



**NEWSLETTER | OCT / NOV 2013**

**Disability Federation of Ireland**

An advocate for the voluntary disability sector

Supporting organisations to enable people with disabilities

## **Promoting Disability Rights and Interests at European Level is a Priority For DFI**

**The Disability Federation of Ireland (DFI) represents people with disabilities and disability organisations at local, national and European level. Eighty million people in Europe are living with a disability<sup>1</sup> and DFI firmly believes that the European Union (EU) must become a 'One Europe for all', fully inclusive of people with disabilities.**

To this end, DFI have been members of the European Association of Service providers for Persons with Disabilities (EASPD) for the past ten years: as Chief Executive of DFI, I sit on its board, as well as being a member of the Policy Impact Group. In 2011, DFI also joined the European Movement of Ireland (EMI), a mainstream, non-disability specific network whose aim is to develop connections between Europe and Ireland. A year later, we joined the European Disability Forum (EDF) as full members. Through these networks DFI is representing Irish disability interests in Europe and exchanging models of good practice. We lobby and contribute to debate and proposals in Europe, keeping up to date with policy and legislative changes that impact disability.

Many of DFI's members are already active in Europe. As you might remember, at the start of the year, we put out a call to those interested in forming a DFI European Network, and we received interest from over 40 organisations. We are slowly developing this network and have identified the 2014 European Elections as one of our priorities. We will keep you up to date on any events or activities that our network is involved in, including our European Election strategy.

We understand that the scope and language of Europe can be daunting but we are doing our best to navigate this new landscape. We will endeavor to communicate our learning through a new quarterly update in our newsletter, and we also invite any members to contribute to this new European segment. Most of all, our objective is to share information and experiences in order to highlight the importance of the European dimension in all our work, so that we all might make sense of Europe together and represent disability to the best degree possible.

**John Dolan, Chief Executive Officer**

**DFI Newsletter Oct – Nov 2013**



## Focus on Europe

DFI is becoming increasingly active at European level, and we are introducing a quarterly European Supplement to our newsletter. This supplement will cover some of the latest goings-on in Europe and how they impact disability in Ireland, as well as looking at the kind of work that DFI carries out in Europe on behalf of people with disabilities and their families.

### International Day of Persons with Disabilities Celebrated Across Europe

**Celebrations for the International Day of Persons with Disabilities were held across Europe on Monday, 3 December 2013.**

The theme of this year's event, aiming to promote better awareness and understanding of disability issues, was "Break barriers, open doors: for an inclusive society for all". Eighty million citizens of the European Union (EU) and over one billion people across the world, or approximately 15% of the global population, live with some form of disability<sup>1</sup>.

#### Irish celebrations

In Ireland, a new disability research report, 'Outside The Circle', was launched on the day in the National Gallery of Ireland in Dublin. Plan Ireland, together with the Dóchas Disability and International Development working group, presented the findings of the report, conducted by the University of Toronto on their behalf. The Disability Federation of Ireland (DFI) is a member of the Dóchas working group involved. The report highlights the widespread discrimination that children with disabilities are subjected to in West Africa, and calls for greater inclusion in development programming by government, civil society and donors. Inclusion Ireland also marked the day when the self-advocacy sub-committee of the organisation's Board gave a briefing to Oireachtas Members on the issues which matter to them. Brendan O'Connor, deputy editor of the Sunday Independent, chaired the

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<sup>1</sup> <http://www.un.org/disabilities/default.asp?id=1607>

briefing, which saw people with intellectual disabilities discuss their interests and concerns with members of the Dáil and Seanad.

### Awareness

The International Day of Persons with Disabilities was established during the International Year for People with Disabilities (1981). As well as raising awareness, the day is intended to encourage practical and concrete action to include disability in all aspects of development. The events and activities organised highlight the need to ensure that people with disabilities have equal opportunities for participation in the political, social, economic and cultural life of their communities.

## European Disability Movement Calls For Inclusive, Sustainable Development

**The European Disability Forum (EDF) has called on European Union (EU) institutions and member states to include people with disabilities and their representative organisations in all decision-making processes at every level.**

The demand came at a conference on ‘Disability and Sustainable Development’, held by the EDF in Vilnius, Lithuania on 16 November, and attended by representatives of its member organisations from across Europe.

### One Europe For All

In a statement endorsed by the EDF, the organisation urged the European Council, European Commission, European Parliament and member states to involve people with disabilities “in the drafting and implementation of legislation, policies and programmes” at national and international levels.

Calls for the adoption of a common EU framework for collecting and analysing data to combat discrimination against people with disabilities, as well as a European Accessibility Act to ensure access to goods and services for people with disabilities, were also put forward.

Chief Executive of the Disability Federation of Ireland (DFI), John Dolan, stated that “DFI counts as one of its goals a European Union that is fully inclusive of people with disabilities: ‘One Europe for All’. The initiatives proposed in this statement support and build toward that goal, and the European Union and its member states should accept and act on this opportunity to work towards it. It is hugely important that active citizenship and participation for people with disabilities be facilitated and promoted through such measures”.

## Conference

Examined from the perspective of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the conference addressed the human rights and social inclusion needs of people with disabilities across the three areas of social, economic and environmental development.



President of the EDF, Yannis Vardakastanis, highlighted that eighty million people in Europe – or 16% of the population – live with a

disability, and one in four families have a family member with a disability. In light of this, he explained that inclusive, sustainable development must take people with disabilities into account, arguing that the €141 billion of development aid funding set aside by the EU must include people with disabilities. “Development that does not include people with disabilities is a direct violation of the UNCRPD. Development should affect every citizen in society without any exclusion or discrimination”, he said.

**President of the EDF, Yannis Vardakastanis, with members of the Lithuanian government at the conference.**

Photo courtesy of the EDF.

## Statement

Reflecting on 2013 as the European Year for People With Disabilities, the statement acknowledges that many Europeans with disabilities still encounter substantial legal and practical barriers when accessing their rights, hindering their inclusion and participation as active citizens at both European and national levels. The EDF, through this statement, therefore contends that all elections should be made fully accessible to all people with

disabilities, with support available for people with disabilities who wish to stand in elections, in order to promote active participation in the political process. Necessary measures which ensure that all people with disabilities can engage in social, cultural and economic activities at every level should be taken.

The statement notes that people with disabilities often face difficulties in participating in political and social life, as well as confronting restrictions in accessing public information tools, employment, transport, education, and judicial processes, among others. The EDF is therefore proposing a European Accessibility Act in order to ensure access to goods and services for all persons with disabilities.

Proposals are also put forward for a European Mobility Card which permits EU nationals with disabilities visiting other member states to receive the same benefits and access to services as provided to those living in that member state. The statement also calls for the development of a common EU framework “for the collection and analysis of reliable, comparable and disintegrated data” which could be used to combat discrimination and ensure equality.

### **Commitment**

Along with the statement, the conference focused on the need for action on the sustainable growth for Europe with the inclusion of people with disabilities. Key speakers addressing the conference included Facundo Chavez, representative of the United Nations (UN) Office of the High Commissioner of Human Rights, and John van Geuzendam, head of the disability division of the European Union (EU) Commission. Representatives from the EDF also included the director and deputy directors of the organisation, Carlotta Besozzi and Javier Guemes; Donata Vivanti, Vice President; and Rodolfo Cattani, EDF secretary.

For more information on the conference and the statement, visit [http://www.edf-feph.org/Page\\_Generale.asp?DocID=13855&thebloc=33133](http://www.edf-feph.org/Page_Generale.asp?DocID=13855&thebloc=33133). The presentations given by the speakers at the conference are available at <http://bit.ly/180MmEc>

## European Union Agrees On New Budgeting and Funding Measures

The Disability Federation of Ireland (DFI) continues to actively represent people with disabilities in budgeting and funding negotiations at the European level. Currently, the European Union (EU) is entering a new funding cycle (2014-2020), with the new EU budget recently agreed upon. The 2014 European Semester has also been launched with the European Commission publishing the Annual Growth Survey, a guiding document relating to EU annual objectives and funding priorities. Here, DFI takes you through some of the latest updates on EU funding news.

