

National Federation of Voluntary Bodies

Annual Report 2007



15/5/07 P. 4

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability is a national umbrella organisation for voluntary/non-statutory agencies who provide direct services to people with intellectual disability in Ireland. Our 63 Member Organisations provide services to 22,000 people with intellectual disability and their families in the Republic of Ireland and account for in excess of 85% of this country's direct service provision to people with an intellectual disability. The services provided to people with an intellectual disability are founded on the values as set out in the O'Brien (1997) Principles of Inclusion, Choice, Dignity, Respect, Participation and Contribution. They are rooted in the rights based perspective that people with intellectual disability have the right to live full and active lives, and be active participating members of their own community.

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

**Oranmore Business Park,
Oranmore, Galway.
Tel: (091) 792316
Fax: (091) 792317
Email: secretariat@fedvol.ie
Web: www.fedvol.ie**

**National Federation of
Voluntary Bodies**
Annual Report 2007

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

**Oranmore Business Park,
Oranmore, Galway, Ireland
Tel: + 353 91 792316
Fax: + 353 91 792317
Email: secretariat@fedvol.ie
Website: www.fedvol.ie**

Table of Contents:	Page No
Chairperson’s Statement	1
Chief Executive’s Introduction	3
Section 1: Membership Support Services.....	5
National Federation of Voluntary Bodies Strategic & Structural Review Group	5
Engagement with HSE	5
Long Stay Residential Charges	6
National Intellectual Disability Database Committee Annual Report.....	6
Education Sub-Committee	7
Early Intervention Working Group	8
Vocational Training & Employment Sub-Committee.....	8
Section 2: Quality & Innovation	9
Health Information & Quality Authority (HIQA) Standards for Designated Services to People with Disabilities	9
Performance Verification Process	9
Health Services National Partnership Forum (HSNPF)	9
Training & Development	10
Managing for the Future: Building your skills as a Front Line Manager in a Person Centred Environment – Front Line Managers Training Programme	10
Bereavement Training Programme for Clinicians	11
PAS-ADD Training Programme	11
Managing People – Management Development Programme	12
HSE Learning Centre	12
APPM Funding	12
SKILL Project.....	13
Health & Social Care Professionals Council	13
Human Resources Sub-Committee	13
Garda Vetting	14
HSE - Employers Agency	14
Reduction in the Working Week of Nurses.....	15
Recruitment Advertising	16
HSE Complaints Policy & Procedure	16

Section 3: Research & Policy Development	17
New Director of Research & Policy Development	17
Research Sub-Committee	17
National Federation of Voluntary Bodies Conference “New Ideas New Approaches – Innovation in Services and Supports to People with an Intellectual Disability”	18
Informing Families Project	19
Production of DVD film “Words You Never Forget”	21
National Launch	21
Dissemination and Implementation	21
Cork Implementation Project	21
Development of an Inclusive Research Network – IRN	22
T.I.L.D.A. (Irish Longitudinal Study on Ageing)	23
Doing Disability Research NIID – Marie Curie Transfer of Knowledge	24
Prof. Kelley Johnson, Director of Norah Fry Research Centre, Bristol (Formally with the NIID, Trinity College, Dublin)	24
Audit by Research of Abuse in Disability Services	24
European Association of Service Providers for People with Disabilities (EASPD)	25
National Housing Strategy for People with a Disability	25
National Disability Strategy.....	26
Person Centred Medication Management	26
Mental Health Act 2001	27
Community Participation & Inclusion of People with Intellectual Disability.....	27
Volunteering Supports.....	28
Appendices	29
Appendix 1:	
National Federation of Voluntary Bodies Board of Directors	29
Appendix 2:	
National Federation of Voluntary Bodies Sub Committees & Working Groups as at 31st December, 2007	30
Appendix 3:	
National Federation Representatives on National Committees & Working Groups as at 31st December, 2007	34
Appendix 4:	
National Federation of Voluntary Bodies Financial Data 2007 – 2006	36



Chairperson's Statement

2007 was a particularly demanding year with heavy internal and external agenda. Internally, the main focus was on expediting a structural review on foot of the internal changes within HSE. Within three months of its establishment, the working group's Terms of Reference were extended to incorporate a broad strategic review. We were greatly assisted in this by the input of an external, independent perspective from Mr. Pat Harvey of Harwyn Management Consultants. By year end, the working group had formulated a set of options to place before the membership. Four key strategic objectives have also been identified.

Externally, 2007 was a year of very high engagement with HSE on the implications of their Transformation Programme and their evolving ideas about the scope and character of service-level agreements. At the beginning of the year there was much concern that we were losing priority and traction on HSE's overall agenda. However, following a co-ordinated cross-disability approach to Professor Drumm, the situation greatly improved and a very effective communication and negotiation channel with HSE's disability "governance group" emerged.

The highlights of the year (personal view) were:

The Innovation Conference in October (its huge success is attributable in very large measure to Edel Tierney's relentless pursuit of clarity and preparedness);

The presentation to the Board of Directors at their April meeting by Brian Donohoe and Cabrini Debarra of the Community Participation & Inclusion Sub-Committee of the key recommendations from the report on their consultative workshop;

HSE's grasping of the nettle of the issue of citizens with disability who continue to live in congregate care settings. The National Federation are well represented on the national Working Group which is being chaired with great skill and commitment by Pat Dolan of HSE, and driven by the unique energies of Christy Lynch in his Project Manager capacity;

The launch of the Informing Families Guidelines in December – hats off to Alison Harnett for landing this beautifully realised project which has registered an immediate national and international resonance.

While the investments and achievements of this very busy year would not have been secured without the huge voluntary input of Board and Sub-Committee members, the glue binding it altogether is the tireless, generous, and uniquely good-humoured crew at Oranmore under Brian O'Donnell's very special brand of leadership.

Brendan Broderick
Chairperson



Chief Executive's Introduction

I am happy to present the Annual Report of the activities of the Secretariat of the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability for 2007.

2007 was another extremely busy year for the National Federation of Voluntary Bodies. Service Providers again rose to the challenges presented by the National Disability Strategy and the transforming Health Service. The Federation also played an active role in the National Disability Strategy Stakeholders Monitoring Group, which was established to oversee and monitor progress on the Strategy, including the development of Sectoral Plans by six Government Departments and the development of new services and supports for people with disabilities in Ireland.

The signing of the UN Convention on the Rights of People with Disabilities in New York in August 2006, together with the National Disability Strategy prompted much anticipation and hope in people with disabilities and their families. Mindful of the expectations which these developments created, our Federation commenced a reflection of how best to configure ourselves to support people with intellectual disabilities into the future. We acknowledged that it was timely for us to embrace new ideas and to be innovative in terms of how services and supports should be provided. In November 2007, we hosted our annual conference on the topic "New Ideas, New Approaches – Supporting Innovation in Services & Supports to People with Intellectual Disability". Attended by over 300 delegates, the conference was an outstanding success achieving all of the objectives set for it by our hand working Conference Organising Sub-Committee.

We continue to highlight issues of concern to our sector and during the course of 2007, a number of meetings between the National Federation of Voluntary Bodies and the Health Services Executive were arranged to discuss and agree action agendas in relation to a range of issues of mutual concern, including new services development, funding issues, implementation of the Disability Act, Service Level Agreements etc.

Effective ongoing communication and consultation with our member organisations continue to be priority issues for us and in this regard over 150 communications, including news updates, policy position papers, newsletters and bulletins issued during 2007. Work also commenced on a review of our website to develop an intranet facility to accommodate the establishment of Special Interest Research Groups.

In this time of constant change the need for a focused strategic approach to the development of training and education of the 16,000 staff working in our sector is self evident. We are also conscious of the need to promote the interests of all staff working in our sector and in this regard the excellent work done by both our Human Resources and Training & Development Sub-Committees is outlined in Section 2 of this report.

During 2007, the National Federation continued its work in promoting the social inclusion of people with intellectual disabilities to live full and active lives. This work is overseen by our very active Community Participation & Social Inclusion Sub-Committee, which is comprised of people who access services and support staff, all of whom have a particular expertise and interest in social inclusion issues.

Research & Policy Development are key functions of the National Federation of Voluntary Bodies. In May 2007, Edel Tierney took up the position of Director of Research & Policy Development and wasted no time in commencing work on the development of a Research Strategy for the National Federation, under the guidance of the National Federation's Research Sub-Committee, to cover the six year period 2008-2013. A major achievement in 2007 was the launch of our best practice guidelines in informing families of the diagnosis of their child's disability. The guidelines which are the product of a major three year research project were launched by Ms. Mary Harney, T. D., Minister for Health & Children at a very special event in Dublin on 3rd December, 2007.

In conclusion, I would like to convey my gratitude to our Chairperson, Mr. Brendan Broderick, for his unstinting commitment, support and guidance during 2007. I would also like to express my appreciation to all 63 member organisations of the National Federation of Voluntary Bodies for their staff involvement in, and support for, all of our activities during 2007.

Finally, it will be noted from this report that while the range of activities carried out by the Secretariat Staff, on behalf of the National Federation, is extensive and their achievements impressive, our staffing resources are limited. Apart from myself as Chief Executive, the Secretariat's core staff comprises Edel Tierney, Director of Research & Policy Development; Maria McMahon, Office Manager; Caroline Looney & Mary Barrett, who job share as Administrative Officer; Brendan Dolan, part-time Administrative Officer and Brian Donohoe, part-time Clerical Officer. We also employ three Project Managers on specified term contracts in the area of Policy Development, Breda Casey; Developing Best Practice Guidelines in informing families about the diagnosis of a disability, Alison Harnett and implementation of the Action Plan for People Management in the Intellectual Disability Sector, Jillian Sexton. I would like to pay tribute to all of my colleagues for their dedication and professionalism during what was an extremely demanding and busy year.

*Brian O'Donnell,
Chief Executive.*

Section 1

Membership Support Services

NATIONAL FEDERATION OF VOLUNTARY BODIES STRATEGIC &

STRUCTURAL REVIEW GROUP REVIEW GROUP:

In spring 2007, the Board of the National Federation of Voluntary Bodies established a Review Group to (1) carry out a Strategic Review of the National Federation of Voluntary Bodies having regard to the Government's National Disability Strategy and the HSE's Transformation Programme, and (2) advise on an appropriate structure for the Federation which best supports the Federation's strategic direction.

Key Achievements in 2007:

- The Board approved the establishment of 5 Interim Area Federation Fora to advise members on the state of progress of the Strategic / Structural Review Group and to update members on developments nationally.
- The Review Group met on four occasions during 2007 and commissioned Harwyn Consultants Ltd to carry out a comprehensive consultation exercise with external stakeholders and a sample of member organisations.

ENGAGEMENT WITH HSE:

During the course of 2007, a number of meetings between the National Federation of Voluntary Bodies and HSE were arranged to discuss and agree action agendas in relation to a range of issues of mutual concern and interest as follows:

- Value for Money Cutbacks;
- Service Costing methodologies;
- Capital Projects – Securing State's Interest;
- Congregated Settings – Deinstitutionalisation;
- Waiting Lists for Services;
- Long Stay Residential Charges;
- HSE 2007 – Employment Control Framework;
- Disability Act;
- Core Funding Deficits;
- Service Level Agreements;
- Health Services Transformation Programme;
- Dementia Services.

