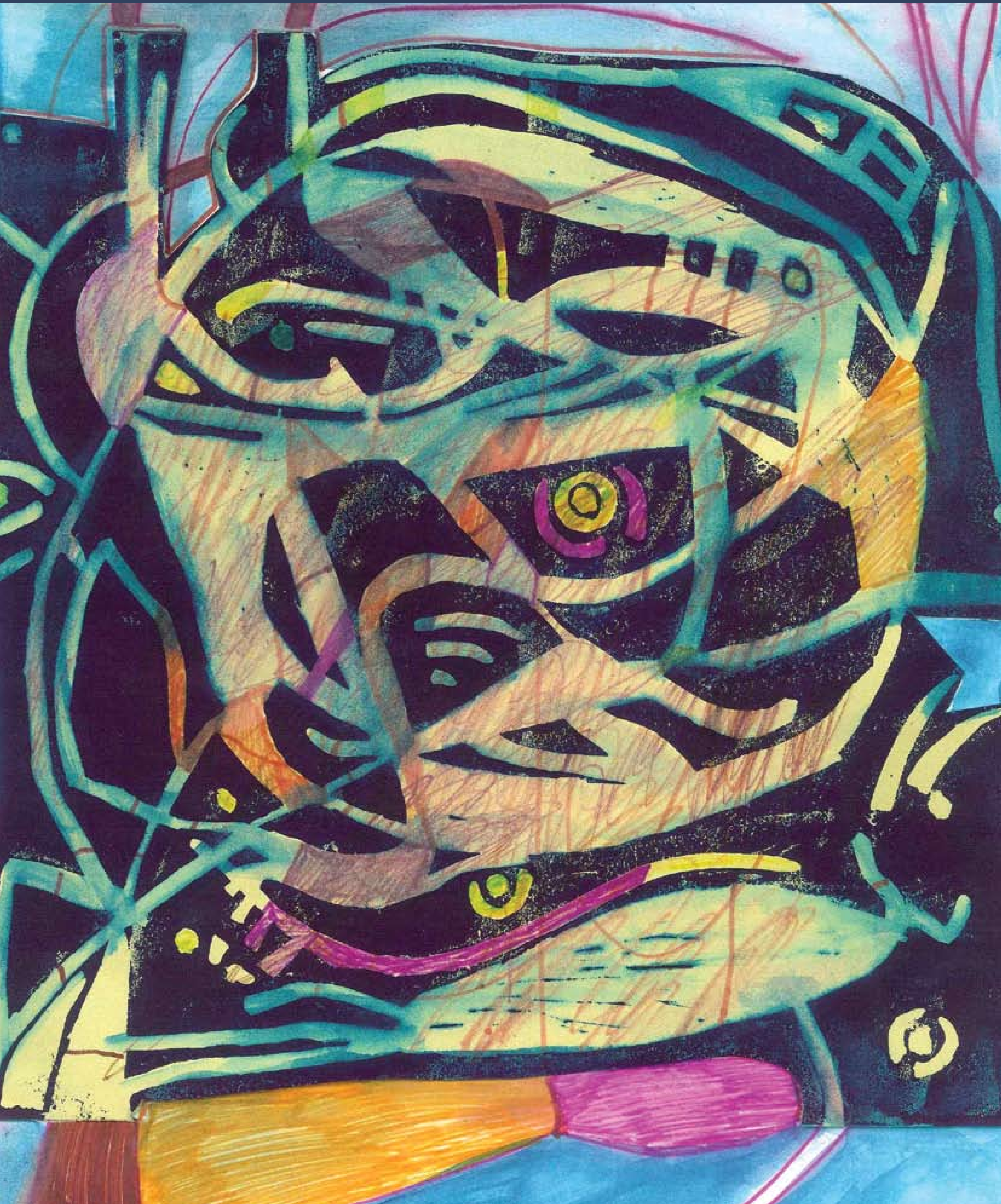
National Federation of Voluntary Bodies

Providing Services to People with Intellectual Disability

Annual Report 2008



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NATIONAL FEDERATION OF VOLUNTARY BODIES

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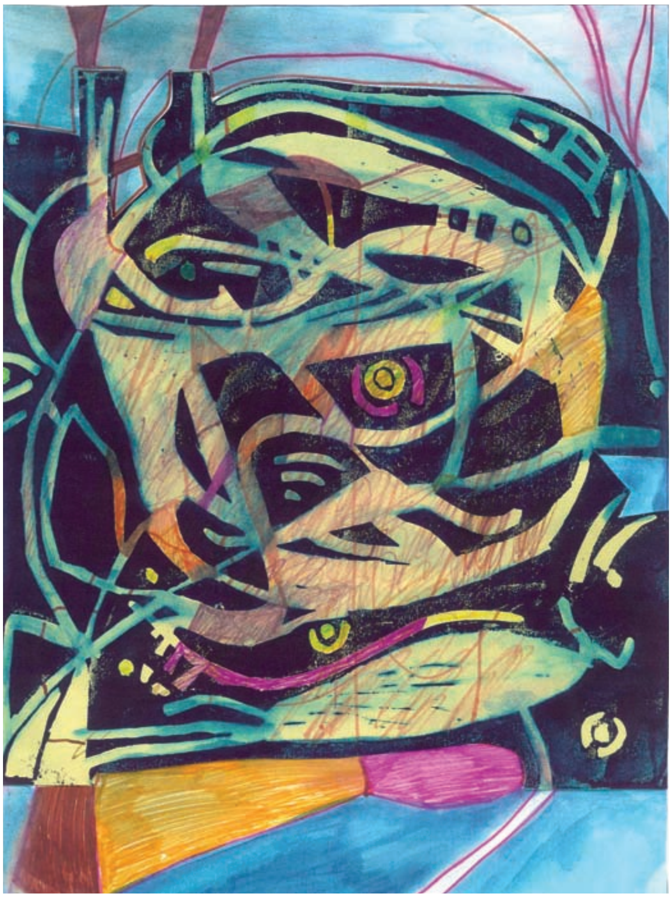

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Chairperson’s Statement

In October of 2008 I was honoured by the Board of Directors to be selected as their Chairperson for the next 2 years. I received both congratulations and commiserations in equal measure as all were aware of the rapidly changing economic environment in the country at that time. At the beginning of 2008, it would have been impossible to imagine the extent of the deterioration in the economic climate that would occur during 2008. We experienced a definite end to the multi-annual funding programme which was replaced by cut-backs right across the public sector and of course in our own sector also. In anticipation of these cut-backs the National Federation, in partnership with Inclusion Ireland and the National Parents & Siblings Alliance held a very successful pre-Budget press conference, and while the sector did receive a 1% cut back in that budget this was considerably less than the percentage attributed to the broader health sector, and indeed the public service generally. The 1% cut back was, however, very difficult for organisations to take on board as many were already struggling to deal with core budget deficits and service pressures. Member organisations however, consistent with their voluntary ethos, put in place various strategies to meet the cut-backs, while at the same time protecting front line services to the greatest degree possible.

The National Federation sought, and were successful in securing the establishment of a national forum where the HSE would engage in partnership with the umbrella bodies to steer and monitor the implementation of the cut backs. This partnership approach to the challenge facing the HSE and agencies has worked well and remains in place at year end.

As part of the communication of the October Budget, Mr. John Moloney, T.D., Minister of State at the Department of Health & Children, with responsibility for Disability Services, announced the commencement of a review of the role of voluntary organisations in the provision of services to people with disabilities in Ireland. This review will examine the effectiveness and efficiency of the present configuration of service provision and the National Federation will engage with this process to demonstrate the value the voluntary sector brings to this service delivery area. The exact terms of reference for this group have not been decided at year end.

During 2008 the challenges which the changing economic circumstances brought were naturally the main focus of the National Federation membership but work continued in other areas including:

- the Congregated Settings Project;
- the Volunteering Project, Volunteering in Intellectual Disability Services in Ireland: *Supporting People to Live the Life of their own Choice in their own Community”,* which was finalised and culminated in a launch in Mallow by Minister Carey in October 2008;
- the National Adult Day Services Review.

The affairs of the National Federation in 2008 were very ably steered by the Board of Directors, and its former Chairperson Brendan Broderick. The National Federation is also informed and influenced by the Sub-Committee structure and also the member organisations through the vehicle of the General Assembly meetings and regional fora. Back at the ranch in Oranmore, Brian O’Donnell and his team provide a professional and excellent support to the Chair, the Board, and the National Federation’s member organisations, which is much appreciated.

While the horizon remains extremely challenging for 2009, the National Federation and member organisations are committed to achieving the best possible results for people who use services and also to the promotion of the voluntary sector as an essential in this endeavour.

John O’Dea,
Chairperson

Chief Executive's Introduction

I am very happy to present the Annual Report of the activities of the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability for 2008.

The sharp deterioration in the economic well being of our country has radically changed the context in which services to people with disabilities are provided. Since 2006, the multi-annual funding programme under the National Disability Strategy had enabled us to continue to address the needs of people who are on waiting lists for services, while simultaneously enhancing the supports available to people already receiving services. Unfortunately, this investment came to a halt in 2008 and we were faced with the new challenge of maintaining services with reducing resources.

In response to our own Harvey Review, and in anticipation of the Government's likely decision to carry out a review of the non-statutory disability services sector, the Board of the National Federation, at its meeting held in July 2008, decided to establish a Working Group to assess how best to demonstrate and promote ourselves as a value adding services providing sector. The Working Group recognised that the transforming health and social care landscape is bringing about major change in terms of how services will be configured and provided into the future. The Working Group met on four occasions during 2008 and will be developing a set of proposals for consultation with member organisations in early 2009.

During 2009, we continued to highlight issues of concern to our sector and represented the National Federation of Voluntary Bodies view on all aspects of policy relevant to our sector, both nationally and internationally. In the course of this work, it is necessary for us to draw on the expertise and experience of the many dedicated professionals from within our member organisations who participate on, and contribute to, the work of our various Standing Committees and Task Groups which are outlined in the Appendix 2 to this report. I would like to place on record my appreciation of their important input.

In September 2008, Brendan Broderick stepped down as Chairperson of the National Federation of Voluntary Bodies following a three year term of office. I would like to express my gratitude to Brendan for his dedicated and generous service to the National Federation and also to his successor John O'Dea to whom we convey our best wishes and full support. Our thanks also goes to each member of our Board of Directors for their commitment and wise counsel and also to all 62 member organisations of the National Federation of Voluntary Bodies for their positive contribution to our work and activities.

The range of activities set out in this report, which were carried out by my Secretariat colleagues, on behalf of the National Federation of Voluntary Bodies during 2008, is extensive and their achievements are many. I commend and thank each one of them for their commitment, loyalty and professionalism during 2008.

Brian O'Donnell,
Chief Executive.

