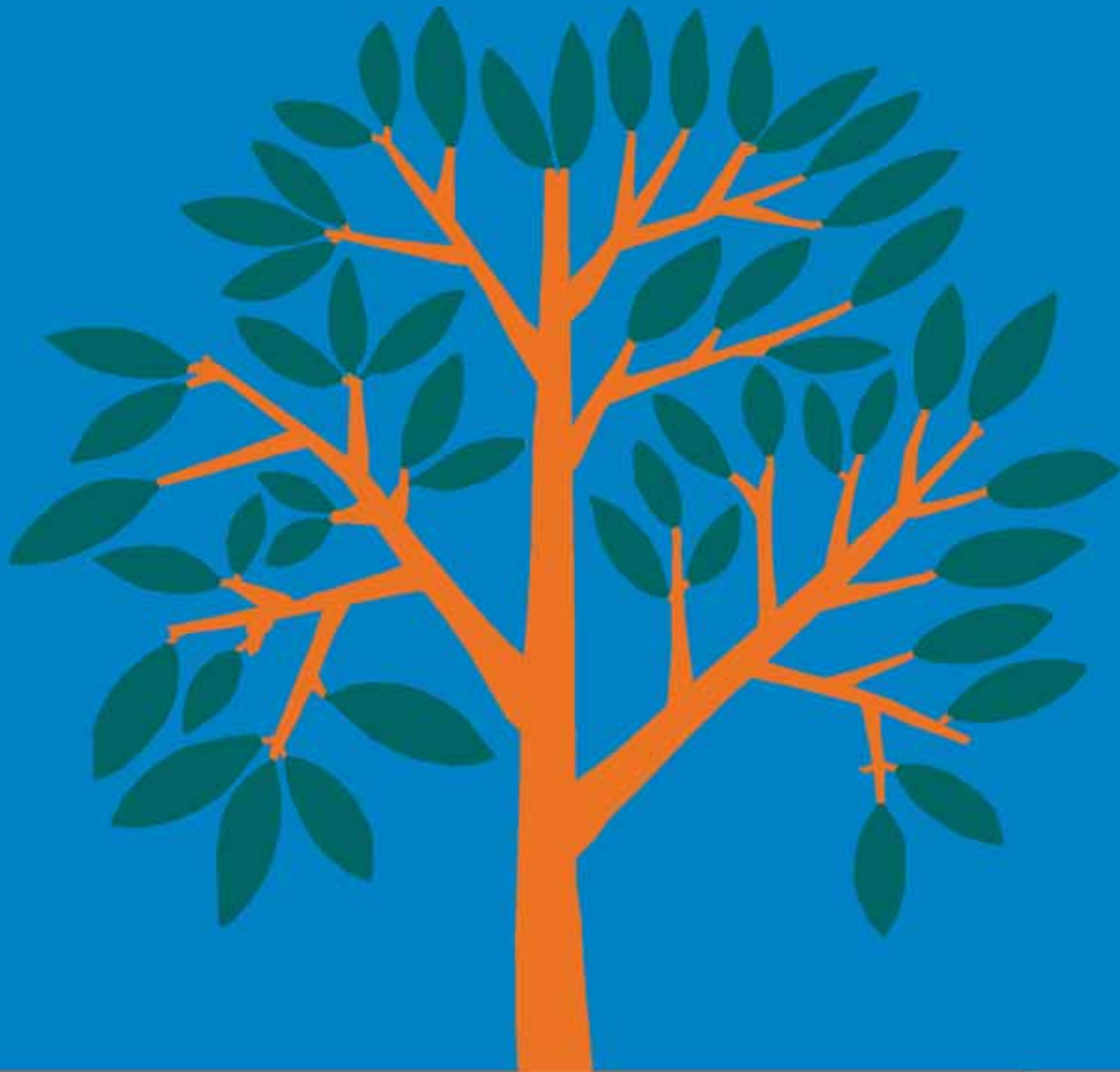




Disability Federation of Ireland
Annual Review 2004



Partnership
Legislation Advocacy
Inclusion Support Funding
Services

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CHAIRPERSON'S REPORT



*John Saunders
Chairperson*

The Annual Review of the Disability Federation of Ireland provides an opportunity to highlight the activities of the organisation throughout the year. 2004 was significant for DFI across a wide range of areas and activities.

A seven year Strategic Plan, designed to bring DFI to the end of the decade, was adopted by the National Council in December 2003. Work then commenced to develop a more detailed and targeted Operational Plan. I want to focus on one of the three Strategic Objectives in the plan, that of providing support and services to our member organisations.

Conscious of the growing need within organisations for practical assistance in areas such as governance, strategic planning and organisational development, we are pleased that 2004 proved to be the first full year in the operation of our Training and Support Service, funded through the Department of Community, Rural and Gaeltacht Affairs. While this was a significant development, there is clearly a lot more to do.

DFI was instrumental in the establishment of BoardMatch, which was operational by the end of the year. This development has the potential to make significant human resource skills of those with relevant expertise available to the Boards and key decision makers in organisations. As a sector we have major needs in this area, and while there continues to be a vacuum in relation to legislation and regulation of the voluntary sector, along with the continued shortfall in resourcing to promote best organisational practice and

systems, DFI, I am proud to say, has provided leadership and taken practical steps to address this area.

On the policy side there was much activity in areas such as Health Service Reform, the Disability Bill, and Social Partnership.

There were frustrations around the Health Service Reform Programme, most notably the reluctance of the Interim Health Service Executive to acknowledge the vital role which our sector plays in shaping and delivering health services.

The Disability Bill, expected early in the year, was eventually published in September along with departmental sectoral plans and a commitment to multi-annual funding for services. While the provision of a multi-annual funding mechanism is highly significant, and to be welcomed, there has been growing disappointment with the provisions of the Bill around specialist support services and ensuring the mainstreaming of disability across a range of Government Departments and public bodies.

Summer brought the mid-term review of Sustaining Progress, where, along with our colleagues on the Community and Voluntary Pillar, we focused on the need to implement the commitments made in the Agreement, highlighting the importance of national Budgets in doing so. Budget 2005 improved the dismal trend of the previous two Budgets, and brought a number of gains in relation to issues which we had been promoting, namely, an increased rate of disability allowance, commitments to adults with significant disabilities (young chronic sick), personal assistance, and accommodation for people experiencing mental illness in the community.

We ran a very focused Campaign, *Housing – The Vital Element*, in the run up to the Local Authority Elections, and later in the year, through our Social Partnership engagement, we influenced the National Economic

and Social Council Report No.112, *Housing in Ireland: Performance and Policy*, in which it was acknowledged that there is a necessity for a National Housing Strategy for people with disabilities, and which, crucially, committed to the development of this Strategy. This is just one example of DFI's ability to strategically influence public policy and practice in favour of people with disabilities in Ireland, irrespective of the nature or type of disability.

We continue to regard the NDA as occupying a unique position to influence the development of policy and practice in favour of people with disabilities in Ireland. The organisation is well placed within the orbit of the public service and the voluntary disability sector. DFI has expressed concerns to the NDA during the year in relation to its approach to the voluntary disability sector. We are of the view that the important role that the voluntary sector plays in the area of disability is not sufficiently valued by the NDA at the present time.

DFI is in a unique position as an organisation which gives support and leadership to a broad and varied sector. We continue to operate in ways which value the independence and autonomy of each organisation within a shared vision. That vision is set out in the Strategic Plan 2004 – 2010, as agreed by our National Council, which states that

"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."

As an organisation we continue to be careful to promote issues and strive to develop policy in ways that assist the broad sector. This is obvious in areas such as support and development needs for organisations, Health Service Reform, Disability Bill and other legislative areas, Strategic Review of Disability Services, income support and cost of disability, and through the Social Partnership Process.

The last day of 2004 was the last day of operation of the Health Boards. It is right to acknowledge with thanks the work and commitment of countless officials across all Boards and the ERHA who have supported us in meeting the health and personal social service needs of people with disabilities and their families. We wish them all well in the new structures and hopefully we will be working together again.

I would also like to express my appreciation to the National Council for its support.

I wish to thank my fellow Board Members for their role in guiding the work of the Federation throughout the year. All of us on the Board act in a voluntary capacity, bringing sector-wide experience and perspective to the role. I would like to mention in particular my fellow officers, Ann-Marie Flanagan, Vice-Chairperson until May 2004, Marie Lynch, current Vice-Chairperson, and Geraldine Clare, Honorary Treasurer, for their particular support and work.

