

National Federation of Voluntary Bodies

Annual Report 2003

Table of Contents

Introduction from Mr. Paul Ledwidge, Chairman	3
Statement from Mr. Brian O'Donnell, Chief Executive	4
Member Organisations	5
Mission.	5
Values	5
Goals and Objectives	5
How we are Governed.	6
Activities in 2003	
• Policy Work & Campaigning	7
• Membership Services	12
• Research and Development	20
Appendices	
1. Board and Secretariat	25
2. Member Organisations of the National Federation	26
3. Membership of National Federation's Sub-Committees.	27
4. National Federation's Representatives on Various Committees	29
5. National Federation's Financial Data 2003 - 2002	32



Introduction from Chairperson

It is my privilege to introduce the 2003 Annual Report of the National Federation of Voluntary Bodies Ltd.

The National Federation has continued to develop and extend the services provided to its members. We purchased our first premises in Oranmore Business Park, Oranmore, Galway, and moved into the property in March 2003. The development of the conference facilities on site has also enabled us to extend our services.

2003 will always be remembered as the year of the Special Olympics and I would like to take this opportunity to congratulate everybody associated with the Special Olympics' World Games and to say how proud we all were to be associated with such a wonderful event which highlighted the positive contributions made by people with intellectual disabilities to our society.

2003 like any other year has brought many challenges.

- The *Health Services Reform Programme* which commenced in 2003 provided us with the opportunity through the Action Project Teams to outline the needs of people with intellectual disabilities. The National Federation was represented on the Primary, Community and Continuing Care Action Project Team by our Chief Executive, Brian O'Donnell. This Team agreed that most National Federation Organisations would have Service Agreements with the Regional Health Offices in the new structures.
- *Sustaining Progress* and the commitment of the Dept. of Health and Children to carry out a strategic review of intellectual disability services has provided us with a wonderful opportunity to influence the direction and policies in intellectual disabilities. The last major policy statement in this sector dates back to *Needs and Abilities* published in July 1990 and I am delighted that the National Federation has been able to nominate representatives to participate on each of the 17 working groups.
- *Sustaining Progress* also established the performance verification group and the Federation was appointed by the Dept. of Health to collate all of the submissions under this process. To date we have had a very positive response from the performance verification group to the submissions made.
- The *Health Services Employers Agency* formalised its links with the Federation in 2003 and we are fortunate to have our Chief Executive as a full member of the HSEA Board. The Chairperson of our HR Sub-Committee is invited to attend all meetings of the Board.

I would particularly like to take this opportunity to thank the members and especially the Chairpersons of each of the Sub-Committees of the Federation. Without their work and commitment the Federation could not provide the level of service which it currently does.

To conclude, I would like to thank the Chief Executive and his team for the support which they have provided to me as Chairperson and on behalf of the members of the Federation to thank them for their continued excellent services to all of our member organisations.

Paul Ledwidge
Chairperson

Statement from Chief Executive

I am very happy to present the Annual Report of the activities of the Secretariat of the National Federation of Voluntary Bodies for 2003.

2003 was once again an extremely busy year for the Secretariat in terms of the scale of activities in which we were involved. Waiting lists for services continues to be a major priority for the National Federation and as a National Federation we articulated our serious disappointment and concern with the contents of Budget 2003. The Budget made no provision for the development of new services for people with intellectual disabilities who are on waiting lists, nor was there any provision for emergencies or crisis situations arising, or for the creation of places for young people graduating from schools later in 2003. The National Federation engaged in an extensive lobby campaign in the first half of 2003 drawing the Governments attention to the serious hardship which this was creating for people with intellectual disability and their families. During Summer 2003, Government announced additional funding of €25m to deal with emergencies and for the creation of appropriate places for the young graduates.

During the year we made comprehensive submissions to Government on the Disability Bill and the Education for Persons with Disabilities Bill 2003. Our commitment to information sharing and ensuring that members are kept fully informed on all issues affecting them is reflected in the extensive range of communications which issued during the year.

