

Submission to the Department of Health  
on the future of Disability Policy in Ireland

Submission made on behalf of  
The Carers Association and Care Alliance Ireland



**Submission made by the Carers Association and Care Alliance Ireland to the  
Department of Health on the Review of Disability Policy**

The Carers Association and Care Alliance Ireland thank the Department of Health and Children for the opportunity to participate in the consultative process regarding the future of disability policy in Ireland. We congratulate the Department on recognising the importance of providing a framework through which people with disabilities, their Carers, and other interested parties have the opportunity to contribute to key decisions being made with reference to disability related issues and to ensure that not only the needs of people with disabilities, but the needs of their Carers are reflected in the Departments disabilities policies.

This submission outlines the feedback of the Carers Association and Carers Alliance Ireland and is based on our experience of supporting Family Carers, most of whom provide care to people with a disability.

**The Carers Association**

The Carers Association is Ireland's national voluntary organisation for Family Carers in the home. Established in 1987 The Carers Association aims to provide Family Carers with emotional and practical supports and to promote the interests of Family Carers and those receiving care in the home through effective partnership, lobbying and advocacy and to gain recognition and social justice for Carers invaluable contribution to Irish society. The Carers Association provides a number of services nationwide including in-home respite, training, advocacy and lobbying, promoting Carer rights and a Carers Help Line.

**Care Alliance Ireland**

Established in 1995 Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life for Family Carers. We achieve this by supporting our 72 member organisations in their direct work with Family Carers through the provision of information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.

## **Who Cares?**

Family Carers are relatives, friends or neighbours who provide *unpaid* care for people and children with a disability, mental illness, chronic condition or frail older people. Because Carers must be constantly available due to the heavy demands and responsibilities of caring many are unable to take up employment and so are reliant on Government supports. In addition, there are significant financial costs associated with caring such as extra heating costs, special dietary requirements, transport and medical expenses which very often must be met by the Carer.

Family Carers provide over 3.7 million hours of care each week and save the State almost €4 billion a year<sup>1</sup>. This means that on average a full-time Family Carer saves the State €62,000 per year. The savings made by Carers is even more apparent when one considers 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 week<sup>2</sup>.

## **Statistics from the Census of Population 2006<sup>3</sup>**

- 160,917 Carers in Ireland representing 4.8% of the total population.
- In 2010 the CSO estimated that Ireland could now have as many as 274,000 Family Carers<sup>4</sup>.
- 40,883 Carers provide full time care (i.e. 43 or more hours per week). This is more than the 39,000 nurses employed by the HSE<sup>5</sup>.
- 5,433 Young Carers in Ireland aged between 15 and 19 years<sup>6</sup>.

## **Social Welfare Statistics<sup>7</sup>**

- 51,455 in receipt of Carers Allowance (including the Half Rate Carers Allowance).
- 21,718 receive the Half Rate Carers Allowance.
- 1,768 receive Carers Benefit.
- 70,000 Carers received the Respite Care Grant in 2010.

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<sup>1</sup> Calculations are based on the hourly rate of €25 per hour which is the average cost of HSE home helps.

<sup>2</sup> Age Action Ireland: A Fair Price for Care 2006

<sup>3</sup> Statistics from the Census of Population 2011 caring section will not be available until November 2012.

<sup>4</sup> Based on finding from the CSO Quarterly National Household Survey Q3, 2009. Published July 2010.

<sup>5</sup> HSE Annual Report 2008

<sup>6</sup> Prof Saul Becker, a leading expert on young Carers estimates that Ireland could have as many as 24,000 young Carers aged under 18 years.

<sup>7</sup> Source Department of Social Protection August 2011.