Section 1
Membership Support Services

Objective:	**Key Achievements in 2008:**
HSE Disability Governance Group	
To prioritise issues identified through consultation with member organisations for discussion with HSE during 2008 which included: **- Funding reductions and impact on frontline services;** **- Government's Review of Non Statutory Disability Organisations;** **- Development of new Service Level Agreement Template;** **- Implementation of Guidelines in designated Residential Settings.**	• Two meetings were held with Laverne McGuinness, National Director, Primary, Community & Continuing Care; Seamus McNulty, Assistant National Director PCCC, with national lead responsibility for Disability and Mental Health, to progress our issues. • The National Federation of Voluntary Bodies nominated representatives to a number of HSE constituted Working Groups including: - Disability Act 0-5 years and 6-18 years; - PCCC National Partnership Working Group; - Securing State's Interest in Capital Projects Working Group; - Service Level Agreement Working Group; - In addition, Christy Lynch, CEO, KARE, was nominated to project manage the De-institutionalisation of Congregated Settings Project on a full time secondment basis for one year.
National Federation of Voluntary Bodies Pension Scheme	
To review overall performance of the Fund Management and Administration of the Pension Scheme.	• The Pension Scheme Trustees engaged Watson Wyatt Consultants to advise on the performance of the Fund Manager and the options open to them to best safeguard the members' interests. • Having taken the Consultants advice the Trustees decided to retain the current Fund Manager, New Ireland Assurance, but changed the investment product to IRIS Consensus. • Following a number of meetings between New Ireland and the National Federation of Voluntary Bodies Secretariat, a number of initiatives were taken to ensure effective administration of the pension scheme. • A total of six meetings of the Pension Scheme Trustees were arranged during 2008. • A workshop was arranged for Pension Administrators employed by member organisations to appraise them on all aspects of the Scheme, including administration, fund performance, members benefits etc.
Strategic Review of the National Federation of Voluntary Bodies	
To complete the Strategic Review of the National Federation of Voluntary	In 2008, the Board of the National Federation of Voluntary Bodies committed itself to completing the Strategic Review of the National Federation, which was initiated with a view to:

Bodies.	(a) Revisiting its mission and objectives as set out in our Memorandum and Articles of Association; and (b) Identifying an appropriate structure which takes account of the HSE's Transformation Programme. • The Board established a Strategic / Structural Review Group to oversee consultation with member organisation on an appropriate structure for the National Federation of Voluntary Bodies. • Following a full consultation day held on 30th April, 2008, the membership agreed to establish five Area Federation Committees on an interim basis pending finalisation of the HSE's Regional Structures. • It was agreed that there should be no alteration to the Memorandum and Articles of Association until the HSE's regional structures were finalised.
National Health Repayment Scheme	
To address anomalies in respect of the 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 which were made by some Federation members on behalf of people accessing services were successful, others providing very similar services were refused. During 2008, a number of actions to resolve this matter were taken as follows: • A meeting was held with the National Scheme Administrator to establish the rationale employed to refuse applications made on behalf of certain persons with an intellectual disability. • Following this, separate meetings between the Scheme Administrator, the Department of Health & Children, and the Service Providers whose applications on behalf of persons availing of services who were refused, were arranged to resolve the matter in an equitable way.
Education	
To address issues relating to the education of persons with an intellectual disability.	• During 2007 the Education Sub-Committee was supported in its role in advising the Board of the National Federation of Voluntary Bodies on pertinent issues relating to the education of children and adults with an intellectual disability. • The Sub-Committee provided a forum where members could consult on priority issues and network to share information relating to education provision to people availing of the services throughout the membership. • Monitored National and European perspectives pertaining to special education and from an international perspective through the EASPD Standing Committee on Education of which Maura Nash, Chief Executive, COPE Foundation, is a member.

To liaise with the National Council for Special Education.	• Helen Guinan, COPE Foundation, a member of the Education Sub-Committee, is the National Federation of Voluntary Bodies' representative on the National Council for Special Education (NCSE). In this capacity, Helen attended consultations with the NCSE on the Draft Literature Review on the Principles and Practices Relating to Inclusive Education for Children with Special Educational Needs. This project aims to develop and report criteria that can be used to assess a school's level of inclusiveness, and to create a tool for all schools to use as part of their development plans in relation to including pupils with special educational needs and disability. • Helen briefed the Sub-Committee on the draft Literature Review which was published by the National Council for Special Education in November 2008.
To plan a conference on Inclusive Education which will be co-hosted by the National Federation of Voluntary Bodies and EASPD in November 2009.	• A venue for the 2009 conference - "***Salamanca – 15 years on – Inclusion A School for All***" which is planned for 12th and 13th November, 2009 was sourced and booked. • The draft programme received from EASPD was reviewed and it was agreed that conference speakers from Ireland would be included in order to attract Irish delegates. • Agreement was secured from Minister Batt O Keefe, Minister for Education, to address the conference delegates.
To complete and publish the findings of the '*Survey on Staffing Levels for Children with Intellectual Disability in the 0-6 Age Group'*.	• During 2008 the responses received from National Federation member organisations in relation to the '*Survey on Staffing Levels for Children with Intellectual Disability in 0-6 Age Group*' were collated and analysed. • A summary report was compiled and presented to the Board of Directors in April 2008. • Following approval of the report by the Board it was circulated to all member organisations for their information.
To liaise with the National Steering Group on the implementation of the Disability Act 2005.	• The Education Sub-Committee continued to liaise with the National Steering Group set up to oversee the implementation of the Disability Act 2005, which became law on 1st June, 2007, for children under 5. Stephen Kealy, Sisters of Charity of Jesus & Mary, and Moira King, Brothers of Charity Southern Services, are the National Federation's representatives on this group.
National Federation Website	
To develop further and manage the information contained on the National Federation's website – www.fedvol.ie	• An audit of the National Federations website, which included consultation with member organisations, was carried out during 2008. The audit aimed to identify the websites usefulness as an up-to-date information resource for member organisations. • Following this audit a workplan for 2009 was agreed which focuses on redesigning the website to ensure that it is clear, professional and modern and has an enhanced accessibility level for its customers. • The website is updated monthly with some items being updated more frequently as the need arises.

Information Dissemination	
To monitor and disseminate relevant information and resources to the secretariat and member organisations.	• The National Federation Secretariat team distributed regular emails and fact sheets covering a wide range of issues to both the Secretariat Team and to the wider Member Organisations e.g. research reports, policy updates, funding opportunities, media coverage, work updates etc. • Regular news flashes detailing current national and international developments and/or new publications e.g., charities legislation, Government social inclusion policies, HSE Service Plan, Budget 2009 etc were disseminated. • 4 National Federation newsletters were published in 2008.
Accessible Information	
To develop a range of 'Easy-to-Read' information resources.	• Supported member services by producing Easy-to-Read information resources for people who avail of services e.g. annual report, research strategy, conference report, summaries of various workshops and focus groups that took place during 2008.
Vocational Training & Employment	
To advise the Board of the National Federation of Voluntary Bodies on issues relating to the vocational training and employment of people with intellectual disability.	• Supported the Vocational Training & Employment Sub-Committee in its role in advising the Board of the National Federation of Voluntary Bodies on issues relating to vocational training & employment of adults with an intellectual disability. • Provided a forum where members can consult on key issues and share information.
To complete a '*Review of Day Service Provision for Adults with Intellectual Disabilities*' Questionnaire.	• A Day Service Questionnaire was circulated to all members of the National Federation of Voluntary Bodies. The questionnaire sought to demonstrate: - The range of ability of adults availing of day services in the intellectual disability sector; - The range of activities each category of adults are engaged in; and - The types of staff employed and levels of funding within Day Services. • The results of the questionnaire were analysed by the Vocational Training & Employment Sub-Committee and a report was drafted based on the information provided.
To represent the National Federation of Voluntary Bodies on the HSE National Review of Adult Day Services for People with Disabilities.	• Pat Reen, Prosper Fingal, is the National Federation's representative on National Review of HSE Funded Adult Day Services. Pat Reen provided regular updates to the National Federation and the Vocational Training & Employment Sub-Committee on the progress of the National Review during 2008.

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.

Training & Development:
The initiatives outlined below which were undertaken during 2008 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 was seen as being of paramount importance. The actions implemented during 2008 were set within the overall context and objectives of the Action Plan for People Management (APPM) and the National Federation's Training and Development Sub-Committee continued to act as the central conduit through which these initiatives were developed and realised. The National Federation of Voluntary Bodies continued 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.

The terms of reference of the National Federations Training & Development Sub-Committee are as follows:

1. To advise the Board of the National Federation of Voluntary Bodies on recommendations to meet the learning requirements of staff of member organisations through education, training and development
2. To facilitate the identification and prioritisation of and plan appropriate responses to the education, training, development and learning requirements of member organisations.
3. To influence the provision of options and resources to address the education, training, development and learning needs of member organisations.
4. To act as a network, to share information and resources regarding staff training and associated HR related matters.
5. To develop national criteria for standards in education, training, development and learning across a wide variety of priority roles.
6. To provide a programme of activities to meet education, training, development and learning needs.
7. To review education, training, development and learning course content to ascertain consistency with core principles and ethos of National Federation of Voluntary Bodies.
8. To ensure that the specific staff training and development interests of the non-statutory bodies are understood and included in people management planning at a corporate level in the regional health authorities.

The work of the Training & Development Sub-Committee during 2008 was expertly steered by the Chairperson Brendan Broderick who was supported by a committed group of training and development personnel who form the membership of the Sub-Committee. A list of the members of the Sub-Committee is contained in Appendix 2.

Objectives:	**Key Achievements in 2008:**
Training & Development Sub-Committee	
To support the work of the Training & Development Sub-Committee.	• Members of the National Federation's Training & Development Sub-Committee met on a quarterly basis during 2008 (January/June/September/ December 2008). The Sub-Committee, which is comprised of training and development professionals from across a number of National Federation member organisations, shared their considerable expertise in supporting the work of the Sub-Committee. • In early 2008, a Training & Development Activities Programme was agreed by the Training & Development Sub-Committee which guided the work of the Sub-Committee throughout the year.
To arrange a '*Supporting the Effective Transfer of Learning*' Event for March 2008.	• In March 2008, the Training & Development Sub-Committee organised a very successful workshop which focused on '***Supporting the Effective Transfer of Learning within Organisations'***. The event was facilitated by Dr. Paul Donovan, Irish Management Institute, who has developed an inventory that measures the ***learning transfer system*** within an organisation i.e. the factors that help and hinder the transfer of learning from a training intervention back into the workplace. This transfer system highlights where an organisation is effective (or not) in ensuring that the key knowledge acquired from training interventions is applied back on the job. Specifically the event aimed to: - Establish what transfer factors are associated with maximum return on investment / identify the elements that need to be emphasized in order to gain maximum transfer of learning from training interventions into the workplace; - Identify the barriers to learning transfer; - Identify what factors are the best predictors of transfer of learning; - Assist practitioners to identify how their training efforts can be maximized into application back in the workplace. There was a large attendance at the workshop with participants representing personnel from a range of disciplines that are involved in training and development activities e.g. training and development, human resources, quality, nursing, service management / development, etc. A summary report outlining the main findings and learning points arising from the event was compiled which outlines the '***Top 10 Tips for the Effective Transfer of Learning'***. Copies of this report can be obtained from Jillian Sexton – jillian.sexton@fedvol.ie

Patricia Doherty, Deputy Chief Executive Officer, St. Michael's House, speaking at the 'Supporting the Effective Transfer of Learning' event, March 2008. The programme was organised by the National Federation of Voluntary Bodies in conjunction with St. Michael's House as part of its commitment to the promotion of best practice in training and development.

Participants busy at work in a group session of the 'Supporting the Effective Transfer of Learning' event

Training Programmes / Initiatives 2008:	
To deliver an accredited programme for Front Line Managers - '*Managing for the Future: Building your skills as a Front Line Manager in a Person Centred Environment*'.	• Following the pilot of the Front Line Managers Training Programme '*Managing for the Future: Building your Skills as a Front Line Manager in a Person Centred Environment*' which took place in the University of Limerick (UL) during 2007, a total of 16 Managers graduated at the conferring ceremony which took place in UL in Summer 2008. • The overall objective of the programme 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 human resource 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. • The programme modules were evaluated on an on-going basis with the final programme evaluation completed in spring 2008. This highlighted the primary outcomes arising from the programme and identified key areas in which programme delivery could be enhanced. • Based on the on-going feedback provided by the programme participants the be-spoke programme materials were revised and updated where necessary to reflect changes in current legislation, policy, etc. • Given the positive outcomes from the pilot programme it was agreed that further programmes would be delivered and work commenced on the organisation of same. • The Steering Committee, which was established to oversee the development and piloting of the Programme continued to meet during 2008 and to advise on further developments in relation to the Programme roll-out.
To support the development / implementation of SKILL Programme.	During 2008 the National Federation of Voluntary Bodies continued to support the implementation of the SKILL Programme within National Federation member organisations. Specific achievements during 2008 were as follows: • A total of 142 Support Service Staff and 15 Support Service Managers were nominated to participate in SKILL Training Programmes at FETAC Levels 5 and 6 respectively. • The National Federation Secretariat continued to process payments due to member organisations in respect of participants engaged in SKILL Project training. • In summer 2008 a summary review was undertaken with National Federation Member Organisations seeking feedback on their experiences in relation to learner's participation in the SKILL Project to date. • The National Federation of Voluntary Bodies continued to liaise with the Disability Federation of Ireland (DFI) in relation to issues of common concern regarding the implementation of the SKILL Programme in the disability sector. This culminated in the submission of a joint proposal to the SKILL Programme National Steering Committee, which was focused on customising existing SKILL Programme materials to the needs of learners from the disability sector and also identifying possible new modules. Such customising of the instructional content of current SKILL modules will ensure that participants gain maximum learning and benefit from their involvement in the SKILL Project. The familiarisation of tutors responsible for

