Service Plan 2008



INTRODUCTION:

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 disabilities in Ireland. Our members are both voluntary and religious bodies with a clear vision rooted in the respect for and the dignity of the person. In all, our National Federation comprises some 63 affiliated organisations who between them account for in excess of 85% of this country's direct service provision to people with intellectual disabilities.

Our members employ 15,500 staff covering a wide range of professional and support disciplines, providing services and supports to 22,000 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.

The purpose of the Secretariat is to support member organisations through a range of activities including information sharing, research and policy development, consultation and consensus building. Our overarching objective is to support the development of high quality, person centred services and supports for people with intellectual disability in Ireland.

CONTEXT:

This is a time of rapid and fundamental change for the providers of services and supports to people with intellectual disabilities in Ireland. Many challenges and opportunities have arisen out of the Health Services Transformation Programme and the National Disability Strategy in particular.

The restructured health service is bringing about major change in terms of how services and supports will be configured and provided going forward. There is a need for proactive engagement with the Health Services Executive to agree arrangements regarding the configuration of services, assessments of need, identification of priorities for new services development and resourcing.

The National Disability Strategy, which underpins the participation of people with disabilities in society, was launched by the Government on 21st September, 2004, and comprises four elements:

- 1. Disability Legislation;
- 2. The Citizens Information Bill 2006 (formerly known as the Comhairle [Amendment] Bill), which provides for the establishment of a Personal Advocacy Service, specifically aimed at people with disabilities:
- 3. Outline Sectoral Plans by six Government Departments, which set out programmes for action to improve service provision and access to infrastructure by people with disabilities;
- 4. A Multi-Annual Investment Programme for high priority disability support services, the details of which were announced in Budget 2005.

Clearly, these are exciting times for people with disabilities, their families and the people and organisations who provide services and supports to them. While the overall climate is one of opportunity there are also many challenges to be met to ensure that world class person centred services and supports can be delivered to people with disabilities in Ireland into the future.

The Secretariat of the National Federation of Voluntary Bodies plays a key role in ensuring that the opportunities and challenges described above are met in a proactive way. Accordingly, we have organised our resources in such a way as to ensure that this work is done in the most effective manner possible. It should be noted that our National Federation membership is a diverse organisation, comprised by large, medium and smaller organisations, some of whom are religious organisations, others parents and friends associations, all with their own ethos, but united by a set of values and common goals. What is contained in our enclosed Service Plan for 2008 is a series of actions which support all of our member organisations in meeting the many challenges and opportunities which will arise in 2008 and beyond.

AIMS FOR 2008:

While we will continue to develop the range of services provided to our membership in 2007, our focus in 2008 will be on supporting our member organisations in meeting the challenges arising from the National Disability Strategy and the restructured Health Service. A priority for us will be the completion of a strategic review of the National Federation of Voluntary Bodies.

While our activities are quite diverse covering a wide range of issues and topics, for ease of reference our Service Plan outlines activities under three main headings as follows:

- 1. Membership Support Services
- 2. Quality & Innovation
- 3. Research & Policy Development

SECRETARIAT RESOURCES:

While our Service Plan for 2008 is comprehensive and ambitious, our staffing resources to implement it are limited. The National Federation's core staff comprises a Chief Executive, a Director of Research & Policy Development, an Office Manager, one whole time equivalent Administrative Officer and one part time clerical officer. We also employ three Project Managers on specified term contracts in the area of policy development; developing best practice guidelines in informing families about the diagnosis of a disability; and implementation of the Action Plan for People Management in the intellectual disability sector.

Brian O'Donnell Chief Executive

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Section 1

Membership Support Services

Engagement between National Federation of Voluntary Bodies & Health Sector:

In 2007 agreement was reached between the National Federation of Voluntary Bodies and the HSE with regard to engagement arrangements between both parties on issues of mutual concern.

Objective:

To progress issues of concern to member organisations with the HSE Disability Governance Group.

Key Actions:

- Identify priority issues of member organisations for resolution with HSE through consultation with Interim Area Federation Committees and General Assemblies.
- Arrange bi-annual meeting with Ms. Laverne McGuinness, National Director PCCC, HSE.
- Nominate representatives of the National Federation of Voluntary Bodies to all relevant Task Groups and Working Groups established by the HSE e.g. Disability Act 6-18 years; PCCC Transformation Groups; De-institutionalisation etc.
- Meet with Mr. Seamus McNulty, Assistant National Director, PCCC, HSE West with national lead responsibility for Disability and Mental Health, accompanied by the Lead Local Health Manager, representing the four HSE Areas.

National Federation of Voluntary Bodies Pension Scheme:

The National Federation of Voluntary Bodies Pension Scheme was established in 1996 to provide retirement and life assurance benefits for its members who are those people employed in the sector who are not covered by the Nominated Health Service Superannuation Scheme (NHSSS). Currently there are approximately 2723 people from 23 different member organisations benefiting from the Scheme.

Objective:

To review overall performance of the fund management and administration of the Scheme.