We continue to highlight issues of concern to our sector. The National Federation of Voluntary Bodies organised the very successful ReSpeCt Symposium which was developed in partnership with the Irish Sex Education Network, in Killarney, Co. Kerry, on 5th and 6th November, 2003. Attended by some 300 delegates the conference dealt with the issue of informed consent and capacity in decision making and the right to relationships and protection.

As previously acknowledged, we are very fortunate within the National Federation to have available to us very many people who are experts in their field and who give of their time and expertise voluntarily and unselfishly for the betterment of the National Federation through their work on our many Sub Committees and Task Groups. We are deeply appreciative of their important input.

In conclusion, I would like to place on record my gratitude to our Chairpersons, Mr. Paul Ledwidge, and previously, Ms. Winifred O'Hanrahan, and the National Federation's Board of Directors for their support and guidance. I would also like to express my appreciation to all 62 National Federation member organisations for their positive contributions to all our activities and finally, to the Secretariat Staff for their dedication and professionalism during what was another extremely busy and demanding year.

Brian O'Donnell
Chief Executive

National Federation of Voluntary Bodies

Member Organisations

The National Federation is a national umbrella organisation for voluntary/non-statutory agencies who provide direct services to people with an intellectual disability in Ireland. The members of the National Federation are both voluntary and religious bodies with a clear vision rooted in the respect for and the dignity of the person. In all, our National Federation comprises some 62 affiliated organisations who between them account for in excess of 85% of this country's direct service provision for people with an intellectual disability. Our members employ approximately 14,000 staff covering a wide range of professional disciplines providing services and supports to over 20,000 people.

See Appendix 1 for full list of all member organisations of the National Federation.

Mission

The National Federation of Voluntary Bodies aims to promote the equalisation of opportunities for persons in the care of member organisations through the provision, maintenance and development of appropriate high quality services. The objectives are achieved through information sharing and through the development and promotion of codes of best practice. The National Federation also acts as a lobbying agent on a national and international basis and works in co-operation with advocacy organisations on behalf of person with an intellectual disability.

Values

The National Federation of Voluntary Bodies promotes and actively pursues four fundamental principles. People with an intellectual disability have:

- The right to a normal pattern of life within the community;
- The right to be treated as an individual with dignity and respect;
- The right to care and support in developing their maximum potential;
- The right to participate in the decision making process on issues affecting their lives.

We support the following internationally agreed statements:

- The United Nations Declaration on Human Rights and on the Rights of Intellectually Disabled Persons;
- The United Nations Standard Rules for the Equalisation of Opportunities for People with Disabilities;
- The United Nations Convention on the Rights of the Child.

Goals and Objectives

While the National Federation and its members are constantly open to new challenges and opportunities the goals are:

- The sharing of information relating to the provision, maintenance and development of services;
- The development of strategies in areas of common interest;

- The provision of information and support to individual members and local groups of members, when required, and in supporting member organisations in their advocacy on behalf of individual persons;
- Making representations to the Departments of State, other public authorities and national and international bodies on issues agreed by the members;
- Entering into negotiations on behalf of National Federation members as required;
- Promoting and undertaking public education and information actions, and by issuing public statements on behalf of the members, on matters already agreed;
- Appointing or nominating, as appropriate, representatives on deputation's and as members of other relevant bodies, committees, commissions, working parties and boards;
- Undertaking the co-ordination of activities agreed by the members and which are appropriate to the role and functions of the National Federation;
- Drawing up codes of good practice or guidelines for the provision of intellectual disability services by its members;
- Stimulating the growth of the voluntary sector in areas of need and promoting the interlinking of voluntary agencies to promote the interests of persons with an intellectual disability.

How we are Governed

Each of our member organisations is described as a Nominating Body with the power to nominate two persons to represent their organisation in the general assembly of the National Federation. These people also represent their organisation on the Area Federation Committee (AFC) in the area within which their services are provided. In all, there are ten Area Federation Committees which cover the same geographic areas as those covered by the ten Regional Health Boards. The members of the Area Federation Committees elect from within their ranks a Chairperson and Vice Chairperson as well as a recording Secretary.

