



DISABILITY FEDERATION OF IRELAND

Funding the National Disability Strategy

PRE-BUDGET SUBMISSION 2006

“The Government’s core social objective is to ensure that people have the resources and opportunities to live life with dignity and have access to the quality public services that underpin life chances and experiences.”

Taoiseach Bertie Ahern, T.D., Launch of National Disability Strategy, September 2004.

CONTENTS

| | | |
|-----------|---|-----------|
| | Summary of Recommendations for Budget 2006 | 2 |
| 1. | Introduction | 3 |
| 2. | Budget Issues | 5 |
| | I. INCOME | 5 |
| | ■ Cost of Disability Payment | 5 |
| | ■ Disability Allowance | 5 |
| | II. INFRASTRUCTURE OF CARE | 6 |
| | ■ Community Employment | 6 |
| | ■ Accommodation and Services for People who Experience Mental Illness | 7 |
| | ■ Adults with Significant Disabilities | 8 |
| | ■ Disabled Person's Housing Grant (DPG) | 9 |
| | ■ Children as Carers to People with Disabilities | 10 |
| | III. CAPACITY BUILDING | 11 |
| | ■ Funding for Voluntary Disability Organisations | 11 |
| 3. | Conclusion | 13 |
| | DFI – National Council and Associate Membership 2005 | 14 |

SUMMARY OF RECOMMENDATIONS FOR BUDGET 2006

Income

- Government to introduce a Cost of Disability Payment of €40 a week for people with disabilities currently in receipt of a means tested social welfare payment. This payment to be extended to all people with disabilities in the subsequent two Budgets.
- Disability Allowance to be increased by €17 to €165.80 in line with the commitment in the NAPS review.

Community Employment

- Government to begin the mainstreaming of the 1,651 participants and 100 supervisors on the CE schemes which provide services to people with disabilities by allocating an extra €11.2m.

Accommodation and Services for People who Experience Mental Illness

- Government to invest €13.9m to provide a range of appropriate supports and training for people who are long-stay in mental hospitals, and a further €13.9m in next year's Budget.
- Government to invest €50m towards the provision of a range of housing options, in addition to the revenue raised through the sale of State land and property. The housing options should include crisis, respite, and supported residential accommodation.

Adults with Significant Disabilities

- Government to invest €50m to address the residential needs of adults with significant disabilities who are inappropriately accommodated at present.
- Government to invest €25m in Budget 2006 in home support, respite care, personal assistance and day care places for adults with significant disabilities and a further €25m in Budget 2007 in recognition of the commitment given to providing the linked services required by this group of people within the multi-annual funding package.

Disabled Person's Housing Grant

- Government to increase the overall allocation to DPG by €35m to €105m and amend the Grant Scheme so that Local Authorities can recoup the full cost of DPG from Central Exchequer Funds.
- Government to reform the scheme, so that Local Authorities are given the power to pay the full costs of adaptations undertaken by people with disabilities.

Children as Carers of People with Disabilities

- Government to commit to undertaking a study on children as carers.
- Government to invest an additional €20m in services such as personal assistance, care attendants and home help, so that people with disabilities are no longer dependent on their children for their basic everyday care. Government to invest a further €20m in Budget 2007.

Funding for Voluntary Disability Organisations

- Government to provide core funding of €5m within a distinct budget line to secure the future of voluntary disability organisations and grant them the opportunity to build the capacity of the voluntary disability sector.
- Government to provide a further additional investment of €5m in Budget 2007 and continue this line of investment in subsequent Budgets to support the capacity building of the sector.

1. INTRODUCTION

Budget 2006 will be an important indicator of the Government's ongoing commitment to addressing the needs of people with disabilities and in supporting them to achieve their full potential. We welcome and acknowledge the focus on, and the increased funding for, people with disabilities and disability services in Budget 2005. We also welcome the introduction of the process of multi-annual funding last year. However, this was just a first step in dealing with the significant unmet needs which deny many people with disabilities basic services and prevent them from participating in and contributing to Irish society.

Last year we called for a sustained and increased investment for the remainder of the Government's term of office. In Budget 2005, the Government responded and delivered some of the additional resources required. This must not be a once off occurrence and in Budget 2006 the Government must allocate a second installment of additional funding for supports and services for people with disabilities to build on this foundation.

While the multi-annual funding announced last year was an important development, it represented just a fraction of the resources required to undo decades of under funding. The multi-annual funding package targeted a small number of support services with limited resources. The actual funding allocated was insufficient to meet the service improvements it was proposed this funding would deliver. In last year's Budget it was announced that 250,000 extra hours in home support and personal assistance services would be funded per annum from 2005 to 2009. However, the projected cost of providing these services was made on the basis of an hourly cost of €10.50, when the actual cost of delivering these services is approximately €20. Indeed, not only have we a long way to go to address unmet needs, there are many areas of great need which have yet to be officially recorded.

