the public will be invited.

2. A deadline for the receipt of

spriocdháta faoina mbeidh aighneachtaí le bheith faighte ag an CCPS.

3. Suífidh an CCPS go príobháideach ar an gcéad ásc chun cinneadh a dhéanamh faoin réimse áirithe a n-iarrfaidh sé aighneachtaí ina thaobh.

4. Tar éis aighneachtaí a bheith faighte, suífidh an CCPS arís go príobháideach chun breithniú a dhéanamh ar arb inghlactha aighneachtaí agus chun breithniú a dhéanamh freisin i dtaobh cén beart a dhéanfar i ndáil le haighneachtaí atá inghlactha.

5. Féadfar suíonna príobháideacha den CCPS a thionól i gceann de na Seomraí Coiste.

6. I gcás inar dóigh leis an CCPS gur cuí duine nó eagraíocht a éisteacht maidir le haighneacht inghlactha a cuireadh faoina bhráid, féadfaidh sé a shocrú go dtionólfar seisiún poiblí nó seisiún príobháideach.

7. Féadfar aon seisiúin phoiblí den sórt sin, a n-iarrfar ar dhuine nó ar eagraíocht amháin nó níos mó aitheasc a thabhairt lena linn, agus a bhféadfaidh daoine den phobal freastal orthu, a thionól i seomra an tSeanaid lasmuigh d'amanna suí agus féadfar iad a chraoladh ar an teilifís.

Teimpléad le haghaidh Inghlacthacht Aighneachtaí chuig Coiste Comhairliúcháin Poiblí an tSeanaid

(1) Féadfar aighneachtaí a dhéanamh leis an ríomhphost nó leis an bpost. Déanfar na nithe seo a leanas a chur in iúl go soiléir ar gach aighneacht: -

(a) ainm an duine /na cuideachta/ na heagraíochta ag a mbeidh an aighneacht á déanamh; agus

submissions by the SPCC shall also be specified and publicised.

3. The SPCC shall sit in private in the first instance to decide upon the particular area upon which it will invite submissions.

4. Once submissions have been received, the SPCC shall again sit in private to consider whether submissions are admissible and to consider further what action to take in relation to admissible submissions.

5. Private sittings of the SPCC may take place in one of the Committee Rooms.

6. Where the SPCC considers it appropriate to hear from a person or organisation in respect of an admissible submission made to it, it may arrange for the holding of a public or private session.

7. Any such public sessions, which one or more persons or organisations may be invited to address, and which members of the public may attend, may be held in the Seanad chamber outside of sitting times and may be televised.

Template for Admissibility of Submissions to Seanad Public Consultation Committee.

(1) Submissions may be made by email or post. Each submission shall clearly indicate: -

(a) the name of the person/company/organisation making the submission; and

(b) seoladh poist nó seoladh ríomhphoist.

(2) Beidh aighneacht inghlactha mura rud é:

(a) go n-iarrtar ar an Seanad san aighneacht aon ní a dhéanamh seachas nithe a bhfuil cumhacht ag an Seanad chun iad a dhéanamh;

(b) nach gcomhlíonann sí na Buan-Ordúithe nó nach mbeidh sí san fhoirm chúí thairis sin;

(c) go mbeidh sí *sub-judice* mar a mhínítear i mBuan-Ordú 47;

(d) go mbeidh duine aonair nó daoine aonair ainmnithe inti;

(e) go mbeidh caint inti atá maslach nó clúmhilleach; agus

(f) gurb ionann í nó gurb ionann a téarmaí go substainteach agus aighneacht a rinne an duine céanna, an chuideachta céanna nó an eagraíocht céanna nó a rinneadh thar a gceann siúd le linn shaolré an Choiste.

(3) Féadfaidh an CCPS, maidir le haon aighneachtaí inghlactha faoin tsaincheist áirithe ar iarradh aighneachtaí ina taobh, aon cheann de na nithe seo a leanas a dhéanamh:-

(a) a iarraidh ar aon duine/ aon chuideachta/ eagraíocht díobh siúd a rinne aighneachtaí inghlactha aitheasc a thabhairt maidir leis an gcéanna i seisiún poiblí;

(b) tuarascáil scríofa a ullmhú ar an tsaincheist a bheidh bunaithe ar bhreithniú na haighneachta inghlactha nó na n-aighneachtaí inghlactha a rinneadh chuige faoin tsaincheist sin;

(c) an tuarascáil agus aon mholtaí a bheidh inti a tharchur chuig an Seanad le haghaidh díospóireachta;

(d) an tuarascáil agus aon mholtaí a bheidh inti a tharchur chuig an gComhchoiste le haghaidh

(b) a postal and/or email address.

(2) A submission is admissible unless it:

(a) requests the Seanad to do anything other than the Seanad has power to do;

(b) does not comply with Standing Orders or is otherwise not in proper form;

(c) is sub-judice as defined in Standing Order 47;

(d) contains the name or names of individuals;

(e) contains language which is offensive or defamatory; and

(f) is the same as, or in substantially similar terms to, a submission made by or on behalf of the same person, company or organisation during the lifetime of the Committee.

(3) In respect of any admissible submissions on the particular issue on which submissions have been invited, the SPCC may:-

(a) invite any of the persons/company/organisations who have made admissible submissions to address it in public session;

(b) prepare a written report on the issue based upon consideration of the admissible submission or submissions made to it on that issue;

(c) refer the report and any recommendations therein to Seanad Éireann for debate;

díospóireachta; agus
(e) an tuarascáil a leagan faoi bhráid
Sheanad Éireann.

- (d) refer the report and any
recommendations therein to the
relevant Joint Committee for
debate; and
- (e) lay the report before Seanad
Éireann.”.