During the year a number of Board Members retired, namely, Anne Hughes (Dyslexia Association), Michael Dineen (MS Ireland), and Paul Daly (Down Syndrome Ireland). I wish to acknowledge and thank them for their service. I welcome Nick Killian (IASBAH), Mike Glynn (Brainwave), and Eithne Frost (Irish Motor Neurone Disease Association) to the Board.

Many other people throughout the membership of DFI provide voluntary service to its mission and work on a regular basis – they too are to be acknowledged and thanked. I specifically want to note the work which our representatives across the Co-Ordinating Committees have done on behalf of the wider membership.

Finally, I would like to thank our Chief Executive, John Dolan, and staff members, for their continued dedication to ensuring that the objectives of the Disability Federation of Ireland are achieved.

John Saunders
Chairperson

CHIEF EXECUTIVE OFFICER'S INTRODUCTION



John Dolan
CEO

The past year was one of consolidation on a number of fronts, which included staffing, social partnership, providing supports to member organisations and developing an Operational Plan to support the Strategic Plan.

Yet there were new and renewed challenges in areas such as Health Service Reform and in securing increased resourcing for necessary services across the sector.

With the completion of the ten strong Regional Support Team we established a post to manage and support the team. This post also strengthened the effectiveness of the Management Team.

Along with establishing the Training and Support Service, made possible by Department of Community, Rural and Gaeltacht Affairs Funding, we were proactive in bringing the BoardMatch concept to Ireland, with the active support of the Association of Chartered and Certified Accountants. In terms of the needs of our member organisations, these initiatives are a very good start to addressing these needs, identifying as they do the importance of having a range of supports across the sector, from governance to operational issues. As noted by the Chairperson, this is a key area of work in our Strategic Plan, and it sits strongly beside our other two Strategic Objectives concerning policy and the development of greater sectoral coherence.

The year under review was our first full year of involvement in the Community and Voluntary Pillar of social partnership, marking significant achievements, notably around the Budget, and the acceptance by NESC of the need for a national housing strategy for people with disabilities.

Much work and effort went into the Health Service Reform Programme with mixed results. While there was a strong engagement with the Department of Health and Children, we were continually frustrated that the interim Health Service Executive did not engage actively with us around the role played by our sector in the development and delivery of health services. Now that the Health Service Executive is established on a statutory basis we anticipate a full and ongoing engagement. It is important to acknowledge the great assistance and support around this issue received by DFI staff from our broad membership. In particular I note the preparation and engagement for the Workshop which the Interim Health Service Executive set up for us in June.

Both staff and organisations have played a strong role as part of the DFI input into the Strategic Review of Disability Services within the Department of Health and Children. That Review is significant for a number of reasons. Firstly, it is strategic in nature. Secondly, it encompasses all areas of disability and disabling conditions. Thirdly, it stretches out beyond the delivery of specialist support services to rightfully consider access for people with disabilities to general health services, which is appropriate in the mainstreaming context.

The recent Budget brought positive movement after the previous two. The introduction of multi-annual funding, along with the specific commitments, was a

significant acknowledgement of the work of DFI members and staff over the year in question, and going further back.

The year started with an expectation of the early publication of the Disability Bill. However, it was not until the last quarter that it was published and the final piece of the National Disability Strategy was not unveiled until the Budget in December. Again, a lot of work went into that area and we appreciate the support of the other members of the Disability Legislation Consultation Group (DLCG) with whom we worked throughout the year. Again, staff and member organisations are to be complimented for the input that has been made, and which continues to be made, in our efforts to go beyond the great disappointment with the Bill as published, in order to have it amended in line with the position of the DLCG, as set out in *Equal Citizens: Proposals for Core Elements of Disability Legislation*.

As you read through the many and varied areas which we engaged in during the year, it is important to acknowledge the work and effort of a number of distinct groups within DFI. The National Council and Board provide our Governance, and, within that context, the staff team work to further the objectives of DFI. Members of the Council and Board all operate on a voluntary basis. Board Members, who meet on a monthly basis, are often called upon to give additional time and expertise. For this I am grateful. Board Officers have specific roles and responsibilities. In particular, I wish to pay tribute to John Saunders, Chairperson, for his sustained work throughout the year and his advice and support to me as CEO. We also have other volunteers who represent DFI's interests on a range of Working Groups and Committees. They too play an important role on behalf of our membership.

The success of DFI is due to its team, staff and volunteers (Council, Board and others). Their cooperation and work has greatly assisted the Management Team and myself throughout the year.

John Dolan
Chief Executive Officer

VISION AND MISSION

The 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, and supports organisations to further enable people with disabilities.

DFI is the national support mechanism for voluntary organisations in Ireland, covering all areas of disability and disabling conditions (hidden, intellectual, mental health, physical, sensory and emotional disability). Currently DFI represents and supports over one hundred and fifty voluntary disability organisations and groups of which seventy-two comprise its National Council, and twenty-four 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, training and support, organisational and management development, research and policy development, advocacy, representation and networking to voluntary organisations which will enable them to deliver the best possible range of services to people with disabilities. DFI also supports the broad voluntary disability sector through its representation of the disability interest within the Community and Voluntary Pillar of the social partnership process as well as through a range of other fora and structures.

BUILDING A NATIONAL PLATFORM

In line with its Strategic Plan, DFI has continued to develop and consolidate a National Platform to articulate the views and perspectives of the disability sector, as is clearly evident throughout this Report. As part of this process DFI actively involves member organisations in identifying and promoting issues and concerns.

Through its work alongside Health Boards and the disability sector, as well as in collaboration with a wide range of other Government and community and voluntary agencies, DFI works to ensure that the needs and concerns of the sector are promoted and addressed. In developing strategic alliances and otherwise fostering links between the disability sector and these other agencies, DFI actively promotes a shared understanding of the work of the sector and leaves the door open for more collaborative working between these groups and agencies and the sector.

A wide range of organisations and representative structures operate at local and regional levels, including the Community Platforms, Strategic Policy Committees and Social Inclusion Measures Groups. DFI works with these groups and organisations to ensure that the regional platform issues of the disability sector are adequately represented on these structures. DFI actively supports representatives on many of these Committees, offering them a feedback mechanism to the disability organisations in the local area.

Some other key examples of this aspect of our work relate to legislation, the Disability Legislation Consultation Group (DLCG), the development of National Standards for Disability Services, the Health Service Reform Programme, and Social Partnership.

Other areas and issues being addressed are highlighted throughout this Report.

ADVOCATE FOR THE SECTOR AND POLICY DEVELOPMENT



*Aisling Walsh
Senior Executive
Officer – Policy and
Research*

DFI recognises the vital importance of its continued contribution to the development of policies that support the work of the sector. Given the ongoing pressure on all voluntary organisations in the sector to ensure that people with disabilities and their families have access to appropriate services, and because many organisations have been at the forefront of developing and funding services, it is sometimes easily assumed that the sector is simply a collection of service providers. Our member organisations are and always have been the first advocate for people with disabilities and their families. The provision of direct services is part of that response.

DFI has continued to develop and promote policy and change while acting as an advocate for the sector at local, regional, national and international levels. Some of the organisations, groups and structures through which this was promoted in 2004 are listed in the back of this document.

DFI has built and consolidated relationships with key personnel in strategic roles within Government Departments, Health Boards and Local Authorities, other statutory agencies, members of the Oireachtas and the broad community and voluntary sector.

Throughout 2004 there have been a number of constants in relation to policy: Rights Based Disability Legislation, Social Partnership, DFI Budget Campaign Issues, Health Service Reform and the Strategic Review of Disability Services.

RIGHTS BASED DISABILITY LEGISLATION

Following the publication of *Equal Citizens – Proposals for Core Elements of Disability Legislation* (2003), by the Disability Legislation Consultation Group (DLCG), DFI continued to work alongside the DLCG to have the legislation published.

From early 2004 we were informed that publication of the legislation was imminent. Eventually, the legislation was published on 21st September 2004, as part of Government's National Disability Strategy. This Strategy included the Disability Bill, Draft Sectoral Plans and the Comhairle (Amendment 2004) Bill. Information on the multi-annual funding package for disability services, which forms part of the Strategy, was announced later in the year as part of Budget 2005.