We note that the Government is aware of the need for ongoing investment in disability services. Minister Cowan, in his Budget speech stated that additional and increased resources on an ongoing basis are necessary for disability

services. We expect the Government to follow through on this commitment in Budget 2006.

*"What I am dealing with today are certain high-priority services. However, I want to make it clear that other disability services will also continue to be dealt with as a normal part of the annual estimates process and will receive extra funding going forward as overall budgetary circumstances permit."*¹ Minister Brian Cowan T.D., December 2004.

The most recent economic forecasts from a number of Government and independent sources indicate that the Irish economy is growing strongly at present. The Department of Finance, the ESRI and the Central Bank predict that Irish GNP will grow by between 4.7% and 5.4% in 2005². This economic growth provides the Government with the capacity and considerable resources to address the many deficits in our social services. It is imperative that the Government continues to invest in people with disabilities so that they can play their full part in Irish society.

Budget 2006 is also significant in that it precedes the negotiation of a new National Agreement to succeed "Sustaining Progress". In 2003, DFI became a social partner representing the voluntary disability sector as part of the Community and Voluntary Pillar. We have fully participated in and contributed to the process. It is important that Government responds in a positive way to the matters we bring forward in the process, so that social partnership can be seen as delivering meaningful and tangible results for people with disabilities. In Budget 2006 we need to see some progress on the issues that

What we propose in this Submission is a three pronged approach so that there is balanced and sustainable progress. The Government must deliver greater income support for people with disabilities. It must further develop an infrastructure of care and it must continue to build the capacity of the voluntary disability sector.

¹ Budget Statement by Minister Brian Cowan, T.D., Dáil Éireann, December 1st 2004.

² Page 3, Department of Finance Monthly Economic Bulletin, August 2005.

have been deliberated on within Social Partnership, such as the Cost of Disability Payment and the Infrastructure of Care.

The publication of the National Disability Strategy last year represented another potential significant development. DFI supports the approach that ensuring equality for people with disabilities can only be achieved with the effective combination of legislation, policies, institutional arrangements and services underpinned by multi-annual funding packages. However, the Strategy must be resourced now and well into the future, if it is to make a real and positive difference in the everyday lives of people with disabilities. At the launch of the National Disability Strategy the Taoiseach stated;

*“The Government’s core social objective is to ensure that people have the resources and opportunities to live life with dignity and have access to the quality public services that underpin life chances and experiences.”*³ Taoiseach Bertie Ahern T.D., September 2004.

We welcome that commitment and acknowledge that in Budget 2005 the Government did take significant first steps in addressing a number of issues. However, as a society, we still have some way to go to make the Government’s stated objective a reality for all. As a key instrument of Government policy, it is important that Budget 2006 provides continued investment in supports and services for people with disabilities so that they can live life with dignity and achieve their full potential.

What we propose in this Submission is a three pronged approach so that there is balanced and sustainable progress. In Budget 2006, the Government must deliver:

- Greater income support for people with disabilities.
- Further develop an infrastructure of care for people with disabilities.
- Continue to build the capacity of the voluntary disability sector.

In summary, in Budget 2006 the Government must fund the National Disability Strategy so as to provide the means by which people with disabilities can vindicate and fully exercise their civil, social and human rights.

3 Mr. Bertie Ahern, T.D. Speech by An Taoiseach at the launch of the National Disability Strategy, September 21st 2004.

2. BUDGET ISSUES

I. Income

Cost of Disability Payment

A key measure in supporting people with disabilities to participate fully in Irish society would be the introduction of a Cost of Disability Payment. The cost of disability can be defined as the amount it costs a disabled person to achieve the same standard of living as a non-disabled person. It is recognised nationally and internationally that people with disabilities incur many extra, but ordinary, costs such as food, heating and clothing as a result of their disability. Therefore, DFI calls on the Government to introduce a Cost of Disability Payment scheme in Budget 2006. This matter was studied by both the Commission on the Status of People with Disabilities⁴ and the National Economic and Social Forum⁵ and they both recommended this payment.

As a result of a commitment in the “Programme for Prosperity and Fairness”, an Interdepartmental Working Group was set up in 2000 to examine the feasibility of introducing a Cost of Disability Payment Scheme. As part of this process, the National Disability Authority also commissioned and published research on this issue in 2004. The findings of this research “*Disability and the Cost of Living*”⁶ are based on international evidence and suggest that the extra cost of living imposed by a disability is approximately €40 per week.

The Government has taken major action to address child poverty in recent years, with Child Benefit rising from €38 a month in 1997 to €141.60 in 2005. We now believe that the Government must make a similar effort to tackle poverty among people with disabilities.

A Cost of Disability Payment in line with the recommendations of the Commission on the Status of People with Disabilities, the NESF and NDA Reports would not only alleviate the problem of deprivation

and poverty, but address issues such as equality and participation. The Government has taken major action to address child poverty in recent years, with Child Benefit rising from €38 a month in 1997 to €141.60 in 2005. We now believe that the Government must make a similar effort to tackle poverty among people with disabilities. We believe that all people with disabilities should receive this payment within three years. However, as a first step towards this, the Government in Budget 2006 should introduce a Cost of Disability Payment of €40 a week for people with disabilities currently in receipt of a social welfare means tested payment.