Key Achievements for 2007:

- A Joint Working Group to consider the issues of Securing the State's Interest in Capital Projects was established. The National Federation is represented on the Group by Ms. Breda Crehan Roche, Chief Executive, Ability West and Mr. Pat O'Toole, Chief Executive St. Christopher's Service Longford.
- A National Working Group was established to develop proposals on the de-institutionalisation of certain services located in congregated settings. The National Federation is represented on the Group by Mr. Brendan Broderick, Chief Executive, Sisters of Charity of Jesus & Mary; Bro. Laurence Kearns, Provincial, Hospitaller Order of St. John of Gods and Ms. Winifred O'Hanrahan, National Director, Brothers of Charity Services. Mr. Christy Lynch, Chief Executive, KARE, has been seconded to work on the project on full time basis.
- A derogation from the HSE 2007 Employment Control Framework was sought and obtained in relation to new service developments in the Intellectual Disability Sector.
- Value for money cutbacks were not administered in the Intellectual Disability Sector in 2007 following discussions between the National Federation of Voluntary Bodies and HSE in relation to this matter.
- The National Federation of Voluntary Bodies established a Working Group to prepare a submission to the HSE in relation to implementation of the Disability Act 2005 for 0-5 year olds.
- An amount of €10m was allocated throughout the sector to commence the process of addressing the issue of historic core funding deficits.
- The National Federation of Voluntary Bodies engaged with both the HSE and Tribal Secta Consultants in

relation to the preparation of a new Service Level Agreement Template.

- A National Steering Committee, together with a National Reference Group, to advise on the Transformation Process in respect of Primary, Community & Continuing Care were established. Mr. Brian O'Donnell, Chief Executive, represents the Federation on the National Steering Group and Mr. John O'Dea, Executive Director, Western Care Association, represents the Federation on the National Reference Group.
- Following discussions between the National Federation of Voluntary Bodies and the HSE, it was agreed that the Federation would be represented on each of the HSE Area Senior Management Fora. The Federation is represented at these Fora as follows:
 - HSE Dublin - Mid Leinster - Mr. Brendan Broderick, Chief Executive, Sisters of Charity of Jesus & Mary;
 - HSE Dublin – North East – Mr. Paul Ledwidge, Chief Executive, St. Michael's House;
 - HSE South – Ms. Maura Nash, Chief Executive, COPE Foundation;
 - HSE West – Mr. John O'Dea, Executive Director, Western Care Association.
- The HSE established a National Working Group to examine all matters relating to HSE Funded Adult Day Services. The National Federation of Voluntary Bodies is represented on the Group by Mr. Pat Reen, Chief Executive, Prosper Fingal.
- The HSE established a National Working Group on Dementia. The National Federation of Voluntary Bodies is represented on the group by Prof. Mary McCarron, Associate Professor of Nursing & Director of Research, School of Nursing & Midwifery Studies, Trinity College Dublin.

LONG STAY RESIDENTIAL CHARGES:

In January 2007, a Working Group was established to examine member organisation's issues with regard to the implementation of the above charges. The Working Group devised a strategy to highlight the various issues arising for member organisations following on from the introduction of Regulations which gave effect to the charges.

Key Achievements in 2007:

- A meeting was arranged with Ms. Mary Harney, T.D., Minister for Health & Children during which the issues arising for the Intellectual Disability sector were raised and a call was made to the Minister to either introduce new legislation or amend the existing legislation to address the anomalous and inequitable situations arising for people with an intellectual disability who are being supported by member organisations.
- A series of meetings was arranged with senior officials in the HSE to bring our concerns to their attention.

NATIONAL INTELLECTUAL DISABILITY DATABASE COMMITTEE

ANNUAL REPORT:

The National Federation of Voluntary Bodies works closely with the Health Research Board and the Department of Health & Children in the formulation and publication of the National Intellectual Disability Database Annual Report. The Database report is an essential services information and planning tool.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies through its membership provided comprehensive information on current services provision on current unmet need and on future service requirements.
- The National Federation of Voluntary Bodies organised an art competition for service users within its membership to design the cover of the National Intellectual Disability Database Committee Annual Report for 2007. Over 450 entries from services all over the country were received. The National Federation of Voluntary Bodies organised an award ceremony involving Mr. Jimmy Devins, Minister of State, Department of Health & Children, with responsibility for Disability and Mental Health, who presented the winners prize to Ms. Helen Flynn, Stewarts Hospital, Palmerstown, Dublin. Helen's painting was entitled 'A day in the park'.



Helen Flynn is pictured above with Fionnuala Kelly, Health Research Board; Dr. Jimmy Devins, TD, Minister of State, Department of Health & Children with responsibility for Disability and Mental Health; Brian O'Donnell, Chief Executive, National Federation of Voluntary Bodies and Caraiosa Kelly, Health Research Board.

EDUCATION SUB-COMMITTEE:

The Education Sub-Committee is a long standing Sub-Committee that was set up to advise the Board of National Federation of Voluntary Bodies on issues relevant to the education of children and adults with intellectual disability and to provide a forum to consult with members on priority issues.

Key Achievements in 2007:

- The Education Sub-Committee met three times during 2007 in January, March and September. The Committee reviewed the Early Interventions Services and the different models in operation throughout the Federation Membership.
- The Committee is currently reviewing the 36 recommendations which were generated as a result of the National Federation of Voluntary Bodies Conference entitled "Making Appropriate Education a Reality for Pupils with Severe and Profound Intellectual Disability". The current status of the recommendations is being reviewed to ascertain if they have been implemented.
- Mr. Stephen Kealy, Sisters of Charity of Jesus & Mary, and Ms. Moira King, Brothers of Charity Southern Services, are the representatives of the National Federation of Voluntary Bodies on the National Steering Group that has been set up to oversee the implementation of the Disability Act 2005 which became law on 1st June, 2007 for children under 5. This Act, which is filtered down to each local health area, entitles all children under the age of 5 to an independent assessment of their health and education needs arising from their disability. It also entitles them to an assessment report and statement of the services they will receive and also to make a complaint if they are not happy with the process.
- The Sub-Committee liaised with the Early Intervention Working Group, chaired by Mr. Stephen Kealy, Sisters of Charity of Jesus & Mary. This group was set up in 2006 to develop a report on Early Intervention Services.
- Ms. Helen Guinan, COPE Foundation, is the National Federation of Voluntary Bodies representative on the National Council for Special Education. During the year, Helen briefed the Sub-Committee on the National Council for Special Education's "Implementation Report Plan for the Phased Implementation of the EPSEN Act 2004". This document was submitted to the Ms. Mary Hanafin, T.D., Minister for Education & Science at the end of 2006 but as yet has not been signed off by the Department.
- National and European perspectives are constantly monitored by the Sub-Committee including Dail and

Seanad Debates pertaining to special education and from an international perspective through the EASPD Standing Committee on Education.

EARLY INTERVENTION WORKING GROUP:

During 2006, the Education Sub-Committee proposed the establishment of a Working Group whose key aim was to develop a National Federation of Voluntary Bodies report on Early Services which would contain proposals for the best way forward in Early Intervention Services. This group commenced work in October 2006.

Key Achievements in 2007

- The report on Early Intervention Services, compiled by the Working Group which was chaired by Mr. Stephen Kealy, Director of Psychology, Sisters of Charity of Jesus & Mary, was produced in early 2007.
- It was circulated to all members of National Federation of Voluntary Bodies, following which it was then submitted to Health Service Executive for consideration in the context of the implementation of the Disability Act for 0-6 age group.
- Following the conclusion of its work this committee has now disbanded.

VOCATIONAL TRAINING & EMPLOYMENT SUB-COMMITTEE:

The Vocational Training & Employment Sub-Committee was set up to advise the Board of National Federation of Voluntary Bodies on issues relating to the vocational training and employment of service users. The group met four times during 2007.

Key Achievements in 2007:

- A Day Service Questionnaire was circulated to all the members of National Federation of Voluntary Bodies. The results of the questionnaire are currently undergoing analysis by the committee.
- Mr. Pat Reen, Prosper Fingal, is the National Federation's representative on National Review of HSE Funded Day Services and a presentation was made to the National Federation General Assembly meeting in September 2007 in relation to this. A series of Sub-Groups have been established in relation to this review by the HSE and reports from these are expected mid 2008.
- Mr. Christy Lynch, Chief Executive, KARE, who was Chairperson of the Sub-Committee, has taken a leave of absence from KARE in order to take up the post of Project Manager on the Congregated Settings Project from December, 2007. We wish him every success with the project.

Section 2

Quality & Innovation

HEALTH INFORMATION & QUALITY AUTHORITY (HIQA) STANDARDS

FOR DESIGNATED SERVICES TO PEOPLE WITH DISABILITIES:

HIQA have statutory responsibility for the development and monitoring of standards across all settings including disability services in the Health and Social Care Services. With regard to the development of standards in disability services, HIQA established a National Standards Advisory Committee.

Key Achievements in 2007:

- Mr. Brian O'Donnell, Chief Executive, was invited to represent the National Federation of Voluntary Bodies on the National Standards Advisory Committee.
- The National Federation of Voluntary Bodies re-constituted its Quality Sub-Committee to act as a Reference Group in relation to the development of the standards.

PERFORMANCE VERIFICATION PROCESS:

The Performance Verification Process requires that all organisations within the Health & Social Care Sectors who receive public funding, submit progress reports on the attainment of objectives set out in the Action Plan associated with the National Social Partnership Agreements. In the case of the Voluntary Intellectual Disability Sector, the National Federation of Voluntary Bodies was requested by Government to co-ordinate and prepare the sector report.

Assessment of verified progress is undertaken by the Performance Verification Group (PVG) in respect of the sector as a whole and the organisations and grades within the sector, following receipt of the reports and an assessment on progress by the Secretary General of the Department of Health & Children.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies co-ordinated the completion of the PVG Template by all its member organisations.
- The National Federation of Voluntary Bodies prepared and submitted an overall sector report to the PVG encompassing the contents of the individual organisation reports submitted.
- The National Federation of Voluntary Bodies arranged one site visit for the PVG.
- The National Federation of Voluntary Bodies made a presentation to the PVG on progress made in the Intellectual Disability Sector.
- The report of the National Federation of Voluntary Bodies in respect of Phase III was commended by the PVG and the national pay award to all staff categories was sanctioned by the Department of Health & Children without qualification.

HEALTH SERVICES NATIONAL PARTNERSHIP FORUM (HSNPF):

The Health Services National Partnership Forum (HSNPF) established a Primary, Community & Continuing Care (PCCC) National Partnership Working Group to support and facilitate the partnership processes associated with the implementation of the PCCC Transformation Programme. Mr. Brian O'Donnell, Chief Executive, represents the National Federation of Voluntary Bodies on this group.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies made submissions to the Group on managing the implications for PCCC of new legislation particularly relevant to the Intellectual Disability Sector such as Mental Health Act 2001; Disability Act 2005; Children's Act 2001; Education for Persons with Special Needs Act 2004 and the Citizens Information Bill 2006.

- The National Federation of Voluntary Bodies contributed to major discussion by the Group on the development of a planned and national approach to funding the community / voluntary sector.
- The National Federation of Voluntary Bodies submitted proposals to the group regarding the interface between Primary Care Teams and Voluntary Service Providers at the local level.
- The Working Group established a National Reference Group to discuss points of issue with different stakeholders. Mr. John O'Dea, Executive Director, Western Care Association, represents the National Federation of Voluntary Bodies on this group.

TRAINING & DEVELOPMENT:

The National Federations Training & Development Sub-Committee met on 4 occasions during 2007, with members of the Committee continuing to share their considerable expertise in relation to the promotion of best practice in a range of training and development related areas. The Sub-Committee is chaired by Mr. Brendan Broderick, Sisters of Charity of Jesus & Mary. The Committee acts a co-ordination point for a number of Action Plan for People Management (APPM) training and development actions that are undertaken by the National Federation of Voluntary Bodies.

MANAGING FOR THE FUTURE: BUILDING YOUR SKILLS AS A FRONT LINE

MANAGER IN A PERSON CENTRED ENVIRONMENT' – FRONT LINE MANAGERS

TRAINING PROGRAMME:

October 2007 saw the completion of the pilot programme for front Line Managers which had been running throughout the year in the University of Limerick. The programme was seen as being central in building the capacity of Front Line Managers to lead the development and implementation of world class person centred services and supports to people with intellectual disability in Ireland. The overall aim of the programme, which was accredited as a Certificate in Management, Level 6 National Framework of Qualifications, was: *to enhance the capacity of front line managers in intellectual disability services to effectively carry out their role and to contribute to the human resource function within their organisation in partnership with key stakeholders.*

Specifically the programme aimed:

- To enhance and clarify learners understanding of their role as a front line manager.
- To develop a specific set of skills and competencies required by front line managers and to build their confidence in their role.
- To develop learners people management skills and knowledge of relevant HR policies and procedures and employment law.
- To develop managers people management skills and ability to lead a team.
- To develop knowledge and practical skills in managing change.
- To provide a basis from which participants can progress onto further (accredited) training programmes.