	the delivery of SKILL Modules with the environment and ethos within which Support Service Staff in the disability sector work would also seek to ensure that the SKILL Project is as meaningful and relevant as possible to participants. • The first set of National Conferring Ceremonies for SKILL graduates took place in November 2008 and a total of 133 graduates from the across National Federation Member Organisations were conferred. • A further 3 John F. Kennedy (JFK) Fellowships were awarded to staff members working in intellectual disability services during 2008 – from the Daughters of Charity, Stewarts Hospital and the Brothers of Charity, Limerick. The aim of the fellowships is to support learners who wish to undertake accredited studies.
To arrange a review / support session for participants who completed the Bereavement Training Programme.	• Following the successful Bereavement Training Programme for Clinicians that was delivered by personnel from St. Michael's House in 2007, it was agreed that a follow-up / review session would be arranged for the clinicians who undertook the training. This review session, which took place in May 2008, was hosted by the Daughters of Charity Limerick, and provided an opportunity for those present to share their experiences in relation to the delivery of the training programme / materials within their respective organisations. The review session also provided the opportunity for further skill enhancement with inputs being provided by various guest speakers. • One of the main recommendations arising from this event was that a national support network be established to support Clinicians involved in this area of work. This will be followed up on in 2009.
Health Services Executive (HSE)	
To develop links with the HSE – Performance and Development Function.	• During 2008 the National Federation of Voluntary Bodies continued to liaise with personnel from the HSE Performance & Development Function in the implementation of training and learning initiatives aimed at supporting employee development.
To participate in the HSE eLearning Project.	• During 2008 the HSE engaged in a tendering process in relation to the extension of the learning modules that are available on the existing HSE Learning Centre – www.hseland.ie. As a result of this process there will be a range of additional customised / general modules added to the website content, many of which will be of value to those working within the disability sector. The National Federation of Voluntary Bodies is represented on this HSE Working Group by Jillian Sexton, Human Resource Training & Development Co-ordinator, National Federation of Voluntary Bodies.
To support the implementation of the HSE Complaints Policy – '*Your Service, Your Say*'.	In meeting its requirements under Part 9 of the Health Act 2004 the HSE, in conjunction with the relevant stakeholders, developed a feedback Policy '*Your Service, Your Say – Your Guide to the Health Service Executive's Feedback Policy*'. The document details the guiding principles, statutory requirements and the

	policy of the HSE in relation to the handling of complaints received by the HSE and services who are providing a service on their behalf. As National Federation members are funded by the HSE, organisations are bound by the provisions of the HSE document – in support of this the National Federation of Voluntary Bodies during 2008: • Organised three 1-day training sessions for those who were appointed as Complaints Officers within their respective organisations. A total of 60 participants engaged in this training which was delivered by the Office of Consumer Affairs, HSE. • Liaised with the Office of Consumer Affairs in relation to the collection of statistical data pertaining to complaints received by organisations during 2008.
To implement key provisions of the Action Plan for People Management (APPM).	The APPM sets out a wide range of actions and measures which aim to build and enhance managers skills, knowledge and management capacity. Initiatives within the plan aim to ensure that staff are highly skilled, motivated and equipped to deal with current challenges and changes. During 2008, the National Federation of Voluntary Bodies: • Completed a progress report on actions undertaken during the year as part of the National Federation of Voluntary Bodies commitment to the implementation of the provisions of the APPM within the intellectual disability sector. • Sought funding from the APPM Implementation Committee to implement further national initiatives.
Health & Social Care Professionals	
To support the development of a HSE Strategic Framework document – 'Guide to the development of the HSE role in the education and development of Health & Social Care Professionals'.	• During 2008 the HSE issued a call for submissions in relation to the development of a strategic framework to guide its work on the education and development of Health and Social Care Professionals. In response to this invitation a submission was made to the HSE which highlighted a range of issues / recommendations.
To support the work of the Health & Social Care Professionals Council.	The Health & Social Care Professionals Council was established in 2007 with the aim of protecting consumers through promoting high standards of professional conduct, education and competence. The Council was established under the Health and Social Care Professionals Act 2005 and will lead to the statutory registration of twelve health and social care professions none of whom were previously subject to statutory registration. • During 2008 the National Federation continued to support the registration process for Health & Social Care Professionals through its representative on the Council - Tony Darmody, Chief Executive, Kerry Parents & Friends Association.

Human Resources:

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 during 2008, and the regular meetings which were held with the HSE-Employers

Agency, organisations were supported to network with fellow HR professionals and develop common positions on key matters. The work of the Human Resources Sub-Committee during 2008 was guided by Maura Donovan, Stewarts Hospital, who sought to ensure that Federation members were kept abreast of employment and industrial relations related developments. The work of the Sub-Committee was supported by an active and committed group of members - details of the membership are provided in Appendix 2.

The mission of the National Federation in relation to human resources is to:

a) Provide a communication, information and networking forum to Human Resource practitioners within National Federation member organisations whereby they can meet with colleagues and pursue HR objectives of common interest.
b) Gather and disseminate information in relation to key issues of relevance to member organisations and to provide support in relation to human resource related developments.
c) Provide a strategic decision making forum whereby common positions can be developed where this is considered beneficial.
d) Ensure that the intellectual disability sector is recognised, connected and has a voice at national level.
e) Examine and furnish reports on relevant human resource related issues and legislation and to provide advice to member organisations through National Federation structures.

An overview of the key human resources related actions which were undertaken during 2008 are provided below:

Objectives:	**Key Achievements in 2008:**
Human Resources Sub-Committee	
To support the work of the Human Resources Sub-Committee.	Members of the National Federation's Human Resources Sub-Committee met regularly during 2008. The Sub-Committee, which is comprised of human resource professionals from across a number of Federation member organisations, shared their considerable expertise in supporting the work of the Sub-Committee.
To ensure that appropriate garda vetting procedures are in place for employees & volunteers working within NFVB member organisations.	• During 2008 the National Federation of Voluntary Bodies continued to liaise with personnel from the Garda Central Vetting Unit to ensure that National Federation members had access to a timely garda clearance process for staff members and volunteers. • In mid 2008 the Garda Central Vetting Unit advised the National Federation of Voluntary Bodies that a Working Group was being established to examine the issue of International Vetting Arrangements and to develop policy proposals in relation to same. The National Federation of Voluntary Bodies was invited to nominate a representative to join this Group. In order to inform the work of the group, the National Federation was requested to conduct an analysis of members in relation to the requirement for international vetting - numbers of personnel / countries involved, etc and their views in relation to international recruitment and vetting. This brief survey highlighted the challenges facing both organisations and the Vetting Unit in relation to international vetting. The Garda Central Vetting Unit will be progressing the issues arising with other jurisdictions on an on-going basis.

To support recruitment advertising in National Federation of Voluntary Bodies member organisations.	• Throughout 2008 the National Federation of Voluntary Bodies liaised with Independent News & Media in relation to advertising arrangements for member organisations. • Members of the National Federations Recruitment Advertising Group (which falls under the remit of the Human Resources Sub-Committee) met to plan a review of recruitment advertising which was undertaken with National Federation members in July 2008. A brief questionnaire was circulated to all National Federation members that sought feedback on existing advertising arrangements and options in relation to develop web-based advertising. • The findings of this were circulated to members of the Human Resources Sub- Committee and the Board of the National Federation for consideration.
To provide relevant human resource related information & undertake data collection as required.	• During 2008 regular updates were provided to human resource personnel regarding upcoming events, funding opportunities and human resource related developments. • The National Federation of Voluntary Bodies also sought information in relation to key issues of relevance to member organisations (e.g. practices relating to maternity leave arrangements, management of uncertified sick leave, absenteeism, etc).
To support National Federation members in relation to key industrial relations issues.	During 2008 the National Federation of Voluntary Bodies supported member organisations in relation to national deliberations regarding terms / conditions of employment for staff and continued to monitor industrial relation matters of relevance to member organisations and to respond as required. Achievement of this objective included: • Nominating National Federation of Voluntary Bodies representatives to sit on national working groups / committees as required. • Providing support to representatives who sat on national committees on behalf of the Federation members. • Supporting organisations in relation to key industrial relations issues / national agreements e.g. dealing with outstanding issues arising from the Labour Court Recommendation (LCR No. 18049) relating to Social Care Workers; issues arising relating to sleep-overs; Therapy Grades and other matters as they arose. • Gathering information from member organisations in relation to key issues under consideration so as a national picture / shared position could be developed.
To support organisations in relation to the planned reduction in the working week of nurses.	• The National Federation of Voluntary Bodies continued to follow-up on the issues arising from the Nurses dispute which took place in 2007 and to support organisations in relation to the Phase 1 reduction in the working week of nurses (to a 37.5 hour week). • In summer 2008 the Commission on Nursing, whose role is to provide an independent assessment of how a 35 hour week for nurses could be achieved (Phase 2), invited submissions from key stakeholders in relation to this issue. The National

	Federation of Voluntary Bodies held a workshop in August 2008 which formed the basis of a written submission to the Commission. A delegation from the National Federation was subsequently invited to meet with Professor Tom Collins and the other members of the Commission on Nursing Hours (October 2008). The Federation's presentation outlined the difficulties that organisations had in achieving a 37.5 hour week for nurses and highlighted that while in principle the National Federation supported nurses endeavours to secure a 35-hour week this could not be achieved on the same basis as the Phase 1 reduction of 1.5 hours (i.e. on a cost / WTE neutral basis). This and the particular difficulties faced by organisations in the Intellectual Disability Sector were acknowledged by members of the Commission.
HSE - Employers Agency	
To arrange bi-annual meetings with the HSE-Employers Agency.	• During 2008 the National Federation of Voluntary Bodies continued to liaise with the HSE - Employers Agency to ensure that National Federation members were fully informed regarding employment legislation and related policies. • Briefing meetings took place with key personnel from the HSE – Employers Agency in April & December 2008.
To hold a briefing Session on the 'Review of the Clerical / Administrative Job Evaluation Scheme'.	• A presentation was made to Human Resource Managers by the HSE-Employers Agency on the new Job Evaluation scheme in February 2008. The revised scheme is more streamlined in the processing of applications and involves both line managers and human resource departments within organisations. A panel of evaluators, from both management and trade unions were trained to carry out the evaluations under the new scheme. • Full information on the revised scheme was circulated by the HSE-Employers Agency to all employers.
To participate in the Review of Dignity at Work Policy.	• During 2008 the National Federation of Voluntary Bodies participated in the Working Group that reviewed the Dignity at Work Policy. • As part of the review a survey was undertaken with National Federation of Voluntary Bodies members in relation to their experiences of implementing the Dignity at Work Policy at local level. Responses received were fed back to the National Review Working Group. In particular the review has focused on: - The inclusion of a preliminary screening stage to the policy which would determine whether matters arising should be dealt with under the Dignity at Work Policy or another appropriate means. - The further enhancement of the mediation process and the role of mediation in supporting the resolution of complaints of bullying and harassment. • The revised Policy is scheduled for relaunch in early 2009.
Employee Well-being	
To participate as a partner organisation in the EU ROSE – Reducing	The National Federation of Voluntary Bodies was invited to participate as a partner organisation in the ROSE (Reducing Occupational Stress in Employment) Project. This is a European

Occupational Stress in Employment – Project.	Project, funded under the Leonardo Programme, and the lead partner is Waterford Institute of Technology (WIT). The overall aim of the Project is to develop a combined person and work directed stress management programme in order to improve the retention of staff working in intellectual disability / mental health services. • The first Project Steering Committee meeting was held in December 2008. The research project will run over a 2-year period to October 2010.
National Standards in Disability Services	
In early 2008, the Health Information & Quality Authority established a Standards Advisory Group to advise the Authority in drawing up a set of National Standards.	Brian O'Donnell, Chief Executive, was invited by HIQA to represent the National Federation on the National Standards Advisory Group. During 2008, the following actions were taken in the development of the standards: • The National Federation's Quality Sub-Committee acted as a Reference Group in articulating the National Federation's position with regard to the development of the standards. It met on four occasions during 2008 and developed a comprehensive position paper for submission to the National Standards Advisory Group. • The National Federation consulted widely with its members in relation to the draft standards prior to their publication in November 2008.
Performance Verification Process under 2016	
To provide formal verification of progress on the attainment of objectives set out in the Action Plan agreed under Towards 2016 by the National Federation's membership.	During 2008, the following actions were taken: • The Performance Verification Group Report outlining initiatives taken by National Federation members to progress the change and modernisation agenda during 2008 was prepared by the National Federation and submitted to the Performance Verification Group. • One site visit was arranged for the Performance Verification Group.
Health Services National Partnership Forum	
To promote work based partnership in the management of change.	The Health Services National Partnership Forum is a national forum comprising Health Services Management, including Voluntary Hospitals and the Voluntary Intellectual Disability Sector, and National Trade Unions. It was established under the Partnership 2000 Agreement and has evolved and developed through successive social partnership agreements. Its primary purpose is the promotion of work based partnership in the management of change. The National Federation is represented on the Forum by Brian O'Donnell, Chief Executive. During 2008, the following actions were taken: • The National Federation took the lead role in the Forum 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. • Working closely with our Intellectual Disability Partnership Facilitator, our workplace partnership committees were facilitated and supported to develop workplace partnership initiatives.