DFI Recommends:

- Government to introduce a Cost of Disability Payment of €40 a week for people with disabilities currently in receipt of a means tested social welfare payment. This payment should be given to all people with disabilities in the following two Budgets.

Disability Allowance

Disability Allowance (DA) is an income support payment for people with disabilities. Despite a buoyant economy and tight labour market the levels of unemployment among people with disabilities remain high. While the national unemployment rate is currently 4.2%⁷, it is estimated that up to 70% of people with disabilities are unemployed and a recent report indicated that 37.5% of those who

While the national unemployment rate is currently 4.2%, it is estimated that up to 70% of people with disabilities are unemployed and a recent report indicated that 37.5% of those who were ill or disabled were at risk of poverty, 13.2% were experiencing basic deprivation and 7.4% were consistently poor. These rates are more than twice those for the general population.

⁴ Report of the Commission on the Status of People with Disabilities, A Strategy for Equality, Ch. 6, Income and Disability 6.12.

⁵ “Income Maintenance Strategies” Report No 5 NESF 1994.

⁶ A Review of international Findings in Disability and the Cost of Living (2004) suggests the extra cost of disability for people with mild disabilities should be no more than €40 per week, and for people with severe disabilities no less than €40.

⁷ Seasonally Adjusted Standardised Unemployment Rate, Central Statistics Office, June 2005.

were ill or disabled were at risk of poverty, 13.2% were experiencing basic deprivation and 7.4% were consistently poor. These rates are more than twice those for the general population.⁸ Despite a number of projects and initiatives it is clear that there are still significant barriers preventing people with disabilities from accessing the labour market. While the Government must continue to support people with disabilities into employment, it must equally ensure that people with disabilities who are dependent on DA are not living in poverty and experiencing deprivation.

We acknowledge that the Government did increase DA by €14 to €148.80 in Budget 2005 in line with its National Anti Poverty Strategy (NAPS) commitment to achieve a rate of €150 in 2002 terms for the lowest rates of social welfare by 2007⁹. To meet this commitment in Budget 2006, we urge the Government to maintain its commitment to the most vulnerable people with disabilities and increase DA by €17 to €165.80.

DFI Recommends:

- Disability Allowance to be increased by €17 to €165.80 in Budget 2006 in line with the commitment in the NAPS review.

II. Infrastructure of Care

*“We all agree on the history of neglect of people with disabilities. The entire structure of the provision of services for people with disabilities grew up through services provided by the religious, particularly the Catholic Church, and services provided by voluntary bodies. Despite the considerable resources that have been made available in recent years, particularly since 1987, we are still trying to catch up.”*¹⁰ Minister of State, Frank Fahey T.D. May 2005.

Too often investment in supports and services for people with disabilities are only viewed as a cost to the Exchequer. This ignores the fact that investment in an infrastructure of care for people with disabilities not only benefits the individual recipient in the short term, by facilitating them to live more independently, it also benefits the person and the State in the longer term.

It is welcome that the Government recognises that community services for people with disabilities are still inadequate and require significant investment. It is vital that these services are enhanced and further improved through increased resources, as they provide the means by which people with disabilities and their families and carers can achieve a better quality of life, leading to full inclusion and equality. However, we do not present the rationale for investing in community services for people with disabilities as solely being justified on moral or social grounds. In our view it also makes economic sense.

Too often investment in supports and services for people with disabilities are only viewed as a cost to the Exchequer. This ignores the fact that investment in an infrastructure of care for people with disabilities not only benefits the individual recipient in the short term, by facilitating them to live more independently, it also benefits the person and the State in the longer term. When the State provides the resources for better and more appropriate services, it allows people with disabilities, who were previously excluded to access further education, training, employment, and enables them to make a greater contribution to society. Also, properly resourced community services ensure that the challenges of care and support on families is lessened, freeing them to contribute to our community and society.

Community Employment

Disability services have had a long-term dependence upon employment support measures to provide services. This dependence goes back over two decades and progressed through Teamwork, Social Employment Schemes and, later, Community Employment. Through these Schemes community-based supports and services were developed and expanded.

Community Employment (CE) participants are mainly employed in the following roles in relation to services to people with disabilities:

- Care Assistants in residential homes
- Care Assistants in day and training centres
- General Staff for centres
- Drivers for mini-buses
- Personal Assistants

⁸ Disability and Social Inclusion, Gannon and Nolan, ESRI, Report commissioned by the Equality Authority and National Disability Authority 2005.

⁹ “Building an Inclusive Society”, National Anti-Poverty Review, February 2002.

¹⁰ Minister of State Frank Fahey, T.D. Select Committee Meeting on Disability Bill, Dáil Éireann, May 3rd 2005

It must be emphasised that all of these personal social services are very basic and essential services. For many people these were, and are, their only support service and form a lifeline for both people with disabilities and their families. The services provided by CE have now become the mainstay of service provision to people with disabilities.

