

federation

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www.fedvol.ie

newsletter

Welcome

to the Winter edition of the National Federation Newsletter.

Further news and updates are available on our website www.fedvol.ie

Wow... what a great idea that was!!

This year's conference was on the theme of New Ideas New Approaches: Innovations in Services and Supports for people with disabilities.

The conference attracted over 300 delegates and had a new format whereby we recognised that the experts were in our audience as well as on the podium and key speakers included the imminent John O'Brien, the ideas man Ed Bernacki, Peter Cassells, National Centre for Partnership and Performance, Mary Kealy, John Morrissey and Eamon Finn from Brothers of Charity Clare.

John O'Brien spoke to us of the networked desire to create and the need to ask ourselves what it is we want to create. Innovation he said comes from listening and listening grows from creating stillness and connection.

Ed Bernacki asked us to reflect on why we were at the conference and reminded us of the many times we had been to conferences taken notes and never looked at them again. This conference was about harnessing our capacity to innovate i.e., harvesting our people who have the ideas and turning those ideas into action.

Peter Cassells talked about building capacity for change and the changing context for intellectual disability services. This context has implications for service users, services, staff and management.

Brothers of Charity Clare took us on a journey of transformation where John Morrissey showed us his personal journey of returning to his home town of Scarriff after years living away from his native home.

The rest of the conference took on a significantly participatory approach. We were pleased with the success of the parallel



Left to right: Dr. John O'Brien, keynote speaker; Mr. Jimmy Devins, TD, Minister of State, Department of Health and Children, with responsibility for Disability and Mental Health, Mr. Brian O'Donnell Chief Executive, National Federation of Voluntary Bodies, Mr. Brendan Broderick, Chairperson, National Federation of Voluntary Bodies, and Mr. Ed Bernacki, keynote speaker.

sessions which set out to be deliberately provoking and slightly edgy. We called these generating solutions sessions and indeed that was what they became. A thought provocateur kicked off each session with a question (8 sessions in all dealt with issues such as money, health and well being, having a say, managing risks, technology, service delivery, providing choices etc). The thought provocateur was then followed by 3 short presentations of innovative and forward thinking practices which are currently happening here in Ireland, in the UK, in Europe or internationally.

A longer proportion of each of the sessions was devoted to addressing two key questions – what does different look like? and how do we get there?

The strength of this was that the focus of the session was placed on ideas / proposals and actions that have a potential to progress the problem-solving cycle.

This proved to be an exciting yet challenging deviation from the usual parallel session format and though time was tight there were very clear proposals and recommendations emanating from the sessions.

These ideas and themes are currently being compiled in our conference proceedings report which will be available shortly. The ideas progressed at the conference have great potential for us as a National Federation to drive the disability agenda and learn through listening from the inputs of our delegates who represented service users, services, HSE, the voluntary sector and the statutory sector.

During dinner a special award was presented to Phil Dunne on behalf of the Children's Sunshine Home, Leopardstown, Co Dublin to mark their major achievement in 2007 of being the overall winner in the Health Services Innovation Awards. The awards are designed to reward innovation in the health services, and were sponsored by the Health Service National Partnership Forum.

We would like to make a special mention of the entertainment provided on the night by SOS Kilkenny. "Out of the Shadow into the Light" celebrated the Mining Community of Castlecomer and the emergence of people with disabilities in our society as Equals and their film 'the goldfish bowl' won them deservedly a standing ovation and reminded us that whilst we have embarked on the journey of new ideas and innovative practices we still have a long way to go to fulfill the promise of an 'ordinary life' for many people. Sometimes innovation is not about new ideas but about new ways of fulfilling real choices for people.

CHEEVERSTOWN ACCREDITATION

Cheeverstown House received a 2 year Accreditation in November from the Council on Quality and Leadership, being its first such accreditation award.

Cheeverstown adopted the Personal Outcome Measures Quality model three years ago and chose this Quality System as it reflects the organisations' vision of "a future which respects

the contribution and inclusion of people in person-centred services". The lead Accreditor Ms Epp O'Neill, in announcing the Accreditation award, praised the efforts of Cheeverstown noting "Cheeverstown demonstrated a huge commitment to the process and the people they support". The Council acknowledged the commitment and innovative way the

organisation had made information accessible to the people they support.