Each Area Federation Committee elects one person to become a member of the National Federation's Board of Directors. In addition to the ten elected Directors, the National Federation has the power to co-opt up to five additional Directors. The Board elects a Chairperson every two years and is responsible for the governance of the National Federation in accordance with our Articles of Association.

ACTIVITIES IN 2003

2003 was an extremely busy year for the National Federation. For the purposes of this report our work can be divided into three main types of activities as follows:

1. Policy Work and Campaigning
2. Membership Services
3. Research and Development

Policy Work and Campaigning

As a National Federation representing a wide alliance of voluntary organisations we have a unique perspective upon the quality of policy and practice for children and adults with intellectual disabilities. We represent our National Federation's views on all aspects of policy germane to our sector in a number of ways as follows:

- By lobbying the Government and individual Government Departments as appropriate through inputting and responding to new policy;
- By representing the voluntary intellectual disability sector, and occasionally the wider voluntary sector, on specialist groups;
- By bringing members together on common interests with a view to achieving a consensus on policy issues;
- By representing the National Federation at the European level through our membership of, and strong involvement in, the European Association of Service Providers for People with Disabilities (EASPD).

■ Waiting Lists for Services

In response to Budget 2003, which made no provision for the development of any new services for people with intellectual disability who were on waiting lists for services, the Board of the National Federation at its meeting in February 2003 decided on a number of actions as follows:

- Government would be informed of the difficulties being experienced on the ground by people with intellectual disability through an organised process of lobbying and information giving to politicians at local, regional and national levels. Our members engaged in a letter writing campaign to all T.D.s, Senators and local Councillors. Member organisations also met with members of the cabinet residing in their locality.
- The National Federation was instrumental in organising a Dail Debate on the funding crisis in Disability Services and provided relevant information to politicians from all parties.
- The National Federation was represented at a meeting of the Fianna Fail Parliamentary Party held on 2nd April, 2003, during which an opportunity was given to highlight the serious difficulties being experienced by people with intellectual disability and their service providers and the measures required to resolve them.
- Discussions commenced with officials from the Department of Health and Children around the specific measures required to deal with emergency cases in 2003.

- Meetings were arranged with Mr. Tim O'Malley, T.D., Minister of State at the Department of Health and Children on 26th March, 2003 and with Mr. Micheál Martin, T.D., Minister for Health and Children, on 14th May, 2003, at which the negative impact which Budget 2003 was having on people with intellectual disability was highlighted.

In Autumn 2003, the Government announced funding in the amount of €25m to put in place services and supports for emergency cases and for those young people with intellectual disability graduating from schools.

■ Disability Legislation

Disability Bill

The Disability Legislation Consultative Group (DLCG) was established to facilitate meaningful dialogue with the key stakeholders on disability legislation following the withdrawal of the Disabilities Bill 2002. The National Federation is represented on the Group by Mr. Wally Freyne, Daughters of Charity Services; Ms. Winifred O'Hanrahan, Brothers of Charity Services and Mr. Brian O'Donnell, National Federation Secretariat.

Through its involvement in the Disability Legislation Consultation Group (DLCG), the National Federation called for the inclusion of the following provisions in the new Disabilities Bill:

- Statutory entitlement by people with disabilities to an independent assessment of need;
- Positive rights to accessible services;
- An enforceable advocacy system;
- The placing of duties and requirements, aimed at removing barriers to people with disabilities, on public and private service providers.

The DLCG also proposed that an independent advocacy agency be set up under the proposed new legislation and that various measures to integrate people with disabilities into the workforce be granted on a statutory basis. It also made specific proposals on implementation, monitoring, review and enforcement of the new legislation.