DFI, as a member of the DLCG, met with Minister of State, Frank Fahey T.D., at the Department of Justice Equality and Law Reform on October 27th. At that meeting the Ten Fundamental Flaws in the Disability Bill, identified by the DLCG, were outlined and explained to the Minister and his advisors. The Minister committed at the meeting to responding to the concerns raised by the DLCG. By the end of 2004 no response had been received from the Minister.

In November DFI, along with over thirty disability organisations, made presentations to the Oireachtas Joint Committee for Justice, Equality, Defence and Women's Affairs. The high level of consistency in the presentations gave members of the Committee a clear understanding of the dissatisfaction of the disability sector with the proposed legislation.

DFI held a meeting with its member organisations in relation to the National Disability Strategy on 24th November. At that meeting representatives of the organisations set out their concerns and agreed that

DFI should work with the DLCC, and in its own right, to have the proposed legislation amended. Following the meeting DFI commenced planning for a Campaign to have the Bill amended.

DFI SEMINAR – CROKE PARK, 11TH MAY, 2004



'Talking Around the Houses'

The subject of this Seminar was accommodation for people with disabilities. The event was planned to take place as the local election

campaign was in full swing. The Seminar provided a platform for the launch of DFI's Programme for Local Government, '*Housing – The Vital Element*', which identified key challenges which Local Authorities need to address to facilitate the equal inclusion of people with disabilities into their own communities:

- Community Living – Housing for People with Disabilities
 - Disabled Person's Housing Grant
 - People who Experience Mental Illness
 - People with Significant Disabilities
- Local Government Representative Structures, including people with disabilities
- Health Service Reform – An Opportunity for Local Government
- Community Employment

Organisations came together at the Seminar to plan their individual Campaign strategies.

BUDGET 2005 CAMPAIGN

In line with the decision of the Board, a year long plan and Campaign was developed to highlight the needs and issues of our sector. We engaged with and involved our member organisations throughout the year. We continued to focus on the seven core issues in the lead up to Budget 2005:

- Disabled Person's Housing Grant
- Adults with Significant Disabilities (Young Chronic Sick)
- Community Employment
- Children as Carers
- Cost of Disability/Income for People with Disabilities
- Accommodation for People with Mental Illness
- Funding for Voluntary Organisations

On October 6th we launched our 2005 Pre-Budget Submission in the Mansion House, Dublin. Entitled '*Rights, Commitments, Action!*', the Submission called on Government to provide 'not only increased investment in this Budget, but a commitment to an enhanced and sustained investment throughout the rest of the lifetime of this Government'.

Representatives from each of the political parties attended the Launch and responded to our Submission. The Launch was followed by a series of meetings with the political parties and politicians at regional and national levels. DFI also made presentations to the Joint Oireachtas Committee on Social and Family Affairs and to the Oireachtas Committee on Environment and Local Government. We also had a meeting with the Minister for Social and Family Affairs, Seamus Brennan, in late October.

Following the publication of Budget 2005, DFI welcomed it as a positive step forward. In particular, we welcomed the significant focus on disability issues in the Budget speech and presentation. The multi-annual funding package announced for the period 2006 – 2009 was regarded as significant, going some way towards meeting our demands for a sustained programme of investment in health and social services over a number of years. However, the actual 'additional' current funding being made available is far less than the headline figure of €600m suggests.

We welcomed, too, the increase in Disability Allowance by €14 to €148.80, which was in line with our Pre-Budget Submission recommendation. The announcement in the Budget of additional funding for mental health services as part of the multi-annual funding package was also welcomed. DFI also welcomed the response to its call for significant investment in services and supports for adults with significant disabilities (young chronic sick), a group who had in the past been ignored.

In relation to the Disabled Person's Housing Grant (DPG), the allocation for local and social housing increased by 9%, which, although not ideal, may go some way in addressing the shortcomings in the DPG scheme in 2005.

DFI had called for an additional €5m per annum core funding to build the capacity of voluntary disability organisations, and the positive statements made by the Minister concerning the role of the sector to date were welcomed. A scheme of grant aid support for once-off voluntary sector projects which demonstrate an innovative and cost-effective approach to service provision for people with disabilities was announced, and while this additional funding was welcomed, it must be acknowledged that this initiative does not

address the historic under-funding many organisations are still trying to manage.

We have also noted in our post Budget analysis the shortcomings of Budget 2005, and the many important and pressing issues that have been left unresolved, which we will continue to press Government to address.

HEALTH SERVICE REFORM

One of the most significant issues exercising the minds of DFI, voluntary disability organisations, and people with disabilities in the course of the year was the likely impact of the transition from the current delivery of health services to the Health Service Executive. DFI was proactive in its engagement with the interim Health Service Executive (iHSE) throughout the year and sought, without success, to have the iHSE engage with us to ensure that the contribution of the voluntary disability sector be designed into the new structure.

SOCIAL PARTNERSHIP

DFI represents the disability interest in the Community and Voluntary Pillar in relation to the Social Partnership Process. DFI continued to be an active member of the Pillar throughout the year. We operated both an internal and external linkage and feedback network to involve both DFI member organisations and the wider disability sector in the process.

Over the last year, DFI has been an active member of the Social Partnership Process, through:

- Attending Community and Voluntary Pillar Meetings
- Attending quarterly Plenary Meetings
- Participating in sub groups of the Community and Voluntary Pillar

- Attending meetings with Ministers on various Special Initiatives
- Attending bilateral meeting with Department of the Taoiseach

DFI has provided submissions and papers on an ongoing basis to the Pillar, Department of the Taoiseach, the various line Departments and has generally succeeded in progressing the disability agenda within the process.

In relation to the disability area, we have concentrated on:

- The Disability Bill
- Health Service Reform
- Cost of Disability Payment/Income Supports
- Funding for Voluntary Disability Organisations
- Strategic Review of Disability Services
- Housing and Accommodation
- Importance of developing an infrastructure of care

Specifically in relation to Housing and Accommodation, we influenced, through the Community and Voluntary Pillar, the National Economic and Social Council in formulating their Report No.112, *Housing in Ireland: Performance and Policy*. This Report references our 2004 document *Housing – The Vital Element*, and repeats our call for a national housing strategy for people with disabilities.

In relation to the Mid Term Review of *Sustaining Progress*, DFI has put forward suggestions for key actions under each of the Special Initiatives.



Allen Dunne, SEO - Operations;
Joan Bradley, Post Polio
Support Group

Minister Frank Fahey, T.D.



LAUNCH OF DFI PRE-BUDGET SUBMISSION

'Rights, Commitment, Action!'

The Launch of 'Rights, Commitment, Action!' took place in the Mansion House on 6th October. As in previous years, the focus of DFI's Budget Campaign 2005 was on raising awareness around the following issues:

- Income for People with Disabilities
- Cost of Disability Payment
- Community Services
- Community Employment
- Accommodation for People with Disabilities
- Adults with Significant Disabilities
- Disabled Person's Housing Grant
- Child Carers
- Funding for Voluntary Disability Organisations

In his opening remarks John Saunders, Chairperson of DFI, commented that 'If we continue to return to these issues again and again at Budget time there will be a serious question about the bona fides of the Government in relation to addressing the disability agenda.'

The Launch was attended by the Minister of State in the Department of Health and Children, Mr Tim O'Malley, Minister Frank Fahey, T.D., Minister of State in the Department of Justice, Equality and Law Reform, and a large number of TDs and Senators from all Oireachtas Parties. A speaker from each of the parties made a response to the Federation's proposals.

NATIONAL ECONOMIC AND SOCIAL FORUM

DFI has represented the disability interest in NESF since the Forum's inception in 1993. The Forum was re-established in 2004. DFI made submissions to the workplan of the NESF during the year and has participated on the NESF Project Team, *Care for Older People*.

An external linkage and feedback mechanism has been established to assist DFI in supporting the broad disability interest in the Forum.

DEPARTMENT OF HEALTH AND CHILDREN STRATEGIC REVIEW OF DISABILITY SERVICES

Under the *Care – Children, People with Disabilities and Older People Special Initiative, Sustaining Progress* commits the Department of Health and Children to a Strategic Review of Disability Services. Throughout 2004, DFI has participated in a number of the Specialist Study Groups formed under the Review Process, and otherwise has outlined the following issues with the Department:

- The importance of the Government policy of mainstreaming being at the centre of the Review.
- The Review should not be restricted to specialised health and personal social services.
- The cross cutting nature of the Review.
- The importance of fully including mental health in the Review.