## **GENERAL COMMENTS ON THE REVIEW OF DISABILITY POLICY**

Families are increasingly providing care for people with complex health and social needs. It is clear that people from all ages and backgrounds are now providing essential caring tasks for people with disabilities, often without adequate supports. The reality is that enabling people with high level needs to remain in their own homes requires the transfer and redirection of resources through additional investment in Home Care Packages, respite provision and training for Family Carers. The Carers Association and Care Alliance Ireland are not satisfied that the report sufficiently recognises the critical role played by Family Carers in supporting people with disabilities to live full and independent lives nor does it adequately describe how reforms in disability policy will do more to meet the needs of Family Carers. This concern was echoed in the 2010 Value for Money consultation report where just 11 percent of respondents felt that the current disability objective that *'Carers would be acknowledged and supported in their caring role'* was being met. (p44).

### **National Carer Strategy**

The Carers Association and Care Alliance Ireland are heartened to see the recognition given to Family Carers in the Programme for Government, in particular the commitment to publish the National Carers Strategy. We believe that the Strategy remains the only opportunity to address Carers needs in a coherent, sustainable and cost effective way. By setting out Government's vision for Family Carers and establishing goals in areas such as income, healthcare, housing, information and transport, Government will take an important step in recognising the enormous contribution of Carers and the vital role they play in our health and social care system. Finding ways to support Family Carers is a win-win-win approach - for the care recipient; the Family Carer; and the public purse.

A critical aspect of the National Carers Strategy is the *'whole of Government'* approach that it will provide; recognising that Carer needs cannot be met in isolation by any single Government Department. This current deficit can be seen clearly when one considers the current anomaly whereby the consequences of cuts imposed by one Department are felt by another. For example in the case of reductions in the number of people receiving Carers Allowance, the outcome is that people with a disability will become more likely to require hospital or residential care.

## **Carer Needs Assessment**

We believe that Carers should be seen as partners in health and social care and be given access to an assessment process which would allow them to identify their needs, be given information and advice, explore difficulties they may experience, and make contingency plans if they are ill or are unable to continue to provide care. Carers Assessments can build Carer morale and capacity and are central to care planning. They can provide timely feedback to health and social care professionals and can inform policy and service provision. Family Carers must also be positioned at the centre of service provision. In doing so, resources will be attached to the Carer as well as to the person receiving care.

Carers Needs Assessments should form part of the disability policy review because they:

- Identify the supports, equipment and aids needed by Carers:
- Support Carer Health and Wellbeing:
- Support the needs of people with disabilities who are often themselves Carers:
- Support Carers to meet the changing demands of their caring role:
- Avoid Caregiver Burden and Burnout:
- Will help address financial considerations;

and most importantly,

- the interests of person with a disability and their Carers are often inseparable.

## **CONSIDERATION OF THE QUESTIONS POSED IN THE CONSULTATION DOCUMENT:**

### **1. Do you agree that the current system of delivery of services for people with disabilities needs to be improved?**

The Carers Association and Care Alliance Ireland welcome the Departments review of disability policy in Ireland and regard this as an opportune time to strengthen the Disability Services Programme and align it more closely with the policy objective *‘to realise a society where people with disabilities are supported to participate fully in economic and social life and have access to a range of quality supports and services to enhance their quality of life and well-being’*.

The traditional service-led approach has often meant that people with disabilities have not received the right services at the right time or at a place most suited to them, nor have they been able to shape the kind of support they need. It has also frequently ignored the needs of Family Carers (as acknowledged on page 51 of the Disability Policy Review report) who provide the majority of the care requirements of people with disabilities and play a key role in avoiding and/or delaying entry of people with disabilities to expensive acute/long term care settings. Family Carers are therefore critical to the success of this policy objective and as such their role must be more adequately addressed in the Policy Review. For example with:

- Development of a National Carers Strategy
- Work-Life Balance Policies;
- Inclusion of a Carer Needs Assessment in addition to the assessment of need of the person with a disability;
- Requirement for additional community supports including respite, home help and Home Care Packages;
- Funding towards dedicated Carer training;
- Flexible supports to meet both the needs of the Carer and those with a disability.