	- Following detailed submissions by the National Federation, funding was allocated by the Health Services National Partnership Forum to pilot the Informing Families Project Guidelines in Cork. A presentation of the work carried out on the project was made to a full meeting of the Forum in June 2008.
To participate in key HSNPF skill development initiatives.	The HSNPF is a joint management / trade union steering committee for workplace partnership within the health service which aims to promote a partnership approach to change and problem solving in the health services. During 2008, the National Federation of Voluntary Bodies liaised with the HSNPF on the following key training and development related initiatives: • **Managing Transformation Programme – HSE West:** The National Federation of Voluntary Bodies participated on the Programme Steering Committee which oversaw the delivery of the Managing Transformation Programme and also the nomination of participants from intellectual disability services based in the western region. • **'Managing Together - Organisational Change Programme'** During 2008 the National Federation of Voluntary Bodies supported the development of the Organisational Change Programme – '*Changing Together–Skills Development Programme for Managers, Employees and Union Representatives*' - which was developed jointly by the HSE, HSNPF and the LRC. The programme is FETAC accredited and aims to provide a range of skills to strengthen people's ability to handle organisational change. The programme, which will be piloted in early 2009, will be delivered in a variety of locations.

Section 3
Research & Policy Development

The National Federation of Voluntary Bodies aims to promote best practice in services to children and adults with intellectual disabilities. We recognise that appropriate high quality research is a necessary pre-requisite to ensuring best practice in services development and delivery and in policy formulation. Consequently the National Federation is committed to supporting the development of a strong research base within National Federation member organisations and initiating and collaborating in research relevant to the lives of people with intellectual disability.

In August 2008, the National Federation published its first Research Strategy which sets out a vision for the research activities of the National Federation of Voluntary Bodies for six years (2008-2013). The strategy aims to develop a positive environment of discovery and learning. The guiding principles underpinning the strategy are that people with disabilities must be given the opportunity to live as full a life as possible. People are being supported to live with their families for as long as possible and to be included as individuals, with a contribution to make, in their own communities.

In more recent years, the publication of our Government's National Disability Strategy and the UN Convention on the Rights of People with Disabilities has provided the impetus for us to pursue these goals. Key to the achievement of these goals and the pursuit of excellence is a need for assurance that what we do is evidence based. The research strategy was developed through extensive consultation with our member organisations and people who use our services and was the basis for the research activities of the National Federation in 2008. The Research Strategy was supported and developed by the members of the Research Sub-Committee. The Research Sub-Committee has the following terms of reference:

- To advise the Board of the National Federation of Voluntary Bodies on research issues;
- To identify key areas of research for the National Federation of Voluntary Bodies and to explore potential of developing a cohesive plan of research actions;
- To assist the National Federation in developing research proposals for funded and non-funded research;
- To provide support for National Federation research projects through participation in project advisory committees;
- To disseminate the research undertaken by the National Federation and the member organisations, and to highlight the benefits for persons with an intellectual disability and their families (using Federation website, newsletters, conferences, etc.);
- To encourage informal networking and to facilitate interagency cooperation on research projects among the member organisations;
- To highlight the research activities of the National Federation and its members with EASPD, IASSID and the NDA and to encourage closer cooperation where appropriate; and
- To debate best practice and develop guidelines in disability research based on national and international evidence.

The objectives outlined below describe the research activities of the National Federation in 2008.

Objective:	**Key Achievements in 2008:**
Research Sub-Committee	
To advise the Board of the National Federation on research issues pertaining to intellectual disability.	The Research Sub-Committee, under the chair of Dr. Brian McClean, continued to advise the Board of the National Federation on research issues. Members of the Sub-Committee met four times during 2008: • March 31st • June 30th • September 22nd and • December 1st The work of the Research Sub-Committee focused on the development of the Research Strategy in the first half of the year and in the latter half focused on pursuing the implementation of the Strategy (see below for detail).
National Research Strategy	
To develop a National Federation of Voluntary Bodies Research Strategy.	In August 2008 the National Federation launched its National Intellectual Disability Strategy. Dissemination of the Research Strategy followed the publication with presentations made to various stakeholders, including: • Board of Directors (July 2008) • General Assembly (September 2008) • International Association for the Scientific Study of Intellectual Disability Conference (September 2008) • Psychological Society of Ireland learning disabilities special interest group Carlow (November 2008)
To publish an 'Easy to Read' Version of Research Strategy.	• An "Easy-to-read" version of the Research Strategy was also published and made available through the National Federation's website
Research Priorities 2008-2013 (as identified in Research Strategy)	
1. To define the priority areas for research as identified through consultation with people who use services, Chief Executive Officers of organisations, management and frontline staff.	• Priority areas for research were identified through the consultation process outlined in the research strategy document. • These topics were identified by people with disabilities, advocacy, self-advocacy groups, front-line and management staff and researchers. • Eleven topics were identified as priorities (see Appendix 4) • At the final meeting of the Research Sub-Committee in December 2008 it was decided to pursue the topic of *Living Options* as a priority during 2009.
2. To identify a list of key designated experts in the Irish research community who will support the dissemination of research and assessment materials in these areas. These key experts will provide expert knowledge on these topics thus enhancing the knowledge base among members.	• National Designated Experts (NDE's) were identified, through the Research Sub-Committee, on key topics for research. A listing of the NDE's and their topics of expertise is attached (Appendix 4). • The NDE's agreed to support the National Federation by posting literature updates on key topics on our website - www.fedvol.ie/research. • National designated experts updated this resource in 2008

3. To develop quality indicators for research in intellectual disability and guidelines for evidence based practices.	• This was identified as a priority to be pursued in 2009
4. To measure performance of research activities.	• This was identified as a priority to be pursued in 2009
5. To identify key people who may be called upon to act as associate members of the National Federation Research Sub-Committee as need and circumstances arise.	• Associate members were identified in the same way as the National Designated Experts (NDE's). When an NDE agreed to accept this role they also agreed to be contacted as associated members as need arose for advice and expertise on particular topics. • Associate members have agreed to advise and support the Research Sub-Committee when occasion arises.
6. To develop research collaborations with national and international research centres.	• The development of research collaborations with University Departments and Research Centres is underway and a Table of affiliated collaborators is attached in Appendix 4. • The first meeting of Research Collaborators took place on September 22nd 2008 to discuss potential areas of collaboration and the implementation of the Research Strategy.
7. To develop a capacity to advise on how research could be funded in the future.	• This was identified as a priority to be pursued in 2009.
8. To develop a register of disability stakeholders. This will enable communication on research issues with key stakeholders e.g., member organisations, government departments, statutory and non-statutory bodies, people with disabilities and family members.	• Work commenced on this priority during 2008. • When consulting with member organisations on the development of the research strategy, member organisations were asked to identity the contact person for research in their organisation. This was the basis for a research contacts register. • It is proposed to develop a register of various stakeholder groups who may be contacted on research topics or be kept informed of research initiatives in intellectual disability. • The legal and data protection issues pertaining to this priority were examined towards the end of the year. • Further review of relevant legislation and development of a policy statement regarding a stakeholder's register shall continue in 2009.
9. To continue to develop a register of intellectual disability research as per National Federation of Voluntary Bodies website.	• The database of Intellectual Disability Research has been in existence since 2000. The template for updating research was sent out to member organisations in 2008 and a number of updates/abstracts were received. • This is the most comprehensive listing of intellectual disability research in member organisations that currently exists. • A research study analyzing the quality and type of research conducted since 2000 has been recommended for 2009.

10. To develop a National Research Ethics Committee with key national representation.	• Work has been ongoing into this priority, the purpose of which is to develop capacity among member organisations and reflexive thinking on ethical issues in intellectual disability research. • A conference organised by the Centre for Bioethical Research and Analysis (COBRA) on ethical issues in Research was attended on 16th-18th October 2008 and an NDA round table on research ethics was attended on November 11th 2008. • Based on the learning acquired at these events a conclusion was reached that resources are required in order to pursue this issue as a priority. • An interim solution was proposed by the Research Sub-Committee at its meeting on 1st December 2008 that the National Federation would recommend approved centres for Research Ethics Approval. These centres would be existing centres among member organizations who have established research ethics committees in place. • These centres could act as a resource for multi-site research approval or as a resource for smaller organisations that do not have a research ethics committee.
11. To continue to consult with and listen to people who use the services through research initiatives such as the Inclusive Research Network and continue to develop experience and expertise in participatory research methodologies.	• Advocacy and Self advocacy groups were consulted in the development of the research strategy. See Research Strategy consultations www.fedvol.ie/research • Work has commenced on pursuing the aims of the Inclusive Research Network (IRN). A series of 3 workshops took place between 2008 and early 2009. The demand was such that two series of workshops ran concurrently in Dublin and Galway with 30 people attending the workshops in Dublin and 25 in Galway. The purpose of the workshops was to train people in inclusive research methodologies and to increase the number of inclusive research projects happening around the country. A second aim was to bring people together who have interest in researching similar topics and in this way people will be able to support one another. The ultimate aim of the IRN is to encourage people with disabilities to conduct their own research on topics of interest. • An evaluation of the work of the IRN was built into the workshops and this is ongoing. A report on this work will be available in 2009.

Members of the Inclusive Research Network learn about developing listening skills from facilitator Ray Murray at NIID Dublin.

Members of the Inclusive Research Network practice their interviewing skills at a Galway workshop held in November 2008.

12. To regularly review the research strategy.	• The Research Sub-Committee committed to review the strategy at its meetings as the strategy is rolled-out and implemented. • Updates were provided at each meeting.
Factsheets	
To develop a series of Factsheets in the areas of research definitions, ethical principles and consent.	• The Research Sub-Committee developed a series of fact sheets which are available to download from the Federations website. It was envisaged that these would provide support to individuals throughout member organisations who are undertaking research and would provide guidance in the following areas : o Factsheet No. 1: Research Definitions o Factsheet No. 2: Basic Ethical Principles o Factsheet No. 3: Consent in Research o Factsheet No. 4: Research Proposal Template • A template of a Research Proposal Form can also be downloaded from the Federations website www.fedvol.ie/research
To Publish the Research Activities of the National Federation of Voluntary Bodies.	To fulfil the obligation of dissemination and provide quality indicators of the research activities of the National Federation the following articles/resources were published in 2008: • Development of a National Research Strategy for Intellectual Disability; the National Federation of Voluntary Bodies Research Strategy 2008-2013: Frontline Magazine Issue 73, 2008; • Informing Families of their Child's Disability, Frontline Magazine, Issue No. 73 2008 • Publication of conference proceedings report and easy to read version
Input to Expert Advisory Groups and Research Collaborations	
To provide support and membership on expert advisory groups and research collaborations.	Throughout 2008 the National Federation of Voluntary Bodies continued to support the research initiatives and projects of some national projects. It also continued to provide its support in an advisory capacity through membership on research advisory groups. These national projects are briefly summarised below:
The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (TILDA) - Ireland's First Longitudinal Study on Ageing in Persons with Intellectual Disability.	The largest study on ageing in persons with intellectual disability undertaken in Ireland was launched in Dublin on December 3rd, 2008 by the Minister for Equality, Disability and Mental Health, John Moloney, TD in the School of Nursing and Midwifery, Trinity College. The occasion of the launch took place on the International Day of Persons with Disabilities. The study will involve approximately 800 persons with intellectual disability aged 40 years and over, charting their health, social, economic, environmental and psychological status as they age over a 10 year period. The sample will be drawn from the National Intellectual Disability Database. The study, the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (TILDA) is a collaboration with