Key Actions:

- To engage Watson Wyatt consultants to advise the Scheme's Trustees on the performance of the fund manager and the options open to them to best safeguard the interest of the members of the Scheme.
- To liase with New Ireland Assurance regarding the effective administration of the pension scheme on an ongoing basis.
- To facilitate and arrange meetings of the Pension Scheme Trustees at regular intervals throughout 2008.
- To arrange workshops for Pension Administrators employed by member organisations to keep them fully informed on all aspects of the Scheme, including administration, fund performance, members benefits etc

Information Sharing:

Information sharing and awareness raising are key functions of the Secretariat. It is imperative that awareness bulletins updating member organisations on policy developments, legislation and developments in services are issued on a regular basis.

Objective:

Facilitate the sharing and exchange of information among Member Organisations.

Key Actions:

- Distributing regular emails and fact sheets covering a wide range
 of issues to both staff members working within the Secretariat
 and to the wider Member Organisations. In particular, emails and
 a monthly email newsletter will be provided on a variety of issues,
 such as policy updates, grants, media coverage and work
 updates. Regular news flashes are drafted detailing current
 national and international developments and/or new publications
 e.g. information on the UN Convention on the Rights of People
 with Disabilities, charities legislation, Government social inclusion
 policies etc.
- Organising and taking responsibility for managing the information on the National Federation's website – www.fedvol.ie, which will provide Member Organisations with up to date information.
- Enhancing links with The Wheel and the Irish Charities Tax Research Group in areas of common interest e.g. charities legislation, etc.
- Arrange 4 General Assemblies during which there will be opportunities for information exchange.
- Arrange information days and workshops as appropriate on topics of concern and interest to Federation members.

Ensure that the general public and statutory authorities are informed of good innovative practice within intellectual disability services.

 Engage an external PR Consultant to advise on external PR strategy.

Education:

The Education Sub Committee was set up to advise the Board of National Federation of Voluntary Bodies on issues relevant to education of children and adults with intellectual disability and identify national and international issues in relation to appropriate education provision. Sub Committee members consider all areas of education of interest to member organisations. This includes early intervention (including pre-schools), special schools, and mainstream schools for people with an intellectual disability and adult education or lifelong learning. They also provide a forum to consult with members and a network to share information.

Objective:

Education Staffing Levels Survey

Key Actions:

- Finish Collation of information received from Questionnaire on staffing levels.
- Present to Board of Directors
- Circulate to member organisations for their information.

Identify Education Issues

- Advise the Board of Directors of National Federation of Voluntary Bodies on issues relevant to education of people with intellectual disability.
- Helen Guinan, COPE Foundation, is the National Federation of Voluntary Bodies representative on National Council for Special Education and she will continue to update the committee on the National Council Special Education Implementation Report for the Phased Implementation of the EPSEN Act 2004.
- The Education Sub Committee will monitor the progress on any elements of the EPSEN Act that are due for implementation in 2008.
- Continue to provide a network for members to share information on education issues.

National Steering Group on the role out of Implementation of the Disability Act 2005. Mr. Stephen Kealy, Sisters of Charity of Jesus & Mary, and Ms Moira King, Brothers of Charity Southern Services, will continue as representatives of the National Federation of Voluntary Bodies on the National Steering Group that has been set up to oversee the role out of Implementation of the Disability Act 2005 which became law on June 1st 2007 for children under 5 and the Education Sub Committee will continue to liaise with them on matters relating to this.

Strategic Review of the National Federation of Voluntary Bodies:

In 2007, the Board of the National Federation of Voluntary Bodies committed itself to carry out a Strategic Review of the Federation with a view to (a) revisiting its mission and objectives as set out in our Articles & Memorandum of Association and (b) identifying an appropriate structure which takes account of the Health Services Executive's Transformation Programme and the Government's National Disability Strategy. In this regard, the Board established a Strategic / Structural Review Group to oversee this work.

Objective:

Complete the strategic review by the end of 2008.

Key Actions:

- Consultation with member organisations on an appropriate structure for the National Federation of Voluntary Bodies which takes account of national developments in the Health Services Executive and in Government.
- To consider the recommendations contained in the report by Harwyn Consultants with regard to the Federation's future strategic direction.
- Have in place new structures and revised arrangements for the election of Board membership.

National Health Repayment Scheme:

The Long Stay Repayment Scheme is a State backed scheme to repay those people, including people with an intellectual disability resident in long stay institutions, who were wrongly charged public long stay charges. While applications for refunds made on behalf of service users by some Federation members were successful, others providing very similar services were refused.

Objective:

Establish rationale used by the Scheme Administrator to refuse applications made on behalf of certain service users.

Key Actions:

- Arrange meeting between Scheme Administrator and the service providers whose applications on behalf of service users were refused.
- Write to Department of Health & Children advising them of anomalous situation and seek separate meeting to resolve the matter.

Vocational Training & Employment:

The Vocational Training & Employment sub committee will advise the Board of National Federation of Voluntary Bodies on issues relating to the vocational training, and employment of service users and will continue to address future topics in relation to Vocational Training & Employment.

Objective:

National Review of Adult Day Services for People with Disabilities.

Key Actions:

- The HSE is currently carrying out a National Review of Sheltered Services for People with Disabilities. The purpose of that review is to obtain information on all aspects of Sheltered Services, including establishing a listing of services by location, capacity and occupational activities. This review was informed by work initiated early in 2005 by the Department of Health and Children regarding funding arrangements for Sheltered Work Services.
- A National Working Group representative of all stakeholders was established in August 2007 to conduct a National Review within a 12 month timeframe.
- Mr. Pat Reen, ProsperFingal, who is a member of our Vocational Training & Employment Sub Committee is representing the National Federation of Voluntary Bodies on this working.