CE puts considerable strain and pressure on the service users and on the organisations providing services. They lose highly experienced, well-trained and committed staff on an ongoing basis when their time on CE expires. The voluntary organisations providing services have to repeatedly train new participants, who, in turn, have to acquire skills and experience and most importantly, develop relationships with service users. However, all stakeholders, service users, voluntary organisations and the health services have become dependent on them remaining in place. This must change.

In its 2002 Programme for Government this Administration stated “We are committed to building service provision and legislative frameworks which enable people with disabilities to fulfil their potential and make a full contribution to the economic and social life of our country.”¹¹

CE puts considerable strain and pressure on the service users and on the organisations providing services. They lose highly experienced, well-trained and committed staff on an ongoing basis when their time on CE expires.

In order to meet this commitment, the Government must begin in Budget 2006 to mainstream the services currently provided to people with disabilities through CE. Mainstreaming requires the transfer of funding for services provided to people with disabilities through CE from FÁS to the Health Service Executive. DFI has identified 1,651 CE participants and 100 Supervisors¹² providing services to people with disabilities. We estimate that the cost of mainstreaming these positions into mainstream health services is just over €34m. However, we estimate that the Department of Enterprise, Trade and Employment and FÁS currently invest €22.8m in these specific schemes. Therefore, to achieve the full mainstreaming of these specific CE schemes would cost an additional €11.2m.

11 An Agreed Programme for Government Between Fianna Fáil and The Progressive Democrats, June 2002, Department of the Taoiseach, Page 28.

12 Disability Federation of Ireland/Irish Wheelchair Association, Submission to Joint Oireachtas Committee on Health and Children, Mainstreaming Services provided to People with Disabilities through Community Employment, August 2005.

13 The National Review of Mental Health Services Report, 2004, Page 121.

14 Ministerial Presentation to Joint Oireachtas Committee on Health and Children by Tánaiste and Minister for Health and Children, Mary Harney, T.D. July 20th 2005.

15 The National Review of Mental Health Services Report, 2004, Page 114.

DFI Recommends:

- Government to begin the mainstreaming of the 1,651 participants and 100 supervisors on the CE Schemes which provide services to people with disabilities by allocating an additional €11.2m.

Accommodation and Services for People who Experience Mental Illness

The percentage of overall health funding allocated to mental health services has declined steadily in recent years. At present current funding lies at 7% compared to 9.2% in Northern Ireland and 11% in England and Wales.¹³ The under investment in mental health services was brought into sharp focus recently when Tánaiste and Minister for Health and Children, Mary Harney T.D., stated that the facilities available to people at one facility, the Central Mental Hospital, “is not a facility of which any of us could be proud. It is appalling and worse than my worst nightmares”.¹⁴

People who experience mental illness require a range of accommodation options including crisis, respite, and supported residential accommodation. Having access to a range of accommodation options would enable people who experience mental illness to live in the community and decrease their need to stay long-term in hospital or acute units. The lack of sufficient community-based services and accommodation is resulting in significant numbers of people who experience mental illness either living long-term in mental health hospitals or being forced to remain in the family home beyond a time of their choosing, as outlined in the 2004 report of the Inspector of Mental Health Services.

“In Ireland, it is clear that the move towards community-based care has not always been successful. There continues to be large numbers of long stay patients in services such as East Galway, South Tipperary, Wexford, Waterford, Carlow/Kilkenny, Longford/Westmeath, Cork and Kerry. Other services have high rates of 24-hour staffed community places in addition to high numbers of hospital beds, suggesting that these services are still very traditional and bed based.”¹⁵

The percentage of overall health funding allocated to mental health services has declined steadily in recent years. At present, current funding lies at 7% compared to 9.2% in Northern Ireland and 11% in England and Wales.

The most up to date figures¹⁶ indicate that there are over 1,857 people long stay in psychiatric hospitals and units, although a detailed study into the housing needs of those with enduring mental illness is required to identify the true needs in this area. We acknowledge that in Budget 2005 the Government announced additional funding to create 400 new places in community-based mental health facilities, 100 per annum between 2006 and 2009. This development is important, however it falls short of what is required. We are concerned that this allocation will only cater for less than a quarter of those currently unnecessarily in psychiatric hospitals and units. We therefore call on the Government to provide additional resources in Budget 2006 to transfer all those inappropriately in hospitals to community settings and to provide the resources to support in the community people who experience mental illness.

DFI Recommends:

- Government to invest €13.9m¹⁷ to provide a range of appropriate supports and training for people who are long-stay in mental hospitals, and a further €13.9m¹⁷ in next year's Budget.
- Government to invest €50m¹⁸ towards the provision of a range of housing options, in addition to the revenue raised through the sale of the State land and property. The housing options should include crisis, respite, and supported residential accommodation.