Key Achievements in 2007:

- A Steering Committee, chaired by Mr. Liam Murphy, Human Resources Manager, Brothers of Charity, Cork, oversaw the development and implementation of the Pilot Programme.
- Successful accreditation was negotiated for the programme with the University of Limerick.
- A total of 21 participants, drawn from 14 agencies, participated in the pilot programme which was delivered by personnel from The Performance Partnership and the Kemmy Business School, University of Limerick. The piloting of programme provided the opportunity to test the materials which were specifically developed for the programme and following some minor revisions these will be made widely available to National Federation of Voluntary Bodies members in 2008.
- The Steering Committee that oversaw the development of the materials and the pilot programme are currently considering options in relation to the further roll-out of the programme.

BEREAVEMENT TRAINING PROGRAMME

FOR CLINICIANS:



Ms. Sile Reynolds, Senior Occupational Therapist, St. Michael's House.

In May 2007, the National Federation of Voluntary Bodies, in conjunction with St. Michael's House, organised a Bereavement Training Programme for Clinicians. Loss and bereavement are complex life experiences for everyone and this is equally true for people with an intellectual disability. In order to acknowledge and address the bereavement needs of people with intellectual disabilities, their families and carers, clinicians from St. Michael's House developed a comprehensive bereavement training programme which was designed to meet the bereavement education and practical support requirements of people with intellectual disability, their families and carers in the event of the loss of a loved one. The training was delivered by Ms. Sile Reynolds, Senior Occupational Therapist, and Ms. Lucy Walsh, Senior Clinical Psychologist, St. Michael's House. Specifically the training sought to:

- Educate and train clinicians as bereavement trainers to a prescribed standard of knowledge and practice necessary to facilitate the provision of a comprehensive bereavement service (to people with intellectual disabilities, their families and support staff).
- Present the contents of the bereavement training programme materials developed by St. Michael's House for clinicians.
- Provide an overview of current research and literature.
- Examine attachment theory and the grief process.
- Identify bereavement issues specific to people with intellectual disabilities.

Key Achievements in 2007:

- A 'Bereavement Training Programme for Clinicians', organised in conjunction with St. Michael's House, took place over 3-days in May 2007 which catered for 30 participants / clinicians.
- On completion of the training programme each participant received a set of materials 'Live & Let Die' which were developed by St. Michael's House.
- A follow-up session will be held in early 2008 with the programme participants to review how they have been progressing with the roll-out of the training within their respective organisations and to determine what future supports might be required.



Ms. Lucy Walsh, Senior Clinical Psychologist, St. Michael's House,

PAS-ADD TRAINING PROGRAMME:

Recognising and responding to mental health needs has been one of the most important developments in the field of intellectual disability over the past 15 years. The PAS-ADD (Psychiatric Assessment Schedules for Adults with Developmental Disabilities) training programme was targeted at personnel involved in mental health assessment, including experienced clinicians and the programme aimed to provide participants with the opportunity to become a certified user of the mini-PAS-ADD informant interview and also provided an introduction to the PAS-ADD10 for clinical interviewing of people with intellectual disability.

Key Achievements in 2007:

- In June 2007 Dr. Steve Moss facilitated a 2-day training programme on the PAS-ADD system for staff working in the intellectual disability sector - a total of 24 personnel from across National Federation of Voluntary Bodies members took part in the training.
- Further training in this area will be provided in 2008.

'MANAGING PEOPLE – MANAGEMENT DEVELOPMENT PROGRAMME'

The series of 'Managing People – Management Development Programmes' organised by the National Federation of Voluntary Bodies aimed to enhance managers' understanding of competency frameworks and particularly to develop their competencies in the area of 'Managing People'. Specifically the 'Managing People - Management Development Programmes' aimed to ensure that managers are familiar with the process, materials and resources involved in the management competency frameworks and focused on skills training in the following 'Managing People' competencies:

- (a) Supporting Personal Development
- (b) Creating Team Spirit
- (c) Being the communication channel
- (d) Managing Individual Performance
- (e) Influencing people & events

Key Achievements in 2007:

- The final programme in the series of 'Managing People – Management Development Programmes' took place in spring 2007. This 3-day programme was delivered by the Open Training College and was grounded in the principles and practice of person centred planning.
- Following the conclusion of the series of programmes which took place, a final concluding event was held for all managers – over 140 - that participated in the programmes. This event took place in November 2007 and its aim was to celebrate people's participation in the programmes, present certificates and share some of the findings of the evaluation that was undertaken. Mr. Brendan Broderick, Chairperson, National Federation of Voluntary Bodies, 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.
- A final evaluation / programme report was completed for submission to the HSE who provided funding for the programmes.

HSE LEARNING CENTRE:

In 2007, the HSE began work on the expansion of the range of programmes and learning materials which are available on its eLearning site – www.hseland.ie. This on-going initiative will involve the development of a range of customised and generic learning programmes for staff working across the health and social care sector. This is an exciting development and a resource which organisations will be able to access to complement the existing range of training programmes available to staff.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies was represented on the National Working Group established to oversee the expansion of the HSE eLearning site with the aim of ensuring that organisations have access to a range of on-line learning tools / training materials which can complement other forms of learning occurring within organisations.

APPM FUNDING:

The Action Plan for People Management (APPM) sets out a wide range of actions and measures which aim to build and enhance managers skills, knowledge and management capacity. It aims to provide a road map for developments in people management within the health and social care sector and outlines a range of key action areas to be addressed. Initiatives within the plan aim to ensure that staff are highly skilled, committed, and equipped to deal with the challenges and changes that are occurring within the health and social care sector.

Key Achievements in 2007:

- A successful application was made by the National Federation of Voluntary Bodies to the Action Plan for People Management (APPM) to continue its work on implementing national initiatives.

- A progress report on the delivery of APPM related actions within the intellectual disability sector was submitted to the APPM Implementation Monitoring Committee during 2007.

SKILL PROJECT:

2007 saw the allocation of a further quota of SKILL Project places to Support Service Staff and Managers employed within National Federation member organisations. The aim of the SKILL Project is to provide education, training and development opportunities to support service staff within the health and social services. During 2007 increased funding was made available to organisations towards the cost of releasing learners to participate in the SKILL Project Training. The National Federation of Voluntary Bodies played a co-ordinating role in relation to the allocation of the quota to member organisations and arranging meetings with members of the national SKILL Project Team to discuss issues arising relating to the operation of the SKILL Project.

In autumn 2007 the SKILL Project embarked on a new development called "Critical Mass Sites" and this approach sought to facilitate a larger number of support staff from a single organisation to move through their training 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 and that there will be minimum disruption within the workplace.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies continued to be represented on the SKILL Project National Steering Committee by Mr. Brendan Broderick, Sisters of Charity of Jesus & Mary.
- The quota for training places within the SKILL Project was allocated to all National Federation of Voluntary Bodies members with the result that over 130 Support Service Staff and 12 Support Service Managers put themselves forward to commence training at FETAC Levels 3 / 4, 5 and 6 commencing in September 2007.
- In late 2007 the SKILL Project team and SKILLVEC met with a number of organisations to discuss the 'Critical Mass Sites' approach to providing training for Support Service Staff.
- Members of the National Federations Training & Development Sub-Committee met with representatives of the SKILL Project Team to discuss issues relating to the delivery of the SKILL Project within the intellectual disability sector.

HEALTH & SOCIAL CARE PROFESSIONALS COUNCIL:

The Health and Social Care Professional Council was established in 2007 under the Health and Social Care Professionals Act 2005. The purpose of the 25 person Council is to protect the public by promoting high standards of professional conduct, education, and competence and the work of the Council will lead to the statutory registration of 12 health and social care professions.

Key Achievements in 2007:

- Mr. Tony Darmody, Kerry Parents & Friends Association, was nominated to represent the National Federation on the Health & Social Care Professionals Council. During 2007 the work of the Council focused on getting its internal affairs in order and on practical matters such as the recruitment of Council staff, location of offices and issues such as 'Fitness to Practice', 'Conduct Performance & Ethics', 'Governance and Service Planning'. Council members also liaised with their counterparts in the UK to learn from their experience in this area.
- It is envisaged that the process of registration of a number of the disciplines covered under the Health & Social Care Professionals Act, 2005 will commence in early-mid 2008.

HUMAN RESOURCES SUB-COMMITTEE:

The work of the Human Resources Sub-Committee is overseen by Ms. Maura Donovan, Chief Executive, Stewarts Hospital. The Committee continues to act as a very important forum for networking in relation to human resource matters and bringing together human resource personnel from across National Federation of Voluntary Bodies member organisations.

GARDA VETTING:

The issue of securing garda clearance for personnel and volunteers working in the intellectual disability sector continued to be a priority for organisations during 2007. Representatives of the National Federation of Voluntary Bodies met with Inspector Pat Burke and his team in the Garda Central Vetting Unit on a number of occasions during 2007 to ensure that individual organisations have the necessary procedures in place to deal with vetting and can secure vetting in a timely manner.

Key Achievements in 2007:

- The Garda Vetting Working Group, which was established under the auspices of the Human Resources Sub-Committee, continued its work during 2007 to ensure that appropriate procedures are in place to enable organisations secure vetting for staff and volunteers.
- Individual organisations have appointed Authorised Signatories and a majority of the signatories have undertaken the required training with personnel from the Garda Central Vetting Unit. Organisations that are not processing a large number of vetting applications per annum have been developing links with other agencies who will undertake vetting on their behalf.

HSE – EMPLOYERS AGENCY:

The National Federation of Voluntary Bodies continued to hold bi-annual meetings with the HSE – Employers Agency during 2007. These meetings serve as a valuable means of ensuring that all National Federation member organisations are kept abreast of developments in the area of employment legislation and industrial relations. The National Federation of Voluntary Bodies is represented on the HSE – Employers Agency Employers National Advisory Committee by Mr. Brian O'Donnell, Chief Executive, National Federation of Voluntary Bodies, Ms. Maura Donovan, Chief Executive, Stewarts Hospital and Mr. John Pepper, Director of Human Resources, St. John of God Hospitaller Services.

Key Achievements in 2007:

Bi-annual meetings:

Meetings were held with key members of the HSE-Employers Agency during 2007 aimed at keeping staff members from the National Federation of Voluntary Bodies fully briefed on employment related matters in the health service.

Briefing Session - Equal Opportunities / Diversity Policy:

An overview of the main equality and diversity policy documents was provided by the HSE – Employers Agency at a briefing session organised by the National Federation of Voluntary Bodies in February 2007. The session focused on the HSE – Employers Agency *'Equality in Employment Action Plan 2006 / 2007'* and *'Strategy & Action Plan for the Employment of People with Disabilities in the Health Service, 2007'*.

Review of Clerical Administrative Job Evaluation Scheme:

The review that has been underway of the job evaluation scheme for Clerical / Administrative grades was completed in 2007. The new scheme will be more streamlined in processing applications and will require a more active involvement by both Line Managers and Human Resource departments within organisations. A panel of evaluators, which includes representatives from the Intellectual Disability sector, has been trained to carry out evaluations under the Scheme. A leaflet on the new job evaluation scheme has been drafted by the HSE – Employers Agency and a briefing session on the operation of the new scheme will take place for National Federation of Voluntary Bodies members in early 2008. Ms. Dymphna Gibbons, Daughters of Charity, represented the National Federation of Voluntary Bodies on the working group.