Day Services Questionnaire

- Final Analysis of the Day Service Questionnaire will be completed by the sub committee in early 2008.
- A report of the findings will be prepared for consideration by the Vocational Training & Employment Sub Committee and disseminated to member organisation.

Section 2

Quality & Innovation

The National Federation of Voluntary Bodies is committed to achieving the highest possible standards in the quality of the services and supports provided to the people who access our services. Our members are increasingly taking a person centred approach which is challenging and demands flexibility and innovation in service design and delivery.

Training & Development:

The initiatives outlined below are focused on supporting the on-going development and skill enhancement of personnel employed across National Federation of Voluntary Bodies member organisations. In a time of constant change, a focus on a comprehensive and strategic approach to the development of training, learning and education initiatives is paramount. The actions to be implemented during 2008 are set within the overall context and objectives of the Action Plan for People Management (APPM). The National Federation's Training and Development Sub Committee will continue to act as the central conduit through which these initiatives are developed and realized. The National Federation of Voluntary Bodies will continue to develop links with the HSE Performance and Development Function which aims to develop a high performance culture and a highly competent and motivated workforce within the HSE to ensure efficiency and excellence in service delivery.

Objective:	Key Actions:
Training & Developmen	nt Sub Committee
Training & Development Sub Committee	Hold approximately 4 meetings of the Training & Development Sub Committee during 2008
Training & Development Plan for 2008	 Agree training and development plan of work / actions to be undertaken during 2008
Transfer of Learning Event	 Arrange workshop with Dr. Paul Donovan, Irish Management Institute, focusing on supporting the 'Effective Transfer of Learning within Organisations'. This event will be jointly organized with St. Michael's House as part of a commitment to the sharing of best practice in training and development Finalise venue, promote programme, booking of participants, etc Circulate summary notes on event

Objective:

Key Actions:

Management Development Programmes

'Managing for the Future: Building your Skills as a Front Line Manager in a Person Centred Environment'

- Completion of the pilot programme 2007/8- Graduate Conferring, etc
- Liaise with The Performance Partnership in relation to reviewing the programme materials arising from the pilot programme
- Link with SNAP Printing regarding the production of training materials for future programmes – packs / CD's
- Decision in relation to the further roll-out of the front line managers training programme during 2008 – Steering Committee / Training & Development Sub Committee
- Establish tendering process for the appointment of a training provider(s) for the delivery of any future programme(s) / Development of contract agreement
- Advertising of programme(s) and recruitment of participants
- Arrangement of venues / catering, etc
- Commencement of Programme(s) in Autumn 2008

Managing People – Management Development Programmes

- Completion of final evaluation report for submission to HSE Performance & Development Function
- Explore possible sources of funding for further training in this area

Delivery of Training Programmes

- PAS-ADD: Liaise with Dr. Steve Moss regarding the delivery of an additional PAS-ADD training programme / CAS-ADD programme for professionals working with children
- Bereavement Training Programme: Liaise with personnel from St. Michael's House to arrange a follow-up / review session for clinicians who undertook the 3-day Bereavement Training Programme for Clinicians that was held in May 2007
- Explore the possibility of establishing a National Support Network in this area
- Additional training initiatives 2008:
 - Investigators Training
 - Support Contact Persons
 - Dignity at Work Policy
 - Trust in Care Policy

Action Plan for People Management (APPM)

APPM

- Complete progress report on actions undertaken in 2007 as part of the National Federation of Voluntary Bodies commitment to the implementation of the provisions of the APPM within the intellectual disability sector.
- Identify key APPM related actions and seek funding to implement same through the APPM Implementation Committee, 2008

Objective:

Key Actions:

Securing Knowledge Intra Lifelong Learning

SKILL Project 2008/9

- Facilitate the allocation of the quota of 435 places for Support Service Staff and 15 places for Support Service Managers which are available to the Intellectual Disability Sector through the SKILL Project for 2008/9.
- Submit completed returns to the SKILL Project Team.
- Support organisations who wish to develop a 'critical mass project' as part of the SKILL Project.
- Process payments due to member organisations for participants engaged in SKILL Project training.
- Complete evaluation with members seeking feedback on experience in relation to learners participation in the SKILL Project to date.
- Seek funding from the SKILL Project Team to cover administrative costs incurred by the National Federation of Voluntary Bodies.

HSE

Performance & Development Function

• Continue to liaise with personnel from the HSE Performance & Development Function in the implementation of training and learning initiatives aimed at supporting employee development.

eLearning Project

- Participate in the eLearning Project that has been established by the HSE to further develop the range of modules available on the HSE website – www.hseland.ie.
- Support organisations to utilize eLearning as a blended approach to learning

Complaints Policy & Procedure

- Arrange a series of briefing / training sessions for those who have been appointed as Complaints Officers (Spring 2008)
- Act as a link / contact person with the HSE Office of Consumer Affairs in relation to the Complaints Policy & Procedure

Team Based Performance Management

• Liaise with the HSE Performance & Development Function in relation to further supporting the development of Team Based Performance Management initiatives during 2008

Health Services National Partnership Forum (HSNPF)

Managing Transformation Programme – HSE West

- Represent National Federation of Voluntary Bodies on Programme Steering Committee.
- Support the development of the programme and nominees from the intellectual disability sector to participate in the programme.