Education for Persons with Disabilities Bill 2003

The Education for Persons with Disabilities Bill 2003 was launched by Mr. Noel Dempsey, T.D., Minister for Education and Science on 16th July, 2003. Following its launch the Minister provided for a consultation period on the Bill during which time the National Federation, through its Education Sub Committee, prepared detailed reports for the National Federation's Board of Directors. Following on from this a submission was made to the Department of Education and Science. Following receipt of the submission, the National Federation was invited to make a presentation to the Oireachtas Joint Committee on Education and Science and the presentation was made by Ms. Maura Nash, Chairperson, National Federation's Education Sub Committee and Ms. Maria Walls, Director of Research and Membership Services, National Federation Secretariat.

The Education Sub Committee had a busy year responding to the various drafts of the Education for Persons with Disabilities Bill detailed above. In addition, the Committee prepared a response to the NCCA Draft Curriculum following a consultation forum.

■ Sustaining Progress – Strategic Review of Disability Services

The National Federation welcomed the announcement by the Department of Health and Children in 2003 of its intention to carry out a Strategic Review of Disability Services. In welcoming the announcement the National Federation pointed to the particular need to review the Intellectual Disability Sector given that the last major policy statement in the sector dates back to “*Needs and Abilities*” (1990). Since 1990, there has been a range of demographic, societal, legislative and structural changes, which have effectively re-defined the general context.

As part of its preparation for the review on 19th April, 2003, the National Federation’s Board of Directors carried out a full day examination of the critical issues which required to be addressed in the national review. The day was facilitated by Professor Roy McConkey and resulted in the production of a detailed paper which was submitted to the Department of Health and Children.

The Department of Health and Children established 17 different Working Groups to consider different aspects of the strategic review and in response to invitations from the Department of Health and Children, the National Federation nominated representatives to work on all 17 groups.

■ Health Services Reform Programme

The work of the Action Project Teams which were established in September 2003 with a view to developing a preliminary report on the systems changes required to give effect to the Government decision regarding the Health Services Reform Programme was completed in early December 2003.

The National Federation was represented on the Primary, Community and Continuing Care (PCCC) Action Project Team by our Chief Executive, Mr. Brian O’Donnell. The PCCC Action Project Team agreed to accept the recommendations of the position paper prepared by the National Federation, which re-examined *Enhancing the Partnership / Widening the Partnership* and recommended necessary amendments so that the document could map onto the new structures. An important acceptance by the PCCC Action Project Team was that most National Federation member organisations would have Service Agreements with the Regional Health Offices in the new structures.

■ Expert Group on Mental Health Policy

Following on from the establishment of an Expert Group on Mental Health Policy by the Department of Health and Children, the National Federation formed a Task Group, under the Chairmanship of Ms. Winifred O’Hanrahan, to prepare a detailed submission for consideration by the Expert Group. The submission contained a set of detailed recommendations regarding mental health services for people with intellectual disability. A meeting was also arranged between the National Federation and the Royal College of Psychiatrists to discuss this issue and also to consider some options on the best way forward.

■ Performance Verification Process

The Performance Verification Group (PVG) was established by Government to verify and progress on the modernisation agenda under Sustaining Progress. The National Federation of Voluntary Bodies was appointed by the Department of Health and Children to prepare a report for submission to the PVG in respect of the Intellectual Disability Sector. Five priority areas were identified as being most significant for modernisation – customer service; industrial relations; performance management; reform; and value for money.

Upon receipt of the sector report in September 2003, the PVG carried out a site visit in Stewarts Hospital which was representative of the sector as a whole. The PVG expressed their satisfaction with both the sector report and the site visit and payment of the 3% increase under Sustaining Progress, effective from 1st January, 2004, was approved.