National Working Groups:

The National Federation of Voluntary Bodies is represented on the following national groups which have been established through the offices of the HSE – Employers Agency:

Policy on Workplace Disclosure:

The working group which was established to consider the issue of 'whistle-blowing' continued its work during 2007. The policy aims to support employees who report concerns in relation to their workplace without fear of reprisal. The Working Group comprises representatives of all health service employers and unions and Mr. Brendan Broderick, Sisters of Charity of Jesus and Mary, represents the National Federation of Voluntary Bodies on the Group.

Dignity at Work Policy:

A national Working Group was established in February 2007 to review the Dignity at Work Policy for the Health Service. This review is being conducted on a partnership basis between health service employers and unions. The focus of the review is on enhancing the existing infrastructure to further support the implementation of the Dignity at Work Policy, in particular the mediation process and the role of the Support Contact Persons. Issues that have arisen through the review include dealing with counter allegations of bullying/harassment, the introduction of a preliminary screening process to determine if the complaint should be processed under the Dignity at Work Policy or the grievance procedure, training for Support Contact Persons and on-going promotion of the policy. Feedback was sought from National Federation of Voluntary Bodies members in relation to their experiences in implementing the policy since its introduction in 2004.

The National Federation of Voluntary Bodies is represented on this Working Group by Ms. Maura Donovan, Stewarts Hospital and Ms. Jillian Sexton, National Federation of Voluntary Bodies. During 2008 the Working Group will be working on an "action plan" to assist employers with the structured roll out of the Dignity at Work Policy at local level.

REDUCTION IN THE WORKING WEEK OF NURSES:

Following industrial action by nurses during 2007 the National Implementation Body (NIB) proposed a two step solution which was accepted by both the INO and the PNA following balloting of their members. Phase 1 involved a reduction in nursing staff working hours from a 39 hour week to 37.5 hours while Phase 2 provided for the establishment of a Commission to produce an independent assessment of how a 35 hour week for nurses could be achieved.

In relation to the first phase it was agreed that the initial reduction would be implemented on a cost neutral basis and without diminution of services to clients on the basis of:

- a) the parameters of change especially in rosters, skill mix and other productivity measures which have been agreed at national level;
- b) individual service locations would use these parameters to draw up a package of local changes which would enable the initial reduction in working hours to be implemented on a cost neutral basis in a manner which reflected the nature of the service being delivered in that location;
- c) the Health Sector Performance verification group would provide an independent validation process to confirm that the changes planned for each location were sufficient to support the initial reduction and to verify delivery of these changes in advance of a target date for the reduction;
- d) The initial reduction would be implemented in each location on foot of such verification.

It was further agreed that the reduction of 1.5 hours to 37.5 hours be implemented with effect from 1st June 2008 and in this regard feedback was sought from employers in relation to the achievement of this by 21st December 2007.

In respect of Phase 2, the NIB recommended the establishment of a Commission to produce an independent assessment of how a 35 hour week for nurses could be achieved. In this regard tenders were sought in respect of a feasibility study to be undertaken and Howarth Consulting Ireland was awarded the tender.

Key Achievements in 2007:

- Mr. John Pepper, Director of Human Resources, St. John of God Hospitaller Services, represented the National Federation of Voluntary Bodies at the national talks.
- In order to ensure that there was a full awareness and appreciation of the issues of concern to National Federation of Voluntary Bodies member organisations the National Federation sought to nominate a person with knowledge, experience and expertise in the Intellectual Disability Sector to authoritatively inform the deliberations of Howarth Consulting Ireland in their work. In this regard the National Federation's Board of Directors approved the nomination of Ms. Anna Plunkett, Director of Nursing, St. John of God Menni Services as the Federation nominee to work alongside Howarth Consulting Ireland.
- The National Federation of Voluntary Bodies will continue to monitor the situation in relation to nursing matters during 2008.

RECRUITMENT ADVERTISING:

Organisations continued to advertise during 2007 with Independent News and Media under the banner of the National Federation of Voluntary Bodies and in so doing availed of significant reductions in their advertising costs. Advertising under the banner of the National Federation of Voluntary Bodies has helped with the development of an identifiable brand image for the intellectual disability sector.

Key Achievements in 2007:

- It was estimated that as a result of the group scheme operated by the National Federation of Voluntary Bodies a saving in the region of €1 million has been secured for National Federation member organisations.

HSE COMPLAINTS POLICY & PROCEDURE:

The National Federation of Voluntary Bodies was involved in the consultation process relating to the development of a HSE Policy on the management of complaints in relation to Part 9 of the Health Act, 2004. This policy seeks to provide a means for the management of complaints that facilitates effective feedback from and communication to all service users. January 2007 saw the enactment of the relevant legislation and there is now a requirement on organisations to comply with the legislation. Under the Act, Complaints Officers are designated within organisations and training will be provided to enable them to deal with complaints in line with best practice and legislative requirements.

Key Achievements in 2007:

- During October 2007 a series of briefing sessions were organised with the HSE Office of Consumer Affairs in relation to the HSE Complaints Policy and Procedures and these were held in a number of regional venues.
- Training for those appointed as Complaints Officers will take place in spring 2008.

Section 3

Research & Policy Development

NEW DIRECTOR OF RESEARCH & POLICY DEVELOPMENT:

In May 2007 Edel Tierney took up the position of Director of Research and Policy Development with the National Federation of Voluntary Bodies. Edel was formerly Research Co-ordinator with COPE Foundation in Cork and is a native of Galway City.

RESEARCH SUB-COMMITTEE:

In 2007 the Research Sub-Committee met three times, in February, May and December. The Sub-Committee saw many changes in 2007 with the resignation of Dr. Bob McCormack as Chairperson of the Group and the retirement of Ms. Anne McCarthy who represented Stewarts Hospital on the group. Dr. McCormack took up a new position as Chief Executive Officer of Dara Residential Services this year. We wish them both well in the future and would like to take this opportunity to thank them both for their very valuable input into the activities of the Research Sub-Committee over the past few years.

In addition the Sub-Committee recruited some new members to kick start the activities of the Sub-Committee in 2008. These are Dr. Brian McClean from Brothers of Charity in Roscommon, Dr. Mark Stanton from Brothers of Charity in Clare, Dr. Mary McCarron from Trinity College Dublin and Daughters of Charity in Dublin and Ms. Mary Desmond from COPE Foundation. We feel that their contribution to the Research Sub-Committee in the coming year will be invaluable.

Key Achievements in 2007:

The committee continued to:

- Advise the Board of the National Federation of Voluntary Bodies on research issues
- Provide support for National Federation research projects through participation in project advisory committees at Trinity College Dublin and the National Institute of Intellectual Disability TCD.
- Disseminate the research undertaken by the National Federation and the member organisations, this was done via website emails and information bulletins.
- Encourage informal networking through the organisation of the conference and the Inclusive Research Network.
- Highlight the research activities of the National Federation and its members through various presentations at national and international conferences.
- Debate best practice and develop guidelines in disability research based on national and international evidence.
- In May a Lecture by Dr. Kelley Johnson was given to the committee on Inclusive Research. At that time Kelley was a research fellow with the National Institute for Intellectual Disability (NIID), Trinity College Dublin
- Following discussion between Ms. Edel Tierney, Director of Research & Policy Development, and Dr. Kelley Johnson it was agreed that a Participatory or Inclusive Research Network should be formed (see more below).
- Fact-sheets were developed on topics of Consent, Introduction to Research, Ethical Principles and Forms for CEO's when approached by personnel to conduct research within the Organisation. These fact sheets will be posted on the National Federation website as a source of information to member organisation on these research issues.
- At the last meeting of the Sub-Committee in December it was agreed to develop a Research Strategy for the National Federation and this strategy will subsequently drive the activities of this group for the next five years. This strategy will identify key areas of research for the National Federation of Voluntary Bodies and explore the potential of developing a cohesive plan of research actions.
- The Research Strategy will also assist the National Federation of Voluntary Bodies in developing

research proposals for funded and non-funded research

- The national conference on 'New Ideas New Approaches' innovation in services and supports to people with disabilities served to highlight some research currently being conducted around the country (see section on conference).



John O'Brien, Minister Jimmy Devins, Brian O'Donnell, Brendan Broderick and Ed Bernacki at opening of conference.

NATIONAL FEDERATION OF VOLUNTARY BODIES CONFERENCE

"NEW IDEAS NEW APPROACHES – INNOVATION IN SERVICES AND SUPPORTS TO PEOPLE WITH AN INTELLECTUAL DISABILITY":

The National Federation of Voluntary Bodies dedicated the conference in 2007 to the topic of innovation in services and supports to people with intellectual disabilities: The objectives of the conference were:

- To orient people towards innovation and best practice internationally;
- To showcase examples of innovative practices nationally;
- To generate a range of new ideas/solutions on some core issues and challenges;
- To give people a live experience of collaboratively generating ideas;
- To link people with networks that can assist them in progressing ideas after the conference;
- To promote reflection of our organisational cultures in the context of the person centred challenges that confront us.

The conference took on a more participatory approach with workshops designed to encourage lively participation from delegates and ample opportunity for discussion.

Its' format sought to determine what does different look like and how can we get there in 8 key areas:

- How can we work together?
- How can we help people have their say?
- How can we respond creatively to what we hear?
- How do we promote best value?
- How can we promote health and well being?
- How can technology assist?
- How can managing risks create opportunities?
- How can people get their money?



Members of the Dreamtime Studio performing their show 'Out of the Shadow into the Light' for the conference participants during dinner.

The sessions were designed to promote problem solving and generate innovative solutions for providing supports to people with intellectual disabilities and their families.

The conference was attended by over 300 delegates and feedback received was very positive on the outcomes of the workshops. A conference report has been compiled which details the conference programme and the generated solutions and will be posted to our specially designed website <http://conference.fedvol.ie/>

INFORMING FAMILIES PROJECT:

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 being:

1. To ensure improved outcomes for families being told of their child's disability through the implementation of best practice.
2. To provide improved support, guidance, education and training for professionals in the important task of delivering this news.

The scope of the project included the disclosure of a child's diagnosis of physical, sensory, intellectual or multiple disabilities, and autistic spectrum disorders. The Guidelines that were produced relate to the diagnosis of a child's disability during pregnancy, at birth, or in the case of a diagnosis which evolves over time, and are relevant for disclosure that takes place in hospital, community or disability service settings.

The development of the Guidelines was guided by the Informing Families 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 stakeholders such as parents, disability service providers, the Health Services National Partnership Forum, the Health Services Executive, the Department of Health and Children, the Royal College of Physicians of Ireland, and nominees from the professional bodies and trade-unions of various disciplines involved in informing families. (A full list of members is available in the appendix). The project was coordinated and facilitated by the Informing Families Project Co-ordinator based in the National Federation of Voluntary Bodies Secretariat.

Key Achievements in 2007:

Research and Consultation

In order to ensure that the Guidelines were grounded in evidence-based research, the Informing Families Steering Committee directed the undertaking of a comprehensive consultation and research programme. Specialist statistical and academic support was provided by Dr. Suzanne Guerin from the School of Psychology in UCD. The process was concluded in 2007 with the analysis, collation and write-up of all strands of the research and consultation programme. The methodology leading to the development of the *National Best Practice Guidelines* included:

Stage 1

- A review of relevant national and international literature, and an examination of the national policies relating to this area.
- Initial exploratory research with families and professionals.

Stage 2

- Seven consultative focus groups with parents of children with disabilities (physical, sensory, intellectual, multiple disabilities and autistic spectrum disorders) from around Ireland.
- Consultative focus groups with 15 disciplines of professionals from medical, nursing and allied health professions involved in communicating to parents the news that their child has a disability, or in supporting them immediately thereafter.

Stage 3

- A National Questionnaire Survey disseminated to 584 parents of children with disabilities, using the National Intellectual Disability Database as a sampling base (along with assistance from Visiting Teachers for the Deaf, the NCBI, Enable Ireland and the Central Remedial Clinic with regards to children with physical and sensory disabilities)
- A National Questionnaire Survey disseminated to 1588 professionals in 27 disciplines who provide the news to families of their child's disability, or support families who have just received a diagnosis.