Adults with Significant Disabilities

This is a cohort of people aged between 18 and 65 who have either been born with or acquired a significant disability. This group includes people with a progressive

neurological condition and/or those who have an acquired brain injury. A significant disability can be characterised by a set of complex needs that are persistent or episodic and long-term in nature.

The Department of Health and Children have identified approximately 2,000 people with significant disabilities nationally who are awaiting appropriate accommodation.

The lack of appropriate accommodation for this group in the community means that many of them end up in inappropriate settings, such as acute hospitals and nursing homes for older people. A substantial number of adults with significant disabilities living in the community are residing with their families, who experience enormous pressure due to the limited support available to them. The Department of Health and Children have identified approximately 2,000 people with significant disabilities nationally who are awaiting appropriate accommodation¹⁹.

Budget 2005 represented a significant new departure in that the Government acknowledged the specific needs of this group and allocated funding to provide a projected 380 residential places. While this initial allocation of funding is welcome, it is imperative that the Government commit to an increased and sustained investment not only in Budget 2006, but in the ongoing multi-annual funding package from 2007-2009. This is vital as Budget 2005 only addressed the accommodation needs of less than 20% of those currently identified adults with significant disabilities.

This group also require significant complementary services such as home support, specialist, respite and day services. In the National Health Strategy,²⁰ the Government committed itself to a "Programme of Investment" to enhance "Home support services, respite care, day care places, residential care including additional places for people with chronic conditions, other multi-disciplinary support services and Aids and Appliances".

16 The National Review of Mental Health Services Report, 2004, Page 32.

17 Cost of providing care in the community is based on the East Coast Area Health Board costing for Day Placements of €15,000 per annum. 1857 people x €15,000 = €27.8m.

18 Department of Environment, Heritage and Local Government Capital Assistance Scheme average allocation per bed room for city and county council areas is €104,350. With an overall figure of 1857 people who need to be offered housing, this totals €193,777,950. This is a gross figure and does not take into account the potential revenue from the sale of existing mental health facilities which no longer serve a purpose with mental health services. From these findings DFI recommend an investment of €50m over the next two budgets and a detailed study into the housing needs of those with enduring mental illness.

19 Department of Health and Children Outline Sectoral Plan under the Disability Bill 2004.

20 National Health Strategy, Quality and Fairness-A Health System for You, Department of Health and Children 2001.

The Government made a small gesture in Budget 2005 in this regard by providing additional funding for 1,200,000 extra hours for all home support and personal assistance services by 2009. This global amount of extra hours would be wholly inadequate, even if it were solely allocated for adults with significant disabilities; however, this funding was allocated to meet needs across all disability services. Taking into account the significant care needs of this group, some of whom would require 24-hour care, the allocation of funding for 250,000 extra hours per annum is but a small step in the right direction. While some adults with significant disabilities already have care packages in place, significant increased investment will be required over the coming years to fully address the needs of all adults with significant disabilities. The costs of providing services to any one of the people described here is individual to the person and his/her needs. Reports from the HSE around the country and services providers estimate that costs vary from €50,000 for basic community supports to €250,000 for a wrap around service for a person with one to one needs or challenging behaviour.

DFI Recommends:

- Government to invest €50m to address the residential needs of adults with significant disabilities who are inappropriately accommodated at present.
- Government to invest €25m in home support, respite care, personal assistance and day care places for adults with significant disabilities and a further €25m in Budget 2007, in recognition of the commitment given to providing the linked services required by this group of people within the multi-annual funding package.

Disabled Person's Housing Grant (DPG)

In recent decades, successive Governments have failed to adequately address the housing needs of people with disabilities. As a result, many people with disabilities are trapped in unsuitable, inaccessible and potentially dangerous homes. Adaptations are not lifestyle choices but basic necessities.

*"The operation of the Disabled Person's Grant Scheme is at present under review in my Department. On completion of the review, which I envisage being finalised in the next few months, I will be in a position to determine the changes, if any, required to the regulations governing the scheme."*²¹

Minister of State, Noel Ahern, T.D. April 1st 2003.

In recent decades, successive Governments have failed to adequately address the housing needs of people with disabilities. As a result, many people with disabilities are trapped in unsuitable, inaccessible and potentially dangerous homes. Adaptations are not lifestyle choices but basic necessities.

Despite numerous commitments that this Review would be finalised in recent years, it is still not officially completed or published. While we acknowledge that increased funding has been allocated to the Scheme, we believe that it must be reformed, as it no longer meets the needs of all people with disabilities, is deficient and lacks uniformity. In many cases City/County Councils are using different criteria for assessment, resulting in qualification for the Grant being dependent on your Local Authority area rather than on your need.

There are two key problems with the Scheme. Firstly, Local Authorities have to find 33% of this grant from their own budgets, and as a result, many are having difficulties in funding even the most severe cases. This has resulted in long waiting lists in some Local Authority areas which is delaying urgent adaptations and causing unnecessary hardship for people with disabilities. In some areas, we are also aware of the introduction of arbitrary means testing procedures. We believe that central Government should meet all the costs of the DPG.