Cheeverstown looks forward to improving the Quality of the services provided and to prepare for the next Accreditation under the Council on Quality and Leadership's newest Quality Measures.

ST. MICHAELS HOUSE ACCREDITATION

In November 2007, St. Michael's House was awarded accreditation for two years by The Council on Quality and Leadership (CQL).

Of particular interest to CQL, when assessing how the organisation is governed and managed, was the level of involvement of service users,

parents and family members. The team highly commended the organisation for further strengthening parental and family involvement through the introduction of Parent and Family Councils and soon to be established Service Users Councils.

Over the course of the next two years they will be working closely with CQL in relation to a new assessment procedure, which will be based on continuous assessment.

National Project to Review Congregated Settings

The HSE have recently established a National Project to examine the establishment of best practice alternatives for individuals with intellectual, physical and sensory disabilities currently residing in large congregated settings. The project is overseen by a steering committee which includes representatives from the HSE, The National Federation of Voluntary Bodies, The National Disability Authority, Inclusion Ireland, The 'Not for Profit' Business Association and the Department of Health & Children. Christy Lynch has been appointed as Project Manager. The project will identify the number and nature of people currently residing in large congregated settings and will develop a framework which will guide the process of transferring people to community based alternatives. This framework will be developed using evidence based best practice. The project will also indicate the likely revenue and capital resources necessary to effect such a change and the policy issues which will need to be addressed. The project is scheduled to report by the end of 2008.

Delivering Outcomes to People Project

Quality of Life of People with Disabilities

This study was undertaken by the Delivering Outcomes to People Project. The Report was written by Dr. Bob Mc Cormack and Margaret Farrell and can be downloaded from the Project website on www.outcomestopeople.ie along with an Easy-to-Read version.

Hard copies are also available, at a cost of €3 per copy, from margaretfarrell@smh.ie

CONVERSION

A report is now completed on 'Conversion: A Pilot Project to Develop and Test a Comprehensive programme on Conversion from Segregated Settings to Inclusive Employment Services' contracted by EASPD.

For more information go to: www.fedvol.ie

NATIONAL REVIEW OF HSE FUNDED ADULT DAY SERVICES '07/8

Closing date for receipt of submissions is February 29th 2008

In October 2005, the HSE commenced a National Review of Sheltered Day Services for People with Disabilities. This was initiated by the HSE as part of its obligations under Equality Legislation and the Disability Act. The purpose of that review was to obtain information on all aspects of Sheltered Day Services, including establishing a listing of services by location, capacity and occupational activities. This review was informed by work initiated early in 2005 by the Department of Health and Children regarding funding arrangements for Sheltered Work Services.

The outcome from this initial review highlighted service delivery issues that needed to be addressed in relation to existing Sheltered Work practices and recommended that in order to fully address all of these issues, a review of all HSE Funded Adult Day Services should be commissioned and delivered as a matter of urgency.

A National Working Group representative of all stakeholders was established in August 2007 to conduct a National Review within a 12 month timeframe.

The National Working Group is interested in hearing from anybody with an interest in the work of the Review. Please email or post your submissions, queries or comments to:

Martina Lanigan, Health Centre, Arden Rd, Tulamore, Co Offaly. Tel 057 9359635 or Email: dayservice.review@hse.ie

Further information is available at www.dayservicereview.ie

HIQA – National Standards Working Group

The Health Information and Quality Authority has established a National Standards Working Group for residential care for people with disabilities.

The working group comprises representatives from the Department of Health and Children, National Disability Authority, and those representing service users and service providers involved in the provision of services. The group, which is meeting monthly since October 2007, aims to have draft standards ready for public consultation in June 2008. It is chaired by Dr. Marion Witton, Chief Inspector, and the National Federation of Voluntary Bodies is represented by Brian O'Donnell, CEO.

The National Federation Quality Sub-Committee will act as a reference group on the development of the standards.