EDUCATION FOR PERSONS WITH SPECIAL EDUCATIONAL NEEDS ACT

The Education for Persons with Special Educational Needs Bill was enacted in July 2004. A number of substantial changes were made to this legislation during the Committee stages of the Oireachtas hearings. DFI engaged with this process providing ongoing information to politicians, both in Government and from opposition

parties, as well as to member organisations, concerning the stages and content of the legislation.

EUROPEAN ASSOCIATION OF SERVICE PROVIDERS FOR PERSONS WITH DISABILITIES

DFI is a member of The European Association of Service Providers for Persons with Disabilities (EASPD), and continued its representation on the Board during 2004. The organisation works to promote the equalisation of opportunities for people with disabilities through effective and high quality service systems in Europe, and represents more than 6,000 service provider organisations in twenty-two European countries. DFI was involved in various EASPD activities during the year, including attendance at General Assembly, Board, and Social Policy Working Group meetings.

DFI INFORMATION MEETING FOR MEMBER ORGANISATIONS

National Disability Strategy

On 24th November 2004 DFI held a meeting in Chief O'Neill's Hotel, in Dublin, for the purpose of furthering the process of informing DFI itself and its member organisations more fully in relation to the Package of measures set out in the National Disability Strategy, focusing particularly on the Disability Bill 2004. The Meeting was called at the request of the Board of DFI as part of the DFI Campaign to secure the full implementation of the position agreed by DFI when it endorsed 'Equal Citizens – Proposals for Core Elements of Disability Legislation', as part of DFI's membership of the Disability Legislation Consultation Group (DLCCG).

Building on the views expressed and suggestions made by its member organisations at the meeting, DFI embarked on a Campaign to ensure that members of the Oireachtas fully understand the extent and reasons for the dissatisfaction with the Disability Bill.

WHITE PAPER: 'SUPPORTING VOLUNTARY ACTIVITY'

In January a major Conference was organised to discuss progress to date in the implementation of the White Paper. DFI, in consultation with member organisations, made a submission to the Charities Reform Consultation document, *Towards a Modern Statutory Framework for Charities*, and actively promoted the regional meetings organised by the Wheel and the Irish Charities Tax Research Group in support of the consultation process.

DFI has continued to contribute to public policy through various Groups and in other key areas

- White Paper, *Supporting Voluntary Activity: Implementation and Advisory Group (IAG) and Community and Voluntary 12 Group (CV12)*
- Health Board Regional Physical and Sensory Disability Co-Ordinating Committees
- National Physical and Sensory Disability Database Committee
- Department of Health and Children Working Group on the Funding of Voluntary Organisations Providing Services to People with Physical and/or Sensory Disabilities
- Department of Health and Children Working Group on Personal Assistance and Home Supports
- National Working Group for Disability Performance Indicators
- Disability Legislation Consultation Group (DLCG)
- *Workway* – Joint ICTU/IBEC initiative
- Community and Voluntary Pillar of Social Partnership
- National Economic and Social Forum (NESF)
- National Economic and Social Council (NESC)
- National Disability Authority (NDA)
- NDA Standards Advisory Committee
- NDA Reference Group on the Development of a Code of Practice for Person Centred Planning in the Provision of Services for People with Disabilities in Ireland
- The Wheel
- Equality Authority – Equal Status Act Advisory Committee on Disability
- Irish Charities Tax Reform Group (ICTRG)
- Women's Health Council National Planning Forum for Women's Health
- Department of Health and Children Strategic Review of Disability Services – Working Groups
 - Assessment, Early Intervention and Pre-School
 - Access to Mental Health Services
 - Disabilities and Older People
 - Information and Databases
 - Mainstreaming
 - Supported Living (Home Supports)
 - Protecting Vulnerable People
 - People with Significant Disabilities including those with acquired brain injury
 - Families and Carers of People with Disabilities
 - Access to General Health Services
- Community Employment/Social Economy
- Accessible Public Transport
- Disability Legal Resource
- Mental Health
- Mainstreaming and crosscutting nature of disability

- Disability Working Groups
- Citizens Information Centre Boards
- Regional Support Agencies
- Community Development Programmes
- Partnership Boards
- Education for Persons with Special Educational Needs Act
- Barcelona Declaration
 - Supporting Local Implementation Teams
- County Development Boards and Local Government
 - Disability Clusters
 - Community and Voluntary Fora
 - Social Inclusion Measures Committees
 - Strategic Policy Committees
- Disability and Ageing
- Department of Health and Children National Health Strategy Consultative Forum
- Legislative and Regulatory Reform of the sector
- Health Service Reform
- Rural Development Forum
- National Employment Strategy (NES)
- Various FÁS Policy Groups
 - National Advisory Committee on Disability
 - National Accreditation Committee
 - Review of Employment Support Scheme
 - Review of Community Employment
- Centre for Early Childcare Education and Development (CECDE) – Development of Principles and Standards in Quality Childcare
- An Bord Altranais Prescribing Committee

HEALTH SERVICE REFORM

A meeting took place between DFI Member Organisations and the interim Health Service Executive, June 3rd 2004, Croke Park

In September 2003 DFI made a detailed Submission to the Office for Health Management in relation to the Health Service Reform Programme in which we raised a range of challenges and issues for the reform process. Since the establishment of the interim Health Service Executive earlier in 2004, DFI sought to engage with them, and in June a 'listening meeting' was offered by the iHSE to the members of DFI.

The presentations on the day were built upon DFI's Submission and work in this area, focusing on the need to get the system right from the perspective of the sector. In addition, the perspectives and experiences, concerns, hopes and fears of the sector were outlined to the iHSE. Organisations attending prepared short position papers outlining the practical issues and problems encountered in relation to the current health service structures, and outlined the impact of these issues on their client/member groups.

At the meeting Kevin Kelly, Chairman of the iHSE, confirmed that an engagement mechanism would be offered to DFI. In response, John Dolan, CEO of DFI, expressed DFI's commitment to playing its part in assisting in the process of designing a health system which is fully accessible to people with disabilities and their representative organisations, and its desire to work in partnership with all other stakeholders to achieve that end.

An update document – *Design Us In – Update of DFI Position and Actions in Relation to Health Service Reform on the First Anniversary of the Reform Programme*, was submitted by DFI in July 2004.

SUPPORTING ORGANISATIONS TO ENABLE PEOPLE WITH DISABILITIES

DISABILITY GROUPINGS AND CROSS DISABILITY

While DFI works at the broader level to ensure that voluntary disability organisations operate in an environment which understands and respects their voluntary role within society, and which enables their optimum participation, it is also necessary to work both collectively and individually with organisations in order to assist them in advancing their aims and objectives. This is done by supporting organisations not only in their disability related work but also by providing any other supports necessary for overall effective functioning.

The policy of mainstreaming disability issues across all Government Departments and public services is actively pursued through our work. It is no longer adequate to assign disability issues to just one agency or organisation. This poses a major challenge for all who work in the sector.

Disability is not a straightforward and clear issue. Not only is there a wide range of disabilities, but the effects of disability on each individual may vary greatly. Initiatives and programmes must accommodate these diverse effects and not presume that benefit will accrue in equal measure. Services which assist people who have a physical disability may be of no assistance to people who have epilepsy, are deaf or experience mental illness. There must be an understanding of the need for different approaches and measures for different disability groups to ensure that developments and outcomes are equitable and balanced.

DFI articulates the views and perspectives of the voluntary disability sector in Ireland, and has continued to develop partnerships and strategic alliances with other disability organisations and the broader community and voluntary sector, in Local Government – County and City Development Boards, and in joint projects with Comhairle and local Citizens Information Centres (CICs).

