Five Innovative & Cost-Effective Ways to Enhance the Independence of Persons with Disabilities in Ireland
What Are Policy Briefings?

The Centre for Disability Law and Policy hosts and sponsors a large amount of comparative law and policy research focused on disability. Much of this research is directly relevant to current policy challenges in Ireland.

The Centre is committed to providing succinct Policy Briefings on a quarterly basis which summarise some of its relevant research and tie it directly to these policy challenges. This is the first in that series. It is intended as a public service to make the public aware of innovative policy solutions adopted elsewhere in the world that may enrich debate in Ireland. We hope you find it useful. Please visit our website for further information on research underway and please log on to our Disability Law Blog (on our website) for up-to-date news of relevant to policy debates in Ireland.

We welcome comments, questions, suggestions and feedback. Please direct your comments to info.cdlp@nuigalway.ie
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Focus of this Policy Brief

The following brief outlines five innovative, cost-effective models of support that have been largely developed in other jurisdictions, which are proving successful at reducing people’s sole dependence on state-run disability services. These innovations are important in the current financial climate since they demonstrate that real and effective change can take place despite financial constraints.

They show that new economic activity can be enabled to take place with smart policy interventions that also sub-serve our disabled citizenry and address in different ways the growing numbers of people awaiting services in Ireland. Each was chosen as they represent readily applicable and sustainable new ways to support persons with disabilities. Moreover, each is underpinned by current and successful advances in other jurisdictions.

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1. Financial Innovation: Enabling Private Funds to Grow to Allow People to Purchase the Services They Want

Financial innovation models seek to address the sole dependence of adults with disabilities on state services. They create long-term savings for the State as well as clear benefits for the individual and their families. These include savings schemes, grants, bonds, etc that are designed to assist families in planning for the long-term financial security of their relatives with disabilities. In some cases, these models have been developed as a way of leveraging government funds, by allowing families build up assets for the future care of their children, rather than becoming dependent on state-funded services from adulthood onwards. Financial innovation models have been developed in Canada, England and Northern Ireland, and are currently being established in the US.

The Canadian approach has been to establish a Registered Disability Savings Plan (RDSP), a savings plan to help families develop long-term financial security for their relatives with disabilities. Any individual that is eligible for the Disability Tax Credit may establish an RDSP. In the case of a minor, a parent or guardian can establish and direct the RDSP. There is a $200,000 lifetime contribution limit, but there is no annual limit on contributions. Contributions are permitted by the individual, family members and/or friends. There are no restrictions on when the funds can be used or for what purpose. Specific annual government grants and bonds can be paid into the plan, matching contributions to 100%-300% depending on the beneficiary’s family income and the amount contributed. Government bonds of up to $1,000 a year can also be paid into the RDSPs of low income Canadians, regardless of the contribution made. Upon withdrawal, the investment is taxed in the hands of the beneficiary, but is likely to be taxed at a much lower rate. Most provinces
have now exempted the RDSP as an asset and income when determining a person’s eligibility for provincial disability benefits.

In the US, there is a similar attempt to introduce legislative measures to create a better system of providing for persons with disabilities. The statute entitled Achieving a Better Life Expectancy (ABLE) Act 2009 aims to establish a deferred saving system with distinct tax advantages. This legislation recognises that those who are disabled often have severe obstacles in earning a living as well as medical expenses which could cripple a family. The purpose of the Act is to encourage and assist individuals and families in saving private funds to support individuals with disabilities to maintain health, independence, and quality of life; and to provide secure funding for disability-related expenses\(^2\) on behalf of designated beneficiaries with disabilities. This funding will supplement, but not supplant, benefits provided through private insurance, the Medicaid program, the supplemental security income program, the beneficiary’s employment, and other sources. There are no restrictions on who can pay into the savings plan and there is a $500,000 limit on contributions. Importantly, the savings scheme will not affect the individual’s existing entitlements, e.g. Medicaid and the savings will accrue interest tax-free. This Act is currently being debated in the House of Representatives and the Senate.

The United Kingdom has designed their financial innovation model as a Child Trust Fund (CTF). The CTF was introduced by legislation in 2004\(^3\) as a savings and investment account for children. Children born on or after 1 September 2002 receive a £250 voucher to start their account. The account belongs to the child and cannot be touched until they turn 18, so

\(^2\) The funds can only been spent on a broad list of expenses set out in the Act.