	TILDA and is being led by TCD. Funding has been received from the Health Research Board. This is the first longitudinal study on ageing in persons with intellectual disability in Europe, and the only study with the potential of comparing the ageing of people with intellectual disability directly with the general ageing population. A pilot study will be starting early next year and the full study will commence in September 2009. Collaboration with the Irish Longitudinal Study on Ageing (TILDA), led by Professor RoseAnne Kenny, Principal Investigator of TILDA offers a unique opportunity to compare the Intellectual Disability Supplement findings to that of the general ageing population. Participation in the study will be voluntary. The Health Research Board has committed to supporting the first three-year stage of data collection and analysis. Additional resources are being pursued to support the subsequent stages of data collection and analysis.
Marie Curie European Union Transfer of Knowledge Project at NIID Doing Disability Research 2006 – 2010.	Dr Patricia O'Brien is co-ordinating a Marie Curie European Union Transfer of Knowledge Project involving a number of international experts as well as post-doctoral fellows, who are transferring their knowledge into Trinity College and broader Irish Communities. The aim is to implement a series of projects inclusive of: • A National Survey of people with intellectual disabilities; • A National Survey of family members; • A project to gather and house the life-stories of people with intellectual disabilities; and, • An evaluation of the resource tools developed in the 'No Longer Researching About Us Without Us' project designed for people with intellectual disabilities to learn about Marie Curie Fellows on the project to date include Professor Roy McConkey, University of Ulster, Professor Dorothy Atkinson, The Open University, Dr Jan Walmsley, Debbie Espiner, The University of Auckland, Dr Hasheem Mannan, NIID and Dr Carol Hamilton, NIID research methods and practices.
National review and audit of client protection issues within intellectual disability services.	
To participate in the national review and audit of client protection issues within intellectual disability services.	In December 2007, the Health Service Executive published the Report of Dr. Kevin McCoy on the Western Health Board inquiry into Brothers of Charity Services in Galway. This inquiry was into a number of allegations of past child abuse within Holy Family School and Brothers of Charity Services in Galway. The period covered by the inquiry was 1965 to 1998. After the publication of the McCoy Report, the Health Service Executive announced a number of National Initiatives to ensure the protection and safety of people with a disability. Among these initiatives was an agreement with the National Federation of Voluntary Bodies to carry out a national review and audit of client protection issues within intellectual disability services. A working group was established to oversee the review. The purpose of the study is to: • Identify the numbers and patterns of incidents of abuse, however caused, in intellectual disability services in the period 2007.

	• Review Policies and Procedures currently in use for the protection of persons with an intellectual disability. • Identify examples of good practices and procedures. • Provide information that will assist in developing national policy. • Identify training needs and good current training practices for persons with an intellectual disability, families and staff. The methodology will include an audit of all National Federation Member organisations and HSE intellectual disability service providers (approximately 70 organisations). The methodology will also include: • An interview with the CEO or person in charge. • An interview with the designated person, if such a role has been defined. • Numbers of incidents and allegations of abuse recorded for the year 2007. • Techniques / methods used to record incidents, and investigating allegations and concerns. • A review of sample files. Following the audit a report will be available which is expected to be the basis for more in-depth study into this topic. The project was sent to tender through the HSE procurement process in December 2008.
Conferences	
To present research activities of the National Federation at national and international conferences.	Throughout 2008 a variety of presentations were made at national and international conferences, workshops etc., which represented the work of the National Federation Secretariat: • Presentation to University of Georgia USA Special Education Students on disability service provision and research initiatives in Ireland; • PSI Annual Conference November 2008 interactive workshop to Psychologists working in intellectual disability services on the research strategy and implementation of the priorities; • Additional presentations were made to conferences, AGM's and meetings to disseminate the *National Best Practice Guidelines for Informing Families of their Child's Disability,* as described below.
To attend national and international conferences and to disseminate relevant information.	Throughout 2008 the National Federation Secretariat staff attended conferences and seminars relevant and pertinent to intellectual disability and disseminated relevant information to member organisations. The depth and scope of these conferences covered vast areas relevant to intellectual disability as outlined below: - Relationships and Sexuality, Daughters of Charity, Croke Park, Dublin (February 2008) - Bringing the UN Convention Home to Europe, EASPD Conference, Rome (February 2008) - Psychological Society of Ireland (PSI) Learning Disability Easter Workshop (March 2008) - 'From Planning for Peoples Lives to People having Lives', Brothers of Charity Clare Conference on Inclusive Research,

	(April 2008) - COBRA Conference on Research Ethics (October 2008) - Meetings and round table discussions with the National Disability Authority including; ➢ NDA Conference on Mental Health (October 2008) ➢ NDA Seminar on Research Ethics (November 2008) ➢ NDA Conference on Capacity Legislation (December 2008) - HIQA Conference (December 2008) - Meetings with the Disability Federation of Ireland throughout 2008 - Meetings with the Centre for Disability Law and Policy NUI Galway
To develop an-online library resource for the National Federation Secretariat offices.	• Work on the development of an on-line library system using Reference manager for the National Federation Secretariat began in 2008. • National Federation Newsletters with research news and items of interest e.g., conferences seminars and latest publications were recorded and included in the on-line resource • The work to develop and expand the scope of this resource shall continue in 2009.

Informing Families Project:
One key area of research undertaken by the National Federation is the Informing Families Project, which is a partnership project that began in 2004, and has developed best practice guidelines and materials to support professionals when informing families of their child's disability. The project was initiated in response to feedback from many parents to National Federation member organisations, that the news of their child's disability had been conveyed insensitively or in inappropriate environments; and that their experience of being told the news had caused additional distress at the time of disclosure. Similarly, feedback from professionals delivering the news indicated that they felt there was an absence of training and clear guidance available to support those undertaking the sensitive and challenging task of giving a family the news that their child has a disability.

The *Guidelines for Informing Families of their Child's Disability* were developed through a wide ranging consultation and research process and were launched on 3rd December 2007, by Minister for Health and Children, Mary Harney. Following the launch there has been overwhelming welcome and endorsement of the Guidelines from key parent and professional stakeholders, with national and international interest continuing to develop. Work is being undertaken at two levels; at the national level and at a local level in a pilot implementation project in the Cork region, to utilise a wide range of opportunities to publicise, disseminate and implement the Guidelines, thus allowing the evidence-based best practice recommendations to be made available to the wide range of professionals requiring support in this area.

The National Federation of Voluntary Bodies gratefully acknowledges the significant and generous support of the Health Services National Partnership Forum in its work with the Informing Families Project to date, and in facilitating the progress of a project which has benefit for parents and professionals at the very sensitive time of a the diagnosis of a child's disability.

The work of the project at both a national and a local level in the Cork region in 2008 is set out in the following section.

Informing Families – National Project	
Objective:	**Key Achievements in 2008:**
To disseminate the Informing Families *Best Practice Guidelines*, *Consultation & Research Report* and *Words You Never Forget* DVD.	2,227 printed copies of the Guidelines and 210 Consultation & Research Reports were disseminated nationally and internationally in 2008 in response to requests from: • Voluntary disability service providers • HSE hospital and community services • Professionals from a wide range of disciplines • Publishers (through the ISBN system) • Individual requests • The Guidelines were also made available for download free of charge from www.fedvol.ie and were downloaded in large quantities A DVD film entitled *Words You Never Forget,* depicting the stories of two families and the perspectives of professionals who communicate with families, was produced and presented at the launch of the best practice guidelines in December 2007. • Following very positive feedback and requests for copies the DVD was duplicated and packaged in 2008 for widespread dissemination • An ISBN number was secured to allow for dissemination through the international publishing system • 295 DVD's were disseminated in 2008 in response to requests.
To inform relevant organisations and disciplines about the *Informing Families Guidelines*.	Presentations were made at the following conferences and meetings to inform relevant organisations and disciplines about the Informing Families Guidelines and research: - Health Services National Partnership Forum meeting (January 2008) - Health Services National Partnership Forum Facilitators meeting (April 2008) - Inclusion Ireland AGM and Annual Conference (April 2008) - National Hospitals Office - Executive meeting of Hospital Network Managers and Assistant National Directors (May 2008) - Clinical Conference, National Maternity Hospital (June 2008) - Central Remedial Clinic Multi-disciplinary Team Meeting, Clontarf (also video-conferenced to CRC Waterford, video retained for further use in training) (June 2008) - Clinical Indemnity Scheme Bi-Annual Obstetrics Forum (June 2008) - IASSID (International Association for the Scientific Study of Intellectual Disability) presentation (August 2008) - Irish Association of Directors of Nursing and Midwifery Annual Conference (October 2008) - Trinity College Dublin School of Nursing and Midwifery- 9th Annual Interdisciplinary Research Conference "*Transforming Healthcare through Research Education and Technology.*" (November 2008) - Irish Society of Audiology Annual Conference (November

	2008) - Delivering Personal Outcomes Seminar, Brothers of Charity Roscommon (November 2008) - Psychological Society of Ireland Annual Conference (November 2008)
To record citations and Publications.	Articles Articles about the Informing Families research and guidelines were written in the following publications in 2008: • Psychiatric Nurses Association: PNA Journal, Vol 6 Issue 1 Winter/Spring 2008 • National Council for the Professional Development of Nursing and Midwifery: NCNM Review, Spring/Summer 2008 • Down Syndrome Ireland, Summer 2008 Magazine • Frontline Magazine, Issue No. 73 2008 Citations • RehabCare 2008: *"An investigation into the social support needs of families who experience rare disorders on the island of Ireland".* This report recommended the implementation of the Informing Families Guidelines as one of its 9 key recommendations. • National Council for the Professional Development of Nursing and Midwifery and Nursing and Midwifery Planning & Development Unit, HSE (South), (2008) *Clinical Nurse/Midwife Specialist Role Resource Pack 2nd Edition.* Kilkenny
To plan for mainstreaming.	• Planning meetings took place with the HSE National Hospitals Office Executive to discuss mainstreaming of the Guidelines and their effective dissemination throughout HSE Services. • Further work will take place in 2009, informed by the findings of the Cork Implementation Project, to progress plans for mainstreaming.
To engage in international research and collaboration.	• Comparative research began in 2008 between the Informing Families Project, Harvard Medical School and Boston Children's Hospital. • The study is examining the findings of the Irish national research into how families are informed of their child's disability, in comparison with research carried out in the US and Spain. • Further opportunities for collaboration were developed and will be pursued in 2009, including the placement of a medical student from Harvard Medical School with the National Federation of Voluntary Bodies to facilitate mutual learning and sharing of information. • Liaison between St. George's Hospital in London began in 2008, which has led to an invitation to present the Informing Families Best Practice Guidelines at the hospital, and this will be taken up in 2009 • Evaluation and research tools used by the 'Brighter Tomorrows' programme run by Kentucky University were adapted for use in training programmes for the Informing Families Project, with the aim of providing comparative research opportunities.

To provide input on the Guidelines in Postgraduate Medical Training.	• Training in the Informing Families Guidelines was provided to post-graduate medical students in the University of Limerick in April 2008, including parental input from Katherine O'Leary, Chair of the Informing Families Project – Cork Region.

Informing Families Cork Implementation Steering Project

Following the launch of the national project, a local project was begun to implement the *National Best Practice Guidelines for Informing Families of their Child's Disability* on a pilot basis in the Cork region, and this implementation will be evaluated to inform national roll out of the Guidelines. 2008 saw significant engagement at a local level in the Cork Region from a substantial range of organisations and individuals working in partnership to implement the Guidelines on the ground in the pilot project.

Through a representative Steering Committee and a series of smaller Working Groups, each with a particular focus, a range of initiatives have already taken place and are in planning for 2009 to ensure that professionals receive the necessary support to empower them to make effective use of the best practice guidelines when supporting families at the time of their child's diagnosis. The Steering Committee of the pilot project is chaired by Katherine O'Leary, who is a parent of two children with disabilities; one with a physical disability and one with an intellectual disability. Katherine's involvement helps to promote the family centred approach which is so important at every level of the project.