### EU Budget

After months of negotiations with national governments, on 11 November, the European Parliament voted in favour of the EU's Multiannual Financial Framework (MFF) for the years 2014 to 2020. The consent of the European Parliament clears the way for the final approval by the Council in the coming weeks. The EU's MFF 2014-2020 amounts to €1868.4 billion. If fully activated, this will represent an increase

of €36.8 billion. This budget sets out the European commitment to broad policy areas, as well as the budgets for Structural and Cohesion funds. Funding for unforeseen circumstances (like the Emergency Aid Reserve, the European Globalisation Fund, the Solidarity Fund and the Flexibility instrument) and the European Development Fund are situated outside of the MFF and will come from other sources.

### European Social Fund

The EU budget makes provisions for the European Social Fund (ESF). This is a type of structural fund and Europe's main instrument for supporting employment, helping people to get better jobs and ensuring fairer job opportunities for European citizens. From 2014, the role of the ESF will be reinforced. There will be close cooperation between public



**The EU budget for 2014-2020 is set at €1868.4 billion.**

Image by m\_bartosch used by with courtesy of freedigitalphotos.net

authorities, social partners and bodies representing the civil society – such as DFI - at national, regional and local levels throughout the whole programme cycle. At least 20% of the ESF funding must be allocated to social inclusion measures. It is expected that Ireland will continue to receive a European Social Fund allocation of €901 million for the new period 2014-2020<sup>2</sup>.

Ireland and the European Commission have a Partnership Agreement outlining Ireland's strategic priorities in relation to the use of European Social Funds. DFI has commented on the new priorities as part of the European Anti Poverty Network Ireland. This submission can be found at <http://www.eapn.ie/eapn/submission-to-irelands-partnership-agreement-on-eu-funds-2014-2020>.

### Annual Growth Survey

The European Commission has published the 2014 Annual Growth Survey (AGS) and this will be finalised by March with the European Parliament's approval. The AGS launches the European Semester, an instrument for budgetary and policy coordination between Member States. It is the first step in the annual cycle, setting out the broad EU economic priorities for the year to come. Applications for funding must be in line with the objectives identified in the European Semester. These priorities will determine the funding agenda for the coming year.

DFI participated in discussions on the Annual Growth Survey at the European Association of Service Providers for Persons with Disabilities (EASPD) Conference in Istanbul on 4 December 2013. The next phases of the Semester – National Reform Programme and Country Specific Recommendations – also involve the active participation of organisations representing civil society, and DFI will be making submissions as part of the European Anti-Poverty Network Ireland.

### Erasmus+ Programme

The Erasmus+ is the new programme recently approved by the European Parliament, and it is expected to be approved by the European Council within the coming month. It will bring

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• <sup>2</sup> The European Social Fund is a type of Structural fund.



together all the current EU and international schemes for education, training, youth and sport, replacing seven existing programmes with one<sup>3</sup>.

The programme will support three main types of actions:

1. Learning opportunities including study and training, traineeships, teaching and professional development and non-formal youth activities, such as volunteering.
2. Institutional cooperation between educational institutions, youth organisations, businesses, local and regional authorities, and non-governmental organisations (NGOs) to encourage the development and implementation of innovative practices in education, training and youth activities, and to promote employability, creativity and entrepreneurship.
3. Support for policy reform in Member States and cooperation with non-EU countries, with a focus on strengthening the evidence-base for policy making and exchange of good practices.

It begins in January 2014, providing opportunities to four million people. A seven year programme, it holds a budget of €14.7 billion, representing a 40% increase on the previous seven budgets. It also includes a dedicated budget for sport of around €265 million over seven years, a significant increase in the funds allocated for the development of knowledge and skills, and a new loan scheme for Masters students.

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<sup>3</sup> The following programmes will be merged to form the new Erasmus+ programme: Erasmus, Leonardo da Vinci, Comenius, Grundtvig, Youth in Action, Mundus, Tempus and Alfa.





## Budget 2014

### Budget 2014 Confirms Lack of Coherent Plan of Action For People with Disabilities



The Disability Federation of Ireland joined with a number of national voluntary disability organisations to make a joint statement calling for “the protection of and investment in people with disabilities” to Government in advance of the Budget.

**The Minister of Finance, Michael Noonan, and the Minister of Public Expenditure and Reform, Brendan Howlin, unveiled Government’s financial programme with the announcement of Budget 2014 on 15 October last.**

Among the measures affecting people with disabilities are the abolition of the telephone allowance, and the €113 million savings being sought through a review of the medical card scheme. In the wake of the announcements, John Dolan, Chief Executive of the Disability Federation of Ireland (DFI), explained, “the disability movement has been hit hard by harsh outcomes of previous budgets; the social infrastructure that exists to support them has been decimated and the initiatives announced in this Budget do too little to reverse that”. He continued, “economic concerns have overtaken the social in this Budget. We need to

develop strategic and sustainable plans for social inclusion, but the measures revealed in this Budget have weakened that opportunity.”

In particular, DFI remains concerned over the review of the medical card scheme as detailed by Minister for Health, James Reilly. The Department of Health is seeking to save €113 million by improving the accuracy of the medical card system, changing the income thresholds for those over 70, and introducing amendments to the return to work arrangements. Mr Dolan, stated that “there is no official indication of how the changes to the medical card will be implemented, but it has been speculated that in the region of 100,000 medical cards may be taken out of the system. We are concerned that this review will unduly target those currently receiving discretionary medical cards who may fall over the income threshold, and that the episodic nature of certain illnesses and conditions will not be taken into account”.

Although DFI welcomed some positive measures for people with disabilities and their families – including free GP care for those under five years of age, €20 million for community mental health services, and additional funds for the housing adaptation grants – the organisation is disappointed in the €113 million medical card review and the scrapping of the telephone allowance. The Budget yet again fails to meet people with disabilities’ ambition to live in the community with dignity and independence.

Mr Dolan concluded that “the Government has made several commitments to people with disabilities and their families over the last few years. People with disabilities and their families now clearly understand that government are not determined to keep their promises to them.”

For more information and analysis of the disability aspects of the recent announcements, see our Budget 2014 Newsletter Special at <http://www.disability-federation.ie/userfiles/file/Budget%202014%20Newsletter%20Final.pdf>



## Focus Group Discusses Culture and Operations of Social Protection Services

**Samantha Whelan and Tomás Thompson of Cystic Fibrosis Ireland were among several representatives of organisations working in the community who participated in a focus group held by the Department of Social Protection (DSP) on 15 October.**

Following their participation in the Disability Federation of Ireland (DFI) Network of Interest on DSP Issues, Samantha and Tomas were invited by the department to provide feedback on their experience and perspective on DSP culture and operations.

Joan O'Donnell, support officer with DFI, explains that this work with the DSP is important as “we need to protect the income of people with disabilities in these tough times. We also need to impress upon the department that, when people are applying for their benefits and entitlements, it is often a very stressful time for them and customer service is hugely important as well as providing clear information and having transparent processes”.

### Challenges

The focus group addressed the challenges faced by service users and advocates in liaising with the DSP, as well as generating ideas for the future improvement of DSP services. With full attendance on the day, the focus group aimed to help the DSP in continuing to evolve and meet its growing mandate for government.

Samantha explains that the session began with “an honest and lovely discussion relating to the various challenges faced by service users and advocates” in dealing with the DSP. The main issues raised, many of which have been covered in the DFI Network of Interest groups, included the negative experiences of service users as a result of their treatment by DSP staff and the lack of a customer service culture within the department. In this regard, many service users had reported feelings of intimidation in liaising with the DSP, with a growing perception of a “gatekeeper” mentality and an imbalance of power at the DSP coming to the

fore. It was also noted that some service users feel that the “New Long-Term Unemployed” are prioritized over others when requesting information and services.