The consultation and research strands explored disclosure practice across the range of hospital, community, and disability service settings in which parents may receive the news of their child's disability. The findings indicated the need for specific supports to be put in place to support consistent and universal implementation of best practice guidelines. The report found that there is good basis of practice already present but that where there are deficits in practice this causes significant distress for families, and where professionals feel inadequately prepared or supported in providing the diagnosis it increases the difficulty and stress that can be associated with this emotionally challenging task. Parents who were dissatisfied with how they had been told the news noted inappropriate physical environments in which the news is delivered, a lack of appropriate communication, a lack of continuity of care, and inconsistent provision of comprehensive, accurate and up to date information, as the areas requiring the most urgent improvements.

The Guidelines produced adopt a person-centred approach whereby the child and the family are at the centre of the measures undertaken at the time of disclosure and in the ongoing parent-professional relationship. The implementation of these Guidelines requires a coordinated, comprehensive and coherent approach that works across hospital, community and disability service settings.

The National Best Practice Guidelines for Informing Families of their Child's Disability were launched on 3rd December 2007 by Minister for Health and Children, Mary Harney TD. The Guidelines will be implemented in 2008 on a pilot basis in the Cork region, and this implementation will be evaluated to inform national roll out.



Alex and Max Crowe at the launch of the Informing Families Guidelines, 3 December 2007.
Photos: Tommy Clancy

Production of DVD film 'Words You Never Forget'

Following completion of the best practice guidelines a short film entitled '*Words You Never Forget*' was produced with the dual objectives of providing positive messages for dissemination to media sources at the launch of the Guidelines, and providing a training aid for implementation. The film was professionally produced to broadcast standard, and tells the stories of two families; one who received their child's diagnosis in a positive way and another who received their child's diagnosis in an unhelpful way. The DVD also provides input from the perspectives of professionals who are involved in informing families of this news, and was made in conjunction with Cork University Hospital and Cork University Maternity Hospital.

National Launch

The National Launch of the *Best Practice Guidelines for Informing Families of their Child's Disability* took place on 3rd December 2007 in the Royal College of Physicians, Dublin. The Guidelines were launched by Minister for Health and Children Mary Harney and the launch was hosted by Miriam O'Callahan, RTE. It was attended by 140 invited guests, amongst whom were key stakeholders including parents, professionals, and representatives from the HSE and the Department of Health and Children.

A significant amount of media coverage followed the launch with articles appearing in the Irish Times, Irish Independent, Medicine Weekly, and interviews on the RTE 'News at 1'; INN News, Spin Radio and East Coast Radio. As a result there has been positive feedback and support for the Guidelines with several hundred copies being downloaded from the National Federation of Voluntary Bodies website, numerous requests for copies of the DVD '*Words You Never Forget*' and interest expressed in many quarters for guidance and support for implementation. The Guidelines and Consultation and Research report can be downloaded from the National Federation website www.fedvol.ie, and copies of the DVD can be ordered directly from the Informing Families Project Co-ordinator, Alison Harnett.

Dissemination and Implementation

During 2007, the Guidelines and the methodology leading to their development were presented at the following events:

- Clinical Conference Holles St - October 2007
- National Disability Authority 2007 Research Conference - *Evidence Based Practice in Early Intervention for Children with Disabilities Aged 0-6*. Plenary Session Presentation – November 2007
- Psychological Society of Ireland Annual Conference – November 2007

In addition, a number of other avenues for dissemination were developed

- Initial discussions between the National Federation of Voluntary Bodies and the graduate medical training programme in University of Limerick began to explore the possibility of including the Informing Families Guidelines on the curriculum in 2008. Interest was expressed by other medical training programmes and will be developed over time.
- International interest was expressed in the Guidelines with requests for materials being received from a number of organisations in the UK and US. Opportunities for joint papers with researchers working on projects that examine disclosure taking place in other countries will be further explored in 2008.

Cork Implementation Project:

International experience indicates that if the Guidelines are published and circulated without the back-up of a clear implementation strategy, the recommendations will remain just that, and the needs identified will remain unaddressed. Throughout the national and international literature a recurring point of concern has been the lack of evaluation of communication skills and 'breaking bad news' training in general; and of guidelines for disclosure of disability in particular. With this in mind, the Informing Families Project made a proposal for a new phase of the project; to implement the Guidelines on a pilot basis in the Cork Region and to evaluate the outcomes for parents and professionals of the implementation of this programme. Along with local implementation the wider aim is to gather learning points for national roll-out.



Katherine O'Leary (Parent, Chair of the Informing Families Project – Cork Region), Mary Harney TD (Minister for Health and Children) and Miriam O'Callaghan (RTE) at the Informing Families launch, 3 Dec 2007. Photos: Tommy Clancy

This proposal received funding support from the Health Services National Partnership Forum to proceed, and during 2007 planning, scoping and the establishment of the local Steering Committee in the Cork region took place. The Steering Committee brings together key stakeholders including parents and professionals; management and trade-unions from across hospital, community and disability services in the Cork region and is chaired by Ms. Katherine O'Leary, a parent of two children with disabilities. The key objectives of the Cork Project are:

- To pilot the implementation of the National Best Practice Guidelines.
- To evaluate outcomes for families and professionals following implementation.
- To research the key factors leading to the successful implementation of the Guidelines.
- To develop a template to guide national implementation of the Guidelines.

DEVELOPMENT OF AN INCLUSIVE RESEARCH NETWORK - IRN:

The Inclusive Research Network was set up in 2007 and is a joint venture between the National Federation of Voluntary Bodies and the National Institute of Intellectual Disability Trinity College Dublin. It consists of a group of people who come together to do research or talk about research that is about people with intellectual disabilities. e.g., people from services, self-advocacy groups, organisations, researchers from universities and services and community groups.

Goals of the network:

- 1.To make links and connections between people with intellectual disability researchers, university researchers, people from the community and staff in services.
- 2.To listen to people with disabilities and their supporters so that research is useful and aims to make a positive difference in peoples lives.
- 3.To support research that includes people with intellectual disability as initiators, researchers, and users of research findings.
- 4.To increase the number of inclusive research projects being done in Ireland.
- 5.To develop partnerships for research projects.
- 6.To support members to work closely together on common interests and research projects.
- 7.To set up a list of researchers who are interested in inclusive research.
- 8.To share the information which comes from research.
- 9.To develop a website for the network.

Key Achievements in 2007:

The Network had its first meeting on 1st August 2007.

This workshop was a huge success and attended by self-advocates, researchers, from services and universities, students and staff from services.

At this meeting it was decided that the plan for the Network was that:

- a) Members will meet on a regular basis and share research knowledge and skills.
- b) Members will develop partnerships together on common research interests.
- c) Members can get training in research methods.
- d) Members can be part of a discussion forum for researchers in Ireland.
- e) Members will develop joint proposals.
- f) The network will provide a list of all disability research in Ireland.
- g) The network will share research findings with all members.

This network is based on the philosophy that all members are equal in the research process and all can contribute to the research. The IRN is open to new members. www.fedvol.ie/research or www.tcd.ie/niid/research/irn/

T.I.L.D.A. (Irish Longitudinal Study on Ageing):

Lead by Professor Mary McCarron, the School of Nursing and Midwifery at Trinity College Dublin, in collaboration with the National Federation of Voluntary Bodies, are proposing a 10 Year Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (TILDA). Data will be collected three times over 10 years from 750 people with intellectual disability (over age 40) on physical and psychosocial health, living situations, social networks and quality of life.

Resources of €1.5 million and support for providers throughout Ireland will be needed to support implementation.

Aims:

To include for the first time a representative sample of older people with intellectual disabilities in a longitudinal study of ageing to:

- Identify the principal influences on successful ageing in persons with intellectual disability;
- Understand how health, social support, family caregiving, services, living arrangements and pre-existing life long disability influence successful ageing; and,
- Provide data to support the development of evidence based policies and services to enhance successful ageing of people with intellectual disability.

In 2007 the National Federation was invited to nominate a representative to The Scientific Advisory Committee of the 'Intellectual Disability Supplement to TILDA'. Ms. Edel Tierney, Director of Research and Policy Development represents the National Federation on this group. The role the Scientific Advisory Committee is to:

- Review and identify measures that will both address health, cognitive status, activities of daily living, income, living situations, social life and overall quality of life in persons with intellectual disability and facilitate comparisons of experiences with adults without intellectual disability in the larger TILDA sample.
- Review the proposed medical measurements in the Bio-Medical Sub-Sample of the TILDA Project and advise on to what extent these measurements can /or should be replicated within the Intellectual Disability Strand.
- Review ethical and consent issues and assist in the development of ethical protocols for the study
- Assist in identifying what factors of ageing in persons with intellectual disability would benefit from longitudinal investigation and to consider if the factors selected for investigation are likely to change over time.
- Assist in sample selection including decisions on age of entry and selection of sub samples.
- Identify an advertising strategy for the Project.
- Assist, where possible, in identifying resources to support the project and advise on extending the project to Northern Ireland.
- Identify and communicate the potential implications of the study's findings for generic and disability service providers in Ireland.

Key achievements in 2007/ progress to date:

- The scientific advisory committee met 4 times in 2007 to identify measures to be used in the longitudinal study, review ethical and consent issues, define sample and consider funding options for the future. In October 2007, a meeting with NIDD Committee was held and access to the database for the purposes of drawing a sample for the Intellectual Disability Supplement to TILDA was granted in view of the important nature of the study.
- A number of meetings were also held with Professor RoseAnne Kenny (Principal Investigator) and members of the project team from the main TILDA study throughout 2007.
- For further information on the project and its research design and on how providers can help, please contact the Project Principal Investigator, Prof. Mary McCarron at mccarrm@tcd.ie

DOING DISABILITY RESEARCH NIID: Marie Curie Transfer of Knowledge

In 2007 the National Federation was invited to be a member of the advisory group to the project Doing Disability Research based at the National Institute for Intellectual Disability. The NIID has successfully gained funding from the European Union's Marie Curie Research Action stream. The project is aimed at including people with intellectual disability, family members and researchers in a series of collaborative projects where the answers to the following questions will be sought:

- What is life like for people with intellectual disability/family members in Ireland?
- What support do they get?
- What do they want and need?

The project plans to implement two national surveys, one for people with intellectual disability and the other for family members. At the same time the project will be looking at ways to develop a national archive of peoples' stories to capture a living history of what life is like for both groups in Ireland. Also the overall project will evaluate a set of resources that is being developed within the NIID for people with intellectual disability to learn about research.

The project is funded for four years and the role of the advisory group will be to meet quarterly to advise on how the projects are being implemented as well as comment on their overall progress.

The members of the advisory committee will comprise four major groups: People with intellectual disability optionally supported by a person of their own choice; Parents and siblings; Trinity researchers and staff from other university/research groups; Members of relevant disability services, groups and associations. The members of the overall group will also be invited to join a core consultative group that relates to their specific area of interest such as, the family orientated survey, the survey for people with intellectual disability and/or the life history archive. These core groups may choose to invite other members who have a shared interest in participating in the research process.

The National Federation of Voluntary Bodies continues to support the work of these three projects in an advisory capacity. For more information see www.tcd.ie/niid/research

PROF. KELLEY JOHNSON, DIRECTOR OF THE NORAH FRY RESEARCH CENTRE, BRISTOL (FORMERLY WITH THE NIID, TRINITY COLLEGE, DUBLIN):

In June 2007 Dr. Kelley Johnson delivered a skills building session to the National Federation Secretariat team on including people with disabilities in our work.

A research partnership has been developed between National Federation of Voluntary Bodies and The Norah Fry Research Centre at the University of Bristol, UK. This partnership will develop and collaborate on areas of common research interests. Topics of particular interest are:

- Inclusive research.
- Sexuality and relationships.
- Community living and deinstitutionalisation.