Partnership Facilitators

 Link with HSNPF Partnership Facilitators who are working with organisations in the intellectual disability sector.

Human Resources:

The National Federation of Voluntary Bodies, through the human resources work that it is engaged in, seeks to ensure that its member organisations are kept abreast of employment and industrial relations related developments. The Human Resources Sub Committee is a key forum for the sharing of information and best practice on key human resources related issues and initiatives. Through the work of the Sub Committee, and the regular meetings which are held with the HSE-Employers Agency, organisations are supported to network with fellow HR professionals and develop common positions on key matters. The National Federation of Voluntary Bodies will also continue to work closely with the HSE, in particular with the human resources function, and to participate in the HR Forum which has been established to support those working the human resources field.

An overview of the key human resources related actions to be taken during 2008 are provided below:

Objective:	Key Actions:	
Human Resources Sub Committee		
Quarterly Meetings	Hold a minimum of 4 meetings of the Human Resources Sub Committee during 2008	
Garda Vetting	Continue to Liaise with personnel from the Garda Central Vetting Unit to ensure that National Federation members have access to a timely garda clearance process	
	 Participate in training session arranged by the Vetting Unit for those appointed as Authorized Signatories 	
	 Development of a Code of Practice – for agencies that are providing Vetting on behalf of another agency (dealing with issues such as confidentiality, timeliness, etc) 	
Health & Safety	Design health and safety questionnaire to circulate to member organisations to determine priority issues and concerns.	
	Circulate survey / collate responses	
	 Circulate summary of survey findings for discussion at Human Resources Sub Committee meeting. 	
	Make recommendations regards follow-up actions to be taken.	
Recruitment Advertising	Arrange meeting with members of the Recruitment Advertising Group to review advertising arrangements	
	 Continue to Link with Independent News & Media in relation to advertising for member organisations 	
HSE - Employers Agency		
Bi-annual Meetings	Arrange bi-annual meetings with personnel from the HSE – Employers Agency	
Review of Dignity at Work Policy	 Participate in the Working Group that is reviewing the Dignity at Work Policy / feedback proposed amendments to the Policy to National Federation members 	
	Support the further development of mediation as a means of resolving disputes within the intellectual disability sector	

Nurses Dispute 2007

 Follow-up on issues arising in relation to the Nurses dispute that took place in 2007 and support Mr. John Pepper, St. John of God Hospitaller Services, who is the National Federation's representative at national level.

Health & Social Care Professionals Act 2005

Health & Social Care Professionals Council

 Continue to link with the National Federation representative on the National Health & Social Care Professionals Council / participate in the Working Group that was established to examine the competencies for Social Care Workers.

HSE

Human Resources Forum

 Liaise with human resources personnel from across the HSE through the work of the HR Forum which aims to act as a network for the sharing of information on key human resource related initiatives

Therapist Recruitment Project

• Represent the National Federation on the Steering Committee that has been established to co-ordinate a national approach for the recruitment of basic and senior grade therapists.

National Standards in Disability Services:

The Health Information & Quality Authority was established on a statutory basis in May 2007, following the signing into law of the Health Act 2007. In May 2005, the Minister for Health & Children established under Statutory Instrument the interim Health Information and Quality Authority to make the administrative and organisational plans for the establishment of the Health Information and Quality Authority. HIQA has established a Standards Advisory Group to advise the Authority in drawing up a set of national standards.

Objective:	Key Actions:
Develop standards for designated centres for people with disabilities.	At the invitation of HIQA, Mr. Brian O'Donnell, Chief Executive, will represent the National Federation of Voluntary Bodies on the National Standards Advisory Group.
	 The National Federation of Voluntary Bodies will use it's Quality Sub Committee as a Reference Group in articulating the Federation's position with regard to the development of the standards.
	 The National Federation of Voluntary Bodies will consult widely with its members in relation to the draft standards prior to their publication.

Performance Verification Process under Towards 2016:

Towards 2016, Ten Year Framework Social Partnership Agreement 2006 – 2015 was negotiated in 2006. The agreement provided for the development of an Action Plan agreed between management and the Trade Unions for the modernisation and change agenda for the health and social care sectors during the terms of Towards 2016.

Objective:

Key Actions:

Provide formal verification of progress on the attainment of objectives set out in the Action Plan agreed under Towards 2016 by the National Federation of Voluntary Bodies.

- Arrange for completion of the Performance Verification Group Template by all National Federation of Voluntary Bodies member organisations.
- Prepare an overall sector report on the basis of the templates submitted to the Performance Verification Group.
- Arrange site visits as appropriate by the Performance Verification Group.

Health Services National Partnership Forum:

The Health Services National Partnership Forum has evolved and developed through successive social partnership agreements commencing with the Partnership 2000 agreement. It comprises health service management, including Voluntary Hospitals and the Intellectual Disability Sector, and National Trade Union leaders.

Objective:

Key Actions:

Represent the National Federation of Voluntary Bodies on the Health Services National Partnership Forum and ensure there is a full understanding at the national level of the specific issues arising in the context of workplace partnership in Intellectual Disability Services.

- To agree parameters and structures under which workplace partnership operates in the services.
- To take the lead role in meeting the various requirements set out in the national agreements such as performance verification and change related to the modernisation agenda in the Intellectual Disability Sector.
- To arrange for the establishment of workplace partnership committees and working with our Intellectual Disability
 Partnership Facilitator to facilitate, support, promote and evaluate workplace partnership in our sector.