Arguments were made for the provision of up-skilling and training of carers, better treatment of migrants, and the difficulties encountered in the physical layout of DSP offices, particularly in relation to the hatch cubicles. Positive feedback was given on the layout and the conduct of staff in the newly refurbished offices. Given the number of issues and concerns among the group, the limited time available proved restrictive. However, the general consensus found that many of those participating in the focus group were coming across the same challenges frequently and repeatedly.

### Suggestions

The final part of the focus group required the attendees to offer suggestions to the DSP that would allow the provision of an “ideal” service at the department. Proposals included the development of an open, friendly environment in local DSP offices, with staff trained in customer care and equipped with up-to-date information on all social protection rights and entitlements.

It was felt that all DSP staff should be trained and knowledgeable on the availability of suitable training and skills required for the labour market, and that service users themselves should be more visible and made to feel more central to the provision of services. The group also pointed out that all applications should be processed in a timely and transparent manner, with the example of the ways in which the Revenue Commissioners have embraced change with the use of information technology and the speedy processing of queries referred to on a number of occasions.

The focus group was one of a number of workshops conducted by the DSP over the course of a week, with employers and representatives of DSP staff taking part in those. Along with others, the issues raised during the focus group will be discussed in future DFI Network of Interest in DSP Issues meetings.

For more information, please contact Joan O'Donnell on 086 383 4586 or at [joanodonnell@disability-federation.ie](mailto:joanodonnell@disability-federation.ie).

## Updates To Social Protection Schemes Given At Community Pillar Meeting

Changes to several Department of Social Protection (DSP) schemes and payments in Budget 2014 came under discussion at a Community and Voluntary Pillar meeting of the DSP on 11 November. Here, we take a look at two of those schemes.

### Rent Supplement Scheme

The rent supplement scheme provides short-term support to people living in private rented accommodation whose means cannot cover their accommodation costs, and who do not have accommodation available to them from any other source. Currently, there are 82,000 recipients of the scheme at a cost of €403.4million.

There are no specific exemptions to qualification for rent supplement for people with disabilities, with all customers being treated equally. Entitlement to the scheme is subject to a number of qualifying conditions. At the time of application, a claimant must have been living in private rented accommodation, accommodation for homeless persons or an institution for six of the twelve months prior to the date of claim, or have had an assessment of housing need carried out within the same twelve month period, and subsequently been deemed by a housing authority to be eligible for and in need of social housing support.

Rent supplement is payable where a person has left institutional care and satisfies the conditions of the scheme. If the person concerned requires specialized housing due to the nature of their condition, DSP officials are empowered to pay rent supplement in excess of the prescribed rent limits, thereby fully supporting independent living.

There have been instances where applications for rent supplement have been made to the DSP where the applicants have either remained in institutional care or have moved from one institution to another.

Rent supplement is not payable where an applicant is resident in an institution. An institution is defined as a hospital, convalescent home or home for persons suffering from physical or mental disability, or any other similar establishment which provides residence, maintenance or care for the people living within it.

## Exceptional Needs Payment

Exceptional Needs Payments (ENPs) fall under the Supplementary Welfare Allowance scheme. The purpose of an ENP is to help meet an essential once-off need which a person could not reasonably be expected to meet out of his or her weekly income.

With more than 2,500 ENPs paid out each week by the DSP, it is expected that more than 132,000 will be issued in 2013, worth an estimated €35 million. The main items eligible under the scheme include household appliances, furniture, clothing, funeral expenses and child-related items. There is no automatic entitlement, exhaustive list of items or prescribed amounts covered under the scheme.

Expenditure on the ENPs is being reduced by €2.1 million in 2014, and this will be achieved through ongoing reviews of the recommended payment rates under the scheme, ensuring consistency on a national basis. Depending on the outcome of this review, further guidelines may be issued to DSP staff on the recommended amounts payable for key items of expenditure under this scheme.

Recommended payments do not in any way limit the discretionary powers of staff provided for under the Social Welfare Acts. ENPs will continue to be available to those in need of assistance; details of the recommended maximum amounts for major household appliances and furnishings are as follows:

Adult clothing : €100	Fridge: €140
Child clothing: €50	Fridge/Freezer: €250
Single bed: €120	Washing machine: €250
Double bed: €180	Cooker: €310
Pram/Buggy/Cot: €100	Wardrobe: €150
Double buggy: €150	Chest of drawers (3): €90
Floor covering: €10 (per m <sup>2</sup> )	Chest of drawers (6): €100
Kitchen table: €120	Kitchen chairs: €40 (each)



## Organisational Development

### **Adare's Employment Law and HR Services At A Glance**

- **Contracts** of Employment  
& Employee Handbooks  
containing policies &  
procedures - drafting /  
review / update
- **HR Helpdesk** – provision  
of on-going access to  
Phone / Email HR Advice  
and Support
- **Representation** at  
Workplace Relations  
Commission, Rights  
Commissioners,  
Employment Appeals  
Tribunal (EAT) and other  
external employment  
bodies
- **HR Consultancy Services**  
– Recruitment /  
Investigations / Dispute  
Management

### **Employers Must Accommodate People With Disabilities: HR Update**

**The Disability Federation of Ireland, together with Adare Human Resource Management, operates a support structure which allows member organisations to exclusively avail of discounted Human Resource and Employment Law Support Services.**

Adare Human Resource Management (HRM) provides these services to a large number of organisations within the community and voluntary sector. Organisations are supported by ensuring legal compliance in their practices, policies and procedures, and thus minimizing the risk of exposure to legal challenges.

For more information on this service, please get in touch with your DFI Support Officer or contact Derek McKay at [dmckay@adarehrm.ie](mailto:dmckay@adarehrm.ie) or on 01-612 7092.

Alternatively, visit

<http://www.disability-federation.ie/index.php?uniqueID=50>



## Equality Tribunal Awards Man €63,000 In Discriminatory Dismissal Case

In August 2013, the Equality Tribunal awarded €63,000 to Mr Fergal Reilly in his case against United Parcel Services (UPS). Mr Reilly claimed that UPS discriminated against him on the disability ground, in terms of access to employment, failure to provide reasonable accommodation and discriminatory dismissal. Here, Adare HRM takes us through the case.

### Complainant's Case

On 17 November 2009, Mr Reilly, who began working with UPS in 1999, suffered trauma to his left knee in the course of his duties. Having undergone surgery, he was certified as unfit for work from late 2009 until May 2010, at which point he was approved as fit for light duties. According to Mr Reilly, UPS did not allow him to return to employment as he would be unable to work as Lead Driver, and there were no other open positions for which he could be considered. He tendered his resignation on 10 June 2010, citing the company's failure to give him work, to pay his wages, to communicate and to process grievances that he had previously raised. Correspondence between the two parties led to the offer of a job in the UPS call centre which Mr Reilly refused as he had no previous relevant experience for the position. UPS then accepted his resignation on 4 November 2010. Mr Reilly contended that this amounted to a discriminatory constructive dismissal on the ground of disability.

### Respondent's Case

UPS denied discriminating against Mr Reilly as alleged or at all. The company expressed that Mr Reilly was paid for six weeks while on sick leave with the injury, pointing out that it is not obligated to continue paying an Employee while he or she is on sick leave. It stated that Mr Reilly showed up unannounced on 11 May 2010 with certification from his GP that he was fit to work on light duties. The company made the case that no suitable alternative roles were available at the time, and that the Complainant was required to be certified as fully fit for work in order to return to employment. It stated that it did not wish to accept Mr Reilly's resignation, expecting him to return to full health and resume normal duties.

### Determination

The issues for decision in this case were whether, within the meaning of the Employment Equality Acts, the Complainant was discriminated against and discriminatorily dismissed.

Neither party disputed that Mr Reilly was out sick from November 2009 or that Mr Reilly's condition constituted a disability. The Occupational Health assessment which Mr Reilly attended confirmed him capable of "all non-manual handling activities associated with his job, e.g. planning routes, supervising loading, going out with the driver to direct them, reports etc". Around that time, on 27 April 2010, Mr Reilly also visited his GP, who declared him fit for light duties from 11 May 2010. It was accepted that Mr Reilly would need a helper to complete the manual handling of deliveries. The Operations Manager of UPS explained that hiring an extra person would have cost about €28,000 per year.