Secondly, at present Local Authorities can only contribute up to a maximum of 90% of the cost of the adaptations, up to a maximum amount of €20,320. In many cases they contribute a lot less than 90%. In light of the real cost of building work, and the fact that many people with disabilities are living in poverty, the current provisions of the Grant Scheme are totally inadequate. We are calling on the Government to cover 100% of the costs of the adaptations.

To overcome these problems, DFI calls on the Government to finalise and publish the Review and to engage with DFI and other disability organisations with a view to reforming the DPG along the lines proposed in this Submission, so that it can better meet the needs of people with disabilities.

²¹ Noel Ahern, T.D., Minister for State with responsibility for Housing, Dáil Éireann, 1st April 2003.

DFI Recommends:

- Government to increase the overall allocation to DPG by €35m to €105m and amend the Grant Scheme so that Local Authorities can recoup the full cost of DPG from Central Exchequer Funds.
- Government to reform the scheme, so that Local Authorities are given the power to pay the full costs of adaptations undertaken by people with disabilities.

Children as Carers to People with Disabilities

In recent years, some limited progress has been made in acknowledging the invaluable role and offering increased support to adult carers. However, to date the State has failed to acknowledge or address the phenomenon of children acting as either full or part time carers for parents and or siblings.

As a result of inadequate funding for community and support services, people with disabilities often have no option but to rely on their children for basic care needs. Many children under the age of 18, some as young as 7, are carrying out, often on a regular basis, significant caring tasks and are assuming a level of responsibility more normally associated with adulthood. These tasks include:

- Children giving general care such as assisting with mobility and dispensing medication
- Children performing a range of intimate care tasks, such as toileting and bathing
- Children undertaking a range of domestic tasks and trying to provide emotional support²²

Children are liable to suffer physically, emotionally, socially and educationally as a result of the burden of caring for a parent and/or sibling with a disability. It is clear that the lack of focused action on this issue is in contravention of the UN Convention on the Rights of the Child, which Ireland has signed and ratified²³. The Convention states that the child has the right to rest and to engage in

DFI wants to promote a solution that acknowledges the rights of the child, without undermining the rights of the person with the disability. Therefore, the Government must adopt a holistic approach to this issue, which addresses the support needs of the child and the caring needs of the person with a disability.

leisure, play and recreational activities and to participate in cultural and artistic activities (Article 31) and that the State has an obligation to protect children from engaging in work that constitutes a threat to their health, education or development (Article 32). The State may also be in contravention of Article 17 of the Revised European Social Charter²⁴.

At present there are no definitive statistics on the number of child carers in Ireland. We do know, from the last Census, that 2,996 young people between the ages of 15 and 17 were caring for a family member²⁵. Using comparable studies in the UK²⁶ and the 2002 Census figure, it would indicate that there are up to 10,000 child carers in Ireland. However, until the Government undertakes a proper analysis and study we will not know the true extent of children as carers.

DFI wants to promote a solution that acknowledges the rights of the child, without undermining the rights of the person with the disability. Therefore, the Government must adopt a holistic approach to this issue, which addresses the support needs of the child and the caring needs of the person with a disability.

DFI Recommends:

- Government should commit to undertake a comprehensive and detailed study and analysis to ascertain the true extent and needs of children as carers in Ireland.
- Government to invest an additional €20m in services such as personal assistance, care attendants and home help so that people with disabilities are no

22 Needs of Young Carers in Ireland, Pilot Research Study, Carers Association, Sept 1998.

23 UN Convention on the Rights of the Child, UN General Assembly 1989, Ireland is a signatory to the Convention since 1990, and ratified it in 1992.

24 Revised European Social Charter, Council of Europe, http://www.coe.int/T/E/Human_Rights/Esc/

25 Page 10, Caring before their Time, A review of Literature on Young Carers, Gilligan and Halpenny, Barnardos and the Children's Research Centre, Dublin September 2004.

26 One study in the UK indicated that about 1.4% of children and young people between the ages of 5 and 15 provided informal care. If we were to accept that approximately 1.4% of children between these ages in Ireland are carers (as compared to 4.8% of the population as a whole) that would indicate that there are 7,000 young carers in Ireland.

longer dependent on their children for their basic everyday care. Government to invest a further €20m in Budget 2007.

III. Capacity Building

Funding for Voluntary Disability Organisations

*“I believe that a vibrant civic society, which is so essential to a balanced and, ultimately, happy community, requires us to support engagement and to counter disengagement... we need to consider on a broader basis the policies and actions at official level, which can help or hinder such engagement.”*²⁷

Taoiseach, Bertie Ahern T.D., April 2005.