AUDIT BY RESEARCH OF ABUSE IN DISABILITY SERVICES:

The Health Service Executive in consultation with the National Federation of Voluntary Bodies have initiated a joint HSE/National Federation of Voluntary Bodies Research Project. This will consist of a review of client protection issues within the intellectual disability residential services for children and adults and will include the following elements:

- Identification of numbers and patterns of incidences of abuse by sampling and other appropriate methods.
- A particular consideration will be of service user to service user abuse and identification of all issues arising.

- A review of all related policies and procedures for the protection of service users and the management of identified concerns.
- A consideration of the necessary actions in particular information and training.

The HSE representatives of this advisory group are Ms. Deirdre Scully, Local Health Manager West Cork and Ms. Teresa Dykes, Manager, Cloonamahon Centre, Sligo. The National Federation representatives on the group are Mr. David Kenefick, Assistant CEO of St. Michael's House in Dublin and Ms. Edel Tierney, Director of Research and Policy Development of the National Federation Secretariat. The group is led by Mr. Tom Hogan, Consultant, ToRo Hogan Ltd.

Key achievements in 2007:

- The group was formed in December 2007 and held one meeting before year-end to agree the membership and the groups' terms of reference.

EUROPEAN ASSOCIATION OF SERVICE PROVIDERS FOR PEOPLE WITH DISABILITIES (EASPD):

EASPD is an umbrella organisation for service providers throughout Europe. It now represents over 8,000 service providers providing services to 35 million people with disabilities in the 27 member states of the European Union. The main objective of EASPD is to promote the equalisation of opportunities for people with disabilities through effective high quality services. Its headquarters is located in Brussels, Belgium.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies participated as a partner in a range of EASPD sponsored projects, which promote development and research as a basis for innovation and improvement in services provision. Topics included Employment, Education and Deinstitutionalisation.
- The National Federation of Voluntary Bodies participated on a number of EASPD Working Groups and contributed to a wide range of EASPD policy submissions to the European Institutions on issues affecting service providers.
- Mr. Brian O'Donnell, Chief Executive, National Federation of Voluntary Bodies, continued to lead EASPD on a number of delegations to the European Commission and Parliament during the course of 2007 in his capacity as elected President of EASPD.
- The National Federation of Voluntary Bodies participated on EASPD's Working Group to consider implementation of the adapted Disability Action Plan of the Council of Europe.

NATIONAL HOUSING STRATEGY FOR PEOPLE WITH A DISABILITY:

The Department of the Environment, Heritage and Local Government has established a national group to develop a National Housing Strategy for people with a disability. The Strategy which is a commitment under the Partnership Agreement Towards 2016 will support the provision of tailored housing and supports to people with a disability and will have particular regard to adults with significant disabilities and people who experience mental health issues.

The Strategy will be progressed through the establishment of the National Group under the aegis of the Housing Forum headed by the Department of the Environment, Heritage and Local Government and will involve the Department of Health & Children, the Health Services Executive, Social Partners and other relevant stakeholders.

The Draft Terms of Reference for the National group are as follows:

- To input into government policy on addressing the accommodation needs of people with a disability;
- To advise on the structures and supports required to effectively deliver on the accommodation needs of people with a disability including through the development of inter agency responses;
- To act as an advisory and monitoring body on the implementation of the new strategy.

The National Federation of Voluntary Bodies was invited to nominate a representative to participate on the

national group and in this regard the Board of Directors approved the appointment of Mr. Paul Ledwidge, Chief Executive, St. Michael's House.

Key Achievements in 2007:

- The National Federation of Voluntary Bodies nominated Mr. Paul Ledwidge, Chief Executive, St. Michael's House, to represent it on the National Group.
- The National Federation of Voluntary Bodies prepared a position paper for submission to the Department of Environment, Heritage and Local Government in the context of the strategy.

NATIONAL DISABILITY STRATEGY:

In early 2007, the Government announced the establishment of a National Disability Strategy Monitoring Group (NDSMG). The Group which is chaired by the Department of An Taoiseach monitors progress on the overall implementation of the National Disability Strategy, building on the monitoring and review procedures already in place in each of six Government Departments Sectoral Plans. The Group comprises representatives from the key disability sector umbrella organisations and senior officials representing the Government Departments responsible for implementing the Sectoral plans and a number of other Departments including Finance and Education & Science.

Key Achievements in 2007:

- A Disability Stakeholders Group comprising representatives from Non Government Organisations (NGOs) in the Disability Sector only was established to ensure a coherent voice in the National Disability Stakeholders Monitoring Group.
- A major meeting of the National Disability Stakeholders Monitoring Group was held in July 2007 during which Senior Officials from the six Government Departments gave progress reports on implementation of the Sectoral Plans in their respective Departments to the Disability Stakeholders Group.
- The Disability Stakeholders Group carried out its own independent research into progress on the Sectoral Plans.
- Mr. Brian O'Donnell, Chief Executive, represents the National Federation of Voluntary Bodies on both the National Disability Stakeholders Monitoring Group and Disability Stakeholders Group.
- A comprehensive submission was prepared by the National Federation's Early Intervention Expert Working Group which was established by the Federation's Education Sub-Committee. The submission, which dealt with the myriad of issues arising for 0-5 year olds in our services in the context of the Act, was submitted to the HSE in the first half of 2007 and formed the basis of a series of meetings between the National Federation of Voluntary Bodies and HSE on its contents.

PERSON CENTRED MEDICATION MANAGEMENT:

A Sub-Group comprising membership of the National Federation of Voluntary Bodies has worked over a number of years to formulate National Policy Guidelines on Person Centred Medication Management.

The workings of this Group have been supplemented by the involvement of various and particular expertise from other areas, notably An Bord Altranais, the National Council for the professional development of Nursing & Midwifery, the Department of Health & Children and University College Dublin (UCD).

More recently, a number of other Organisations, notably the Health Information & Quality Authority (HIQA), the Pharmaceutical Society of Ireland (PSI) and the State Claims Agency, have shown a keen interest in and strong support of the work of this sub-group.

Key Achievements in 2007

- In late 2007, Joe Wolfe & Associates was commissioned to bring the document to finality and this work is advancing. Other national developments evolving currently and supported by the Department of Health & Children are impacting on our work and it is felt that we need to reflect these developments within the Guidelines.
- A preliminary presentation was hosted on December 11th, 2007 in Stewarts Hospital, Palmerstown, in association with the Nursing Services of the HSE.

- The potential impact of Nurse & Midwifery prescribing is particularly significant and is a very welcome development which should greatly enhance the capacity of the intellectual disability sector to support and facilitate people with intellectual disabilities to live their lifestyles of choice with the minimum of restrictions.
- It is planned to formally launch National Federation of Voluntary Bodies Person Centred Medication Management Policy Guidelines in autumn 2008.

MENTAL HEALTH ACT 2001:

The Mental Health Commission has a role in overseeing implementation of the Mental Health Act 2001, which came into force on 1st November, 2006. It established a National Implementation Group to plan and co-ordinate implementation of the Act and the National Federation of Voluntary Bodies is represented on the Group by Mr. Brian O'Donnell, Chief Executive and Dr. Mary Staines, Clinical Director, Stewarts Hospital, Dublin.

In March, 2007, the Mental Health Commission published the "Quality Framework for Mental Health Services in Ireland".

Key Achievements in 2007:

- The National Federation of Voluntary Bodies Working Group on Mental Health Services for People with an Intellectual Disability engaged with the Mental Health Commission on all aspects of the legislation relevant to the Intellectual Disability Sector.
- The National Federation of Voluntary Bodies contributed to the "Quality Framework for Mental Health Services in Ireland" and also to the development of the audit toolkit which accompanied the framework.

COMMUNITY PARTICIPATION & INCLUSION OF PEOPLE WITH INTELLECTUAL DISABILITY:

To achieve our aim of empowering and enabling people with intellectual disability to participate in a meaningful way in their community, we applied for grant funding in June 2007 for three years under the Department of Community, Rural & Gaeltacht Affairs Funding Scheme to Support National Organisations in the Community & Voluntary Sector. The application for funding was successful and it will enable the National Federation to continue to employ a Policy Development Co-Ordinator in the Research & Policy development area. Over the period of this grant funding, our Policy Development Co-Ordinator will promote the inclusion, rights, independence and choice of people with intellectual disability within their own communities and within services provided by National Federation Member Organisations.

A challenge facing many service providers today is to find ways of empowering and enabling people who avail of intellectual disability services to live full active lives, of their own choice, within their own communities. Service providers are committed to accepting this challenge and they fully support the Government's vision in its National Action Plan for Social Inclusion of "an Ireland where people with disabilities have ... the opportunity to live a full life with their families and as part of their local community, free from discrimination" (2007). This commitment from Government is also reinforced in their Social Partnership Agreement Towards 2016 and in the current National Development Plan 2007-2013.

During 2007 the National Federation has continued to promote the social inclusion of people with intellectual disability to enable people to live full and active lives of their own choice. This work is supported by a very active and energetic Sub-Committee focusing on Community Participation & Inclusion. This Sub-Committee is comprised of people who access services and staff members who provide services and all the members of the group have a particular expertise and/or interest in social inclusion issues.

Key Achievements in 2007:

- Regular meetings of the Community Participation & Inclusion Sub-Committee have been organised & coordinated around the country. These meetings also involve visiting inclusive community projects that are linked to, or are in partnership with, intellectual disability services.
- Easy to read documents, including agenda, minutes of meetings, other relevant information, have been

developed so that all members of the group can be meaningfully involved in the work of the group. To enable this, computer software, "Boardmaker", was purchased which contains accessible clipart.

- Links have been developed with service user groups around the country, e.g. service user councils, local advocacy groups etc.
- A number of members of the group participated in a 2 day conference in November 2007, organised by the Brothers of Charity National Advocacy Council, exploring the theme of closing institutions.
- Sub-Committee members are kept up to date on news events, funding opportunities, training and reports that relate to community participation and inclusion of people with intellectual disability.
- The People Connecting publication - an easy-to-read document – was launched in June 2007. This publication incorporates the findings from a Consultative Workshop on the Barriers, Incentives and Solutions to Community Participation & Inclusion of People with Intellectual Disability. It also includes recommendations to the Board of the National Federation which were presented to them by Cabrini de Barra and Brian Donohoe on behalf of the Community Participation & Inclusion Sub-Committee.
- The findings of People Connecting have been disseminated to services users, intellectual disability service providers and other disability stakeholders through advocacy groups, National Federation Board & General Assembly meetings, etc.
- Cabrini de Barra and Brian Donohoe, on behalf of the Community Participation & Inclusion, presented People Connecting at a workshop of the National Federation conference "New Ideas New Approaches" in October 2007. The workshop theme was "How can we help people have their say?" and explored innovative ways of consulting with the people we support and their families.

VOLUNTEERING SUPPORTS:

Volunteering is an integral part of community activity within the member organisations of the National Federation of Voluntary Bodies, reducing the levels of social isolation and exclusion often experienced by people with intellectual disabilities within their own community. The National Federation Volunteering Sub-Committee expertly supports the planning and prioritisation of volunteering needs identified by member organisations, whilst informing the Board of Directors on priority issues, key challenges and recommendations in respect of volunteering at a local & national level.

Key Achievements in 2007:

- Regular meetings of the Volunteering Sub-Committee were organised around the country.
- One of the underlying aims of the National Federation Volunteering Sub-Committee was to establish and collate reliable data on volunteering within the member organisations. This would enable the National Federation to plan and prioritise responses to the volunteering needs identified by member organisations, whilst informing the Board of Directors on priority issues, key challenges and recommendations in respect of volunteering at a local & national level. This survey was the first national study on volunteering to be conducted within the intellectual disability services in Ireland and will enable the National Federation Volunteering Sub-Committee to put volunteering on the agenda of the National Federation, Government Departments and other public authorities and national bodies. The survey findings are now complete and the report will be published in 2008.
- One of the main findings from the volunteering survey was the need for a volunteering policy guideline document for member organisations to enable them to recruit, retain, manage and celebrate the valuable contribution of volunteers to the lives of people with intellectual disability. This template has been drafted and is currently being reviewed by a number of our member organisations. This review process will be complete early in 2008 and the policy guideline document will then be published and disseminated.
- Ongoing links have been developed with Best Buddies Ireland, Volunteering Ireland, Volunteer Centres Ireland and Special Olympics.
- A National Federation Network for Volunteer Co-Ordinators who are employed in our member organisations has now been developed and this network will be strengthened over the coming year. This network will enable volunteer managers around the country to link with each other and develop partnerships which involve both the sharing of ideas and organisational resources.
- A number of Sub-Committee members attended a very informative 1 day conference organised by Volunteering Ireland in November 2007 exploring issues vital to managing volunteer programmes.
- Finally, Sub-Committee members are informed on an ongoing basis of news articles, funding opportunities, training events and research publications on volunteering at local, national and international levels.