HSE COMMENTS & COMPLAINTS POLICY & PROCEDURES

A series of briefing sessions were organised in late 2007 with the HSE focusing on the HSE Comments / Complaints Policy & Procedure. The Office of Consumer Affairs will review organisations existing policy (if they have a

Complaints Policy already in place) and make recommendations to align it with the HSE policy. Further training for those who have been appointed as Complaints Officers will take place during spring 2008.

Establishment of Office for Disability and Mental Health

On Wednesday, the 30th of January, 2008, the Government announced the establishment of the Office for Disability and Mental Health. The Office for Disability and Mental Health will focus on supporting implementation of the Health Sectoral Plan under the Disability Act and driving implementation of the recommendations in A Vision for Change and Reach Out. The Office will drive the implementation of Part 2 of the Disability Act which provides people with a disability with an entitlement to:

- An independent assessment of needs,
- A statement of the services which it is proposed to provide,
- Pursue a complaint and if necessary to
- Make an appeal to the independent Disability Appeals Officer

The Office will also monitor and evaluate the implementation of the multi annual investment programme (€900m from 2006 to 2009) for people with a disability. The Office will in particular facilitate the delivery of integrated health and education support services for children with special needs. Arrangements will be put in place between the Office and the Department of Enterprise, Trade & Employment to address the issue of training and employment support services for people with a disability. The Office of the Minister for Disability and Mental Health will bring a new impetus to the implementation of A Vision for Change. It will work in partnership with the HSE to achieve implementation of agreed targets. Through these formal interdepartmental links the Office for Disability and Mental Health will ensure and oversee an integrated 'whole-of-government' approach and implementation of joined up policy.

SKILL PROJECT – QUOTA ALLOCATION

It's that time of year again when organisations have the opportunity to nominate Support Service Staff / Managers to participate in FETAC accredited training that is available through the SKILL Project. Details in relation to the allocation of the quota of places have been circulated to all National Federation member organisations.

Since autumn 2007 the SKILL Project has embarked on a new development called "Critical Mass Sites" and this approach seeks to facilitate a larger number of support staff from the one organisation to go through the programme at the same time. In doing so it is hoped that the impact of the training and the project on the workplace will be more dramatic. Over the past few months, the SKILL Project team and SKILLVEC have met with a number of organisations to discuss this approach to providing training for staff with minimum disruption in the workplace and without compromising the quality of the programmes. For further information please contact: Jillian Sexton at jillian.sexton@fedvol.ie

Congratulations

Certificate Presentations - 'Managing People – Management Development Programme':

An event to mark the conclusion of the series of 'Managing People – Management Development Programmes' which had been running during 2006/7 took place in November 2007 in the Tullamore Court Hotel. The aim of the event was to celebrate people's participation in the programmes, present certificates and share the findings of the programme evaluation. Mr. Brendan Broderick, Chairperson of the National Federation of Voluntary Bodies Training & Development Sub-Committee, oversaw the event and presented the programme Certificates while Mr. Brendan Collins, Open Training College, shared his insights as the programme facilitator and provided an overview of the main findings of the programme evaluation.

'MANAGING FOR THE FUTURE: BUILDING YOUR SKILLS AS A FRONT LINE MANAGER IN A PERSON CENTRED ENVIRONMENT' – COMPLETION OF PILOT PROGRAMME

The pilot programme for front line managers which has been running in the University of Limerick is now complete and students will be conferred at the summer 2008 graduation ceremony. The findings of

the evaluation of the pilot programme are being considered and plans are afoot in relation to the further roll-out of the programme and the associated training materials during 2008.

RESEARCH

Developing a National Research Strategy

The National Federation of Voluntary Bodies is currently developing a National Research Strategy.

This is being led and driven by the Research Sub-committee

Submissions and comments are welcomed from our member organisations.

Please contact edel.tierney@fedvol.ie for further information.

Inclusive Research Network

The Inclusive Research network is now up and running!!

What is an Inclusive Research Network?