DFI supports the sentiments expressed by the Taoiseach on the wider role of the community and voluntary sector beyond that as solely providers of services. While voluntary disability organisations continue to be the primary providers of a range of services and supports for people with disabilities, they also play a valuable role in promoting equality, active citizenship and participation. They do this by working directly with, and for, people with disabilities in building their personal skills and confidence, so that they can reach their potential and achieve the optimum standard and quality of life. These organisations operate at a grassroots level, tackling local disability issues with the support of individuals and groups in their own area. They are also working to promote and build the capacity of individuals to self advocate. DFI welcomes the positive statements made by the Minister for Finance in Budget 2005 concerning the role of our sector to date when he stated that in terms of policy, advocacy and the provision of services *“most of the running had to be made by voluntary organisations”*.

As outlined in the White Paper “Supporting Voluntary Activity” the manner in which the State funds the voluntary disability sector does not truly recognise their role beyond that of service providers.

“The ‘package’ of funding supports under particular schemes is often incomplete. While funding for the primary service which the funder wants to support and a voluntary organisation wants to provide can be available, other funding necessary to the effectiveness of the organisation

*might not be available. For example, to be effective, and to deliver value for money for the funder and a good service or the customer/client, Community and Voluntary organisations need to undertake staff training, management training and development, service evaluation and organisational reviews. These require resources”.*²⁸

As stated many organisations are funded solely for the provision of services, and survive from year to year on service contracts. This approach does not create the necessary environment for organisations to continuously develop themselves so that they in turn can work with service users to build their own capacity to self advocate. In short, organisations must be in a secure position themselves to work with and advocate on behalf of the people they represent. This also forces organisations to divert a disproportionate amount of time, energy, personnel and resources away from the main tasks of service and support provision towards fundraising. This is in spite of the unprecedented resources promised to disability services arising from Budget 2005. The State needs to ensure the provision of core funding for the voluntary disability sector so that it can concentrate on its primary public service work. In other areas, such as the voluntary housing sector the State already provides core organisational funding through distinct budget lines. DFI calls on Government to provide similar funding lines for the voluntary disability sector. This must be allocated as a priority if the voluntary disability sector is to be in a strong position to work at optimal level with the State in the implementation of the National Disability Strategy, the provisions of the Disability Act 2005 and the Departmental Sectoral Plans.

The manner in which voluntary sector disability organisations are funded forces many of them to divert a disproportionate amount of time, energy, personnel and resources away from the main tasks of service and support provision towards fundraising.

²⁷ Speech by Bertie Ahern, T.D. Taoiseach, at the Wheel Conference, Dublin April 2005.

²⁸ “Supporting Voluntary Activity”, A White Paper on a Framework for Supporting Voluntary Activity and for Developing the Relationship between the State and the Community and Voluntary Sector, 2001. Section 5.26, Chapter 5, Page 96.

DFI Recommends:

- Government to provide core funding of €5m within a distinct budget line to secure the future of voluntary disability organisations and grant them the opportunity to build the capacity of the voluntary disability sector.
- Government to provide a further additional investment of €5m in Budget 2007 and continue this line of investment in subsequent Budgets to support the capacity building of the sector.

3. CONCLUSION

Budget 2005 provided a good foundation, but it must be built on with a sustained investment in services and supports for people with disabilities. Politics is about making choices. We trust and expect the Government will continue to make the choice of increased investment in services and supports for people with disabilities as detailed in this Submission. This is not only in the interests of people with disabilities, their families, carers and communities, it is in the interests of the country as a whole to maximise the potential of all its citizens and ensure that no one is left behind.

We note that both the Taoiseach and Tánaiste have in recent months recognised that achieving the full inclusion of people with disabilities remains a work in progress and must continue to be a priority for Government attention and resources. We look forward to those sentiments being translated into reality on Budget day.

Politics is about making choices. We trust and expect the Government will continue to make the choice of increased investment in services and supports for people with disabilities as detailed in this Submission.

*“The Government recognises, however, that this progress is set against a background of historical deficits in the quality and level of service provision. Far too many people with disabilities remain excluded from full participation in society while many gaps remain in the availability of quality care.”*²⁹ Taoiseach, Bertie Ahern T.D., June 2005.

*“A major priority for all of us is the issue of disability.”*³⁰ Tánaiste Mary Harney T.D., July 2005.

The National Disability Strategy (NDS) was launched last year amid much acclaim and debate. We have witnessed the passage of the Disability Act and the beginning of dialogue on the Departmental Sectoral Plans. If given the necessary resources all of these developments have the potential to make a big difference in the lives of people with disabilities. This will only happen if they

are resourced so that they are fully implemented. If the National Disability Strategy is to be a living testament of this Government’s commitment to people with disabilities they need to prioritise funding for the supports and services that people with disabilities require on an ongoing basis.

In Budget 2006, we propose that the Government adopt a three pronged approach by:

- Increasing income supports for people with disabilities to address the high levels of poverty and social exclusion.
- Continuing to invest in an infrastructure of care so that people with disabilities have the support services they require when they need them.
- Providing additional resources to build the capacity of the voluntary disability sector.

We believe that funding the National Disability Strategy would demonstrate the Government’s continued commitment to providing the means by which people with disabilities can live life with dignity, can participate and contribute as citizens and are supported to reach their full potential now and into the future.