APPENDIX 1

NATIONAL FEDERATION OF VOLUNTARY BODIES BOARD OF DIRECTORS

Board of Directors:

Brendan Broderick, Sisters of Charity of Jesus & Mary (Chairperson)

Tony Darmody, Kerry Parents & Friends Association

Maura Donovan, Stewarts Hospital

Wally Freyne, Daughters of Charity Services

Mary Kealy, Brothers of Charity Services Clare

Laurence Kearns, St. John of God Hospitaller Services

Edith Kennedy, MIDWAY

Christy Lynch, KARE

Paul Ledwidge, St. Michael's House

Patricia Lee, Sisters of La Sagesse

Vincent Millet, Irish Sisters of Charity

Maura Nash, COPE Foundation

Michael Noone, Sunbeam House Services

John O'Dea, Western Care Association

Winifred O'Hanrahan, Brothers of Charity Services

APPENDIX 2

NATIONAL FEDERATION OF VOLUNTARY BODIES SUB-COMMITTEES & WORKING GROUPS AS AT 31ST DECEMBER, 2007

Community Participation &

Inclusion Sub-Committee:

Yvonne Bohane, Kildare (Chairperson)
Angela Hynes, Cork
Ann O'Callaghan, Cork
Brian Hogan, Clare
Cabrini de Barra, Waterford
Catherine Devine, Dublin
Claire Maher, Tipperary
Derek Watson, Kilkenny
Des Connolly, Limerick
Eileen O'Keeffe, Cork
Eileen O'Mahony, Dublin
Joe McGrath, Clare
Karen Brennan, Kildare
Kevin Barnes, Dublin
Kevin Ryan, Kerry
Martine Healy, Meath
Mary Gavin, Dublin
Mary Lannon, Dublin
Mary Lucey Pender, Dublin
Richard Collins, Clare
Roisin Deery, Meath
Theresa Doyle, Kildare
Tim O'Connell, Kilkenny
Brian Donohoe, Galway
Breda Casey, Galway

Early Intervention Sub-Committee:

Stephen Kealy, Sisters of Charity of Jesus & Mary, Kildare (Chairperson)
Gabrielle Barrett, Brothers of Charity, Roscommon
Pauline Bergin, St. John of Gods, Dublin
Deirdre Burns, COPE Foundation, Cork
Breda Corcoran, Daughters of Charity, Limerick
Stephenie Dunnett, Cheeverstown House, Dublin
Kathleen Fitzpatrick, St. John of Gods, Dublin
Dr. Sharon Houghton, Brothers of Charity, Limerick
Moiria King-Fitzgerald, Brothers of Charity, Cork/Kerry
Maura Nash, COPE Foundation, Cork
Claire O'Brien, Brothers of Charity, Tipperary
Mary O'Connor, St. Michael's House, Dublin
Mary O'Dwyer, St Josephs Foundation, Cork
Teresa O'Loughlin, Daughters of Charity, Dublin
Hazel Trudgill, CoAction, Cork
Anne Walker, St. Michael's House, Dublin
Mary Barrett, National Federation of Voluntary Bodies

Education Sub-Committee:

Maura Nash, COPE Foundation (Chairperson)
Mary Byrne, St Aidan's
Mary Carrig, Stewarts Hospital
John Colfer, Brothers of Charity, Galway
Sorcha Connellan, Brothers of Charity, Limerick
Denis Cronin, Daughters of Charity, Limerick
Roisin Deery, Midway Services
Noel Dillon, St. Michael's House
Phil Gray, St. John of God Hospitaller Services
Bill Griffin, Ability West
Helen Guinan, COPE Foundation
Catherine Jackman, Cheeverstown House
Martin McGrenery, Sisters of Charity of Jesus & Mary
Mary Barrett, National Federation of Voluntary Bodies

Finance Sub-Committee:

Brendan Broderick, Sisters of Charity of Jesus & Mary (Chairperson)
Tony Darmody, Kerry Parents & Friends
Paul Ledwidge, St. Michael's House
Winifred O'Hanrahan, Brothers of Charity Services
Brian O'Donnell, National Federation of Voluntary Bodies

Human Resources Sub-Committee:

Maura Donovan, Stewart's Hospital (Chairperson)
Pauline Brennan, Western Care Association
Eileen Carr, Malta Services Drogheda
Francis Coughlan, SOS Kilkenny Ltd.
Paul Egan, Sisters of La Sagesse
Karen Fanneran, RehabCare
Pat Fitzgerald, Peamount Hospital
Brian Gallagher, Cheeverstown House
Adrian Harney, Ability West
Olive Leonard, Sisters of Charity of Jesus & Mary
Marie Linehan, Kerry Parents & Friends Assoc.
Margaret Meagher, St. Anne's Service
Gerry Mullholland, Stewart's Hospital Services Limited
Liam Murphy, Brothers of Charity Services Cork
Michele Oppermann, Daughters of Charity
Aine O'Callaghan, COPE Foundation
Kathleen O'Callaghan, St. Joseph's Foundation
Mary O'Connor, KARE
John Pepper, St. John of God Hospitaller Services
Eileen Skehan, Carriglea Caride Services
Jillian Sexton, National Federation of Voluntary Bodies
Caroline Looney, National Federation of Voluntary Bodies

Quality Sub-Committee:

John O'Dea, Western Care Association (Chairperson)
 Brigid Butler, St. John of God Hospitaller Services
 Fiona Coffey, Brothers of Charity Galway
 Eileen Costello-Conneely, Ability West
 Yvonne Downey, Ard Aoibhinn
 Kay Downey Ennis, Daughters of Charity
 Maura Fitzgerald, COPE Foundation;
 Heather Hogan, Sisters of Charity of Jesus & Mary
 Tom Hughes, Western Care Association
 Bob McCormack, DARA Residential Services
 Mary McGrath, Carriglea Cairde Services
 Michael Noone, Sunbeam House Services
 Eileen O'Mahony, Cheeverstown House
 Teresa Ryan, Brothers of Charity Limerick

Research Sub-Committee:

Bob McCormack, St. Michael's House (retired from Committee)
 Nick Blitz, Camphill Communities of Ireland
 Kay Downey-Ennis, Daughters of Charity
 Bernie Fay, Sisters of Charity of Jesus & Mary
 Aine Kelly, St John of God Hospitaller Services
 Gina Magliocco, Brothers of Charity Secretariat
 Anne McCarthy, Stewarts Hospital Services Ltd (retired from Committee)
 Caroline Hart, RehabCare
 Edel Tierney, National Federation of Voluntary Bodies
 Alison Harnett, National Federation of Voluntary Bodies
 Mary Barrett, National Federation of Voluntary Bodies
 Brian McClean, Brothers of Charity Roscommon (new member Dec 2007)
 Mark Stanton, Brothers of Charity Clare (new member Dec 2007)
 Mary McCarron, Trinity College (new member Dec 2007)

Services Development**Sub-Committee:**

Brendan Broderick, Sisters of Charity of Jesus & Mary (Chairperson)
 Tony Darmody, Kerry Parents & Friends
 Paul Ledwidge, St. Michael's House
 Christy Lynch, KARE
 John O'Dea, Western Care Association
 Winifred O'Hanrahan, Brothers of Charity Services
 Pat O'Toole, St. Christopher's
 Brendan Sutton, Cheeverstown House
 Brian O'Donnell, National Federation of Voluntary Bodies

Training & Development**Sub-Committee:**

Brendan Broderick, Sisters of Charity of Jesus & Mary Services (Chairperson)
 Geraldine Boland, St. Michael's House
 Ann Donohue, Brothers of Charity Services, Galway
 Kay Downey Ennis, Daughters of Charity Services
 Karen Finnerty, Open Training College
 Mary Fitzgerald, COPE Foundation
 Adrian Harney, Ability West
 Majella Hayes, Brothers of Charity Services – South East
 Patricia Lee, Sisters of La Sagesse
 Rosaleen McCabe, St. John of God Hospitaller Services
 Anne Rowe Monaghan, Sunbeam House Services
 Gerry Mulholland, Stewarts Hospital Services Ltd
 Mary O'Connor, KARE
 Paula O'Riordan, Cheeverstown House
 Denise Shaw-Kelly / Philip O'Dwyer, Brothers of Charity Services, Limerick
 Jillian Sexton, National Federation of Voluntary Bodies

Vocational Training &**Employment Sub-Committee:**

Christy Lynch, KARE (Chairperson)
 Maureen Cahill, Brothers of Charity Cork
 Kevin Delaney, Brothers of Charity Clare
 Eddie Denihan, Stewarts Hospital
 Mary Desmond, COPE Foundation
 Geraldine Doyle, Prosper Fingal
 TJ Duggan, Cheeverstown House
 Michael Fleming, Brothers of Charity Galway
 Noelin Fox, Brothers of Charity Roscommon
 Kevin Hoey, Sunbeam House Services
 Trevor Jacob, County Wexford Community Workshop
 Enniscorthy
 Edith Kennedy, Midway Services
 Conor McAtasney, CoAction
 John O'Callaghan, Daughters of Charity Limerick
 Bernard O'Regan, Western Care
 Pat Reen, Prosper Fingal
 Sandra Whelan, Walkinstown Association
 Caroline Looney, National Federation of Voluntary Bodies

Volunteering Sub-Committee:

Anne Byrne, KARE (Chairperson)
 Roisin Deery, Midway Services
 Br. Terence Flynn, St. John of God Services (retired from Sub-Committee)
 Rhoda Judge, Daughters of Charity Services
 Linda Keane, Ability West
 Noreen McGarry, Western Care
 Peter McKeivitt, RehabCare
 Gerry McLaughlin, Sisters of Charity of Jesus & Mary

Susan McGill, Brothers of Charity, South Eastern Region
Breda McMahon, Children's Sunshine Home (retired from Sub-Committee)
Jerry Mullane, COPE Foundation
Kathleen O'Callaghan, St. Joseph's Foundation
Mary O'Connell, Brothers of Charity, Limerick
Saretta O'Mahony, St. Joseph's Foundation
Martina Rynne, Brothers of Charity Clare
Kathleen Sherry, SOS Kilkenny Ltd
Breda Casey, National Federation of Voluntary Bodies

Informing Families National

Project Steering Committee:

Dr. John Hillery, President of the Medical Council of Ireland, and Consultant Psychiatrist in Stewart's Hospital (Chairperson)

Ms. Karen Canning, Mr. Anthony Casey, National Parents and Siblings Alliance

Ms. Anne-Marie Ryan*, An Bord Altranais

Ms. Catherine Rourke, Brothers of Charity, Galway

Ms. Ann Field**, Department of Health and Children

Ms. Evelyn Hall, Ms. Breda Kavanagh, Ms. Suzanne Kirwan, Health Services Executive

Mr. Eamon Naughton, Health Services National Partnership Forum

Dr. Claire Collins, Irish College of General Practitioners

Ms. Annette Kennedy, Irish Nurses Organisation

Ms. Anne Mulvihill, Irish Society of Speech and Language Therapists

Ms. Mary Egan, Inclusion Ireland

Mr. Brian O'Donnell, Ms. Alison Harnett, Ms. Edel Tierney***, National Federation of Voluntary Bodies