## **2. Do you agree that a move to individualised supports is the right policy to pursue?**

Moving towards individualised supports means thinking about the care of people with disabilities in an entirely new way. It means putting the person at the centre of the process and acknowledging their strengths, preferences and aspirations. It means that they, along with their families and Carers can together identify their collective needs and make choices about how they are supported. All this requires a significant transformation in how we deliver disability services, but if done correctly will enable people with disabilities to live independently and have complete control and choice in their lives.

This is a completely different system to the current *'one size fits all'* and *'postcode lottery'* approach of individuals having to fit into prescriptive support services that already exist and have been designed from the top down. Under this system families are often made feel that they should be grateful that services are available, rather than expecting services that are tailored to meet their needs specifically.

With regard to how individualised supports will benefit Family Carers, there are two main elements. Firstly, individualisation will better support the cared for person and so will be mutually beneficial to both the person with a disability and their Carer. Secondly, individualisation should address the urgent need for Carer Needs Assessments and so should affect the support provided directly to Family Carers.

While the Carers Association and Care Alliance Ireland welcome the individualisation approach, efforts must be made to ensure that the system does not force families to become employers *per se*, where individualised budgets are used to employ specialist services and support staff. This issue is an unfortunate reality facing many families in Ireland who receive a Home Care Package in the form of a cash grant and so are liable to pay PRSI and honour employment laws.

Moves towards individualisation must be cognisant of the need not to place further pressures on the Family and or the care recipient. Whilst some clients and their families will relish the opportunity to have more control over services, for others, better outcomes for all concerned may be achieved by the use of skilled mediators/advocates/brokers to manage the purchasing of services.

The Carers Association and Care Alliance Ireland are also concerned about some of the terminology used in the Review of Disability Policy report, specifically paragraph one page 16 which states;

*‘As most people with disabilities live with their families; parents, siblings and adult children are key providers of the individualised supports described above. This type of family support is provided by many families on a 24/7 basis, often with little input or support from formal disability or other health services, and has been central to keeping many children and adults with disability out of residential services. Under the new policy proposals a person living in the family home would also have access to individualised support packages, although the components may vary depending on the level of input families can make’.*

The presence of family support cannot be regarded as excuse to retrench formal health and social care supports nor should they be expected to take on additional caring responsibilities. Rather than focusing on reducing costs, we believe that the focus must be on how savings

derived from the retirement of old style residential based institutions will be directed to more community/home based supports and in doing so will also likely better meet the needs and wishes of individuals with disabilities and their Family Carers. The Carers Association and Care Alliance Ireland urge the Department to ensure that people with disabilities who live in the family home are not penalised, but rather will have access to the same level of individualised support packages as those living independently. We also recommend that the first sentence in this paragraph be amended to include young Carers, who also play a considerable role in supporting the care needs of family members with a disability.

**3. Do you agree that the definition of individualised supports in the report is adequate and comprehensive?**

The definition is adequate and comprehensive in describing the assistance and interventions that will be available to the person with a disability, however is inadequate at addressing how individualised support will impact or benefit Family Carers. There are documented examples of how this potential impact can be positive, for example a study in the British Journal of Social Work examining how individual budgets for service users affected Carers, found that individualisation enabled Carers to have more time for themselves, to spend more time with other family members, to not feel guilty about spending time away from the cared for person and, conversely, to enjoy more quality time with the cared for person<sup>8</sup>.

The definition of individualised supports proposed in the report does not address Carer Needs Assessments referred to above.

**4. How do you feel the Government's policy of mainstreaming has worked so far?**

The Carers Association and Care Alliance Ireland are very much in favour of people with disabilities being supported to access mainstream services. However this can only be achieved if appropriate supports are provided to enable people with disabilities to access the services they need. To this end we have some concerns about the limited services available in rural areas, issues with transport, and cuts to frontline services imposed as a result of the current economic climate, such as the recent cuts in Special Needs Assistants in some schools. Even if services are fully mainstreamed, there will always be the need for specialist support services for people with

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<sup>8</sup> Moran N, Arksey H, Glendinning C, Jones K, Netten A and Rabiee P (2011) Personalisation and Carers: Whose rights? Whose benefits? British Journal of Social Work, 41, (published online)



disabilities. Mainstreaming disability services cannot be seen as an opportunity to withdraw such specialist services.