\(^3\) Section 1, Child Trust Funds Act 2004.
that children have some money behind them to start their adult life. The legislation specifies that additional payments will be made by the State when the child is 7 years old, 13 years old, 16 years old and 18 years old. The CTF only continues until the individual reaches the age of majority. To establish the CTF, a legal contract is made with the parents who can assign over the rights to the trust when the child is 16 years old. The UK government recently announced that it will make additional payments into the CTF for children with disabilities. Payments of £100 per year will be made into CTFs of children with disabilities and severely disabled children will receive £200 per year. This will take effect in April 2010 for children in receipt of Disability Living Allowance during 2009-2010.

It is already possible to some extent in Ireland to set up trust funds from the proceeds of public subscriptions to benefit those who are permanently and totally incapacitated under Section 12 of the Finance Act 1999; however, firstly, there is no state contribution to these trusts and secondly, there is no guarantee that the money saved would be disregarded from means-tested eligibility requirements. Given the success of these schemes in other jurisdictions, more could be done to develop a programme to support this model.

The cost savings come from the account’s ability to fund a variety of essential expenses for the person with a disability, including educational expenses; health, prevention, and wellness expenditures; employment training and support; assistive technology; personal supports services; transportation; housing; and other expenses for life necessities. In addition, funds remaining in the accounts at the individual’s death would

be used to “pay-back” the state programmes up to the value of services provided to the individual during life. At the same time, the ABLE Act would give individuals with disabilities and their families an option for saving for their future financial needs in a way that supports their unique situation and would free them from sole-dependence on pre-set services, making it more feasible to live full, productive lives in their communities.

**Recommendation 1:** Develop an innovative financial savings scheme in a manner similar to other jurisdictions. The advantage is that it enables people to access the services they want and when they want them. This is cost-neutral.

**2. Adding Voices: Toward an Effective Cost-Neutral Community-Based Advocacy Scheme**

The purpose of a Community-based Advocacy Scheme is to train independent volunteers, known as “community visitors” to visit various facilities, including hospitals and residential care facilities, to assess the conditions of elderly people, people with mental health difficulties and people with disabilities who reside in these facilities. Community visitors speak with residents and staff, survey living conditions and determine the extent to which residents’ human rights are respected. Community visitors also provide residents with information about their rights and this can help them to make informed decisions about their care. The key findings of Community Visitors’ investigations and proposals for reform are usually presented to parliament in an Annual Report.

This program has been very successful in Australia, most notably in New South Wales and Victoria, where community visitors are given statutory
powers to carry out their functions.\textsuperscript{5} Community Visitors have been instrumental in uncovering abuse of vulnerable adults in these jurisdictions. The program has also played a vital role in the process of deinstitutionalisation and helped many people to move into independent living in the community, with the appropriate support.

The Goodbody Report on \textit{Developing an Advocacy Service for People with Disabilities}\textsuperscript{6} recommended the establishment of a Community Visitors Program in Ireland, to be operated by the Citizens Information Board (CIB). A feasibility study into the potential for establishing such a program in Ireland was a key commitment of the CIB’s Strategic Plan.\textsuperscript{7} However, the impetus to establish a Community Visitors Program within the CIB diminished with the introduction of the Health Information and Quality Authority (HIQA) \textit{National Quality Standards: Residential Services for People with Disabilities}. Unfortunately, the funding needed to allow the Social Services Inspectorate to enforce the standards appears not to be available.\textsuperscript{8}

The use of volunteer Community Visitors, rather than the Social Services Inspectorate to visit residential facilities, could make the program more accessible for people in residential care and individuals might be more willing to come forward if the visitors were perceived as ordinary members of the community and external observers of health care

\textsuperscript{5} In New South Wales, community visitors are appointed by the Minister for Disability under the \textit{Community Services (Complaints, Reviews and Monitoring) Act 1993 (CS - CRAMA)}. In Victoria, Community Visitors are appointed by the Office of the Public Advocate with legislative authority from the Mental Health Act, 1986, the Health Services Act, 1988 and the Disability Act, 2006.

\textsuperscript{6} Goodbody Economic Consultants, “Developing an Advocacy Service for People with Disabilities” (Dublin: Commissioned by Comhairle, 2004), p. 68.


\textsuperscript{8} \url{http://www.irishtimes.com/newspaper/ireland/2009/0512/1224246323831.html}
services, as is the case in Victoria. In addition, the use of volunteers to run the Community Visitors Program would ensure that the initiative is cost-effective, as the cost of training and overheads for a Community Visitors Program within the Citizens Information Board would be far less than the cost of implementing the HIQA guidelines through the Social Services Inspectorate.