Ms. Bernie Fay, National Social Work Qualifications Board

Ms. Margaret Farrelly, Psychological Society of Ireland

Dr. Tony Walsh, Dr. Matt Conran, Royal College of Physicians of Ireland

Dr. Joan Lator, School of Nursing and Midwifery, TCD

Mr. Stephen Kealy, Sisters of Charity of Jesus and Mary Services

Ms. Anne Walker, St. Michael's House

* Previously represented by Mr. Thomas Kearns

* * Previously represented by Ms. Mary O'Reilly

* * * Previously represented by Ms. Maria Walls

Person Centred Medication

Management (PCMM)

Working Group:

David Kieran, St. Anne's, Roscrea (Chairperson)

Peter Boland, St. Ita's, Portrane

Brigid Butler, St. John of God Services

Carmel Byrne, St. Michael's House

Deirdre Carroll, Inclusion Ireland

Hilary Coates, RCSI

Deirdre Fay, Brothers of Charity

Marie Grimes McGrath, St. Anne's Services

Heather Hogan, Sisters of Charity of Jesus and Mary
Christine Hughes, National Council for Nursing and Midwifery

Mary McArdle, Department of Health and Children

Audrey Mee, St. Hilda's, Athlone

Una Nagle, Brothers of Charity, Cork

Patricia Noonan-Walsh, UCD

Linda O'Leary, Dara Residential (RIP)

Anna Plunkett, St. John of God, Drumcar

Anne Marie Ryan, Nursing Board

Luck van Erwegen, Sisters of Charity of Jesus and Mary

Kathleen Walsh, An Bord Altranais

Joe Wolfe, Joe Wolfe and Associates

Performance Indicators

Working Group:

Brendan Sutton, Cheeverstown House (Chairperson)

Brigid Butler, Hospitaller Order of St. John of God

Francis Coughlan, SOS Kilkenny

David Dunne, St. Michael's House

John O'Dea, Western Care Association

Martina Rynne, Brothers of Charity Services Clare

Informing Families Project Cork Implementation Project Steering Committee:

Discipline/Organisation	Represented by:
Line Manager Audiology	Mr. Michael Butler, Care Group Co-ordinator for Physical and Sensory Disability, West Cork
Clinical Nurse Specialist Early Intervention	Ms. Yana O'Donovan, Co-Action
Cork Deaf Association	Ms. Gerrie O'Grady, Manager, Cork Deaf Association
Partnership Facilitator	Mr. Eamon Naughton, Health Services National Partnership Forum
GP	Nomination in progress via Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
HSE Primary, Community and Continuing Care	Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
IMPACT Trade Union	Ms. Maeve McCarthy Barrett, Branch Secretary Cork
Midwifery & Nursing	Ms. Geraldine Keoghane - Director of Midwifery, Cork University Maternity Hospital
National Council of the Blind of Ireland	Ms. Kathleen Vickers, Regional Manager NCBI Southern Region
Neurologist	Dr. Olivia O'Mahony, Consultant Paediatric Neurologist, Cork University Hospital
Neonatologist, IHCA Representative	Dr. Brendan Murphy, Consultant Neonatologist Cork University Maternity Hospital
Obstetrician/Gynaecologist	Dr. Dan McKenna, Consultant Obstetrician Cork University Maternity Hospital
Ophthalmologist	Mr. Gerry O'Connor, Consultant in Ophthalmic Surgery Cork University Hospital
Parent	Ms. Katherine O'Leary, Parent & Director Inclusion Ireland
Paediatrician	Prof. Jonathan Hourihane, Professor of Child Health and Paediatrics, Cork University Hospital
Project Co-ordinator	Ms. Alison Harnett, National Federation of Voluntary Bodies
Psychiatrist	Nomination in progress via Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
Psychologist	Dr. Mary Desmond, Principal Psychologist COPE Foundation
	Dr. Margaret Farrelly, Principal Psychologist St. Joseph's Foundation, Charleville
	Ms. Hilary Lane, Senior Clinical Psychologist, Enable Ireland
Public Health Nurse	Nomination in progress via Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
Research/Evaluation	Ms. Edel Tierney, Director of Research and Policy Development - National Federation of Voluntary Bodies
	Dr. Margaret O'Rourke, Senior Lecturer & Director of Behavioural Science, University College Cork
	Dr. Suzanne Guerin, Lecturer in research design & analysis – University College Dublin
Speech and Language Therapist	Ms. Breda Long, Early Intervention Project Officer
Social Worker	Ms. Joan Cronin, Head of Social Work Department, Brothers of Charity Southern Services
National Hospitals Office Representative	Ms. Mary Owens, Director of Nursing, Mallow General Hospital

APPENDIX 3

National Federation Representatives on National Committees & Working Groups as at 31st December, 2007

DEPARTMENT OF HEALTH & CHILDREN:

National Disability Advisory Committee

Brian O'Donnell, National Federation of Voluntary Bodies

National Intellectual Disability Database

James Roche, Western Care Association

Action Plan for People Management – Monitoring Committee

Brian O'Donnell, National Federation of Voluntary Bodies

Department of Health & Children – Clinical Psychology Training

Brendan Broderick, Sisters of Charity of Jesus & Mary

HSE WORKING GROUPS:

Capital Projects – Protecting State's interest:

Breda Crehan Roche, Galway Association;
Pat O'Toole, St. Christopher's Service;
Gina Magliocco, Brothers of Charity Service.

HSE Funded Adult Day Services Review

Pat Reen, Prosper Fingal

Implementation of Disability Act 2005 (0-5 year olds)

Stephen Kealy, Sisters of Charity of Jesus & Mary;
Moiria King – Fitzgerald, Brothers of Charity Southern Services.

Implementation of Disability Act 2005 (5-18 year olds):

Breda Crehan Roche, Ability West
Francis Coughlan, SOS Kilkenny Ltd.

HSE De-institutionalisation of Congregated Settings:

Christy Lynch, KARE (Project Manager)
Brendan Broderick, Sisters of Charity of Jesus & Mary;
Laurence Kearns, St. John of God Hospitaller Services;
Winifred O'Hanrahan, Brothers of Charity Services.

HSE Working Group on Dementia

Mary McCarron, School of Nursing and Midwifery,
University of Dublin, Trinity College, Dublin

HSE – EMPLOYERS AGENCY:

HSE - EA's Management Team in respect of Therapy Grades:

John Pepper, Hospitaller Order of St. John of Gods

Flexible Working Group

Paul Egan, Sisters of La Sagesse

Health Service National Joint Council

Maura Donovan, Stewarts Hospital

HSE-EA – Compensation Scheme for Assault at Work

Liam Murphy, Brothers of Charity, Cork

Joint Partnership Committee – Non Nursing Grade:

Maura Donovan, Stewarts Hospital, Dublin

Review of Dignity at Work Policy:

Maura Donovan, Stewarts Hospital
Jillian Sexton, National Federation of Voluntary Bodies

Equality of Opportunity / Accommodating Diversity:

Maura Donovan, Stewarts Hospital

NATIONAL DISABILITY AUTHORITY:

National Disability Stakeholders Monitoring Group

Brian O'Donnell, National Federation of Voluntary Bodies

NURSING:

An Bord Altranais Planning Meeting Re: Continuing Education for Nurses

Mary Reynolds, Daughters of Charity

National Council for the Professional Development of Nursing and Midwifery

Maura Nash, COPE Foundation

National Implementation Committee to Oversee the Implementation of a Pre-Registration Nursing Degree Programme

Anna Plunkett, St. John of God Hospitaller Services

OTHER:

Health Services National Partnership Forum:

Brian O'Donnell, National Federation of Voluntary Bodies

HIQA National Standards Advisory Group:

Brian O'Donnell, National Federation of Voluntary Bodies

HIQA Advisory Consultation Group Meetings for Investigation and Enforcement procedures at HIQA

Kay Downey Ennis, Head of Research & Education, DOC

Public Transport Accessibility Committee (PTAC)

Paddy Greally, Sector Manager, BOC Galway

Accredited Course in Advocacy – Comhairle & Sligo Institute of Technology

Gerard Gibbons, Sisters of La Sagesse

National Accreditation Committee:

Eddie Denihan, Stewarts Hospital

Codes of Practice for the Operation of Sheltered Workshops

Christy Lynch, KARE

FOI Public Service Users' Network

Caroline Looney, National Federation of Voluntary Bodies

Department of Social & Family Affairs - Disability Consultative Committee

Patrick McGinley, Brothers of Charity, Galway

National Federation of Voluntary Bodies Pension Scheme Trustees

Tony Darmody, Kerry Parents & Friends Association (Chairman)

Tom Hogan, Ability West

John O'Dea, Western Care Association

Brian O'Donnell, National Federation of Voluntary Bodies

TILDA International Scientific Advisory Group:**Chairperson and PI Affiliation:**

Professor Mary McCarron

Trinity College Dublin

Members Affiliation:

Dr. Philip Dodd

St. Michael's House, Dublin

Ms. Finula Garrahy

Inclusion Ireland, Dublin

Ms. Caraiosa Kelly

Health Research Board, Dublin

Dr. Jean Lane

Daughters of Charity Service, Dublin

Prof. Philip McCallion

University of Albany, State University of New York

Prof. Roy McConkey

University of Ulster, Jordanstown Campus, Antrim

Ms. Marion Meany

HSE South Western Area

Dr. Niamh Mulryan,

Daughters of Charity Service, Dublin

Prof. Patricia Noonan-Walsh

Centre for Disability Studies, UCD

Ms. Kathy O'Grady

Sisters of Charity of Jesus & Mary, Kildare

Ms. Claire O'Regan

TILDA, Trinity College Dublin

Dr. Fintan Sheerin

Trinity College Dublin

Ms. Janet Swinburne

Trinity College Dublin

Ms. Edel Tierney

National Federation of Voluntary Bodies, Galway

Dr. Janette Tyrrell

St. Michael's House, Dublin

National Federation of Voluntary Bodies Secretariat Staff:

Brian O'Donnell, Chief Executive

Edel Tierney, Director of Research & Policy Development

Maria McMahon, Office Manager

Caroline Looney, Administrative Officer (Job Sharer)

Mary Barrett, Administrative Officer (Job Sharer)

Brendan Dolan, Clerical Officer (Fixed Term Contract)

Brian Donohoe, Clerical Officer (1 day per week)

Jillian Sexton, HR & Training & Development Co-ordinator

Alison Harnett, Informing Families Project Co-ordinator

Breda Casey, Policy Development Co-ordinator

APPENDIX 4

National Federation of Voluntary Bodies Financial Data 2007 - 2006

	Year Ended 31/12/07	Year Ended 31/12/06
Income:		
HSE Grant	347,158	307,158
Members Subscription	117,312	116,262
Pension Scheme	58,578	51,257
APPM	50,000	333,011
Informing Families Project	163,371	192,075
Policy Development Grant	27,420	92,590
Other Income	34,513	76,429
	798,352	1,168,782

Expenditure:

Pay Expenditure	368,577	375,486
Non Pay Expenditure	154,130	171,343
APPM	50,000	333,011
Informing Families Project	163,371	192,075
Policy Development Grant	27,420	92,590
	763,498	1,164,505
Surplus for the Year	34,854	4,277

BALANCE SHEET

Tangible Fixed Assets	440,378	451,519
-----------------------	---------	---------

Current Assets:

Debtors	26,455	76,348
Bank	539,446	424,563
	565,901	500,911
Creditors – amounts falling due within 1yr	(517,476)	(474,251)

Net Current Assets

Total Assets Less Current Liabilities	488,803	478,179
Creditors – Amounts falling due after more than 1yr	(332,446)	(356,675)
Total Net Assets	156,357	121,504

Capital & Reserves

Surplus for the Year	121,504	117,227
Reserves	156,357	121,504



Natalie O'Brien (16) has been a student at St Augustine's for the past four years. She is part of the school choir and bodhrán group and has a huge talent in music and creative skills. She is a keen painter and drawer. She received St Augustine's award for student of the year in 2007. She really enjoys cooking, searching the internet, and hanging out with her friends. She also has a flare for fashion, hair and beauty skills.