²⁹ Speech by Bertie Ahern, T.D. Taoiseach, at the opening of the St. John of God’s Conference, Dublin, 20th June 2005.

³⁰ Ministerial Presentation to Joint Oireachtas Committee on Health and Children by Tánaiste and Minister for Health and Children, Mary Harney, T.D. July 20th 2005.

DFI – NATIONAL COUNCIL AND ASSOCIATE MEMBERSHIP 2005

| | | |
|---|--|---|
| Action for Mobility | Cystic Fibrosis Association of Ireland | Leitrim Association of People with Disabilities |
| AHEAD | DEBRA Ireland | Lucan Disability Action Group* |
| Alzheimer Society of Ireland | Diabetes Federation of Ireland Southern Regional Office* | Migraine Association of Ireland* |
| Anne Sullivan Centre* | Disabled Drivers Association | Multiple Sclerosis Society of Ireland |
| APT | Disabled People of Clare | Muscular Dystrophy Ireland |
| Arklow Disability Action Group* | Doorway to Life | National Association for Deaf People |
| Arthritis Ireland | Down Syndrome Ireland | National Council for the Blind of Ireland |
| ASPIRE | Dyslexia Association of Ireland | National Federation of Arch Clubs |
| Asthma Society of Ireland | Dyspraxia Association of Ireland* | Neurofibromatosis Association of Ireland |
| AWARE | Enable Ireland | Noinin Support for Autism* |
| BIH Housing Association | Féach* | North West MS Therapy Centre |
| Bodywhys* | Fibromyalgia Support Group (Midlands)* | Out and About Association* |
| Brainwave | Fighting Blindness | Parkinsons Association of Ireland |
| BRÍ | Focus Ireland | Peacehaven Trust* |
| Caring and Sharing Association | Freidreich's Ataxia Society of Ireland | Peter Bradley Foundation* |
| Center for Independent Living | Galway County Association for Mentally Handicapped Children* | Post Polio Support Group |
| Central Remedial Clinic | Genetic & Inherited Disorders Organisation | Reach Ireland |
| Centre for Independent Living Blanchardstown* | HAIL Housing | Rehab Group |
| Centre for Independent Living Carlow* | Headway Ireland | Royal Hospital Donnybrook |
| Centre for Independent Living Dublin 7* | Heart Children Ireland* | Schizophrenia Ireland |
| Centre for Independent Living Galway* | Huntington's Disease Association of Ireland | Shannon Community Workshops |
| Centre for Independent Living Mayo | Irish Association for Spina Bifida and Hydrocephalus | Sophia Housing Association |
| Centre for Independent Living Offaly* | Irish Deaf Society | Special Olympics Ireland |
| Centre for Independent Living Sligo* | Irish Guide Dogs for the Blind | Spinal Injuries Ireland |
| Centre for Independent Living Tipperary | Irish Haemophilia Society | St. Catherine's Association |
| Centre for Independent Living Waterford* | Irish Kidney Association | St. Gabriel's School and Centre |
| Centre for Independent Living Wexford* | Irish Motor Neurone Disease Association | St. Mary's Hospital & Residential School |
| Cheeverstown House | Irish Raynaud's & Scleroderma Society | St. Michael's House |
| Cheshire Ireland* | Irish Society for Autism | Vantastic |
| Children in Hospital Ireland* | Irish Wheelchair Association | Vergemount Housing Fellowship |
| COPE Foundation | Jack and Jill Children's Foundation | Walkinstown Association |
| Co. Roscommon Support Group of People with Disabilities | KARE | West Limerick Community Workshop |
| | | Western Care Association |

* Associate Members.



***Supporting Organisations to Enable People with Disabilities
An Advocate for the Voluntary Disability Sector***

Disability Federation of Ireland (DFI) is the national support organisation and advocate for voluntary disability organisations in Ireland who provide services to people with disabilities and disabling conditions.

- Hidden
- Mental Health
- Sensory
- Intellectual
- Physical
- Emotional

Disability Federation of Ireland (DFI) works to ensure that Irish society is fully inclusive of people with disabilities and disabling conditions so that they can exercise fully their civil, social and human rights. In pursuit of this vision:

- DFI acts as an advocate for the voluntary disability sector
- Supports organisations to further enable people with disabilities

DFI represents and supports over 150 voluntary disability organisations and groups of which 72 comprise its National Council, and 25 of which are Associate Members. Allied to this, it works with and supports over 200 organisations and groups around the country that have a significant and growing disability interest, mainly coming from the statutory and voluntary sectors. DFI provides:

- Information
- Organisation and Management Development
- Advocacy and Representation
- Training and Support
- Research and Policy Development
- Networking

DFI also supports the broader voluntary and disability sector through its representation of the disability strand within the Community and Voluntary Pillar of the Social Partnership process, as a social partner at the National Economic and Social Forum, Health Board Co-ordinating Committees and other fora at regional, national and European level.

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