The network consists of a group of people who come together to do research or talk about research that is about people with intellectual disabilities. The network is open for anybody to join who is interested in this type of research e.g., people from services, self-advocacy groups, organisations, researchers and community groups. If you would like to join or have a say in research that relates to people with intellectual disabilities please email edel.tierney@fedvol.ie

NDA STUDY RE DISABILITY AND THE IRISH HEALTH SERVICES

Are you interested in talking about your experience of maternity services in Ireland?

Little is known about some women's experiences as they avail of maternity, childhood and other health services during pregnancy, childbirth and early motherhood in Ireland. A research team in Trinity College Dublin is attempting to address this. The team are inviting women to participate in a study who are over 18 years of age and who are pregnant (or have had a baby in the past two years), with one of the following challenges - an intellectual disability, a visual impairment, a hearing impairment; a physical disability; experience as a user of the mental health services.

Taking part in the study will involve –

Being interviewed (on one, two or three occasions - you will choose how often)

One interview will take place during pregnancy, one soon after the birth and one when your baby is one to two years old.

You will be asked for your views about your experience of the maternity hospital, baby clinics and other health services that you have attended.

The rights of privacy and confidentiality will be protected during and after the study.

For more information please contact Denise Lawlor at 086 3789758 or by email:

lawlorde@tcd.ie



People Connecting

Our Publications Corner

www.fedvol.ie/publications

National Best Practice Guidelines for Informing Families of their Child's Disability

Informing Families OF THEIR CHILD'S DISABILITY

Funding Corner

LYONS TEA - FUNDING OPPORTUNITY

<http://www.lyonscharitygiveaway.ie/>

Closing date for final monthly entries is 31.8.2008

There are 12 prizes of €10,000 to be won, with one prize being awarded monthly. First monthly draw took place on 30.9.2007. For more information, please contact:
www.lyonscharitygiveaway.ie

PHILANTHROPY IRELAND. LIST OF GRANT-GIVING ORGANISATIONS

Philanthropy Ireland represents independent philanthropic organisations in Ireland. A list of their members is available on their website. The website contains a grant-seeker zone for advice on obtaining funds from their member organizations.

For more information, please contact:
www.philanthropyireland.ie/directory/full

ENCLUDE – www.enclude.ie

Independent non-profit IT consultancy service to the Irish Nonprofit Sector

ENCLUDE is an independent non-profit IT consultancy service to the Irish Non-profit Sector. It was established in 2006 and is a charity itself.

The ENCLUDEit Programme enables eligible organisations to gain access to donated technology products, allowing them to choose from a wide range of products from Microsoft and Cisco. Offer open to Nonprofit organisations with a Chy Number (terms and conditions apply)

For more information log on to www.enclude.ie

Community Foundation of Ireland – Funding Opportunity

Deadlines: Round 1: February 29th 2008. Round 2: August 31st 2008. Round 3: October 31st 2008

Further information is available at <http://www.communityfoundation.ie/grants/> or (01) 8747354

MULTI-MEDIA :

A lot of people saw these films at our conference 'New Ideas – New Approaches' Innovations in Services and Supports for people with disabilities in October and wanted a copy...

The Ties That Bind

'The Ties That Bind' is the title of a short film which was presented by Mr. Bob Rhodes from the U.K. at our conference 'New Ideas – New Approaches' Innovations in Services and Supports for people with disabilities which was held on the 23rd and 24th of October in Kilkenny. The film describes the effectiveness of facilitated social support networks in addressing the isolation and loneliness of many people including those with intellectual disabilities who live on the margins of society.

The film was very well received by all of those who viewed it at our conference and we have now made arrangements with the producers of the film, PLAN Institute in Canada, to make it available to those who would like a copy.

For more information please contact the National Federation of Voluntary Bodies Secretariat: Phone: 091-792316 or email: secretariat@fedvol.ie

The Goldfish Bowl

"The Goldfish Bowl" - This film was funded by the Department of Arts, Sport & Tourism and

produced by "Glasseye Productions", Thomastown, Co Kilkenny. More importantly the story and script was developed by the actors themselves all of whom are part of the "Steps" (Rehabilitative Training) Programme. This group was facilitated by an external film producer (Niamh Barret) who works in film production. The "Goldfish Bowl" explores the trials and tribulations of Stevie and Ellen and their search for true love in the face of mounting opposition from the management of the service they both attend! The film can be purchased by contacting Margaret Larkin on 056 7764000.