Section 3

Research & Policy Development

Appropriate high quality research is a necessary pre-requisite to ensuring best practice in services development and delivery and in policy formulation. In addition, research has a key role to play in supporting the rights of people with intellectual disability to full and active lives by creating reflective practice on service provision and the wider needs of people with disabilities. The National Federation Secretariat will continue to support the development of a strong research base within National Federation member organisations and will continue to initiate and collaborate in research relevant to the lives of people with intellectual disability. This research will have a strong link with practice and evidence based research shall contribute to the development of policy and guidelines which will guide member organisations in the development of high quality services. Research and Policy development in the National Federation shall be cognisant of the principles as set out by the UN convention on the Rights of People with Disabilities and shall encourage and pursue research projects which address the principles at the heart of the convention.

The Research Sub Committee has a key role in cultivating best practice in services development. The Research Sub Committee is currently involved in developing a National Research Strategy for the National Federation of Voluntary Bodies. This involves consultation with service users, member organisations and other disability stakeholders. This will become a key activity and outcome for the development of research in the National Federation.

The key research priorities for the National Federation are set out in detail below:

Objective:	Key Actions:
New Ideas – New Approaches: Publication of Conference Proceedings Report	 Final draft of report completed and disseminated to member organizations, delegates and other interested parties. Easy to read version of the report published and circulated as a supplement to the National Federation Newsletter Article published on the outcomes of the conference in the Clinical Indemnity Scheme Newsletter and other avenues as arise
Develop a Research Strategy	 Consultation with the research committee – March 31st Consultation with Service Users representatives – March 31st - Seasamh Parliament, Inclusive Research Network and Community Participation & Inclusion Sub Committee. Consultation with Board of Directors Consultation with Secretariat Team through team meetings Consultation with member organisations via email, via subcommittees and through Board of Directors

Objective:	Key Actions:
Research Sub Committee	4 meetings will take place in 2008 (Dates: 31st March, 30th June, 22nd September, 1st December) Development of Research Strategy for National Federation of Voluntary Bodies
	Research Fact Sheets will be developed and posted on website
	3 or 4 Articles will be published in Frontline Magazine
	A Meeting will be organized with the Centre for Law and Policy NUI Galway
	Associated membership of the Research Sub Committee will be discussed and invites issued as appropriate
	 Identification of Designated National Experts on key research issues such as health, challenging behaviour, ageing, autism, human rights and legal issues, inclusion etc.
	The committee will continue to develop and share good practice in research through development of knowledge centres and through the material provided by the designated national experts in key research areas.
Development of a National	Catalogue and log all material currently available
Federation Secretariat	Purchase of Reference Manager tool
Library	Build on existing resources
	Include easy to read materials
	Multi media resources will be included
	Build knowledge centres on key research issues
Inclusive Research Network (IRN)	Continue to meet coordinating group of the IRN to develop the activities of the network.
	Organise one workshop on topic of interest to Service Users. e.g. Deinstitutionalisation, life stories, "having your say"
	IRN will have an Involvement in National Federation Conference this could act as a separate workshop using participatory techniques.
	Develop funding proposal and identify potential funders e.g. NDA, HSE, etc. to develop the IRN
Development of research proposals for funding	Consider the relevance and possibility of the variety of funding opportunities for national research
application	This will be led by topics identified in National Research Strategy
Representation of	These may include:
National Federation	NDA Conference - Oct/Nov 2008
research at national and international research	IASSID Conference - August 2008
conferences	Nursing and Midwifery Conference TCD - Nov 2008
	This list is not exhaustive or definitive. It will be amended as

opportunities arise.

Objective:	Key Actions:
Organise National Joint Research Conference	 Topic - Bringing the UN Convention Home to Ireland Joint Conference with Centre for Disability Law and Policy NUI Galway Involvement of speakers at National and International level Host regular meetings to organise the event Other topics of interest for future conferences will be identified through feedback from 2007 conference Include service user element in the conference as discussed above.
Continue to develop and enhance relationships with disability stakeholders	 Centre for Disability Law and Policy NUI Galway TCD Dept of Nursing and Midwifery National Institute for Intellectual Disability TCD National Disability Authority HSE Inclusion Ireland Disability Federation of Ireland (DFI)
Partnership with Centre for Disability Law & Policy, NUI Galway	 Meeting with Gerard Quinn to identify common goals and topics February 29th 2008 Seek commitment on the following: Development of a research partnership Involvement in the Inclusive Research Network. Collaborate generally on research projects and topics of interest. Involvement in the Formation of a National Research Ethics committee Collaboration between National Federation and Centre for Disability Law & Policy, this would involve the sharing and dissemination of information. Joint conference between National Federation and Centre for Disability Law & Policy on the UN Convention
TILDA – Irish Longitudinal Study on Ageing	 Continue to meet Scientific Advisory Committee – bi-monthly Promotion of the project among member organisations on the project