## Results

The tribunal found that the Operations Director did not attempt to ascertain which manual handling duties Mr Reilly could not carry out, failing to revert to the occupation health expert in this regard. There was also no evidence that the Director made enquiries as to how long the injury would last or considered any alternatives to hiring a helper. UPS simply did not engage with either Mr Reilly or its own doctor.

The tribunal concluded that UPS fell short in the obligations identified by the Labour Court, which involved obtaining full information on the Employee's disability and being proactive. It accepted Mr Reilly's evidence that he was forced to resign from the company's employment. It ruled that, by not providing him with reasonable accommodation, UPS did not discriminate against Mr Reilly in relation to his disability, but that UPS did discriminatorily dismiss Mr Reilly by way of constructive dismissal. It awarded him the sum of €63,000, equalling eighteen months' salary and taking into consideration the size and financial capabilities of the company.

## Organisation Considerations

It is important for organisations to note that, while reasonable accommodation should not involve putting a disproportionate burden on an organisation, it is clear that a failure to consider reasonably accommodating a person, consulting with the person involved, and identifying what can possibly be done to accommodate them may lead to a determination against the Employer.

For more information or to obtain the case in full, contact Adare HRM on [info@adarehrm.ie](mailto:info@adarehrm.ie) or at 01 612 7092.

## DFI Welcomes Two New Member Organisations

**Disability Federation of Ireland (DFI) continues to strengthen its work in the voluntary disability sector, welcoming two new member organisations in the month of November.**

### Lakers Sport and Recreation Club

Lakers Social & Recreational Club is a community-based sports, social and recreation club for children and adults with an intellectual disability. The club provides a wide range of sporting and educational services to members across Leinster from its centre in Bray, Co.

Wicklow. Their members develop skills and abilities through a range of activities such as sport, drama, arts & crafts, cookery and other activities. The teamwork and interaction with other people involved promotes the development of social skills, growth in self-confidence and self-esteem. To learn more about the Lakers, visit [www.braylakers.ie](http://www.braylakers.ie).

### Cork Deaf Association

The Cork Deaf Association is committed to the empowerment of Deaf and Hard of Hearing people in Cork city and county through the provision of information, advocacy and support services. We aim to achieve a more inclusive society, where Deaf and Hard of Hearing people enjoy equality of opportunity, independence and full citizenship. Among the services offered by the organisation are an Information Centre, assistive technology (Deaftech), education, employment and hard of hearing supports, social work services, outreach programmes and support groups. For more information about the Association, visit [www.corkdeaf.ie](http://www.corkdeaf.ie).

## DFI Partner Up To Launch of New Online Portal To Neurological Charities

**The Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAI) have joined together to develop a new online portal to neurological charities in Ireland.**

Neuronetwork offers a unique source of information on the services and supports provided by almost thirty not-for-profit organisations working in the neurological sector in the country. By entering a neurological condition, service type or service provider, visitors to the

website can quickly uncover the services, events, publications and profiles that the various organisations offer nearest to them.

### Information Resource

Designed primarily as a guide to these organisations for health professionals, the programme can also be used by any member of the public, including people with neurological conditions and their families. Currently, over 700,000 Irish people live with neurological conditions affecting the brain and spinal cord, ranging from common conditions such as stroke, migraine, epilepsy, acquired brain injury and multiple sclerosis, to rare and genetic disorders.



**Professor Orla Hardiman, seen here using the website, has praised the Neuronetwork initiative**

Among the twenty-seven organisations represented in Neuronetwork are the Irish Motor Neurone Disease Association, the Irish Heart Foundation, Acquired Brain Injury Ireland, Headway, Muscular Dystrophy Ireland and the Rehab Group. In the neurological sector, non-profit organisations such as these have taken the lead in developing a wide range of services and supports, often stepping in to provide specialist assessment and rehabilitation services which are critically needed. Neuronetwork now offers health professionals an easy understanding of the services that they provide. DFI and NAI also worked in close consultation with potential users and people with neurological conditions to ensure that the website and the information it supplies meet their needs.

### Professional Support

Neuronetwork came into development following a nationwide survey of primary care teams, and was designed with the support of a primary care team based in Dublin South City. Professor Orla Hardiman, Chair of Neurology in Trinity College Dublin, praised the initiative, noting that “Neuronetwork is an example of charities coming together to provide

a practical resource to health professionals. Staff working in the hospital can see at a glance what services are available in each area of the country”.

“Neurological conditions represent a significant challenge for health professionals; with some of the more rare conditions, a health professional working in a primary care team may come across only one or two cases. It is vital that they have the resources to learn more about that condition and refer the person for support”, she said.

To find out more about Neuronetwork or to use its services, visit the website at [www.neuronetwork.ie](http://www.neuronetwork.ie). To learn more about the work of the NAI, visit [www.nai.ie](http://www.nai.ie), while the DFI website can be accessed at [www.disability-federation.ie](http://www.disability-federation.ie).

### DFI Teams With University of Limerick To Host Symposium On Quality

**The Disability Federation of Ireland (DFI) teamed with the University of Limerick (UL) to host a symposium on quality on Friday, 29 November.**

The one-day symposium, which took place in The Pavilion at UL, examined the implementation of quality systems in the voluntary disability sector, as well as the wider community and voluntary sector in Ireland. The topic was discussed from an Irish perspective, exploring the challenges, opportunities and achievements in this area to date.



**Professor Eamon Murphy of UL (far left) with John Dolan and Dermot O'Donnell of DFI at the DFI/UL Symposium on Quality on 29 November.**

John Dolan, Chief Executive of DFI, stated that, “Voluntary disability organisations face a number of challenges in operating effectively within a recession and DFI members are continuing to proactively embed quality within the work that they are doing. In this way can deliver more sustainable and beneficial outcomes for people with disabilities.”

## Quality Research

DFI organised the event, “Developing Quality and Innovation Through Strategic Operations and Alliances in the Voluntary Disability Sector” in conjunction with the Enterprise Research Centre (ERC) at UL. Director and founder of the ERC, Professor Eamon Murphy, was one of the key speakers, with Marie Kehoe-O’Sullivan, Director of Safety and Quality Improvement at the Health Information and Quality Authority (HIQA), also addressing the symposium.

Speaking on the DFI-led PQASSO (Practical Quality Assurance System for Social Organisation) initiative for organisations, Ms Kehoe-O’Sullivan stated, “quality is about trying to do better – better both in the services an organisation offers its users and in the way the organisation is run. PQASSO is a straight forward, user-friendly quality assurance system intended to help run organisations more effectively and efficiently.”

Representatives of DFI, UL, the Centre for Independent Living and Fighting Blindness also took part on the day, with the content of the symposium will be based on research conducted by three post-graduate students of UL. The effectiveness of DFI quality programmes and initiatives, as well as collaborative projects between UL and DFI, was reviewed. The achievements of those who successfully completed “An Introduction to Quality Management for Community and Voluntary Organisations” were also celebrated at the symposium in a graduation ceremony.

As Michael Hennessy, Education Programmes Manager for the Faculty of Science and Engineering at UL, concluded, the event offered an opportunity to share and exchange knowledge of quality tools and to consider how these can best be used to drive innovation in organisations.

“This symposium is the result of the partnership approach between DFI and UL in supporting the development of quality and innovative systems within voluntary disability organisations. The event marks three years of partnership exploring, developing and implementing systems for improved quality across the community and voluntary sector”, he said.

For more information on DFI quality systems, contact Dermot O’Donnell on 086 780 8639 or at [dermotodonnell@disability-federation.ie](mailto:dermotodonnell@disability-federation.ie).