**5. Do you think a move to individualised supports will further the mainstreaming of services?**

Moving towards individualised supports and having the *'money follow the person'* will give people with disabilities and their families more say in what supports they receive and how they are provided. Ultimately it will offer people with disabilities access to universal services and allow them to integrate their care in a way that has not been possible to date. Retaining the individualised approach while facing a period of unprecedented budget cuts will be a key challenge for Government, who must balance the temptation for short term spending cuts against the long term savings that individualisation can potentially deliver, including prevention, early intervention and the integration of care services.

**6. Do you agree that people with disabilities should have the choice to select different services from different service providers and at a time of their choosing?**

People with disabilities should absolutely be able to choose which services they want and from which service provider they wish to purchase them, where they have the capacity to do so. The Carers Association and Care Alliance Ireland believe that people with a disability and their Carers want greater choice and control in their lives, not least of all because of the sense of normally, self-esteem and pride that this will give them. However, we recognise that the growing independence of those with disabilities will need support. For example for those who choose to move out of the family home and live independently. We must recognize that for many people with a disability independence and choice is only available 'to a point'. Thereafter they will continue to rely on the support and care of family members. For example, when travelling on public transport, grocery shopping or cooking meals. The reality is that many people with a disability will continue to need support if they are to be able to access services. At present much of this support is provided by families and Carers. However, the introduction of individualised budget will give them the opportunity to employ people to provide this support. In fact in France, under the law of February 11<sup>th</sup> 2005 people with disabilities can employ family members to provide such support, giving the Family Carer an income and access to employment rights<sup>9</sup>.

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<sup>9</sup> Law 2005-102 of February 11, 2005, on Promoting Equal Rights and Opportunities, Participation, and Citizenship for Disabled Persons.

The ability to choose services should also address the current anomaly whereby some services are available only to those who satisfy certain criteria such as age, address etc. For example when a person with a disability reaches age 18 and can no longer access child respite services.

**7. As people with disabilities make the choice to live in ordinary independent settings which are integrated into their communities, what do you see as the impact of the reconfiguration of existing services on other service users, their families and staff delivering these services?**

It is widely accepted that disability policy reform and the introduction of individualised support has the potential to significantly benefit people with disabilities and improve the delivery of services, however little is known about how Carers will be affected or how they can be supported to make individualisation more effective. Furthermore little is known about how organisations such as ours can help translate policy reform into practice. In the UK for example despite recognition that the successful implementation of policy reform is very much dependent on Family Carers, they have received less attention than other groups in research carried out into the changes taking place as a result of the personalisation agenda (Glendinning et al., 2009).

The transformation of disability services requires significant adjustments which will impact organisations, families and individuals. Studies have identified issues for many of the main stakeholders. For example, local authorities face challenges such as developing procedures, and integrating separate income streams (Browning, 2007; Hudson and Henwood, 2009). Other studies have highlighted some of the implications for the social care workforce.

Carers UK have examined how Carers now have a greater responsibility for ensuring the quality of the support provided to people with a disability as a result of the personalisation agenda<sup>10</sup> With personal budgets specifically, a recent study showed that *'Carers play a central role in helping many personal budget holders to take up and manage their budgets'*, and that *'Carers should be involved on all stages of the personal budget process'*<sup>11</sup>. Family Carers are therefore critical to the disability reform agenda. If organisations are to fully understand the implications of individualised support then having an appreciation of the role Carers will play and the needs that they have is crucial.

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<sup>10</sup> Social Care Institute for Excellence in conjunction with Carers UK, 2009.

<sup>11</sup> Newbronner et al., 2011: pg. 66