■ National Monitoring Committee

The National Monitoring Committee is representative of all the major stakeholders involved in the Intellectual Disability Sector, including the Department of Health and Children, National Federation of Voluntary Bodies, NAMHI, National Parents and Siblings Alliance (NPSA), the Health Boards, the Health Research Board, and is charged with overseeing the following:

- Progress in relation to the implementation of both new and enhanced service developments;
- The monitoring processes which are being used to assess the impact of these service developments on the needs which have been identified for this group;
- The areas with which the Committee can be of assistance in the overall implementation of the development programme;
- The production of an annual report advising the Government on progress made in the development of new services and supports.

The National Federation is represented on the Committee by Mr. Brian O'Donnell and Mr. Tom Hogan. During 2003, the Committee held three meetings at which serious concerns were expressed about the lack of an investment programme in new service developments during 2003.

■ White Paper: "Supporting Voluntary Activity"

In early 2003, the National Federation made application for a support grant under the National Federations and Networks Supports Grants Scheme arising from the White Paper "*Supporting Voluntary Activity*". Allocations under the Grant Scheme were finally announced in September 2003.

The National Federation was successful in its application for a grant and was awarded €47,000 per annum, for three years, which will enable the National Federation to establish a Policy Co-ordinator post. It is expected that the post will be filled in early 2004.

The key tasks of this role will be to:

1. Enhance the capacity of Member Organisation to contribute to and develop policy at National Strategic Policy, Service Development Policy and Organisation Development Policy.
2. Facilitate networking and ensure the exchange, collation and dissemination of information among Member Organisations and with individual member organisations sub-committees and other disability groups.
3. Promote and facilitate Member Organisations to work in partnership and promote participation:
 - with Service Users and their families;
 - within their own organisation and with all stakeholders;
 - with other Member Organisations and other Disability Groups;
 - with the Statutory Bodies and the wider community,
4. Undertake research and analysis into key areas identified by Member Organisations to promote best practice for the benefit of Service Users.
5. Promote Social Inclusion for people with intellectual disability to enable people to live full and active lives.
6. Enhance the capacity of Member Organisations to promote valuable involvement of volunteers and volunteering within their organisations to promote the social inclusion of people with intellectual disability.
7. Explore and maximize the benefits of utilising Information Technology and Asserive Technology resources for the benefit of Member Organisations and their Service Users.

■ **European Association of Service Providers for Persons with Disabilities (Easpd)**

The European Association of Service Providers for Persons with Disabilities (EASPD) now represents more than 6,000 service provider organisations in 22 EU member states. The Association promotes the equalisation of opportunities for people with disabilities through effective and high quality service systems in Europe. It also acts as a strong lobby agent on behalf of service providers at the EU level and during 2003 was awarded participatory status in the Council of Europe.

The National Federation of Voluntary Bodies, as a founding member of EASPD, maintained a strong involvement in all of its activities during 2003, including participation in a number of EASPD projects (see research) and attendance at General Assembly, Board and Project Group Meetings and at conferences in Brussels and Lisbon. Our Chief Executive, Mr. Brian O'Donnell, is currently Vice President of EASPD.

Membership Services

■ Information and Awareness

- Information sharing and awareness raising is a key function of the Secretariat. Regular awareness bulletins updating members on policy developments, legislation and developments in services were issued during 2003;
- A range of briefing papers, research reports and guidelines were produced and disseminated during the year;
- The National Federation Newsletter continues to be produced quarterly and has a circulation in excess of 1500 copies. It is an important contact and reference point for organisations, both voluntary and statutory bringing people up to date in relation to issues of importance relevant to the sector;
- In all, a total of 325 communications were issued to member organisations.

■ Human Resources

The National Federation's Human Resources Sub Committee was extremely busy during 2003. Under the chairpersonship of Ms. Maura Donovan, Stewarts Hospital, it played a lead role in ensuring that member's interests were promoted and protected on a wide range of issues relating to human resources. Major highlights during 2003 were:

Special Olympics World Summer Games 2003

In a letter to Ms. Mary Davis, Chief Executive of the Special Olympics World Summer Games 2003, the National Federation of Voluntary Bodies extended its many congratulations to the organising committee, staff and volunteers on what was a remarkable and memorable World Games. The National Federation stated that everybody involved had brought great credit not just to the Intellectual Disability Sector, but the country at large.