It is important to keep in mind that people with a recognised disability may acquire another disability or disabling condition during their lifetime. There must, therefore, be a particular emphasis across disabilities. Throughout the year DFI has engaged with organisations on a number of cross-disability issues including:

- Developing the capacity of voluntary organisations
- Liaison and Networking
- Disability and Employment
- Disability and Ageing
- Disability Legislation
- Education for Persons with Special Educational Needs Act 2004
- Health Service Reform
- Social Partnership
- Budget Campaign
- Strategic Review of Disability Services
- Housing and Accommodation
- Population Health

SUBMISSIONS, PRESENTATIONS AND PUBLICATIONS

- Submission on the Education for Persons with Disabilities Bill 2003 to OECD Review of Higher Education (February)
- 'Rural Ireland and Disability – Opportunities and Challenges' – Presentation to Cavan Community Forum (April)
- Submission to Department of Community, Rural and Gaeltacht Affairs on the reform of charities legislation – 'Disability Federation of Ireland Submission in Response to Consultation Paper, 'Establishing a Modern Statutory Framework for Charities ' (May)
- DFI Programme for Local Government - *Housing – The Vital Element* (May)
- Written Submissions, jointly with the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, and the Not for Profit Business Association, to the National Disability Authority Draft National Standards for Disability Services (June)
- Health Service Reform – Presentation to a meeting in Croke Park between DFI and the Change Management Team appointed by the Interim Health Service Executive (June)
- Presentations to Local Authorities on 'Housing – The Vital Element', DFI Programme for Local Government (various dates)
- Submission to Limerick City Development Board (July)
- 'Design Us In' – Update of DFI Position and Actions in Relation to Health Service Reform on the First Anniversary of the Reform Programme (July)



- Background Paper to the Social Partnership Process, including DFI's role in Social Partnership (July)
- Pre-Budget Campaign 2005 - Presentation to Joint Oireachtas Committee on Environment, Heritage and Local Government (September)
- Pre-Budget Campaign 2005 - Presentation to Joint Oireachtas Committee on Social and Family Affairs (September)
- 'Disability and Social Policy – Accessing the Community' – Presentation to the Irish Rheumatology Health Professionals Society Annual Conference (October)
- 'Rights, Commitments, Action' – DFI Pre-Budget Submission 2005 (October)
- Critique of, and Proposed Amendments to, The Health Bill (2004) – Joint Position Paper, The Wheel and DFI (November)
- Presentation to Member Organisations in relation to the National Disability Strategy 2004 and 'Equal Citizens', Proposals for Core Elements of Disability Legislation (November)
- Submission on Disability Bill to the Oireachtas Committee on Justice, Equality and Women's Rights (November)
- Submissions and Oral Presentation to Oireachtas Committee on Environment, Heritage and Local Government – *Housing – The Vital Element*
- *Towards an Accessible Taxi Service for All* – Report of a project carried out by DFI in conjunction with the Irish Wheelchair Association, National Council for the Blind of Ireland, National Training and Development Institute, Not For Profit Business Association, and Rehab Care. (August)



REGIONAL SUPPORT SERVICE



*Allen Dunne
Senior Executive
Officer –
Operations*

DFI has ten Regional Support Officers (RSOs). The team is managed by Allen Dunne, Senior Executive Officer (Operational), who was appointed in May 2004.

Throughout the year, RSOs have worked with organisations from across the disability sector. While the RSO's aim is primarily to foster close working relationships between the Health Boards and the disability sector, they also work alongside a wide range of other Government and community and voluntary agencies to ensure that the needs of the disability sector are promoted. Through fostering links between the disability sector and these other agencies, RSOs actively promote the mainstreaming of services for people with disabilities.

RSOs assist disability organisations to identify their own organisational development needs. They also work with statutory and community and voluntary agencies to ensure appropriate responses to the organisational development needs of disability organisations. The supports, either given directly or supported by the RSO through another agency, include training, mentoring, support with Strategic planning, recruitment, and committee skills.

There are a wide range of representative structures at local and regional levels. These include the Community Platforms, Strategic Policy Committees and Social Inclusion Measures Groups. The RSOs are working to ensure that the disability sector is adequately represented on these structures. They actively support representatives on many of these Committees, offering them a feedback mechanism to the disability organisations in the local area.

RSOs assist organisations in understanding how they can best promote the needs of their members. This can include fostering an understanding of how statutory and community and voluntary agencies operate and how to approach these agencies in relation to the needs of the membership of organisations.

To further the development of the disability sector the RSOs have become involved in a wide range of work with a large number of agencies. The following is a list of some of the work in which RSOs are involved in different parts of the country:

- Direct support and advice to voluntary organisations
- Developing the relationship between individual organisations, the voluntary disability sector and the Health Boards
- Supporting Health Boards in their work with disability groups
- Supporting regional and issue based Platforms
- Supporting the representation of the disability sector on Strategic Policy Committees
- Supporting Regional Physical and Sensory Disability Database Development
- Co-ordination of activities between voluntary organisations
- Development of, and support for, networks of voluntary organisations
- Working with City/County Development Boards and Local Authorities in relation to Local Government Reform
- Working with Government agencies, including FÁS, Comhairle and the VECs
- Working with community and voluntary agencies, including Partnership Companies, Community Support Agencies, Family Resource Centres and Community Development Projects

During the year, each RSO continued to sit on the Health Board Regional Physical and Sensory Disability Co-Ordinating Committee in their region. Along with DFI's other representatives, their role is to represent all those organisations that do not get to attend the meetings themselves. The RSOs ensure that the DFI representatives work as a team on behalf of the other organisations, and they avail of all opportunities to promote and include the physical and sensory disability organisations in the development of services at regional level.

REGIONAL PLATFORMS

The RSOs meet with representatives from disability organisations across the disability sector at Regional Platform Meetings. Platforms enable the RSOs to provide the disability organisation with the most up-to-date information on the issues that affect them now and into the future. Information that is common to all organisations can be disseminated at Platform Meetings and collective responses to issues and concerns can be formed. Platform Meetings also provide a space for organisations to meet, network, share ideas and views on topics of concern around disability issues. They also provide support for organisations in exploring avenues of collaboration. Regional Platforms are open to all disability interest groups to join, and they provide opportunities for the voluntary and statutory sectors to interface in a spirit of partnership. They also have a crosscutting role. The Platforms continued to be a major source of assistance and support to organisations throughout 2004. During the year, a range of issues were covered at Meetings including:

- Advising and supporting organisations on the impact of policy developments such as Health Service Reform.
- Information and analysis of the National Disability Strategy

- Creating links and relationships between statutory agencies and local authorities
- DFI Budget Campaign
- Identifying local organisational development supports
- Impact of National Standards for Disability Services
- Advocacy and Representation
- Communication and involvement with emergent organisations

COLLABORATIVE WORK

RSOs were involved in developing seminars, training events and submissions in partnership with a wide range of statutory and voluntary organisations, examples of which include:

- *Person Centred Planning Workshop* - with the Irish Wheelchair Association, held in April in the Southern Region
- *Living with a Disability in the Community* – Submission to Limerick City Development Plan – with DESSA, PAUL Partnership, St Minchin's CDP, Rehab, West Limerick Centre for Independent Living - August, Mid-West Region
- *Schedule for the Evaluation of Individual Quality of Life* – with Western Health Board – May, Western Region
- *Information Sessions on Entitlements for People with Disabilities* – with Midland Health Board, and speakers from Citizens Information Service, Department of Social and Family Affairs, and Community Welfare Officers of the Health Board
- *Research into the Information Needs of the Disability Sector* - With Tipperary Citizens Information Centre, South Tipperary Disability Forum - October, and ongoing. South East Region

MENTAL HEALTH

DFI continued to meet with Mental Health Organisations throughout 2004. A number of conferences relating to mental health issues were attended. The Report of the Expert Group on Mental Health is now awaited. DFI has provided a strong voice to ensure that mental health features in the work of the Department of Health and Children Strategic Review of Disability Services.

INTELLECTUAL DISABILITY

While providing a range of supports and services in this area to our organisations, we continue to recognise the specific work undertaken by The National Association for People with Intellectual Disability – namhi, and the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disabilities. DFI has worked with both of these organisations in relation to a number of issues, including the National Standards for Disability Services and Disability Legislation.

PHYSICAL AND SENSORY DISABILITY

- **Supporting National Physical & Sensory Disability Database Development:** DFI has continued to support the implementation of the National Physical and Sensory Disability Database. At both regional and national levels, through its representation on the Co-Ordinating Committees, DFI assists organisations in the understanding of the Database. DFI also assists the Health Boards in encouraging organisations to participate in the Database, and has promoted the Database to organisations through the Newsletter and through Regional Platforms.
- **Performance Indicators:** DFI has continued involvement on the Working Group for Performance Indicators for Disability Services.

This is an incremental process which will be enhanced and expanded upon over the coming years. During 2004, the process changed slightly to include some reference to the National Standards and some cross cutting issues such as Community Employment and the challenges of measuring performance in a period of change.