## Health Matters

### Importance of Achieving Outcomes for People With Disabilities Raised At NCF

**A meeting of the HSE National Consultative Fora (NCF) was held in November, attended by the Director of Social Care, Pat Healy.** The NCF encompasses representative organisations and agencies from across the disability sector, working with the Health Service Executive (HSE) to develop and promote disability service provision. In his presentation to the fora, Mr Healy emphasised the importance of achieving outcomes for people with disabilities and the ‘movement into the community’ policy objective. He indicated that one area of reform, the Integrated Services Area (ISA) Review, is nearing completion. It is set to recommend structures to succeed the ISAs, reducing the number below the seventeen existing areas.

Mr Healy also explained that the National Service Plan is currently with the Minister for Health. The key priorities for 2014 identified in the Plan include disability services for young people aged between 0-18, the reconfiguration of day services and young people leaving school or rehabilitation programmes, transitions from institutions to homes in the community, and ensuring quality and service user involvement in the development of services. The plan also highlights the Value for Money and Policy Review of Disability Services in Ireland Implementation Framework. The vehicles for moving the policy change forward are the National Implementation Framework: Value for Money and Policy Review Steering Group, the NCF, and the Social Care Management Team.

At the meeting, the Disability Federation of Ireland (DFI) underlined the importance of adequately supporting existing community services and supports essential to the well-being of people with disabilities, as well as the need for mainstream public services to be adapted to accommodate the needs of people with disabilities. For more information on the HSE’s local, regional and national Consultative Fora, please contact your local DFI Support Officer, whose details can be found at the back of this newsletter.

Image by artur84, used with courtesy of freedigitalphotos.net



## Coalition Submits Amendments to Assisted Decision-Making Bill

**The Disability Federation of Ireland (DFI) participates in a coalition of civil society organisations in the fields of disability, mental health and aging which has submitted its proposed amendments on the Bill to the Department of Justice and Equality.**

The amendments are based on international best practice in implementing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), as well as the coalition's collective experience in this area in Ireland.

The second stage debate on the Assisted Decision-Making (Capacity) Bill 2013 took place on 3

December, and coalition members presented its position at an Oireachtas briefing on the same day.

The Bill covers the area of legal capacity, which is the ability to make decisions and have such decisions respected in all areas of one's life.

Key issues the coalition identified as priorities in their submission include the language used in the Bill; the right to legal capacity on an equal basis with others; liability protection for third parties who respect an individual's will and preferences, recognition of advocacy as a support for legal capacity, the duties of decision-making assistants, co decision-makers, decision-making representatives and attorneys, restraint and detention safeguards, and costs and legal aid.

Tentative proposals were made for reform in several areas which were excluded from the Bill, including the law on consent to sex, jury service and the right to vote. For further information, please contact Joan O'Connor of DFI at [joanoconnor@disability-federation.ie](mailto:joanoconnor@disability-federation.ie).

To view the Assisted Decision-Making Bill, visit

<http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf>.



**The Assisted Decision-Making Bill covers the area of legal capacity; the coalition proposed amendments in accordance with the UNCRPD**

Image by Kittisak, courtesy of freedigitalphotos.net



## National Disability Strategy: Update

### Minister Holds Two Thematic Meetings of NDSIP Monitoring Mechanism

**The monitoring mechanism for the National Disability Strategy Implementation Plan (NDSIP) held two thematic meetings during the month of November.**

The first meeting, attended by the Minister for Disability, Kathleen Lynch, covered Irish Sign Language. The meeting sought to address the Programme for Government commitment of examining difference mechanisms to promote the recognition of Irish Sign Language.

The second meeting dealt with housing, focusing on the current barriers in the system which prevent people with disabilities from being adequately housed.

To view the NDSIP, visit <http://www.justice.ie/en/JELR/Pages/PB13000321>. For more on the Disability Federation of Ireland (DFI) response to the publication of the NDSIP, visit <http://www.disability-federation.ie/index.php?uniqueID=10715>.

'Updated' image by Stuart Miles, used with courtesy of freedigitalphotos.net



## News and General Information

### “Concussion Crisis” In Sport To Be Examined At Upcoming Conference

**Acquired Brain Injury Ireland (ABI) has joined with the European Brain Injury Society (EBIS) to host a ‘Brain Injury and Sport’ conference in Dublin this December.**

'News' image by bplanet used with courtesy of freedigitalphotos.net

The conference, aiming to address the issue of concussion in particular, will be held at the Aviva Stadium, Landsdowne Road on Friday, 13 December. The event should appeal especially to players, coaches, clinicians and others involved in elite and non-elite sporting environments.

### Programme

A panel of national and international expert speakers with both sporting and medical backgrounds will discuss the rising concern surrounding concussion and head injuries incurred through sport, intending to boost awareness and education of the topic.

Panellists will include Brian Kerr, former manager of the Irish international soccer team and Rory O'Carroll of the Dublin GAA team. Techniques for best practice on concussion management will also be presented by Professor John Ryan of St Vincent's Hospital and Dr Michael Ryan of the Harvard Medical School. Mark McGovern, a former GAA player and ABI survivor, and Anais Joran, an athlete at the World Championship Paralympic Games, will share their experiences of living with brain injury.

### Film premiere

The premiere of the documentary "Head Games: The International Concussion Crisis", by the Oscar-nominated director Steve James, is also set to take place on Thursday, 12 December as a pre-conference event. The film, which exposes the science and growing impact of head trauma in sport, will be screened in the Astra Hall of University College Dublin (UCD) at 6.30pm, with tickets for the event costing €10.

While the deadline for early-bird tickets to the conference has passed, tickets can still be purchased for €199. EBIS members can avail of a discounted price of €120 before 6 December, rising to €150 after that date.

For more information or to register for the event, visit <http://www.braininjuryandsport.ie>.

## AHEAD To Host Interactive Debate On Mental Health In The Workplace

The Willing Able Mentoring (WAM) programme at AHEAD is hosting a free event addressing mental health in the workplace on Thursday, 12 December, in conjunction with the Electricity Supply Board (ESB).

The event, an interactive debate about stress and other mental illnesses in the workplace, will question whether employers and their management have enough information about mental health promotion in the workplace. Those attending the debate will also be asked to consider whether Ireland should publish an official set of mental health standards for the workplace. In January 2013, Canada became the first country in the world to do so.

AHEAD point out that one in four people in Ireland experience a mental health difficulty, while three in five Irish people actually stop working because of mental illness. 47% believe that disclosing a mental health difficulty at work would have a negative influence on their relations with peers and colleagues. 57% also feel that being open about such issues at work has a damaging effect on their career.

### Registration

The debate will be held in the ESB offices at 27 Fitzwilliam Square Lower, Dublin 2, between 10am and 1pm on Thursday, 12 December. The event is open to everyone, from jobseekers with mental health difficulties to recent graduates and employers to hiring managers.

Although free of charge, booking is essential. To register your place, email [wam@ahead.ie](mailto:wam@ahead.ie) or phone 01-716 8844.

For more information, visit [http://www.ahead.ie/events\\_mentalhealthdebate](http://www.ahead.ie/events_mentalhealthdebate).

## BAI Research Examines Portrayal of People With Disabilities In Broadcasting

**The Broadcasting Authority of Ireland (BAI) is set to host a ‘Conversation’ on Programme Standards in the Broadcast Media on 12 December 2013.**

News of the event was delivered at a meeting of the National Disability Authority (NDA) and BAI Steering Committee on the portrayal and representation of people with disabilities in Irish broadcasting on 28 November. The event gives members of the public an opportunity to share their opinions on the representation of people and groups in society, including people with disabilities. Other standards to come under discussion include the treatment of content of a sexual or violent nature, as well as the use of coarse or offensive language in programming.

## Attitudes

The event will be used as a platform to launch the findings of the Attitudinal Research carried out by the BAI during the course of the year. The BAI commissioned a national survey which asked over 1,000 people to identify the issues causing offense and harm in broadcasting. The results should offer valuable insight into public attitudes towards the portrayal of people with disabilities in Irish programming.