The National Federation of Voluntary Bodies recognised that the mobilisation of 30,000 volunteers and 166 host towns presented huge opportunities for voluntary organisations to re-energise the voluntary input into their activities. In this regard, in September 2003, the National Federation had discussions with Ms. Mary Davis and arising from these discussions the National Federation agreed to support an initiative by Special Olympics Ireland relating to the development of their programme, including the ongoing development of volunteering and details of the initiative were presented to the full meeting of the National Federation on 27th November, 2003.

In support of the Special Olympics the National Federation, through the HR Sub-Committee, undertook a survey of practices within member organisations in relation to leave arrangements for those wishing to participate as volunteers in the event. A sample policy on leave for volunteers was circulated to interested members. A wide range of staff from member organisations were involved in supporting the Games.

Recruitment Advertising

During 2003, the National Federation, under the auspices of the HR Sub Committee, commenced negotiations with Independent Newspapers regarding arrangements for our recruitment advertising going forward. Negotiations were concluded in late 2003 and resulted in the National Federation having a direct business relationship with Independent Newspapers with the following benefits:

- Creative colour concept in the form of a colour template to include National Federation branding. Member organisation logo, whether in colour or mono, or any graphics to be incorporated into individual members adverts;
- Competitive rates unique to National Federation members;
- Sponsorship for National Federation Conferences;
- Quarterly review between National Federation and Independent Newspapers to include free PR regarding any event / initiative organised by the National Federation or any member organisation.

Children's First / Designated Persons

Links were established with Sandra Claxton, Children's First Information Officer, in relation to the role of designated persons. A presentation was made to the National Federation General Assembly meeting in May 2003 in relation to the National Guidelines for the Protection and Welfare of Children.

■ Health Service Employers Agency (HSEA)

In early 2003, arrangements for the official interface between the National Federation of Voluntary Bodies and HSEA were finalised as follows:

- A Sub Group of the National Federation's HR Sub Committee meets with the HSEA on a bi-monthly basis with a fixed agenda;
- Two plenary meetings between the HSEA and the wider National Federation membership every year;
- Mr. Brian O'Donnell, Chief Executive, to continue to represent the National Federation as a full member of the HSEA Board
- Ms. Maura Donovan, Chairperson, HR Sub Committee, is invited to attend meetings of the Board of the HSEA.

During 2003 regular meetings were held with the HSEA which proved to be very beneficial in providing updates on issues of concern and relevance to member organisations. Updates included Labour Court Recommendations, national policy developments, feedback on progress of Working Groups and a presentation on the Agencies Business Plan 2004-2005.

HSEA National Policy Development

HSEA Working Groups that the National Federation has been represented on during 2003 included:

- Dignity at Work – the work of this group was focused on developing a Dignity at Work Policy for the Health Service which would provide an agreed procedure for dealing with complaints of bullying and harassment.
- Serious Physical Assault – this group was established with a view to ascertaining the extent of physical assaults on employees within the general health services.

Social Care Workers / Social Care Leaders

Labour Court Recommendation No. 17368, which issued on 18th December, 2002, recommended new rates of pay and an implementation date of 1st February, 2002, in respect of Social Care Workers / Social Care Leaders in the Intellectual Disability sector. The recommendation also provides for the professionalisation of these grades and the training required for those people in these grades who do not currently hold a relevant qualification.

Following on from a meeting between the HSEA and the National Federation's member organisations held in Stewarts Hospital on 4th March, 2003, an Implementation Committee to oversee implementation of the Labour Court Recommendation was established. Its purpose was to ensure that the full extent of the cost of the deal was understood and that full funding was made available to all member organisations for implementation. The Committee also considers the transition arrangements and identifies the funding required for the training of existing staff, not holding the relevant qualification.