- **National Standards for Disability Services:** DFI has continued to feed into the development of the Standards, and has been represented on the NDA Standards Advisory Committee. DFI has worked closely with the Not for Profit Business Association and the National Federation for Voluntary Bodies in developing joint positions in relation to the National Standards.
- **Department of Health and Children Working Group on Funding of Voluntary Physical and Sensory Disability Organisations Providing Health and Personal Social Services:** This Group was set up in June 2000 to consider and make recommendations on the funding of voluntary organisations providing health and personal social services to people with physical and sensory disabilities. DFI has worked closely with the Not for Profit Business Association to complete the task.
- **Department of Health and Children Working Group on Personal Assistance and Home Supports:** DFI has two representatives on the Working Group. This Group has focused on completing its work on Application and Assessment Procedures and Training.
- **Health Board Regional Physical and Sensory Disability Co-Ordinating Committees:** DFI is represented on each of the ten Health Board Co-Ordinating Committees. These Committees provide a mechanism for the development of services and for the setting of priorities at regional level.

Representatives provide a voice for a range of organisations that do not have direct representation on the Committees. The Committees also provide an opportunity to develop services on a partnership basis and to improve local co-ordination among statutory and voluntary organisations. DFI has three seats on each of the Co-Ordinating Committees (two seats in the Midlands), and the Regional Support Officers support the work of the representative organisations on these Co-Ordinating Committees. A DFI Protocol is in place regarding the appointment of representatives for the Co-Ordinating Committees. On 25th November 2004, the DoHC held an event around reviewing the Co-Ordinating Committees. DFI took part in the review by making a presentation and also nominated ten participants who had experience of Co-Ordinating Committees.

For the past number of years DFI has been working closely with the Department of Health and Children and with the ten Health Boards to ensure that a strong and mutually supportive partnership develops between the voluntary and statutory sectors in this area of physical and sensory disability. There are significant challenges in this work for all of the partners, but equally the opportunities are immense. We welcome and acknowledge the increased engagement and support of the Department of Health and Children, Eastern Regional Health Authority and the Health Boards in these areas and look forward to continued engagement in this period of change.

MANAGEMENT RESOURCE SERVICE



*Kieran Loughran
Director –
Management
Resource Service*

DFI is acutely aware of the changing and demanding environment in which voluntary disability organisations must operate. Apart from the changing operating environment, organisations must now prepare for changes in company law, charities legislation and regulation and national standards. In this regard the Management Resource Service is continually being assessed in an attempt to respond to the variety of needs that emerge amongst members.

The team of Regional Support Officers, with their different skill sets and experiences, further enhances the capacity of DFI to increase the range of supports to member organisations.

The direct DFI service was delivered in two distinct ways in 2004:

- Responding to requests from organisations, usually Boards or Chief Executive Officers, for specific help in relation to the work of the Board (governance), the work of the organisation (operations), or planning work involving the Board and CEO.
- Planned group work where issues identified by managers of organisations, such as management, planning, recruitment, and problem solving issues, are dealt with in group sessions.

DFI has accessed limited funding from the Department of Community, Rural and Gaeltacht Affairs, under the Training and Supports Scheme, and has identified areas for attention such as:

- Group training
- BoardMatch
- CEO Forum
- Update meetings to inform members in relation to Health Service Reform

DFI was also approved for a one year grant of €79,850 from the Dormant Accounts Fund Disbursements Board for a project that aims to offer training and advice to disability organisations and people with disabilities on how they can improve upon their skills in advocating and lobbying for mainstream services.

Funding was also ring fenced for the development of BoardMatch, and the roadmaps and directional support and training for new and emerging organisations.

DFI places great emphasis on working with and promoting other organisations where specialist support can be accessed, such as Comhairle, DESSA, The Wheel, Meitheal, and the Carmichael Centre. DFI sees one of its support roles as being to update and make organisations aware of the different sources of specialist expertise available nationally, regionally, and locally. DFI recognises these specialist agencies as adding value to the service, rather than reinventing programmes already available.

The DFI Management Resource Service continued to support and facilitate closer co-operation and collaboration within the voluntary sector and between

voluntary organisations and the statutory sector. We continued to play a leading role in the development of best management and organisational practice in the provision of quality services to people with disabilities by organisations affiliated to DFI.

With a full regional support team in place DFI can report that almost every member availed of some support nationally, regionally or locally, ranging from the provision of essential information to support and advice to the Board of Directors of our member organisations. Specific areas where the Management Resource Service was utilised by members during the year were as follows:

- Review of organisations' governance and structures with particular emphasis on roles and responsibilities
- Development of Strategic Plans
- Advocating for recognition/funding
- Making representations to statutory bodies
- Advice on promoting organisations
- Advising organisations on the impact of national policy in the regions
- Advocating on behalf of organisations in sensitive negotiations
- Providing an objective view for advancement/development/constructive criticism
- Community Employment
- Benchmarking
- Implications of Health Service Reform

NATIONAL MEDIA

Features relating to the work of DFI appeared in the national newspapers and national radio and television broadcasts at regular intervals throughout the year.

Extensive radio and television coverage, both in News and feature programmes, and interviews on programmes such as RTE 6.1 News, 9 O'Clock News, *Seachtain, Outside the Box*, Network 2 Television News, 11 p.m., Aertel News, Newstalk 106, News and *The Right Hook* News, Q102 (Lite FM) News, FM104, Today FM, INN News, Today FM News and *The Last Word*, and 2 FM.

In the print media, coverage of DFI's work in the sector was contained in The Times Health Supplement, The Offaly Express, Irish Times, Meath Chronicle, Sligo Champion, Leitrim Observer, Sligo Weekender, and the Northern Standard.

In May The Irish Examiner, amongst others, covered the launch of 'Housing, The Vital Element', DFI's Programme for Local Government, quoting DFI as saying that the Report of the Inspector of Mental Hospitals had questioned the continued placement of people in psychiatric units and hospitals, when 'their continued residence in long-stay psychiatric facilities is neither appropriate nor best-suited to their needs.'

The Irish Independent, in September, covered DFI's Submission to the Joint Oireachtas Committee on Environment, Heritage and Local Government, quoting DFI as saying that an extra welfare payment of €40 per week, to cover day to day costs, should be given in the next Budget to people with disabilities who are currently in receipt of a means tested social welfare payment, and that 'This should then be extended to all people with disabilities in the subsequent two Budgets. People with disabilities incur many extraordinary costs as a result of their disability, such as extra heating and taxis to get around.'

The Irish Examiner, in October, reporting on 'Rights, Commitments, Action!', stated 'The Disability Federation of Ireland (DFI) said that €334m is needed in this year's Budget to support the needs of people with disabilities...DFI called on the Government to live up to the promises it made seven years ago by providing the funds for disability services'

In relation to Disability Legislation, DFI was quoted in the Sunday Tribune as saying that 'If it is right that we legislate to ensure a public service which will not discriminate against a disabled person, surely it is equally right that we legislate for the statutory sector to ensure that it does not discriminate in its public policy and planning functions. Such a straightforward provision in the Disability Bill would be a significant rights based provision.'

REGIONAL SUPPORT OFFICERS



*Dominic Verrall
Regional Support Officer
(South East)*



*James Doorley
Regional Support Officer
(North East)*



*Joanne McCarthy
Regional Support Officer
(ERHA – East Coast Area
Health Board)*



*Maria Fox
Regional Support officer
(Midlands)*



*Michael Waugh
Regional Support Officer
(North West)*



*Toni Gleeson
Regional Support Officer
(Mid-West)*



*Martin Naughton
Regional Support Officer
(ERHA – Northern Area
Health Board)*



*Michael Corbett
Regional Support Officer
(West)*



*Anthony Carrick
Regional Support Officer
(ERHA – South Western
Area Health Board)*



*P.J. Cleere
Regional Support Officer
(South East)*



*Marcus Hufsky
Regional Support Officer
(North West)*



*Alison Ryan
Regional Support Officer
(South)*

INFORMATION AND AWARENESS

Information services provided by DFI are a key support to organisations. DFI services ongoing queries from organisations and groups and these queries often lead to other information supports being provided. The information may be of direct benefit or may lead to other opportunities. This service not only responds to the voluntary disability sector, but also to the broad community and voluntary sector and the statutory sector, including the joint activities of Social Inclusion Measures Committees and Citizens' Information Centres' information dissemination and projects. Information gathered by DFI is also crucial in planning and guiding future work. DFI produces policy related materials and instruments and prepares focused reports and submissions.

The DFI Newsletter continues to be produced monthly and has a circulation in excess of 1,300 copies. It is an important contact and reference point for organisations, both voluntary and statutory, and across all kinds of disabilities, making it easier for each to know what the other is doing, helping to identify resources and increasing collaboration.