**The Broadcasting Authority of Ireland is reviewing the portrayal of people with disabilities in the media as part of its new strategy.**

Photo by worradmu, used with permission from freedigitalphotos.net.

The research formed part of the BAI's Review of its Code of Programme Standards which has been underway throughout the year. Following this phase of the review, a draft Code will be produced and presented to the BAI, before going to public consultation in February 2014. International media analyst Andrea Millwood Hargreaves will be in attendance at the event to offer her views on the research results. Donncha O'Connell, Professor of Law at the National University of Ireland Galway (NUIG), will chair the proceedings.

## Live streaming

The event will be streamed live online, with viewers invited both to watch and to participate by submitting questions and comments to the speakers. A sign language interpreter will be present at the event, and, while speed text will be made available, it will not be possible to stream it live. The text of all that happened will be featured on the BAI website after the event.

Those interested in watching the event live and submitting questions to the speakers can visit the webcast channel at <http://webcast.dv4.com/BaiLive>. You will be required to register your details, and an opportunity to perform a technical test will be offered. For more information, visit <http://www.bai.ie/?p=4036>.

## Minister for Disability Launches New Migraine Association Website

**The Minister for Disability, Kathleen Lynch, launched the new website of the Migraine Association at an event held in Dublin on 27 November.**

The Minister praised the association's latest development, noting the importance of having strong and valuable information available to patients and people affected by the condition.

Audrey Craven, President of the Association, explained that the website was designed to "inspire, equip and inform" people both about migraines and the work that the Association carries out. "Providing accurate, reliable, accessible information and getting it out to the people who need it" were the priorities in building the new website, she said.

### Speakers

Along with Ms Craven and Minister Lynch, a number of speakers participated in the event, hosted in the capital's European Parliament House. Chief Executive of the Migraine Association, Patrick Little, provided the welcoming address, while Chief Executive of the Health Research Board, Enda Connolly, and the Chief Executive of the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI) also took part in the morning's proceedings. Both welcomed the development of the Association's new website, pointing to the need to address mental health and neurological disorders with a holistic approach that allows patients, organisations, industry and research bodies to work together effectively.

### Year of the Brain

The event also introduced the Year of the Brain in Europe 2014, a programme to raise awareness and educate in all areas of brain disorders. Following the success of European Month of the Brain in May 2013, the European Brain Council pledged to put plans in place for this new initiative. Over 200 organisations representing patients, health care professionals, industry and the science community have already given their support.

Mr Connolly welcomed the initiative, explaining that "I believe we've created a momentum. There is a coherence of thought that hasn't been there previously. We can bring about a paradigm change around the issue of brain disorders". Closing the event, Ms Craven encouraged other organisations involved in the mental health and neurological field to participate in the Year of the Brain. Those attending were also invited to visit the newly

redesigned Migraine Association website at [www.migraine.ie](http://www.migraine.ie). More information on the Year of the Brain 2014 can be found at <http://www.europeanbraincouncil.org/projects/evob/>.

## Arthritis Ireland Offering Free Specialist Occupational Therapy Programme

**Arthritis Ireland and the University of Limerick are offering a free specialist Occupational Therapy Programme for people with arthritis aged between 18 and 65.**

The programme, 'Working With Arthritis', is designed to develop skills which enable people to consider returning to work, education or volunteering roles. The project is jointly funded by the European Union (EU) Social Fund and The Department of Social Protection.

### Programme Topics

Skilled occupational therapists will deliver the programme on a one-to-one basis from a Galway-based clinic, or, if more suitable, in the homes or communities of those taking part. Advice on fatigue, pain and stress management will be covered, as well as techniques on how best to protect joints. The employment and education options open to participants will be explored, while liaisons with potential employers and educators can be arranged. Work-site visits and ergonomic assessments will take place as part of this.

The programme is open for participation to people with arthritis between the ages of 18 and 65 who receive a disability or illness payment. Participants must be living in the Western, Border or Midland Counties (Donegal, Galway, Laois, Leitrim, Louth, Longford, Mayo, Offaly, Roscommon, Sligo & Westmeath).

For more information, contact Maura O'Neill on 087 609 4209 or at [arthritis@ul.ie](mailto:arthritis@ul.ie).

Alternatively, visit the Arthritis Ireland website page on the programme at [http://www.arthritisireland.ie/go/programmes\\_events/other\\_programmes\\_events/working\\_with\\_arthritis](http://www.arthritisireland.ie/go/programmes_events/other_programmes_events/working_with_arthritis), where you can register your interest.



**The 'Working with Arthritis' aims to bring people with arthritis back to work and education**

Image by Stuart Miles used with courtesy of freedigitalphotos.net



## Care Alliance Begins Planning of National Carers Week 2014

Care Alliance has started planning for National Carers Week 2014 by encouraging individuals, community groups and organisations to consider including an event for the week in their 2014 plans.

National Carers Week, a prominent event for those who work with and support family carers, takes place between 9 and 15 June 2014. In 2013, over 140 events took place across every county in Ireland during the week. Care Alliance is offering advice and tips on organising events and activities, and has committed to supporting those interested in doing so with merchandise, templates and publicity.

### Planning Events

The aim of National Carers Week is to deliver a vibrant week of celebration and the promotion of family carers, leading to a fuller appreciation of their value and contributions.

Whilst raising awareness of family carers in communities across the country, the week is also intended to engage with those not yet availing of carer support services.

Care Alliance is hoping that all events and activities arranged to celebrate National Carers Week reach a greater number of 'hidden' carers and ultimately place all carers higher on the social, political and media agendas. Activities suggested by the organisation include a 'Take Care of Yourself Day' for carers, as well as outings and day trips as respite for family carers. Organisations and individuals could also contact local media, hold a coffee morning, or distribute Carers Week information and posters to businesses, clubs, hospitals, libraries and other public spaces in their local area.

If you're interested in organising an event or activity for National Carers Week, visit <http://carersweek.ie/userfiles/file/EventCheckList2013.pdf> for ideas and advice. For more information on National Carers Week, visit [www.carersweek.ie](http://www.carersweek.ie).



**Care Alliance is encouraging individuals and organisations to come up with creative events to support National Carers Week 2014.**

Image by KROMKRATHOG used with courtesy of freedigitalphotos.net.

## Web Accessibility For People With Disabilities Comes Under Focus

The web accessibility needs of people with cognitive and learning disabilities are to come under the focus of a new Cognitive Accessibility Task Force established by the World Wide Web Consortium (W3C) this month.

The W3C is an international community in which member organisations, staff and the public work and collaborate to develop web standards. A project of its Web Accessibility Initiative (WAI), the new Task Force aims to improve web accessibility for people with

learning disabilities through research and analysis of the current available techniques.

These techniques will be reviewed, areas of risk and opportunities identified, and new features and guidance proposed to make web content and content authoring more accessible and usable for people with disabilities. Using case studies, the group will also build a registry describing various cognitive disabilities and outlining scenarios on how people with different abilities use technology successfully or otherwise.

### Participation

The WAI is currently seeking participants for the Task Force, which will meet both by teleconference and face-to-face. Those taking part are asked to contribute four hours a week, with only members of the WAI's Protocols and Formats Working Group (PFWG) or the Web Content Accessibility Guidelines Working Group (WCAG WG) eligible to join the Task Force. Anyone interested in joining the Task Force is asked to email Janina Sajka, Joshue O'Connor or Andrew Kirkpatrick of the WAI, with their details appearing on <http://www.w3.org/WAI/PF/cognitive-a11y-tf/#participation>. For more information on the Cognitive Ability Task Force, visit their page at <http://www.w3.org/WAI/PF/cognitive-a11y-tf/>.



**The W3C hope to improve web accessibility for people with disabilities through new research and analysis.**

Image by bplanet used with courtesy of freedigitalphotos.net



## Christmas Events

We've hit the month of December, and that means only one thing – Christmas is coming! Many of our member organisations have been busy planning some great events to celebrate the festive season; here, we take a look at some of the festivities they have lined up.