The National Federation's representatives on the Implementation Committee are: Mr. Tony Darmody, Kerry Parents and Friends Association; Ms. Anne Coffey, KARE; Mr. John Gately, St. Hilda's Service; Mr. Adrian Harney, Galway County Association; Mr. Liam Murphy, Brothers of Charity Cork, Mr. James Roche, Western Care Association and Ms. Maria Walls, National Federation Secretariat.

Review of Role of the Registered Nurse Mental Handicap (RNMH)

The National Federation was represented on a Working Group which was established to review the role of the Registered Nurse Mental Handicap (RNMH). The Working Group which completed its work on 18th June, 2003, made recommendations on the following:

- How the skills of the RNMH are fully utilised in the delivery and management of services to persons with an intellectual disability in a wide variety of locations;
- Initiatives to promote the RNMH as a career choice;
- The range of any additional competencies / skills now required and how they can be recognised and fully utilised.

The National Federation was represented on the Working Group by Mr. Sean Abbott, COPE Foundation, Ms. Michele Oppermann, Daughters of Charity, Mr. John Pepper, Hospitaller Order of St. John of God; Ms. Maura Donovan, Stewarts Hospital and Ms. Maria Walls, National Federation Secretariat.

■ National Joint Council

The National Federation is represented by Mr. Nessian Rickard, St. Michael's House, on the National Joint Council. In addition, three National Federation member organisation representatives were nominated to National Joint Council Working Groups to:

- Oversee the implementation of the LRC review of Industrial Relations Recommendations: Mr. John O' Dea, Western Care Association;
- Review and research recent disputes: Mr. Tom Hogan, Galway County Association;
- Devise communication / implementation protocol for agreements: Mr. Tony Darmody, Kerry Parents and Friends Association.

■ Training and Development

The inaugural meeting of the National Federation's Training and Development Sub Committee was held in March 2003. Chaired by Mr. David Kieran, key aims of the Sub Committee include facilitating the development of responses to the education, training, development and learning requirements of member organisations and acting as a network through which information and resources regarding staff training can be shared.

Elements of the Sub-Committees work during 2003 included:

Action Plan for People Management (APPM)

At the National Federation's very successful conference "*Valuing People in a Changing World*" (November 2002) implementation of the APPM in the Intellectual Disability Sector was seen as a vital component in the development and delivery of person centred services.

Following consultation with its members in early 2003, the National Federation developed a proposal to give effect to Theme 1.3.1 "*To Develop a Tailored Training Programme for Frontline Managers in People Management Skills*" and Theme 5 "*To Develop a Strategic Approach to Education, Development and Training*" of the plan. The proposal was submitted to the APPM Monitoring Committee on 8th July, 2003, and funding of €120,000 was approved by the Committee at their meeting on 7th August, 2003.

ReSpeCt Symposium

The National Federation of Voluntary Bodies, in partnership with the Irish Sex Education Network, hosted a very successful symposium in Killarney, Co. Kerry, on 5th and 6th November, 2003. Attended by some 230 delegates the symposium dealt with the issue of consent and capacity to give informed consent by people with intellectual disability in Ireland.

To be successful, such events require detailed planning and this was undertaken by the Training and Development Sub Committee, under the Chairmanship of Mr. David Kieran, who set up a Planning Committee in conjunction with the Irish Sex Education Network. The members of the Committee are as follows:

Mr. David Kieran, St. Anne's Service (Chairperson)
Ms. Geraldine Boland, St. Michael's House
Ms. Anne Coffey, KARE
Ms. Fiona Coffey, Brothers of Charity Services, and ISEN
Ms. Cathy Connolly, KARE, and ISEN
Mr. James Forbes, St. Joseph's School for the Visually Impaired, and ISEN
Mr. Gert Job, Independent Training Consultant, and ISEN
Ms. Patricia Lee, Cregg House
Mr. John Pepper, Hospitaller Order of St. John of God
Mr. Mike Rainsford, Western Care Association
Ms. Jenny Rayson, Chairperson ISEN
Ms. Maria Walls, National Federation of Voluntary Bodies
Ms. Caroline Looney, National Federation of Voluntary Bodies
Ms. Breda Casey, National Federation of Voluntary Bodies

A host of leading international and national experts, including the effective voices of people with intellectual disability and parents, presented on and debated the need for capacity legislation, the necessity for non legal guidelines, sex education practice, safety support mechanisms and implementation strategies.