**Recommendation 2:** Introduce an independent investigative mechanism similar to Community Visitors Scheme in Australia. The advantage is that this is a cost-neutral way of giving voice back to people.

3. **Growing Business by Exploiting Ireland’s Edge in e-Accessibility – and giving our disabled Citizens access to the Information Society**

   **(a) Irish Companies should endorse Universal Design as a way of Expanding into new Markets**

Companies planning to market their ICT goods or service in the USA and sell products to federal government are required to ensure all their products are accessible to people with disabilities (under Section 508 of the Rehab Act). This is increasingly the case in other countries where public procurement requires all ICT products sold to government to be accessible. The European Commission is also considering a new e-Accessibility standard which will be mandated for use in all procurement.⁹ In order for Irish ICT companies to be competitive in these markets they need to ensure their products are accessible.

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⁹ http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=4722
The Irish ICT sector should be encouraged to adopt universal design and e-accessibility as key ways to achieve a competitive edge. This could be achieved in a number of ways through a number of channels including through recent Irish Technology Leadership Group work on venture capital fund of $100m for Irish ICT companies setting up in Silicon Valley.\(^\text{10}\)

\(\text{(b) The Government should lead by adopting Universal Design}\)

Government is currently undergoing a Transforming Government Service programme. A Quality Mark for all Government websites could support universal designed, to incorporate accessibility considerations for people with disabilities, in line with that developed in other European countries such as Holland, Italy, Sweden Germany and Austria. The main findings and recommendations of the OECD Review of the Public Service include “\textit{a renewed emphasis is needed on the role of ICT and eGovernment in strengthening information sharing and integrated service delivery.}\)”\(^\text{11}\)

There is currently huge inconsistency in the quality of public websites. The Ombudsman’s Annual Report in 2008 noted the low number of complaints under the Disability Act and cited as a possible reason the difficulty in finding information on Enquiry Officers on websites.

In respect of cost implications, the Department of Finance is currently emphasising the need to cut down on ICT consultants, and the development of a Quality mark scheme would support this. Such a scheme would be cost neutral at the start and would achieve significant

\(^{10}\) \url{http://www.rte.ie/news/2009/1021/technology.html}

\(^{11}\) \url{http://www.oecd.org/document/31/0,3343,en_2649_33735_40529119_1_1_1_1,00.html}
cost benefits as more people access services via eGovernment websites (see cost-benefit analysis by David McDaid (LSE) in EU report). IT staff in government are capable of developing and designing this quality mark. The only costs outlay would be commissioning and/or development of the automated web evaluation system. As demonstrated by David McDaid (London School of Economics) in an EU report, the available data at present shows a cost-benefit to government by improving access through eGovernment services.

(c) Small and Medium Enterprises (SMEs) should use universal design as a strategy of transforming how they engage with customers

Ireland is a heavily service-based industry economy, with 70% of the Irish work force employed in services. We are also the 10th highest exporter of service in the world. Businesses only generally know what their customers tell them, not what the needs of unmet or hidden customer needs are. Traditionally there is a push on research and development (R&D) to innovate but research also shows that over 50% of innovative companies innovate without performing R&D. Design thinking/Universal Design is key to a rapid, low cost transformation of under performing service companies both for the national and international market place. The provision of support and training on Design Thinking/Universal Design by both public and private organisations which support SMEs in Ireland (e.g. Irish Small and Medium Enterprises Association) could usefully contribute to this, as proposed by Sean

12 http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=4722
13 http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=4722
McNulty in a submission to the government’s Innovation Task Force (September 2009).\textsuperscript{14}

**Recommendation 3:** Develop a more comprehensive e-Accessibility strategy that grows markets for the Irish IT sector taking advantage of new international openings. This could build on Ireland’s IT edge by anticipating where the market is inevitably heading. There is a clear business case to support this model and it serves our disabled citizens.

4. **Using the Information Society to Build Integration into the Community**

The largest challenges facing people with disabilities, particularly people with intellectual disabilities are isolation and enforced dependency. The act of placing individuals in segregated services dislocates them from their communities. The latest National Intellectual Disability Database Report shows that 50.4% of adults (18 and over) with intellectual disabilities live in community group homes, residential centres and other full time services. Community connecting refers to the practice of enabling people with learning disabilities connect with individuals and local organisations in their community; find voluntary and/or paid work; and more generally to lead full and purposeful lives in their communities and to develop a range of friendships, activities and relationships.