Support Staff - l to r – Jacinta Dixon, Noreen Woods, Alison Ryan, Cathy McGrath, Mary Redmond.

PROFILING OF DFI ORGANISATIONS

During the year, DFI undertook a profiling exercise of member organisations. This exercise updated information already received from member organisations through *Painting Our Picture (2000)* and, more recently, the one to one interviews which were carried out with most organisations in the latter part of 2002 as part of the DFI Review.

This exercise will provide us with much needed concrete information with which to build up an accurate and up-to-date profile of the sector, allowing more effective lobbying and contribution to the formulation of policy.

DFI NEWSLETTER

Headlines in the DFI Newsletter during the year included the following:

'The Rights and Wrongs of the Disability Bill' (January)

'The unblemished truth is that people with disabilities have been wrongfully treated by our State.....This legislation must herald and uphold the right of people with disabilities to participate fully in society. The key challenge for this legislation is to put right, for the future, the continuing wrong that has diminished the life chances of people with disabilities in Ireland.'

'Housing – The Vital Element': DFI Programme for Local Government (March / April)

'The Programme highlights the responsibilities of Local Government to respond to the issues and needs of people with disabilities.'

'Health Service Reform Programme – Will We be 'Designed In'?' (June)

'Think of the new system as a public building; it must be fully and equally accessible to the needs of

people with disabilities. This is the once in a lifetime opportunity to 'design us in'. No more to hear the apology followed by 'this is the way the system operates'.

'Sustaining Progress – Mid Term Review' (July)

'We need to continue to focus on services and income supports as a necessary part of the infrastructure of the country. This must now be the priority for implementation of Sustaining Progress'.

'No More Excuses' (September)

'The recent Government Economic Review and Outlook indicates a very positive economic climate in 2004.....There is a real opportunity now for Government...to deal with the issues that DFI will once again promote in its Budget 2005 Campaign'.

'Health Bill 2004' (December)

'The Health Bill 2004 currently exhibits a number of weaknesses in relation to having the necessary partnership and involvement with the community and voluntary health and personal services sector.'

GOVERNANCE STRUCTURE

BOARD

John Saunders *Chairperson*
Schizophrenia Ireland

Marie Lynch *Vice Chairperson (from May 2004)*
Irish Wheelchair Association

Ann-Marie Flanagan *Vice-Chairperson (to May 2004)*
Disabled People of Clare

Geraldine Clare *Honorary Treasurer*
AWARE

Anne Hughes *(to May 2004)*
Dyslexia Association of Ireland

Nick Killian *(from May 2004)*
Irish Association for Spina Bifida and Hydrocephalus

Joe T Mooney
Muscular Dystrophy Ireland

Michael Dineen *(Resigned July 2004)*
MS Society

Mike Glynn *(from October 2004)*
Brainwave

Niall Keane
National Association for Deaf People

Paul Daly *(to September 2004)*
Down Syndrome Ireland

Eithne Frost *(from December 2004)*
Irish Motor Neurone Disease Association

David Burke
Focus Ireland

Desmond Kenny
National Council for the Blind of Ireland

Bernie Murphy
Headway Ireland

MEMBER ORGANISATIONS

NATIONAL COUNCIL

Action for Mobility

AHEAD

Alzheimer Society of Ireland

APT

Arthritis Foundation of Ireland (Now Arthritis Ireland)

ASPIRE

Asthma Society of Ireland

Aware

BIH Housing Association (Irl) Ltd

Brainwave – The Irish Epilepsy Association

BRÍ

CASA – Caring and Sharing Association

Center for Independent Living

Central Remedial Clinic

Centre for Independent Living Mayo

Centre for Independent Living Tipperary

Cheeverstown House

COPE Foundation

Co Roscommon Support Group for People with Disabilities

Cystic Fibrosis Association of Ireland

DEBRA Ireland

Disabled Drivers Association

Disabled People of Clare

Doorway to Life

Down Syndrome Ireland

Dyslexia Association of Ireland

Enable Ireland

Festina Lente Foundation

Fighting Blindness

Focus Ireland

Freidreich's Ataxia Society of Ireland

Genetic and Inherited Disorders Association

HAIL Housing Association for Integrated Living

Headway Ireland

Huntington's Disease Association of Ireland

Independent Living Community Services

Irish Association for Spina Bifida and Hydrocephalus

Irish Deaf Society

Irish Guide Dogs for the Blind

Irish Haemophilia Society

Irish Kidney Association

Irish Motor Neurone Disease Association

Irish Raynauds and Scleroderma Society

Irish Society for Autism

Irish Wheelchair Association

The Jack and Jill Children's Foundation

KARE

Leitrim Association of People with Disabilities

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

National Association for Deaf People

National Council for the Blind of Ireland

National Federation of Arch Clubs

Neurofibromatosis Association of Ireland

North West MS Therapy Centre

Parkinson's Association of Ireland

Polio Fellowship of Ireland

Post Polio Support Group

Reach Ireland

Rehab Group

Riding for the Disabled Association

Royal Hospital Donnybrook

Schizophrenia Ireland

Shannon Community Workshops

Sophia Housing Association Ltd
 Special Olympics Ireland
 Spinal Injuries Ireland
 St Catherine's Association (formerly Co. Wicklow
 Association for the Mentally Handicapped)
 St Gabriel's School and Centre
 St Mary's Hospital and Residential School
 St Michael's House
 Sunbeam House Services
 Vantastic
 Vergemount Housing Fellowship
 Walkinstown Association
 Western Care Association
 West Limerick Community Workshop

Associate Members

Ann Sullivan Centre
 Bodywhys
 Centre for Independent Living Blanchardstown
 Centre for Independent Living Carlow
 Centre for Independent Living Dublin 7
 Centre for Independent Living Galway
 Centre for Independent Living Offaly
 Centre for Independent Living Sligo
 Centre for Independent Living Waterford
 Centre for Independent Living Wexford
 Cheshire Ireland
 Children in Hospital Ireland
 Diabetes Federation of Ireland Southern Regional
 Office
 Dyspraxia Association of Ireland
 Féach

Fibromyalgia Support Group (Midlands)
 Galway County Association for Mentally Handicapped
 Children
 Lucan Disability Action Group
 Migraine Association of Ireland
 Myasthenia Gravis Association
 Noinin Support for Autism
 Out and About Association
 Peacehaven Trust
 Peter Bradley Foundation
 Sovereign and Military Order of Malta

DFI Welcomes New Members in 2004

BRÍ

*Centre for Independent Living Blanchardstown

Center for Independent Living

*Centre for Independent Living Dublin 7

Centre for Independent Living Mayo

*Centre for Independent Living Offaly

*Centre for Independent Living Sligo

*Noinin Support for Autism

St Michael's House

* *Associate Members*

STAFF

MANAGEMENT TEAM

John Dolan	<i>Chief Executive Officer</i>
Kieran Loughran	<i>Director, Management Resource Service</i>
Aisling Walsh	<i>Senior Executive Officer – Policy and Research</i>
Allen Dunne	<i>Senior Executive Officer – Operational (from 1st May 2004) Regional Support Officer SWAHB (to 30th April 2004)</i>

REGIONAL SUPPORT TEAM

Michael Corbett	<i>Regional Support Officer, WHB</i>
James Doorley	<i>Regional Support Officer, NEHB</i>
Maria Fox	<i>Regional Support Officer, MHB</i>
Toni Gleeson	<i>Regional Support Officer, MWHB</i>
Joanne McCarthy	<i>Regional Support Officer, ECAHB</i>
Martin Naughton	<i>Regional Support Officer, NAHB</i>
Anthony Carrick	<i>Regional Support Officer, SWAHB (from 1st November 2004)</i>
Alison Ryan	<i>Regional Support Officer, SHB</i>
Dominic Verrell	<i>Regional Support Officer, SEHB (to 11th January 2004)</i>
P.J. Cleere	<i>Regional Support Officer, SEHB (from 29th March 2004)</i>
Michael Waugh	<i>Regional Support Officer, NWHB (to 30th April 2004)</i>
Marcus Hufsky	<i>Regional Support Officer, NWHB (from 1st July 2004)</i>
Cathy McGrath	<i>RSO Assistant</i>

ADMINISTRATION SUPPORT TEAM

Jacinta Dixon	<i>Support/Administration</i>
Mary Redmond	<i>Support/Administration</i>
Alison Ryan	<i>Support/Administration</i>
Noreen Woods	<i>Support/Administration</i>

ACKNOWLEDGEMENTS

DFI would like to acknowledge those who, in a voluntary capacity, represented our interests on various national Committees and Groups during 2004.