Working Groups:	Key Achievements in 2008:
PR, Dissemination & Mainstreaming Working Group	The central aims of this group are to ensure that all professionals who are involved in the disclosure process in the Cork region are aware of and have access to the Informing Families Guidelines and to ensure mainstreaming of the Guidelines following the pilot. During 2008 dissemination began in a phased and planned manner to ensure that the communication was undertaken effectively – providing management buy-in and support to those implementing the Guidelines on the front line. The dissemination is accompanied by an evaluation and tracking sheet to ensure that learning points can be transferred. A key task which was undertaken ahead of dissemination was to map all of the areas and disciplines in which the Guidelines were needed, in the following service settings: • HSE Primary, Community and Continuing Care settings • Hospital Settings • Voluntary Disability Service Providers • Academic settings in the Cork Region
Training Working Group	Research from the national Informing Families Project indicated that staff members should be trained specifically in good practice for informing families of their child's disability, with key elements such as parental input, communication skills, disability awareness, and reflective practice forming central pillars of the training. The key task therefore, of the Training Group, in close consultation with the Evaluation Group, is to develop training materials that provide this learning experience to staff members. During 2008 training materials were developed and piloted with various groups within academic and service settings. The following pilot training took place:

	• 4th year medical students in University College Cork (December 2008) • Trainee Paediatricians - Cork University Hospital (December 2008) In collaboration with the Evaluation Working Group this training is being assessed, so that it can be amended where necessary and rolled out on a wider basis throughout 2009 to the wide range of organisations and disciplines participating in the Cork Implementation Project.

Katherine O'Leary, Chairperson of the Informing Families Project in Cork, speaks about her experiences as a parent of two children with disabilities, as part of training delivered for the Pilot Implementation Project

Non-Consultant Hospital Doctors from the Neonatal and Paediatric departments in Cork University Hospital and Cork University Maternity Hospital take part in training

Information Working Group	The main work of the Information Working Group is to develop an accessible, up-to-date, culturally appropriate information resource readily available to professionals for supply to parents at the time of diagnosis disclosure. During 2008 the Information Working Group gathered and catalogued suitable information materials already available in the English language, providing information on the following: • General disability support information for supply to parents at the time of their child's diagnosis (e.g. signposts to Entitlements and Benefits, emotional support, advice on searching the Internet, informing siblings, etc.) • Diagnosis-specific information, (gathered by relevant clinicians and from specialist support groups for individual disabilities) • Information specifically for professionals (e.g. Informing Families Guidelines, HSE Intercultural Health Strategy, protocols, checklists etc) During 2009 these resources will be made available online, and a localisation project will take place to provide translation and cultural review of the English resources to ensure equality of multilingual information provision. The initial design work for the online information resource was also completed and signed off by the Steering Committee in 2008.
Teamwork, Liaison & Planning Working Group	Given that one of the key findings of the national research was that deficits currently exist in the continuity of care provided to families at the time of their child's diagnosis, the central task of the Teamwork & Liaison Working Group is to enhance continuity of care for families, and to promote teamwork, partnership and liaison between professionals who communicate the news to the family. • A workshop on *Teamwork & Liaison at the time of a child's diagnosis with a disability - an integrated care pathway* was held in November 2008 for 23 professionals from across medical nursing and allied health disciplines in acute, community and disability services, co-facilitated by HSNPF facilitators and the Informing Families Project Co-ordinator. • Feedback was extremely positive and will lead to further developments in providing appropriate liaison and integration within and between teams in the various sectors. • A one-page protocol for informing families, based on the *'Safe Cross Code'* was developed by this group, and will be disseminated to professionals along with the Guidelines • An initiative to create shared documentation between acute and community services began in 2008 to try to ensure that the family do not have to repeat their history over and over, and that services have a consistent picture of the needs of the family.
Built Environment Working Group	The key task of the Built Environment Group is to assess the privacy of spaces available within all service settings where families are informed of their child's disability; to address issues that arise and to report to management on areas that require additional improvement.

	During 2008 planning took place for a photographic study which will be completed in 2009, documenting the available spaces, where possible introducing enhancements, and where necessary making recommendations for future improvement.
Evaluation Working Group	The role of the Evaluation Working Group is to examine the process of implementation of the project to capture learning points for national roll-out. During 2008 the pilot training developed and delivered to groups from academic and in-service settings was evaluated with the guidance of the Evaluation Working Group using a set of research tools developed in the US and used in over 30 Paediatric training courses across the US. The Evaluation Working Group also developed a tracking tool to monitor participants' experience of the implementation project, and planned the overall evaluation of the pilot project taking on board the progress of each of the Working Groups as described above.

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 participated 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

Objective:	**Key Achievements in 2008:**
To 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 Sectoral Plans.	During 2008 the following actions were taken: • The National Federation was represented at the two high level meetings of the National Disability Strategy Stakeholders Monitoring Group held in 2008. The National Disability Strategy Stakeholders Monitoring Group comprises members of the Disability Stakeholders Group, outlined above, and the Senior Officials Group on Disability. The Senior Officials Group on Disability which reports to the Cabinet Sub Committee on Social Inclusion, comprises officials representing the six Government Departments responsible for preparing and implementing Sectoral plans for disability services in the Departments of Justice, Equality & Law Reform; Environment and Local Government; Health & Children; Heritage, Marine & Communications; Transport; and Enterprise, Trade & Employment. The Senior Officials Group on Disability is chaired by the Department of An Taoiseach. • The National Federation of Voluntary Bodies made a submission to the National Disability Strategy Stakeholders Monitoring Group in respect of its views on progress in each of

	the Sectoral Plans. • Brian O'Donnell, Chief Executive, Chaired the Disability Stakeholders Sub Group on Environment and Local Government and oversaw preparation of the submission relating to that Department's Sectoral Plan. • The National Federation of Voluntary Bodies held four meetings with the Disability Federation of Ireland (DFI) 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 National Social Partnership Forum.
Mental Health Commission	
To review the operation of Part 2 of the Mental Health Act.	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. Key actions in this regard in 2008 were as follows: • At the invitation of the Mental Health Commission Brian O'Donnell, Chief Executive, represented the National Federation of Voluntary Bodies on the Consultative Group which was established by the Commission to advise it generally on the conduct of the review. • The National Federation of Voluntary Bodies invited submissions in relation to the review from all member organisations. • The National Federation prepared an overall sector submission for the Commission, on the basis of the submissions received by the member organisations.

European Association of Service Provides for Persons with Disabilities

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.

Objective:	**Key Achievements in 2008:**
To contribute to the development of policy in respect of Disability issues at the European level.	• The National Federation of Voluntary Bodies participated as a partner in two European Projects relating to (a) the transition of people with intellectual disability moving from sheltered employment to supported employment in the open labour market (Conversion Project) and (b) employee well-being in social care settings (ROSE Project). • During 2008 the National Federation participated in two EASPD's Working Groups dealing with 'Employment of people with disabilities' and 'Inclusive Education' respectively. • The National Federation of Voluntary Bodies contributed to all EASPD policy submissions and statements and to its Action Plan for 2008. • Brian O'Donnell, Chief Executive, continued to provide a leadership role to EASPD in his capacity as the elected President of the Association until the completion of his term of office in September 2008.

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 was secured in January 2008 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 and to address some of the key issues concerned. 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.

Objective:	**Key Achievements in 2008:**
Social Inclusion Best Practice	
Developing Guidelines for Accessible Information	
To represent the National Federation on the National Accessible Information Working Group.	• The National Accessible Information Working Group, which represents all relevant stakeholders, aims to develop a national guideline document to make information accessible for all people with disabilities and people who may not have English as their first language. • The guideline document will be published in 2009. • Breda Casey, Policy Development Co-Ordinator, represents the National Federation on this Working Group.
Community Participation & Inclusion	
To support the work of the Community Participation & Inclusion Sub-Committee.	• The Community Participation & Inclusion Sub-Committee met on 4 occasions in 2008. • Yvonne Bohane resigned as chair of the group in May 2008. We would like to thank Yvonne for guiding the group over the past three years and we are happy that Yvonne has decided to stay on as a member of the group. • Richard Collins took over as chair of the group in June 2008. We would like to thank Richard for his commitment to working with the group over the next two years. • Claire Maher co-chaired one meeting with Richard at the end of 2008. We would like to thank Claire for volunteering to co-chair and setting a high standard for the future. • Mary Gavin has written a great article called “The Things I’d Like to Change” and this article will be published in 2009. Congratulations to Mary on producing the first news article. • The Sub-Committee continued to disseminate the findings from *People Connecting,* including meetings with advocacy councils etc. Over 900 copies of People Connecting have now been circulated. • Ongoing documentation of each step of how this inclusive Sub-Committee works together to provide a learning opportunity for other Sub-Committees and groups is being developed.

To develop a set of guiding principles for meetings.	The group adopted a set of principles for their Sub-Committee meetings: • Only one person speaks at a time. • The group listens to the person who is speaking. • People cannot talk for too long. • Mobile phones must be turned off. • People in the group should respect each other.
To identify agreed topics for group discussion.	The group discussed a range of issues during the year, including: - Capacity and consent - Inclusive research - Transport issues, especially in rural areas, - Developing life stories - People managing their own money - Community Food Project. This is a joint project with the HSE and the Department of Agriculture & Food to develop community gardens around the country. - Claire Maher updated the group on the work of the Gold Star Task Group in Cashel, Co. Tipperary. Claire is a member of this group. This group is looking at issues like, access, awareness, involvement in social activities, transport etc. for people with disabilities. It's a very good example of a group that involves everyone in decisions that affect their local area.
To participate in relevant consultations, workshops and conferences.	• The Community Participation & Inclusion Sub-Committee made a presentation to the National Federation Research Sub-Committee on areas of possible research, based on the "People Connecting" consultation document. This presentation formed part of the Research Sub-Committee's consultation process with people who access services to determine what research is important to them. • Sub-Committee members delivered training on working with Consultation Groups to the Inclusive Research Network workshops. The Inclusive Research Network is a group of people who come together to do or talk about research that is about people with intellectual disabilities. • Two research interns from the National Institute of Intellectual Disability (NIID) who were involved in assisting with the organization, setting up and transcription of focus groups for the National Survey of people with intellectual disabilities facilitated focus group training in Dublin and Clare. The training involved how to set up a focus group and also training for people to become focus group co-facilitators. A number of people from the Community Participation group attended the training and a copy of the documentation "Action Skills for Focus Groups" was made available to all members of the group. • A number of Sub-Committee members attended the following workshops / conferences: - "A Sense of Belonging" – by David Pitonyak. This was a workshop organised by Brothers of Charity Clare. - Taking Control conference – a conference on individualized funding organized by an alliance of disability organizations. Also included a workshop by PLAN Canada.

	- A “How to Guide” to Social Inclusion organised by Nurture Development, Dublin - 1-day workshop entitled “What is a Home?” facilitated by Darcy Elks from the US. This was organised by Brothers of Charity Services Clare. - A workshop on the development of an EU policy on Social Farming, facilitated by UCD, was also attended.
To circulate relevant publications to Sub-Committee members.	• Best practice documentation is provided to our Sub-Committee members on an ongoing basis • The group also examined the following publications: - “Public Attitudes to Disability in Ireland” published by the National Disability Authority. - An easy-to-read guide on accessibility published by the National Disability Authority - a Code of Practice for public organisations like government departments, county councils, local authorities, public libraries - “The Right Living Space”, a document on housing and homes which was produced by the Citizens Information Board and Disability Federation of Ireland - EASPD draft position paper on “Strategies Facilitating the Development of Community Based Settings and Person Centred Services”. - National Federation Innovation Conference Proceedings (October 2007). An easy-to-read version of the conference proceedings were prepared by Brian Donohoe and circulated to the group. - “A Sense of Belonging” – by David Pitonyak. - Circles Initiative – Information Guide – Working to Open Doors to Community Life - “In Praise of Slow Inclusion” written by Peter Bates from the National Development Team in the UK - HIQA draft standards for disability services – easy to read version - National Federation Research Strategy – easy to read - Volunteering in Intellectual Disability Services in Ireland

Volunteering Supports:
Launch of “Volunteering in Intellectual Disability Services in Ireland: *“Supporting People to Live the Life of their own Choice in their own Community”*

Minister Pat Carey, TD, Government Chief Whip and Minister of State with special responsibility for Active Citizenship, launched the findings of a national survey on volunteering in intellectual disability services in Ireland in the Hibernian Hotel, Mallow on Monday 6th October 2008. The survey was carried out and published by the National Federation of Voluntary Bodies and is the first national study on volunteering to be conducted within intellectual disability services in Ireland.