Ongoing dissemination of information relating to the project

Objective:	Key Actions:
Partnership with TCD School of Nursing and Midwifery	 Assist in dissemination of research material Joint collaboration on research issues relating to aging in people with intellectual disability as per discussion with Prof. Mary McCarron Additional issues: Development of a research partnership. Collaborate generally on research projects and topics of interest. Involvement in the Formation of a National Research Ethics committee Collaboration between National Federation and School of Nursing & Midwifery, this would involve the sharing and dissemination of information.
National Institute of Intellectual Disability (NIID) – Doing Disability Research	 Continue to meet Advisory Committee Support and assist in dissemination, information & consultation etc. regarding 3 projects Development of other research collaborations as arise
Joint committee on audit of abuse of people with intellectual disability in residential settings	 Continue to be a member of advisory group Contribute to the development of audit proposal Oversee commissioning and conducting of research
Development of Research Partnership with Norah Fry Research Centre University of Bristol, UK	 Visit Norah Fry Research Centre Invitation to Prof Kelley Johnson to Inclusive Research Network workshop Invitation to Prof Kelley Johnson to become associate member of Research Sub Committee Explore possibilities of joint research proposals in areas as identified by the Research Strategy.

Mental Health Commission:

The Mental Health Commission was established under the Mental Health Act 2001. Section 42(4) of the Act requires the Mental Health Commission to submit a report to the Minister for Health & Children on the operation of Part 2 of the Mental Health Act by 30th April, 2008.

Objective:	Key Actions:
To contribute to and oversee preparation of the report to be submitted to the Minister for Health & Children by 30th April, 2008	 At the invitation of the Mental Health Commission, Mr. Brian O'Donnell, Chief Executive, will represent the National Federation of Voluntary Bodies on the consultative group established by the Commission to advise it generally on the conduct of the review. The National Federation of Voluntary Bodies will invite submissions in relation to the review by all member organisations. The National Federation of Voluntary Bodies will prepare an overall sector submission on the basis of the submission received by the member organisations.

Informing Families Project:

In response to a proposal by the National Federation of Voluntary Bodies to mark the European Year of People with Disabilities 2003, the Health Services National Partnership Forum agreed to provide funding for a project which would make a real difference to people with disabilities in Ireland and particularly to their families. Having consulted with families and people working in the Disability Sector, it was agreed that the development of National Best Practice Guidelines for Informing Families of their Child's Disability would be a significant way to mark the year, while also leaving a substantial legacy by way of addressing an important issue which has remained unaddressed over many years.

National Best Practice Guidelines for Informing Families of their Child's Disability were therefore developed through a comprehensive process of consultation and research with parents and professionals by the National Federation of Voluntary Bodies, in a project that began in 2004 with the appointment of a Project Coordinator, and was completed in 2007. The project was guided by a Steering Committee of key stakeholders including parents and professionals; voluntary and statutory agencies; and chaired by Dr. John Hillery (President of the Medical council 2004-2007). The National Best Practice Guidelines for Informing Families of their Child's Disability were launched on 3rd December 2007 in the Royal College of Physicians of Ireland, by Minister for Health and Children Mary Harney, TD, at an event hosted by Ms. Miriam O'Callaghan (RTE).

The Informing Families Guidelines have received endorsement, welcome and support from all key stakeholders; including parents of children with disabilities, the Informing Families Project National Steering Committee, the Department of Health and Children, the Minister for Health and Children, and the HSE. However, national and international experience indicates that if best practice guidelines are published and circulated without the back-up of a clear implementation strategy, the recommendations will remain just that, and the needs identified clearly through the research and in Irish policy documents relating to the disclosure of disability over the past eighteen years, will remain unaddressed. The priority for 2008 in the Informing Families Project is therefore to develop and execute a comprehensive implementation strategy for the Guidelines, to ensure that all professionals to whom they apply have access to the recommendations with the aim of improving outcomes both for families and professionals who communicate the news of a child's disability. The strategy will take effect in two strands; at the national level, and at a pilot implementation project which is underway in the Cork region, supported by the Health Services National Partnership Forum.

Informing Families Project - National Implementation Strategy

Initiatives for the implementation of the Informing Families Guidelines at a national level are set out below:

Objective:

Key Actions:

Development of National Implementation Steering Committee

- Establishment of National Implementation Steering Committee
 that represents all key stakeholders who are in a position to
 progress the dissemination of the Guidelines within their discipline
 or organisation.
- Integrated approach across hospital, community and disability service settings will place the needs of families at the centre of the disclosure process.
- Action plan to be developed with each organisation and discipline to determine the most effective method of ensuring the Guidelines becoming embedded in the system and are available both now and in the future to those who communicate the news and support families immediately thereafter.