Conference Corner For more extensive information visit www.fedvol.ie

HSE Population Health Children and Young People's Conference

"Researching Children's Worlds
Conference: Sharing Knowledge to
Improve Action"

Date: 26 - 27th February 2008

Venue: Ardilaun Hotel, Taylor's Hill,
Galway

For more information:
www.researchingchildrensworlds.com

Europe in Action 2008 - "Education for All!"

Date: 10 - 12 April 2008

Venue: Kardinal König Haus — Vienna
For more information: www.inclusion-europe.org

Quality and Safety Conference in Healthcare

Date: 14 - 15 April, 2008

Venue: TBA

Further details, booking form, contact information for the conference will be available on the HSE website shortly.

26th National Learning Disability Nurses' Call for Abstracts

Conference on Health Inequalities:
Addressing the Challenges

Date: 23 - 24 June

Venue: Trinity College Dublin

For more information:
office@NNLDNConference.com or
www.ncnm.ie

Conference on 'Legal Frameworks to facilitate the development of Community Based Settings and Persons Centred Services'

Date: 14-15 February 2008

Venue: Gran Hotel Palazzo Carpegna
Via Aurelia, 481 00165 Rome Italy

For more information: info@easpd.eu or
www.easpd.eu

IASSID 13th World Congress

Date: 25 - 30 August 2008

Venue: Cape Town International
Convention Centre (CTICC)

For more information:

g.h.murphy@kent.ac.uk: or
www.iassid.org

RUA

Raising Understanding and Awareness
about Ones Self, Friendships,
Relationships and Sexuality. - An
Introduction to Friendships,
Relationships and Sexuality in
Intellectual Disability

1 Day Workshop

Date: 11th February 2008

Venue: RUA, Crinken House, Crinken
Lane, Shankill, Co Dublin

For more information: Phone: 01-272
1030/ 281 4139 or email: rua@sjog.ie

PSI Learning Disability Special Interest Group

Date: 26 - 27 March 2008

Venue: Ardilaun Hotel, Taylors Hill,
Galway.

Applications to: Caitríona Ní Mhurchú,
PSI Office, CX House 2A Corn
exchange Place, Poolbeg St. Dublin 2.

Art Competition Winner



Special congratulations to Helen Flynn, winner of the art competition to design the cover of the NIDD Annual Report 2007. Her painting, 'A day in the park', was the selected winner from more than 400 entries in a national competition organised by the Health Research Board in conjunction with the National Federation of Voluntary Bodies. The full report is available online at www.hrb.ie. Helen Flynn is pictured here with Fionnuala Kelly, HRB, Mr. Jimmy Devins, TD, Minister of State, Department of Health & Children with responsibility for Disability and Mental Health, Brian O'Donnell, Chief Executive of the National Federation of Voluntary Bodies, and Caraiosa Kelly of the Health Research Board.

We hope you find this newsletter useful and we would welcome your comments or suggestions to secretariat@fedvol.ie.
Further news and information updates are available on our website at www.fedvol.ie.

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

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Informing Families of their Child's Disability – Development of National Best Practice Guidelines

The development of National Best Practice Guidelines for informing families of their child's disability was a substantial consultation and research project undertaken by the National Federation of Voluntary Bodies over the past three years, and was completed in December 2007.



Informing
Families

OF THEIR CHILD'S DISABILITY



Left to Right: Larry Walsh (Chief Executive, Health Services National Partnership Forum), Alison Harnett (National Federation of Voluntary Bodies), Brian O'Donnell (Chief Executive, National Federation of Voluntary Bodies).

The project was initiated in response to feedback from many parents to National Federation member organisations, that the news of their child's disability had been conveyed insensitively or in inappropriate environments; and that their experience of being told the news had caused additional distress at the time of disclosure. Similarly, feedback from professionals delivering the news indicated that they felt there was an absence of training and clear guidance available to support those undertaking the sensitive and challenging task of giving a family the news that their child has a disability. With this in mind, in 2003 the National Federation made a funding proposal to the Health Services National Partnership Forum (HSNPF), who generously provided support for the project. In April 2004 the National Federation appointed Alison Harnett as the Informing Families Project Co-ordinator.