COMMITTEES AND GROUPS – GENERAL

- **An Bord Altranais Prescribing Committee for Nurses and Midwives** – Collette Hempenstall (Cheeverstown House)
- **Barcelona Declaration** – Marie Lynch (Irish Wheelchair Association)
- **Dormant Accounts Disbursement Board** – Gerry Ryan (Formerly General Secretary, namhi, representing the voluntary disability sector)
- **ERHA Regional Provider Forum** – Joan Bradley (Post Polio Support Group)
- **Working Group on the Funding of Voluntary Physical and Sensory Disability Organisations Providing Health and Personal Social Services** – The voluntary sector has five representatives on the Working Group: Eithne Frost (Irish Motor Neurone Disease Association), Clodagh O'Brien (Not for Profit Business Association), Des Kenny (National Council for the Blind of Ireland), Mark Blake-Knox (Cheshire Ireland)
- **Workway** – Ronnie Conlon (Irish Wheelchair Association), Paul Fagan (CIL Donegal), Mary Grandfield (Kerry CIC), Adrian Stewart (National Training and Development Institute)
- **Department of Health and Children Strategic Review of Disability Services – Study Groups**
 - **Assessment, Early Intervention and Pre-School** - Jonathan Irwin (Jack and Jill Foundation)
 - **Access to Mental Health Services** - John Saunders (Schizophrenia Ireland), Margaret Webb (Eve Holdings)

- **Disabilities and Older People** - Maurice O'Connell (Alzheimer Society), Robin Webster (Age Action Ireland)
- **Protecting Vulnerable People** Nick Killian (Irish Association for Spina Bifida and Hydrocephalus)
- **Families and Carers of People with Disabilities** - Enda Egan (Carers Association)

HEALTH BOARD REGIONAL PHYSICAL AND SENSORY CO-ORDINATING COMMITTEES

North East Health Board

James Doorley, *DFI*

Noreen O'Donnell, *Brainwave – The Irish Epilepsy Association* (from March 2004)

Rex Lee, *North Meath Partnership*

Irene Hamill, *Headway Ireland* (from May 2004)

South East Health Board

Dominic Verrall, *DFI* (to January 2004)

P.J. Cleere, *DFI* (from April 2004)

Katie Hourigan, *MS Society of Ireland*

Nan Sibbald, *CIL Carlow, Alternate*

Midland Health Board

Maria Fox, *DFI*

Molly Buckley, *Irish Wheelchair Association* (to October 2004)

Michelle Gilligan, *Irish Association for Spina Bifida and Hydrocephalus* (from October 2004)

Brendan McElligot, *Muscular Dystrophy Ireland* (to October 2004), *Alternate*

Margaret Bassett, *Brainwave – The Irish Epilepsy Association* (from October 2004), *Alternate*

Mid West Health Board

Toni Gleeson, *DFI*

Noreen Mullane, *Post Polio Support Group (to July 2004)*

Jim Casey, *Tipperary Centre for Independent Living*

Dermot Hayes, *Disabled People of Clare (to July 2004), Alternate*

Anna Kelly, *Brainwave – The Irish Epilepsy Association (from July 2004)*

Ann Marie Flanagan, *Disabled People of Clare (from July 2004), Alternate*

Western Health Board

Michael Corbett, *DFI*

Aidan Larkin, *MS Society of Ireland (from March 2004)*

Coleen Mullanney, *Irish Society for Spina Bifida and Hydrocephalus (from September 2004)*

Caroline Moran, *Muscular Dystrophy Ireland, (to early 2004) Alternate*

Rebecca Leavey, *Brainwave - The Irish Epilepsy Association, (from September 2004), Alternate*

North West Health Board

Michael Waugh, *DFI (to March 2004)*

Marcus Hufsky, *DFI (from July 2004)*

Josephine Mannion, *MS North West Therapy Centre*

Brian Crummy, *Disabled Drivers Association, Alternate*

Southern Health Board

Alison Ryan, *DFI*

Carmel Coughlan, *MS Society*

Una Barry, *Brainwave – The Irish Epilepsy Association (from October 2004)*

Liz Owens, *Headway Ireland, (to September 2004)*

Nicola Meacle, *CIL Cork, (to September 2004)*

Trudy Renshaw, *Muscular Dystrophy Ireland (from October 2004) Alternate*

EASTERN REGIONAL HEALTH AUTHORITY

East Coast Area Health Board

Joanne McCarthy, *DFI*

Ava Battles, *Brainwave – The Irish Epilepsy Association (from May 2004)*

Eithne Diamond, *Muscular Dystrophy Ireland (from May 2004)*

Jennifer Reilly, *MS Ireland (from May 2004) Alternate*

Northern Area Health Board

Martin Naughton, *DFI*

Joe T Mooney, *Muscular Dystrophy Ireland*

Bernie Murphy, *Headway Ireland*

Sean Kinsella, *MS Society, (from May 2004), Alternate*

South Western Area Health Board

Allen Dunne, *DFI (to October 04)*

Anthony Carrick, *DFI (from November 2004)*

Michael Dineen, *MS Society of Ireland (to May 2004)*

Nick Killian, *Irish Association for Spina Bifida and Hydrocephalus (from May 2004)*

Joan Bradley, *Post Polio Support Group*

Sonya McLean, *Lucan Disability Action Group, (from May 2004) Alternate*

ORGANISATIONS, GROUPS AND STRUCTURES WITH WHOM DFI WORKED DURING 2004

- Age Action Ireland
- An Bord Altranais
- Anti-Poverty Networks
- Association of Health Boards in Ireland
- ADM & Partnership Companies
- Interim Health Service Executive
- Barnardos and The Children's Research Centre
- Carers Association
- Carmichael Centre for Voluntary Groups
- Centre for Early Childhood Development (cecde)
- Childrens' Rights Alliance
- Comhairle
- Congress Centres Network
- CORI Justice Commission
- Crisis Pregnancy Agency
- Dáil and Seanad Eireann
- Disability Action (N.I.)
- Disability Legislation Consultation Group (DLCG)
- Disability Equality Specialist Support Agency (DESSA)
- Dormant Accounts Disbursement Board
- East Coast Area Health Board
- Eastern Regional Health Authority
- European Association of Service Providers to People with Disabilities
- FÁS
- Federation of Voluntary Bodies Providing Services to People with Intellectual Disability
- Irish Council for Social Housing
- Irish National Organisation for the Unemployed (INOUE)
- Irish Rural Link
- Irish Senior Citizens Parliament
- namhi
- National Association of Building Co-Operatives
- National Disability Authority
- National Economic and Social Council (NESC)
- National Economic and Social Forum (NESF)
- National Rehabilitation Hospital
- National Women's Council of Ireland
- National Youth Council of Ireland
- North/South Health Services Partnership
- Not for Profit Business Association
- Office for Health Management
- People with Disabilities in Ireland Ltd
- Pavee Point
- Regional and Area Health Boards
- Rural Development Forum
- Senior Citizens Parliament
- Society of St Vincent de Paul
- The Wheel
- Vocational Education Committees
- Institute for Design and Disability
- Udarás Na Gaeltacht
- Western Development Commission
- County and City Development Boards

DFI IS A MEMBER OF THE FOLLOWING ORGANISATIONS

- Irish Council for Social Housing (ICSH)
- European Association of Service Providers to People with Disabilities (EASPD)
- Irish Charity Tax Research Group (ICTRG)
- The Wheel

STATUTORY BODIES

We wish to acknowledge the following statutory bodies for their co-operation with DFI in its work:

- Comhairle
- Dáil and Seanad Eireann
- Department of Community, Rural and Gaeltacht Affairs
- Department of Health and Children
- Department of Justice, Equality and Law Reform
- Department of Social and Family Affairs
- Department of Education and Science
- Department of The Taoiseach
- FÁS
- Health Boards/Eastern Regional Health Authority
- Interim Health Service Executive
- National Disability Authority

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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
- Intellectual
- Mental Health
- Physical
- Sensory
- 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 currently 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
- Training and Support
- Organisation and Management Development
- Research and Policy Development
- Advocacy and Representation
- Networking

DFI also supports the broader voluntary and disability sector through its representation of the disability strand with 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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