Objective:	Key Actions:
Continued dissemination of Guidelines and Consultation and Research Report	 Continued dissemination of the Guidelines and Consultation and Research Report in response to requests from disability services, HSE community and hospital services, training providers & universities, publishers (through the ISBN system), and individuals.
Release of DVD film 'Words You Never Forget'	• A short film entitled 'Words You Never Forget' was produced in 2007 to support the Informing Families Project launch and publication of the best practice guidelines. This DVD 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. A significant amount of media coverage followed the launch and as a result there have been many requests for copies of the DVD 'Words You Never Forget'.
	 DVD to be packaged, duplicated and made available for order through National Federation website in February 2008
	 ISBN number to be applied to DVD to allow for national and international orders through established publishing channels
	 DVD to be widely disseminated for use as a training aid in medical, nursing and allied health professional training courses, and for use hospital, community and disability services.
Presentations of the National Best Practice Guidelines	In order to ensure that the Guidelines receive the appropriate exposure to facilitate structured dissemination so that all relevant professionals on the front line have access to the Informing Families materials, presentations will be made to various stakeholder groups, conferences and national organisations. These will include:
	 Presentation to Health Services National Partnership Forum, Enfield 29th January 2008.
	 Inclusion Ireland Annual AGM & Conference, Tullamore 12th April 2008.
	 Presentation to HSE National Hospitals Office Executive, Dr. Steeven's Hospital, 17th April 2008.
	Abstracts will be submitted to conferences as calls for papers arise, e.g. Trinity College School of Nursing and Midwifery Conference, 9th Annual Interdisciplinary Research Conference 5th – 7th November 2008.
	Invitations have been received from various hospitals, disability service providers and other organisations to provide presentations and information sessions regarding the Informing Families Guidelines. These invitations and other presentations that arise will be facilitated and organisation as the year progresses.
Articles and publications	In order to maximise exposure of the Informing Families Guidelines in the academic arena and to make effective use of the significant research data gathered through the Informing Families Project,

articles will be submitted to various publications throughout 2008. These will include:

- NDA Conference Proceedings 2007 Paper to be included on the Informing Families Project presentation made during "Evidence-based practice in Early Intervention for children with disabilities aged 0-6 years" Conference. Due for publication March 2008.
- Article for Frontline Magazine regarding the development of the Guidelines.
- Exploration with Dr. Brian Skotko, Harvard Medical School and Boston Children's Hospital, to compare US and Spanish data with Irish data gathered through the Informing Families Consultation and Research program.
- Further articles in academic journals will be explored during the course of 2008.
- Links with professional bodies and trade-unions have led to invitations to provide articles for newsletters and websites, which will be provided throughout 2008.

Objective:

Key Actions:

Collaboration with University of Limerick Graduate Medical Training

- In 2008, the Informing Families Guidelines will become part of the curriculum of the graduate medical training programme in University of Limerick.
- The first input will be given on 16th April 2008, when Katherine O'Leary, parent of two children with disabilities and Chair of the Informing Families Project in the Cork Region, will present on the experiences of parents of children with disability, and further input and direct training in best practice for disclosing diagnosis will be given as the course progresses. Additional topics that relate to the whole life perspective of people with intellectual disability will be explored in this collaboration in during 2008 and into the future.
- Interest has been expressed by other medical training programmes and will be developed over time.

Informing Families - Cork Implementation Project:

Throughout the national and international literature, a recurring point of concern has been the lack of evaluation of communication skills and 'breaking bad news' in general, and of guidelines for disclosure of disability in particular. With this in mind, the Informing Families Project will implement the Guidelines on a pilot basis in the Cork region in 2008 and evaluate outcomes for families and professionals of the implementation of this programme. Along with local implementation, the wider aim will be to gather learning points for national roll-out. Initiatives for the implementation of the Informing Families Guidelines in the Cork region in 2008, across hospital, community, and disability service settings, are set out below.

Objective:

Key Actions:

Establish Local Working Groups and implement best practice recommendations Working Groups will be established to take on specific tasks within the implementation programme. Working groups to include members of Local Steering Committee, and non-members with particular expertise or role in the various pieces of work being undertaken.

Establish Local Working Groups and implement best practice recommendations

- Working Groups to be fully established, with necessary expertise and representation by April 2008
- Suggested Working Groups include:
 - Communications Working Group
 - Evaluation Working Group
 - Information Provision Working Group
 - Built Environment Working Group
- Training and Education Working Group

Following establishment of the Working Groups, the Best Practice Guidelines will be broken down into sections for

- individual implementation
- team implementation
- regional implementation, and
- tertiary centre (regional referrals to national centre) implementation

All recommendations to be addressed through this process

Objective:

Key Actions:

Evaluate outcomes for families and professionals as a result of implementation of the Guidelines

Following establishment of the Evaluation Working Group the following tasks will be undertaken:

- Methodology for evaluation to be agreed
- Research Tools to be developed
- Access to Sampling Frame to be agreed
- Ethical Approval to be secured
- Research to be carried out to establish the outcomes of implementation

Development of Template for National Implementation

Analysis of the evaluation will be carried out in order to:

- Indicate the key factors leading to successful implementation of the Guidelines, including barriers and enablers.
- To develop a template to guide national implementation of the Guidelines.
- To provide research data of national and international relevance regarding the evaluation of communications skills training.

Social Inclusion Best Practice & Volunteering Supports:

The National Federation Secretariat is committed to enabling capacity building in member organisations which 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.

Funding has been secured for a further 3 year period under the Department of Community, Rural & Gaeltacht Affairs Funding Scheme to Support National Organisations in the Community & Voluntary Sector. This will enable our Policy Development Co-Ordinator to concentrate on Social Inclusion Best Practice and Volunteering Policy & Supports over the three year funding period to address some of these issues. The Policy Development Co-Ordinator will be supported by the Community Participation & Inclusion Sub Committee – whose representation includes people who access

services and staff who provide services – and the Volunteering Sub Committee who represents member organisations volunteering services to people with intellectual disability.

The workplan for 2008 will also build on participatory research which was undertaken in 2006 and facilitated by the National Federation Community Participation & Inclusion Sub Committee. This research has now been published in an easy-to-read document, "People Connecting" and highlights issues that are important to people with intellectual disability in order for them to live the life of their choice and be meaningfully included in their own communities.