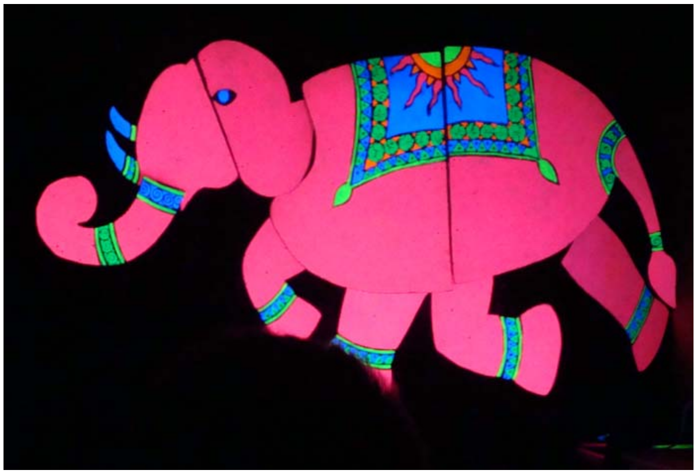
Pictured at the Volunteering Launch

Back row (l to r): John O'Dea, Western Care; Jerry Mullane, Cope Foundation; Noreen McGarry, Western Care; Ann Byrne, KARE; Breda Casey, National Federation of Voluntary Bodies;
Front row (l to r): Linda Keane, Ability West; Maura Nash, Cope Foundation, Brian O'Donnell, National Federation of Voluntary Bodies, Roisin Deery, Midway Services; Mary O'Connell, Brothers of Charity Services Limerick.

The launch included:

- A presentation from Philip Crosbie who lives independently in Tramore and is supported by Brothers of Charity in Waterford. Philip spoke about his experience of benefiting from the support of a volunteer and also about his own experience of volunteering in his own community.
- A drama interlude from the Kaleidoscope Drama Group – a group of people with intellectual disability from Cork whose drama group is fully supported by volunteers
- A DVD from Western Care Association in Mayo outlining the experience and benefits of volunteering from the perspective of persons with an intellectual disability, families, volunteers and staff.

At the launch, Minister Carey outlined that "we all recognise that volunteering plays an important part in active citizenship and social inclusion, through strengthening our local communities, in particular enhancing the community involvement of people with intellectual disabilities and facilitating their involvement in mainstream activities. Volunteers also have a vital role to play in breaking down barriers and enabling awareness, working to reduce and minimize the levels of social exclusion and isolation that might be experienced by people with intellectual disability." The Minister also highlighted "that as social creatures, our greatest human impulse is that instinctual desire to connect with others, either to make a connection of friendship or to help another, to want to make a difference in someone else's life. Volunteers make a very significant contribution to society by giving of their time for the benefit of others without seeking any form of payment or monetary reward."



Members of the Kaleidoscope Drama Group create a colourful on-stage collage during their drama performance at the launch of the national study on volunteering

Findings from the Survey

The findings from the volunteering survey indicate that in 33 National Federation member organisations, over 3,000 volunteers are contributing approximately 7 hours per month to the social inclusion of people who avail of intellectual disability services, making volunteering an integral part of community activity within these organisations. The contribution of volunteers is greatly valued and respected and their contribution is celebrated by member organisations.

The most successful methods of volunteer recruitment are through local bulletins/newsletters, by word of mouth and through advertisements in the local press and posters. Members of Boards of Management, Fundraisers, Befrienders / Best Buddies and Support Workers are the main roles provided by volunteers. Volunteer skills, talents and interests are matched with the needs of the person who avails of intellectual disability services. Volunteering supports are provided by member organisations on both a formal and an informal basis. While the majority of organisations do not have a formal written volunteering policy, a number of these organizations have plans to develop a written volunteering policy in the near future.

Volunteering supports people with intellectual disability to really connect with people in their own communities, to have a better quality of life and make new friendships. It also supports them to be active citizens in their own communities, thereby achieving their full potential and living the life of their choice. Volunteering also supports people with intellectual disability to develop new skills through their participation in activities e.g. recreation, arts, sports and to have positive valued social roles within their own community.

Volunteers see their volunteering activities as an opportunity to give something back to their community, to use the experience as a stepping stone to employment and to experience personal satisfaction i.e. feel-good factor.

Volunteering activities in intellectual disability services support the recommendations of the Government Taskforce on Active Citizenship and Government’s commitment to people with intellectual disability to enable them to live the life of their own choice in their own community. They also support the UN Convention on the Rights of Persons with Disabilities, in particular Article 19 which outlines “States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community…..” (Article 19, United Nations Convention on the Rights of Persons with Disabilities, 2006).

A copy of the report "Volunteering in Intellectual Disability Services in Ireland: "Supporting People to Live the Life of their own Choice in their own Community" is available on the National Federation website at http://www.fedvol.ie/publications/.

Objective:	**Key Achievements in 2008:**
To support the work of the Volunteering Sub-Committee.	• The Volunteering Sub-Committee, chaired by Anne Byrne and Gerry McLaughlin met on 5 occasions in 2008. • It was an extremely busy year for the Sub-Committee and they provided much appreciated expertise, commitment and support throughout the year in bringing the volunteering survey findings to launch stage.
To support Member Organisations to ensure best practice in the recruitment, selection, training, ongoing support, monitoring and celebration of their volunteer's contributions.	• 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.
To disseminate the findings of the Volunteering Survey.	• Presentations on the findings and recommendations from *Volunteering in Intellectual Disability Services in Ireland* were delivered to the Board and General Assembly of the National Federation of Voluntary Bodies.

APPENDIX 1:

NATIONAL FEDERATION OF VOLUNTARY BODIES BOARD OF DIRECTORS

Brendan Broderick, Sisters of Charity of Jesus & Mary (Chairperson until September 2008)
Tony Darmody, Kerry Parents & Friends Association
Maura Donovan, Stewarts Hospital
Wally Freyne, Daughters of Charity Services
Mary Kealy, Brothers of Charity Services Clare
Bro 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 (Chairperson from September 2008)
Winifred O'Hanrahan, Brothers of Charity Services

APPENDIX 2:

NATIONAL FEDERATION OF VOLUNTARY BODIES SUB-COMMITTEES & WORKING GROUPS AS AT 31ST DECEMBER, 2008

Community Participation & Inclusion Sub-Committee
(List of people who attended one or more meetings during 2008)
Yvonne Bohane, Kildare (Chairperson until May 2008)
Richard Collins, Clare (Chairperson from May 2008)
Karen Brennan, Kildare
Mary Carty, Waterford
Roisin Deery, Meath
Theresa Doyle, Kildare
Catherine Devine, Dublin
Ann Finlay, Kildare
Veronica Freeney, Kildare
Mary Gavin, Dublin
Martine Healy, Meath
Brian Hogan, Clare
Angela Hynes, Cork
Rosemary Kearns, Galway
Aine Kerr, Dublin
Mary Lannon, Dublin
Grainne Lee, Kildare
Kareena McGeeney, Kildare
Joe McGrath, Clare
Mary Lucey Pender, Dublin
Claire Maher, Tipperary (co-chair for one meeting)
Ann Marie McDermott, Kildare
Noreen McGarry, Mayo
Lorraine McNicholas Dublin
Ann O'Callaghan, Cork
Tim O'Connell, Kilkenny
Eileen O'Keeffe, Cork
Tricia Shelley, Tipperary
Joan Skeffington, Tipperary
Derek Watson, 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
Moira 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
Denis Cronin, Daughters of Charity
Noel Dillon, St. Michael’s House
Roisin Deery, Midway Services
Phil Gray, Hospitaller Order of St. John of God
Bill Griffin, Ability West
Helen Guinan, COPE Foundation
Catherine Jackman, Cheeverstown House
Martin McGrenary, 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 Cairde 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

Volunteering Sub-Committee:
(List of people who attended one or more meetings during 2008)
Anne Byrne, KARE (Chairperson)
Philip Crosbie, Waterford
Roisin Deery, MIDWAY Services
Rhoda Judge, Daughters of Charity Services
Linda Keane, Ability West
Rosemarie Kearns, Brothers of Charity Services Galway
Gerry McLaughlin, Sisters of Charity of Jesus & Mary
Noreen McGarry, Western Care
Susan McGill, Brothers of Charity, South Eastern Region
Jerry Mullane, COPE Foundation
Mary O’Connell, Brothers of Charity, Limerick
Martina Rynne, Brothers of Charity Clare
Kathleen Sherry, SOS Kilkenny Ltd.
Breda Casey, National Federation of Voluntary Bodies

Research Sub-Committee:
Brian McClean, Brothers of Charity Services Roscommon (Chairperson)
Nick Blitz, Camphill Communities
Mary Desmond, COPE Foundation
Kay Downey-Ennis, Daughters of Charity
Bernie Fay, Sisters of Charity of Jesus & Mary
Caroline Hart, RehabCare
Aine Kelly, Hospitaller Order of St. John of God
Gina Magliocco, Brothers of Charity Kilcornan
Mary McCarron, Trinity College
Mark Staunton, Brothers of Charity Clare
Edel Tierney, National Federation of Voluntary Bodies
Mary Barrett, National Federation of Voluntary Bodies
Alison Harnett, National Federation of Voluntary Bodies

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
Kevin Hoey, Sunbeam House Services
Trevor Jacob, Co. Wexford Community Workshop
Edith Kennedy, MIDWAY
Conor McAtasney, CoAction
John O’Callaghan, Daughters of Charity Limerick
Bernard O’Regan, Western Care
Sandra Whelan, Walkinstown Association

Informing Families Project Cork Implementation Project Steering Committee:
Katherine O’Leary, Chairperson - Parent & Director Inclusion Ireland
Michael Butler, Care Group Co-ordinator for Physical and Sensory Disability, West Cork
Dr. Mary Desmond, Principal Psychologist COPE Foundation
Dr. Margaret Farrelly, Principal Psychologist St. Joseph’s Foundation, Charleville
Dr. Suzanne Guerin, Lecturer in research design & analysis – University College Dublin Cork
Prof. Jonathan Hourihane, Professor of Child Health and Paediatrics, Cork University Hospital
Alison Harnett, National Federation of Voluntary Bodies
Geraldine Keoghane - Director of Midwifery, Cork University Maternity Hospital
Hilary Lane, Senior Clinical Psychologist, Enable Ireland
Breda Long, Early Intervention Project Officer
Maeve McCarthy Barrett, Branch Secretary Cork
Dr. Dan McKenna, Consultant Obstetrician Cork University Maternity Hospital
Dr. Brendan Murphy, Consultant Neonatologist Cork University Maternity Hospital
Eamon Naughton, Health Services National Partnership Forum

Gabrielle O'Keeffe, General Manager South Lee LHO
Mr. Gerry O'Connor, Consultant in Ophthalmic Surgery Cork University Hospital
Helen O'Connor, Social Worker, Brothers of Charity Southern Services
Mary Owens, Director of Nursing, Mallow General Hospital
Yana O'Donovan, Clinical Nurse Specialist Early Intervention, Co-Action West Cork
Gerrie O'Grady, Manager, Cork Deaf Association
Dr. Olivia O'Mahony, Consultant Paediatric Neurologist, Cork University Hospital
Dr. Margaret O'Rourke, Senior Lecturer & Director of Behavioural Science, UCC
Edel Tierney, Director of Research & Policy Development - National Federation of Vol. Bodies
Kathleen Vickers, Regional Manager NCBI Southern Region

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

APPENDIX 3:

NATIONAL FEDERATION OF VOLUNTARY BODIES REPRESENTATIVES ON NATIONAL COMMITTEES & WORKING GROUPS AS AT 31ST DECEMBER 2008

DEPARTMENT OF HEALTH & CHILDREN:

National Disability Advisory Committee
- Brian O'Donnell, National Federation of Voluntary Bodies

National Intellectual Disability Database
- Patrick McGinley, Brothers of Charity Services, Galway
- James Rocke, 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, Ability West;
- 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 (0-5 year olds)
- Stephen Kealy, Sisters of Charity of Jesus & Mary;
- Moira 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

Health Service National Joint Council
- Maura Donovan, Stewarts Hospital

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 ACCESSIBLE INFORMATION WORKING GROUP
- Breda Casey, National Federation of Voluntary Bodies

TILDA INTERNATIONAL SCIENTIFIC ADVISORY GROUP:
- Prof. Mary McCarron, Trinity College Dublin (Chairperson & Principle Investigator)
- Dr. Philip Dodd, St. Michael's House Dublin
- Finula Garrahy, Inclusion Ireland Dublin
- Caraiosa Kelly, Health Research Board Dublin
- Dr. Jean Lane, Daughters of Charity Dublin
- Prof. Philip McCallion, University of Albany, State University of New York
- Prof. Roy McConkey, University of Ulster
- Marion Meany, HSE South Western Area
- Dr. Niamh Mulryan, Daughters of Charity Dublin
- Prof. Patricia Noonan-Walsh, Centre for Disability Studies, UCD
- Kathy O'Grady, Sisters of Charity of Jesus & Mary Kildare
- Claire O'Regan, TILDA Trinity College Dublin
- Dr. Fintan Sheerin, Trinity College Dublin
- Janet Swinburne, Trinity College Dublin
- Edel Tierney, National Federation of Voluntary Bodies Galway
- Dr. Janet Tyrrell, St. Michael's House Dublin