In other jurisdictions, Community Connecting has been a very successful, cost-effective and sustainable method of supporting individuals in the community, as it fosters natural supports around the person, rather than relying solely on expensive state-run agency services. Examples include

the PLAN Institute in British Columbia, Canada (which operates on a fee-for-service basis), and In Control (which has a fee-for-service and/or individual budget approach) in the UK.

In terms of the operation of community connecting agencies, a ‘community connector’ tries to identify resources within the communities in which an individual lives and spends time. They will therefore look for places where the person would be welcomed, find someone who enjoys spending time with the person, and try to foster reciprocal relationships. As well as sharing their interests, hobbies and skills, they provide valuable support when needed, as well as respite for their family carers in cases when they live at home.

While there have been some community connecting initiatives in Ireland, such as Vela Microboards Ltd. and to a lesser extent, Big Brother, Big Sister, to date these have remained underdeveloped and lack the clear strategic support from national government. While most community connector agencies charge for their service, a government commitment to subsidise this form of support would help reduce families’ sole-dependence on state-funded disability services and lead to more sustainable care options in the community.

**Recommendation 4:** Create a national strategy specifically geared at developing opportunities for non-profit and for-profit Community Connector agencies to work with individuals and their families. The advantage to this model is that it uses new technologies to creatively address an old problem – isolation and segregation.
5. Reducing Healthcare Costs through Smart Technology Homes

Projected increases in elderly and disabled populations in Ireland show that there is an increasing proportion of the population over 65 years in comparison to the working-age population (aged between 15-64 years). These demographic trends and the increasing prevalence of diseases and declining capacities in older people are leading to a rising demand for care services. While the home is generally the preferred site of care, the risk of accidents around the home in many cases, leads to unwanted institutionalisation. In these cases, home modifications (using both low and high technology) allow for an extended and safer use of the home for independent living.

According to the latest World Health Organisation LARES database\textsuperscript{15}, risks of accidents, rates of hospitalisation arising from injury, as well as many of the limitations in daily activities are to a varying degree caused, enhanced or facilitated by disadvantageous housing and environmental conditions. Healthy housing conditions for the elderly and disabled are important to maximise the supportive capacity of one’s home, to stimulate active and healthy old age lifestyle, and to avoid environmental or context-related health and safety threats which result in institutionalisation in nursing or residential homes.

In terms of the costs and consequences, various non-expensive forms of modifications exist, such as information and communication technologies (ICT), telecare, assistive technology services and smart homes for older and disabled people in Ireland. These can all help reduce unwanted

\textsuperscript{15} World Health Organisation, \textit{Large analysis and review of European housing and health status (LARES) Database} (Copenhagen, WHO Regional Office for Europe, 2008).
institutionalisation in nursing homes or residential care settings. In terms of examples from other jurisdictions, the Howard Centre in Vermont operates a Safety Connection Program, which allows many people to maintain her independence in her own apartment. Sensors in a person’s home can be set off by unusual movement and alert a staff member at a central phone line who can communicate with the person and if necessary send a responder to assess the situation and re-arm the system. British Telecom in England has also successfully piloted the development of safe homes with tele-care technology in Liverpool.

This is becoming an important new area and is seeing a lot of new research in Ireland on public attitudes to, and willingness to pay for, ICT for the care and support of dependent people in Ireland as well as economic and social evaluation of community-based integrated ICT projects in Ireland and internationally. In addition, Intel is working with the Irish Centre for Social Gerontology, NUI Galway, on the development of integrated technical and organisational ICT infrastructural models to support the independent living of older people at home and in residential care settings.

This sector, largely led by Intel, as well as various telecom and electronics manufacturing companies, would benefit from a government commitment which supports the realisation of the potential these home-care

18 Irish Centre for Social Gerontology, Recent Themes: http://www.nuigalway.ie/icsg/researchthemes.html and current research on Technology Research for Independent Living (TRIL)
technologies hold as an integrated, proactive, health-enhancing intervention in the care of older and disabled people in different care situations and settings. Supporting Ireland’s edge in technology both creates business and enhances independence for people with disabilities.

**Recommendation 5:** Commit to a strategy to enable Ireland to emerge as a leader in smart home-care technology. Implementing this recommendation could reduce expensive healthcare costs by avoiding accidents. It would also mark a significant step in the direction of lifetime adaptable housing – which is becoming all the more urgent with our ageing population.

**Conclusion**

All of the recommendations proposed are achievable and cost-effective, which is particularly relevant given the current economic climate. The CDLP welcomes feedback on these suggestions and will disseminate this information widely among disability stakeholders, policy decision-makers and those engaged in disability-related research.