Objective:

Key Actions:

National Federation Research Strategy

National Federation Research Strategy

- Invitation from National Federation Research Sub Committee to Community Participation & Inclusion Sub Committee to present our ideas on areas of possible research, based on "People Connecting" consultation. This presentation would form part of the Research Sub Committee's consultation process with people who access services to determine what research is important to them.
- Implement key actions to be identified in the research strategy

Objective:

Key Actions:

Social Inclusion Best Practice

Identify the barriers, incentives and solutions to community participation and inclusion of people with intellectual disability.

- Continue to work with the Community Participation and Inclusion Sub Committee
- Continue to disseminate the findings from People Connecting, including articles for Frontline and Insight disability magazines, meetings with advocacy councils etc.
- Examine best practice in relation to developing partnerships with local communities
- Collate personal life stories/story boards of people who avail of member organisations services. These can be used as a very effective tool to transform negative attitudes towards people who access services.

Promote Member
Organisations to work in
partnership with voluntary
and statutory authorities
at local, regional and at
national level

- Ongoing consultation with service providers and people who access services
- Developing links with government departments, national organisations, statutory bodies, universities and other disability stakeholders e.g. Department of Community, Rural & Gaeltacht Affairs, Department of Health & Children, other Government Departments, HSE, NDA, Equality Authority, Citizens Information Board, National Institute of Intellectual Disability, etc.

Continue to support members of the Community Participation and Inclusion Sub Committee, who have an intellectual disability, to ensure meaningful

- Examine options for ensuring that all members of the Sub Committee are equal and make recommendations to the Board of the National Federation
- Provide easy-to-read agenda, minutes, documentation for Sub Committee meetings.

partnership and participation on this Sub Committee.

 Document each step of how this inclusive Sub Committee works together to provide a learning opportunity for other Sub Committees and groups.

Volunteering Supports

Supporting Member
Organisations to ensure
best practice in the
recruitment, selection,
training, ongoing support,
monitoring and
celebration of their
volunteers contributions.

- Publish the Volunteering Survey Findings and Volunteering Policy Template
- Disseminate to member organisations through meetings, seminars, National Federation website, etc.
- Develop Volunteering Factsheets (easy-to-read) versions for our member organisations and all those who avail of services
- Ongoing development of Volunteering network to support Volunteering Co-Ordinators within member organisations
- Ongoing support to our member organisations so that volunteer resources can be maximised to support people with intellectual disability in their own community
- Ongoing links with Best Buddies Ireland, Special Olympics Ireland, Volunteering Ireland, Volunteer Centres Ireland, Pobal Enhancing Disability Services, and Office of Active Citizenship.

National Disability Strategy Stakeholders Monitoring Group:

The implementation of the National Disability Strategy is the agreed focus of disability policy under Towards 2016. Commitments 33.4 of this agreement provides for the establishment of a National Disability Strategy Stakeholders Monitoring Group to monitor progress of the National Disability Strategy and the arrangements to ensure a continued constructive relationship with stakeholders in this regard. The following stakeholder groups will participate in the new group.

- National Federation of Voluntary Bodies
- Disability Federation of Ireland
- The Not for Profit Business Association
- People with Disabilities Ireland
- Mental Health Ireland
- Inclusion Ireland
- National Disability Authority

The Department of the Taoiseach will chair the group with Ms. Angel Kerins, Chairperson, National Disability Authority, acting as Vice Chairperson.

Objective:

Key Actions:

National Federation Research Strategy

Monitor progress on the overall implementation of the National Disability Strategy, building on the monitoring and review procedures already in place in respect of each of the six Departmental

• To participate in the bi-annual meetings between stakeholders and the Senior Officials Group on Disability (SOGD). The SOGD, which reports to the Cabinet Committee on Social Inclusion, comprises officials representing the six Departments responsible for implementing sectoral plans for disability services and the Departments of the Taoiseach; Justice, Equality & Law Reform; Finance; and Education & Science.

Service Plan 2008

Sectoral Plans.

- The National Federation of Voluntary Bodies will make submissions to the National Disability Strategy Stakeholders Monitoring Group in respect of its view on progress in each of the sectoral plans.
- Mr. Brian O'Donnell, Chief Executive, National Federation of Voluntary Bodies, will chair the National Disability Strategy Stakeholders Monitoring Group Sub Group on Environment and will oversee preparation of submissions in respect of the Department of Environment & Local Government Sectoral Plan.
- The National Federation of Voluntary Bodies will liaise with the Disability Federation of Ireland and the Not for Profit Business Association to ensure that the key issues affecting our sector are highlighted under the Community & Voluntary Pillar of the Social Partnership Forum.

European Association of Service Providers for Persons 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 25 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.

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Key Actions:

Contribute to the development of policy in respect of Disability issues at the European level.

- The National Federation of Voluntary Bodies will participate as a partner in EASPD sponsored projects, which promote development and research as a basis for innovation and improvement of service provision.
- The National Federation of Voluntary Bodies will participate on all relevant EASPD Working Groups and will contribute to all EASPD policy submissions and statements.
- The National Federation of Voluntary Bodies will contribute to EASPD's Action Plan for 2008.
- Mr. Brian O'Donnell will continue to provide a leadership role to EASPD in his capacity as the elected President of the Association.

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

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