NATIONAL REVIEW AND AUDIT OF CLIENT PROTECTION ISSUES WITHIN INTELLECTUAL DISABILITY SERVICES
Members of the Task group in 2008:
- Tom Hogan, Chairperson
- Deirdre Scully, HSE Cork region
- David Kenefick, St. Michael's House
- Teresa Dykes, HSE Cloonmahon Sligo
- Edel Tierney, National Federation of Voluntary Bodies Secretariat

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 (Chairperson)
- Tom Hogan, Ability West
- John O'Dea, Western Care Association
- Brian O'Donnell, National Federation of Voluntary Bodies

National Federation of Voluntary Bodies Secretariat Team:
- 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, P/T Clerical Officer
- 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 RESEARCH STRATEGY 2008-2013

Research Priorities 2008-2013
1. Define the priority areas for research as identified through consultation with people who use services, Chief Executive Officers of organisations, management and frontline staff.
2. Identify a list of key designated experts in the Irish research community who will support the dissemination of research and assessment materials in these areas. These key experts will provide expert knowledge on these topics thus enhancing the knowledge base among members
3. Develop quality indicators for research in intellectual disability and guidelines for evidence based practices.
4. Measure performance of research activities
5. Identify key people who may be called upon to act as associate members of the National Federation Research Sub-Committee as need and circumstances arise.
6. Develop research collaborations with national and international research centres
7. Develop a capacity to advise on how research could be funded in the future.
8. Develop a register of disability stakeholders. This will consist of organisations, governments departments, statutory and non-statutory bodies, people with disabilities and family members.
9. Continue to develop a register of intellectual disability research as per National Federation of Voluntary Bodies website.
10. Develop a National Research Ethics Committee with key national representation.
11. Continue to consult with and listen to people who use the services through research initiatives such as the Inclusive Research Network and continue to develop experience and expertise in participatory research methodologies
12. Regularly review the research strategy.

The full Research Strategy 2008-2013 can be downloaded from our website at www.fedvol.ie/research

Research Collaborators in 2008

Prof. Gerard Quinn, Disability Law & Policy Unit, National University of Ireland Galway
Prof. Patricia Noonan-Walsh, Centre for Disability Studies, UCD
Dr. Patricia O'Brien, National Institute for Intellectual Disability, Trinity College Dublin
Prof. Mary McCarron, School of Nursing & Midwifery Trinity College Dublin
Dr. Mary Van Lieshout, National Disability Authority Dublin
Prof. Richard P. Hastings, School of Psychology Bangor University UK
Prof. David Felce, Learning Disability & Autism Research Network Cardiff University
Dr. Stuart Todd, Learning Disability & Autism Research Network Cardiff University
Dr. Susie Nash, Learning Disability & Autism Research Network North Wales
Prof. Roy McConkey, University of Ulster
Prof. Kelley Johnson, Norah Fry Research Centre, University of Bristol
Luk Zelderloo, European Association of Service Providers for Persons with Disabilities Belgium
Dr. Kerim M. Munir, Children's Hospital Boston MA USA

National Designated Experts in 2008

Themes	Designated Expert	Affiliation
Advocacy	Rebecca Leavy Roisin McClone	Galway Advocacy Service, Galway Institute of Technology Sligo,
Ageing & Health - People with Intellectual Disability	Prof. Mary McCarron	School of Nursing & Midwifery, Trinity College Dublin
Autism	Dr. Christian Ryan	COPE Foundation Cork
Carers/Staff: Impact of Caring	Owen Barr	School of Nursing, University of Ulster
Challenging Behaviour	Dr. Brian McClean	Brothers of Charity Roscommon
Communication Augmentive and Alternative Communication Systems	Colin Griffiths Dr. Martine Smith Caroline Dalton O'Connor	School of Nursing & Midwifery Trinity College Dublin School of Linguistic, Speech & Communication Sciences, Trinity College Dublin School of Nursing & Midwifery, University College Cork
De-institutionalisation	Christy Lynch	KARE Kildare
Down's Syndrome	Joan Murphy	Down Syndrome Ireland Dublin
Dual Diagnosis	Dr Philip Dodd Dr. Noel Hannon	St. Michael's House Dublin Psychiatry of Intellectual Disabilities
Early Services	Dr. Stephen Kealy	Sisters of Charity of Jesus & Mary Kildare
Employment/Training	Christy Lynch	KARE Kildare
Ethical & Related Issues, Legal Capacity, Human Rights & related areas	Dr Mary Keyes	National University of Ireland Galway
Friendships	Prof. Roy McConkey	University of Ulster,
Inclusive Education	Dr. Michael Shevlin	Trinity College Dublin
Legal/Human Rights	Prof Gerard Quinn	Disability Law and Policy Unit, NUI Galway
Living Options/Service Models	Prof. Roy McConkey	University of Ulster
Palliative Care	Phil Dunne	Children's Sunshine Home Dublin
Participatory Research	Prof Patricia O Brien	National Institute for Intellectual Disability, Trinity College Dublin
Profound Multiple Disability	Dr. Jean Ware	St. Patrick 's College Dublin
Quality of Life	Chris Conliffe	Dunmurray, Belfast
Relationships & Sexuality	Gert Job	www.gertjob.com
Research on Families	Dr. Hasheem Mannan	Trinity College Dublin
Research Methods in Intellectual Disability Research	Dr. Suzanne Guerin	School of Psychology, University College Dublin
Bereavement Issues in people with Intellectual Disability	John McEvoy	Midway Services Meath

APPENDIX 5:
NATIONAL FEDERATION OF VOLUNTARY BODIES FINANCIAL DATA 2007/8

	Year Ended 31/12/08	**Year Ended 31/12/07**
Income:		
HSE Grant	347,158	347,158
Members Subscription	142,222	117,312
Pension Scheme	67,123	58,578
APPM	50,000	50,000
Informing Families Project	40,000	163,371
Policy Development Grant	53,000	27,420
HSE – Adult Day Services	149,741	0
Other Income	15,000	34,513
	864,244	798,352
Expenditure:		
Pay Expenditure	416,766	368,577
Non Pay Expenditure	140,626	154,130
APPM	50,000	50,000
Informing Families Project	40,000	163,371
Policy Development Grant	53,000	27,420
HSE – Adult Day Services	149,741	0
	850,133	763,498
Surplus for the Year	14,111	34,854

BALANCE SHEET

Tangible Fixed Assets		429,546		440,378
Current Assets:				
Debtors	71,090		26,455	
Bank	356,067		539,446	
	427,157		565,901	
Creditors – amounts falling due within 1yr	(379,497)		(517,476)	
Net Current Assets		47,660		48,425
Total Assets Less Current Liabilities		477,206		488,803
Creditors – Amounts falling due after more than 1yr		(306,738)		(332,446)
Total Net Assets		**170,468**		**156,357**
Capital & Reserves				
Surplus for the Year		14,111		34,854
Reserves		156,357		121,504
		170,468		**156,357**

APPENDIX 6:

NATIONAL FEDERATION OF VOLUNTARY BODIES MEMBER ORGANISATIONS

Ability West, Blackrock House, Salthill, Galway (formerly known as Galway Association)
Ard Aoibhinn Centre, Belvedere Road, Wexford
Association of Parents & Friends Carrickmacross, Corcrin, Carrickmacross, Co. Monaghan
Beam Services, Chestnut Court, Royal Oak Road, Bagenalstown, Co. Carlow
Brothers of Charity Services Clare, Banner House, Clare Road, Ennis, Co. Clare
Brothers of Charity Services Galway, Woodlands, Renmore, Galway
Brothers of Charity Services Limerick, Blackberry Park, Ballykeeffe, Dock Road, Limerick
Brothers of Charity Services Roscommon, Lanesbro Street, Roscommon
Brothers of Charity Services South East, Belmont Park, Waterford
Brothers of Charity Southern Services, Lota, Glanmire, Co. Cork
Cairdeas Centre, Tullow, Co. Carlow
Camphill Communities of Ireland, Ballytobin, Callan, Co. Kilkenny
Carriglea Cairde Services, Carriglea, Dungarvan, Co. Waterford
CASA - Caring & Sharing Association, Carmichael Centre, North Brunswick Street, Dublin 7
Cheeverstown House, Templeogue, Dublin 6W
Children’s Sunshine Home, Leopardstown Road, Foxrock, Dublin 18
Clann Mór Ltd., Clann Mór House, Commons Road, Navan, Co. Meath (formerly known as Meath Association)
Clones Branch, Cairde Activation Centre, Canal Stores, Clones, Co. Monaghan
CoAction West Cork, Slip, Bantry, County Cork
COPE Foundation, Bonnington, Montenotte, Cork
Cork Association for Autism, 61 Oliver Plunkett Street, Cork
County Wexford Community Workshop, Beelefield, Enniscorthy, Co. Wexford
County Wexford Community Workshop, Marshmeadows, New Ross, Co. Wexford
DARA Residential Services, 8 The Avenue, Castletown, Celbridge, Co. Kildare
Daughters of Charity Service, St. Vincent’s Centre, Navan Road, Dublin 7
Delta Centre, Strawhall, Carlow
Drumlin House, Cootehill, County Cavan
Gheel Autism Service, Milltown Road, Milltown, Dublin 6
Holy Angels Day Care Centre, Strawhall Industrial Estate, Carlow
KARE, Newbridge Industrial Estate, Newbridge, County Kildare
KASMHA, College Gardens, Callan Road, Kilkenny
Kerry Parents & Friends Association, Old Monastery, Port Road, Killarney, Co. Kerry
L’Arche Ireland Secretariat, Cluain Aoibhinn, Fairgreen Lane, Callan, Co. Kilkenny
Malta Services Drogheda, Malta House, Fair Street, Drogheda, Co. Louth
MIDWAY Services, Beechmount Industrial Estate, Navan, Co. Meath
Moorehaven Centre, O’Brien Street, Tipperary
North West Parents & Friends Association, Holy Family Day Centre, Ballytivnan, Sligo
Peacehaven, 1-2 Hillside, Greystones, Co. Wicklow
Peamount, Newcastle, County Dublin
Prosper Fingal, Strand Street, Skerries, Co. Dublin
Rehabcare, Roslyn Park, Beach Road, Sandymount, Dublin 4
Sisters of Charity of Jesus & Mary, Moore Abbey, Monasterevin, Co. Kildare
Sisters of La Sagesse, Cregg House, Sligo
SOS Kilkenny Ltd., Seville Lodge, Callan Road, Kilkenny
St. Aidan’s Service, Millands, Gorey, Co. Wexford
St. Catherine’s Association, Newcastle, Co. Wicklow
St. Christopher’s Service, Leamore Park, Battery Road, Longford
St. Cronan’s Association, Grange, Roscrea, Co. Tipperary
St. Hilda’s Services, Grace Park Road, Athlone, Co. Westmeath
St. John of God Hospitaller Services, Provincial Administration, Stillorgan, Co. Dublin
St. Joseph’s Foundation, Bakers Road, Charleville, Co. Cork
St. Margaret’s Centre, Moorehampton Road, Donnybrook, Dublin 4
St. Michael’s House, Ballymun Road, Ballymun, Dublin 9
St. Patrick’s Centre (Kilkenny), Kells Road, Kilkenny
St. Vincent’s Centre, St. Mary’s Road, Cork
Stewarts Hospital Services Ltd., Palmerstown, Dublin 20
Sunbeam House Services, Cedar Estate, Killarney Road, Bray, Co. Wicklow
Tipperary Association, Cashel, Co. Tipperary
Walkinstown Association, 1 Longmile Road, Dublin 12
Waterford Intellectual Disability Association, Spring Garden Workshop, Ashley Drive, Cherrymount, Waterford
Western Care Association, Pool Road, Castlebar, Co. Mayo
Windmill Therapeutic Training Unit, Larkins Lane, South Main Street, Wexford

NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

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 62 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.

Oranmore Business Park,
Oranmore, Galway.
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NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

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