### 6 December

The **Walkinstown Association**'s Christmas Wonderland kicks off in Drimnagh Castle, Dublin 12 on Friday, 6 December, raising money for their Green Kitchen project. The Wonderland runs throughout the weekend, with an outdoor crib, pets corner, face painting and visits from Santa to look forward to. Tickets cost €15 per child, with accompanying adults going free. All details are at <http://www.eventbrite.ie/e/a-christmas-wonderland-walk-tickets-8870713543?aff=es2&rank=1&sid=c6dd4e914df711e3aef812313b0a99d4>.

### 7 December

The Jingle Bells 5km Run is taking place in the Phoenix Park, Dublin on Saturday, 7 December, with **DEBRA Ireland** selected as the beneficiary charity of this year's event. Although registration fees go to the run organisers, Donore Harriers, all donations and sponsorship money goes straight to DEBRA Ireland. For more information, visit <https://debraireland.org/events/jingle-bells-run-2013/>.

### 10 December

**Ability West** is holding a Gala Christmas Show in the Clayton Hotel, Ballybrit, County Galway on Tuesday, 10 December, with over 150 of its service users showcasing their talents on the night. Thirteen different acts from as many different centres across Galway are set to take

part. Doors open at 7pm and the show itself starts at 8pm sharp. Tickets cost €10 and can be purchased either at local Ability West centres or from the website at [www.abilitywest.ie](http://www.abilitywest.ie).

### **13 December**

**MS Ireland's** Reach for a Star collection day takes place in Blanchardstown Shopping Centre between 11am and 7pm on Friday, 13 December. The day will feature face-painters, choirs singing Christmas carols and an MS Ireland Christmas shop. If you're interested in volunteering at the event, contact [fundraising@ms-society.ie](mailto:fundraising@ms-society.ie)

### **15 December**

**Move4Parkinsons'** Voices of Hope Choir are returning to Balally Church, Ballaly, Dublin 16 to present "Carols by Candlelight – An evening of Christmas Spirit" on Sunday, 15 December at 5pm. Tickets are free of charge, but donations would be greatly appreciated. More details at <http://www.move4parkinsons.com/portfolio/an-evening-of-christmas-spirit/>. Two more choirs are in action on the day, with Il Coro Italiano di Dublino and Rhapsody performing some festive numbers in aid of the **MS Ireland Care Centre** in Dublin 6. Tickets, available for purchase on the MS Ireland online shop, cost €20, with a glass of wine on arrival and festive treats available for the guests. The event starts at 5pm in the MS Care Centre, Rathgar, Dublin 6, with more information at <http://www.ms-society.ie/events/4925>.

### **21 December**

The **Carmichael Centre** will be holding a Christmas Carol Fundraiser on Saturday, 21 December in Blanchardstown Shopping Centre from 4 – 5.30pm. The Goethe Institut Choir will sing the Christmas Carols, with all proceeds going towards the provision of a range of much-needed services and facilities to the Centre's resident members and charities around the country.

The **National Council for the Blind Ireland** (NCBI) is holding its Make A Dark Day Brighter Campaign throughout the Christmas period. You can sponsor a bulb on one of their Trees of Light in Dublin, Cork and Galway and at Dublin Airport, with the names of all sponsors appearing in the Irish Independent on 21 December. NCBI is also selling a range of high-quality scented candles as part of the campaign, costing €3 each or €10 for four. These can be bought at NCBI retail shops or at <http://www.ncbi.ie/fundraising/fundraising-events>.



## Features and Opinions

### Working Towards 'A Normal Life' For People With Disabilities In Romania

**A recent trip to Romania left John Dolan, CEO of the Disability Federation of Ireland, struck at the “utterly basic” level of services and supports for people with disabilities.**

Invited by Adriana Tontsch, founder and president of the Romanian Association of Spina Bifida and Hydrocephalus (ARBSH), John witnessed first-hand the huge difficulties facing people with disabilities in the country. For him, "the visit to Romania was an opportunity to get a sense of the situation in the eastern countries that joined the European Union (EU) in the past decade, given that they are recently democratic and in need of significant development. Their situation is very different from that of the more developed western democracies in the EU".

Visiting a number of hospitals and orphanages over the five-day stay, and meeting families affected by disability, he reveals that the experience “confirms very strongly how fortunate and lucky we are in Ireland to have a culture of inclusion for people with disabilities”.

#### Invisibility

Arriving in Bucharest on 29 July, John spent a few days in the capital before moving onto the more rural cities of Campulung and Pitesti with Adriana. Reflecting on all he saw, he paints a picture of a country hampered by “serious economic underdevelopment and flawed national governance”. Few social or community institutions are in place to assist or advocate for those who need it. As a result, services and supports for people with disabilities appear to be virtually non-existent, and the impetus for inclusion just isn't there. “People with disabilities aren't seen in Romania. They're invisible; they're ‘the other’”. In most Western countries, including Ireland, the issue for people with disabilities is ‘quality of

life'. In Romania, it's just 'life'." Adriana adds that people with disabilities "are hidden; disability is seen as a stigma. Many children with disabilities are hidden in institutions, because everyone only wants to see people without problems."

### Difficult System

These institutions can pose huge hardships for the children living there. Adriana describes how "the children are hungry; their clothes are not clean. They are all the time in bed; nobody tries to show them affection. There have been many, many cases of violence". Poor infrastructure across the country compounds the problem; describing facilities at the country's largest children's hospital, the Marie Curie Hospital in Bucharest, for instance, John notes its low ceilings, narrow corridors, squashed beds and lack of air conditioning. The needs and rights of people with disabilities seem to take little priority.

Added to this is a health system in which neurosurgeons' wages are so low that they are compelled to seek more income from patients to cover the costs of treatment and drugs. One mother in Adriana's organisation told John of having to pay €1000 to support her child's operation, despite the ARSBH having bought the equipment that was needed for it. In a country with a GDP (Gross Domestic Product) less than half of the European average, this means that accessing treatment is often impossible for families.

Having seen these shortcomings for people with disabilities in Romania, John is grateful for the attitude and determination for inclusion here. "People in Ireland have always wanted and struggled to keep their family members with disabilities at home. Our capacity to achieve it improved with our development from the 1960s onwards. That piece of the puzzle is missing in Romania. If someone in Ireland has a baby born with Spina Bifida this week, they know they're not alone. They know there's a visibility about disability groups. That isn't there in Romania. There's not much to help or to give them hope".

### Challenges

Adriana accepts that these challenges can be very difficult for her organisation to tackle. Romanian-born but living in Germany for over two decades, she was asked for help in fundraising for Maria Savu, a young girl with Spina Bifida Hydrocephalus, in 2004. After successfully raising the €12,000 needed for Maria's treatment in Vienna, Adriana established the organisation the following year. Her main priority is to provide surgery and

shunts, which drain fluid from the brain in cases of Hydrocephalus, for the children who require it. Costing €400 each, their provision accounts for the bulk of her funding, meaning that she often has to set her other goals aside. Developing information booklets, training neurosurgeons, visiting children and parents, and meeting authorities all costs money which Adriana has to weigh up against the cost of offering a child the life-saving operation.

“I cannot do anything else if the children have to die because of a lack of shunts. It's hard: I know what we have to do, and what we can do. They are two different things. The next problem is that we want to build a therapy centre. We have the land, we have the plans, but we don't have money. Eighty children would be able to live there during their treatment. The Government would have to pay for parts like the energy, water, electricity, and I'm not sure they want to. So before we build it, we have to provide the shunts”.

### Future

With most of her funding having come from Germany and Austria, the continuing impact of the European financial crisis now sees the ARSBH in serious financial difficulty. Both Adriana and John recognise the pressing need for redevelopment and coherence in the treatment of people with disabilities in Romania, but concerns remain. “Even leaving the funding aside, there would be worries as to who's going to take over the work, who will be the next leader”, John contends. “There's a need to situate the organisation in a much broader understanding, but there's no coalition of those supports and services in Romania. Where will the pressure come from for change?