The research and consultation was guided by a Steering Committee chaired by Dr. John Hillery (President of the Medical Council of Ireland 2004-2007 and Consultant Psychiatrist with

Stewart's Hospital and St. John of God Hospitaller Services). The Steering Committee had representation from key groupings such as parents, disability service providers, the HSNPF, the

Health Services Executive, the Department of Health and Children, the Royal College of Physicians of Ireland, the National Federation of Voluntary Bodies and nominees from the professional bodies and trade-unions of various disciplines involved in informing families.

The aim of the Informing Families Project was to develop evidence-based National Best Practice Guidelines, education, and training; on appropriate procedures to inform families of their child's disability when communicating a diagnosis or concern. The fundamental goals of implementing these Guidelines are to ensure improved outcomes for families being told of their child's disability, through the implementation of best practice; and to provide improved support, guidance, education and training for professionals in the important and sensitive task of delivering this news.

Significant research and consultation, including twenty two focus groups with parents and professionals, and a national questionnaire survey of 584 families and 1588 professionals were



Alex and Max Crowe at the launch of the Informing Families Best Practice Guidelines.



Left to Right: Brendan Broderick, (Chairperson National Federation of Voluntary Bodies), Mary Harney, TD (Minister for Health and Children), Brian O'Donnell (Chief Executive, National Federation of Voluntary Bodies), Alison Harnett (National Federation of Voluntary Bodies).

undertaken, the findings of which were analysed and collated to produce the Guidelines. The scope of the project included the disclosure of a child's diagnosis of intellectual, physical, sensory and multiple disabilities, and autistic spectrum disorders; and the Guidelines relate to the diagnosis of a child's disability during pregnancy, at birth, or in the case of a diagnosis which evolves over time.

National Launch

Minister for Health and Children, Mary Harney, TD launched the National Best Practice Guidelines for Informing Families of their Child's Disability on 3rd December 2007. The launch took place in the Royal College of Physicians, and was chaired by Miriam O'Callaghan (RTE) and attended by approximately 140 people, including families and professionals from a wide range of organisations and disciplines. A short film produced to accompany the Guidelines, entitled 'Words You Never Forget' received its first airing at the launch. It tells the stories of how two families received their children's diagnosis. It also explores positive ways that professionals who inform families of the news, or support them through the process of diagnosis can approach this important task sensitively and effectively. The Minister indicated her full support for the Informing Families Project and noted that the priority must now be implementation. She warmly welcomed the next phase of the project, which is the development of a national implementation strategy in tandem with a specific pilot implementation project in the Cork region.

Next Steps...

The pilot implementation project taking place in the Cork region will involve all key stakeholders and will specifically seek to ensure that an integrated approach is taken to implementation, across hospital, community and voluntary services. The pilot project provides a vital opportunity to transition these important guidelines from theory to practice. An evaluation of the process taking place in Cork will provide important information to guide the dissemination and implementation which will be ongoing on a national basis. The trade-unions, professional bodies and

Informing Families of their Child's Disability

Development of National Best Practice Guidelines



Informing Families

OF THEIR CHILD'S DISABILITY

statutory bodies who were involved in the development of the Guidelines are also taking part in the dissemination of the Guidelines through the various communication channels identified as being key to embedding best practice in this area.

Resources Available

The National Best Practice Guidelines for Informing Families of their Child's Disability, and the Consultation and Research Report are both available to download from www.fedvol.ie. Printed copies of these resources and the DVD 'Words You Never Forget' can be requested by contacting the Project Co-ordinator, Alison Harnett. (alison.harnett@fedvol.ie).

Tel: (091) 792316.



Left to Right: Katherine O'Leary (Chair Informing Families Cork Region), Mary Harney, TD (Minister for Health and Children), Miriam O'Callaghan (RTE), Alison Harnett (National Federation of Voluntary Bodies). Photos Tommy Clancy.