Adriana is resolved to raise that pressure. Next year, she hopes to organise a protest with members of her organisation at the EU Parliament to highlight the situation for children with Spina Bifida and people with disabilities in Romania. Despite the challenges, she won't give up easily. “I have a dream for the children. It's the same dream as their parents. We want the children to have a normal life”.

For more information on Adriana and the ARSBH, visit <http://www.arsbh.ro/en/> or <http://www.eurordis.org/content/arsbh-creating-equality-across-borders>.



## **Personal Notes**

# DFI MEMBER ORGANISATIONS | NEWSLETTER DIRECTORY

**For information, please contact the member organisations directly.**

Ability - Newsletter of the Irish Association for Spina Bifida and Hydrocephalus, Tel: 01 4572329, E-mail: [info@iasbah.ie](mailto:info@iasbah.ie)

Acquired Brain Injury Ireland Newsletter, Tel 01 2804164 email: [cbrack@abiireland.ie](mailto:cbrack@abiireland.ie),

Arthritis Ireland - Newsletter—Tel: 01 661 8188 , E-mail: [info@arthritisireland.ie](mailto:info@arthritisireland.ie)

Aspire - Asperger Syndrome Association of Ireland. 01-8780027/9, E-mail: [admin@aspire-irl.org](mailto:admin@aspire-irl.org)

Asthma Society News - Tel: 01-8788511,

E-mail: [office@asthasociety.ie](mailto:office@asthasociety.ie)

Brainstorm - Migraine Association of Ireland, Tel: 01-8064121, E-mail: [info@migraine.ie](mailto:info@migraine.ie)

Brainwave - Quarterly Newsletter, Tel: 01 4557500, E-mail: [info@epilepsy.ie](mailto:info@epilepsy.ie)

Care Alliance Ireland - E-mail: [ndo@carealliance.ie](mailto:ndo@carealliance.ie)

Clar na nÓg - National Youth Council of Ireland Tel: 01-4784122 E-mail: [info@nyci.ie](mailto:info@nyci.ie)

Cleft Lip and Palate Association of Ireland - [www.cleft.ie/newsletter/index.htm](http://www.cleft.ie/newsletter/index.htm), Tel: (01) 2848227,

E-mail: [georginawade@cleft.ie](mailto:georginawade@cleft.ie)

Connect - Irish Motor Neuron Disease Association. E-mail: [info@imnda.ie](mailto:info@imnda.ie) Freefone 1800 403 403

Community Workers' Co-operative – Community Work News. E-mail: [info@cwci.ie](mailto:info@cwci.ie) Tel: +353 (0) 91 779 030

Debra Ireland Newsletter, Tel: 01 678 5044, E-mail: [info@debraireland.org](mailto:info@debraireland.org)

Down Syndrome Ireland - Tel: 01-8730999, E-mail: [info@downsyndrome.ie](mailto:info@downsyndrome.ie)

Enable Ireland - Newsletter—Tel: 1850 204 304 E-mail: [communications@enableireland.ie](mailto:communications@enableireland.ie)

Féach - Support to parents of blind and visually impaired children. Tel: 01 493 1896, E-mail: [info@feach.ie](mailto:info@feach.ie)

Fighting Blindness - Tel: 01 7093050, E-mail: [avril.daly@fightingblindness.ie](mailto:avril.daly@fightingblindness.ie)

Frontline of Learning Disability -Tel: 01-2862649. E-mail: [frontline@indigo.ie](mailto:frontline@indigo.ie)

GROWing - Information on Mental Health, Tel: 1890 474 474, E-mail: [info@grow.ie](mailto:info@grow.ie)

Guidelines - Irish Guide Dogs Association. Tel: 021 4878200 E-mail: [info@guidedogs.ie](mailto:info@guidedogs.ie)

Headway Ireland - National Association for Acquired Brain Injury -‘Making Headway’, Tel: 01-8102066, E-mail: [info@headway.ie](mailto:info@headway.ie)

Heartstrings - Newsletter of Heart Children Ireland, published quarterly, Tel: 1850 217017

E-mail: [heartchildren@eircom.net](mailto:heartchildren@eircom.net)

Heatwave - Irish Raynauds Scleroderma Society, E-mail: [info@irishraynauds.com](mailto:info@irishraynauds.com) Tel: 01 2020184

HOPE - Huntington's Disease Association of Ireland. Tel: 01-872 1303, E-mail: [hdai@indigo.ie](mailto:hdai@indigo.ie)

Inclusion Ireland - Tel: 01 8559891,

E-mail: [info@inclusionireland.ie](mailto:info@inclusionireland.ie)

Irish Deaf News - Irish Deaf Society. Minicom: 01-8601910; 01-8601878; E-mail: [info@irishdeafsociety.ie](mailto:info@irishdeafsociety.ie)

Irish Wheelchair Association - ‘Spokeout’, Tel: 01-8186 400, E-mail: [Joanna.marsden@iwa.ie](mailto:Joanna.marsden@iwa.ie)

Kerry Network of People with Disabilities - Network News 066-7180611, E-mail: [kerryPWDI@eircom.net](mailto:kerryPWDI@eircom.net)

MS News—Newsletter of MS Ireland. Tel: 01 6781600, E-mail: [info@ms-society.ie](mailto:info@ms-society.ie)

Muscular Dystrophy Ireland - MDI News Update Tel: 01-6236414, or 01- 6236415 E-mail: [info@mdi.ie](mailto:info@mdi.ie)

DeafHear.ie - Link Magazine - Tel: 01 8723800, E-mail: [info@deafhear.ie](mailto:info@deafhear.ie) Minicom: (01) 817 5777

NCBI News - Newsletter of the National Council for the Blind of Ireland, Tel: 01 8307033, E-mail: [press@ncbi.ie](mailto:press@ncbi.ie) [www.ncbi.ie](http://www.ncbi.ie)

Neuro News - Neurofibromatosis Association of Ireland, Tel: 01-8726338, E-mail: [nfaireland@eircom.net](mailto:nfaireland@eircom.net)

People First - Central Remedial Clinic Tel: 01-8057400 E-mail: [yvmcutch@crc.ie](mailto:yvmcutch@crc.ie)

Post Polio Support Group - Newsletter, Tel: 071 64791 E-mail: [newsletter@ppsg.ie](mailto:newsletter@ppsg.ie)

Poverty Today - Combat Poverty Agency. Tel:01-670 6746

Rehab News -Tel: 01-2057200 E-mail: [dara.duffy@rehab.ie](mailto:dara.duffy@rehab.ie)

Social Housing - Irish Council for Social Housing Tel: 01-6618334;

E-mail: [info@icsh.ie](mailto:info@icsh.ie)

Sonass aPc – Tel (01) 2608138. [www.sonassapc.ie](http://www.sonassapc.ie).

Speaking up for Advocacy – Citizens Information Board Newsletter on advocacy. Tel: 01 6059035, E-mail: [mairide.woods@ciboard.ie](mailto:mairide.woods@ciboard.ie)

Wheel E-Bulletin Tel:01- 454 8727,

E-mail: [info@wheel.ie](mailto:info@wheel.ie)

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**Representing the interests and expectations of people with disabilities to be fully included.  
Comprising organisations that represent and support people with disabilities.**

**The Disability Federation of Ireland (DFI) represents the interests and the expectations of people with disabilities to be fully included in Irish society. It comprises organisations that represent and support people with disabilities and disabling conditions.**

The vision of DFI is that Irish society is fully inclusive of people with disabilities and disabling conditions so that they can exercise their full civil, economic, social and human rights and that they are enabled to reach their full potential in life. DFI's mission is to act as an advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives.

There are over 120 organisations within membership or as associates of DFI. DFI also works with a growing number of organisations and groups around the country that have a significant disability interest, mainly from the statutory and voluntary sectors. DFI provides:

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

DFI works on the basis that disability is a societal issue and so works with Government, and across the social and economic strands and interests of society.

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