Drawing on the contributions made by these speakers the symposium concluded by committing to ground breaking actions which will effectively promote the rights of people with intellectual disability to develop and enjoy healthy relationships in a safe and secure way.

Other important outcomes of the symposium included:

- The formation of an alliance of organisations to work together to shape capacity legislation and guidelines to promote the self-determination of people with intellectual disability in Ireland.
- As an interim step in the absence of legislation - the immediate development of national guidelines to enable the right of people with intellectual disability to the formation of relationships and expression of sexuality.
- The development by the Department of Health and Children of national guidelines in the management of allegations of abuse of vulnerable adults.
- The hosting of regional seminars to engage with people with intellectual disability, parents and staff to discuss consent, capacity and the process to enable the formation of relationships and expression of sexuality.

The National Federation wishes to express their sincere thanks to David Kieran and the Planning Committee for all their work.

A small Sub Committee of the National Federation of Voluntary Bodies are currently engaging with the Law Reform Commission to discuss the conference outcomes.

■ Office for Health Management (OHM)

Regular contact was maintained with the Office for Health Management (OHM) during 2003 with updates provided on new developments at Sub-Committee meetings. The OHM launched its Management Competency User Packs for Health and Social Care Professionals and Clerical / Administrative Managers and support was secured to host two 1-day seminars in relation to the use of the packs in early 2004.

The National Federation of Voluntary Bodies was represented on the E-Learning Working Group by Ms. Sarah Baars, St. Michael's House. A consultation survey was carried out to establish the views of members on the issues pertinent to the development of e-learning. Ms. Maria Walls is the National Federation's representative on the OHM Consultative Group, which meets quarterly.

■ Health Services National Partnership Forum

The Health Services National Partnership Forum was established to promote and support the development of partnership in the health and social care services in Ireland. Following the success of our initial pilot partnership committee in Western Care Association further work was done during the course of 2003 to establish new partnership committees with the assistance of our Partnership Facilitator Mr. Eamon Naughton. New Partnership Committees were established in three new member organisations during 2003 with strong expressions of interest by a significant number of others.

Training and Life Long Learning Survey

SHL consultants were commissioned, by the Health Service National Partnership Forum, to examine the current status of learning, training and development activities across all health funded services. The National Federation of Voluntary Bodies was a participant in this project and a number of Member Organisations were included within the survey. The findings of this report reinforced the commitment to training within the intellectual disability sector

■ Enhancing the Partnership / Widening the Partnership

The National Federation of Voluntary Bodies continued its involvement in the Implementation Committee as provided for in Enhancing the Partnership. During the course of 2003, the Implementation Committee, which is chaired by the Department of Health and Children, met on 3 occasions and at these meetings the National Federation raised issues arising from the operation of Enhancing the Partnership / Widening the Partnership, particularly in relation to Section 26 funding, the operation of service agreements, payment of national pay agreements by health boards to voluntary organisations and progress in relation to the Harmon / Wolfe process. Issues around core funding deficits and securing the State's interest in capital projects were also considered.

The National Federation is represented on the Implementation Committee by Mr. Tom Hogan, Galway County Association; Mr. Paul Ledwidge, St. Michael's House; Ms. Winifred O'Hanrahan, Brothers of Charity Services and Mr. Brian O'Donnell, National Federation Secretariat.

■ Quality

The primary focus of the National Federation's Quality Sub Committee during 2003 was on preparing responses to the draft National Standards in Disability Services

During the course of 2003, the National Disability Authority (NDA), in partnership with the Department of Health and Children, continued their work in the development of National Standards in Disability Services. The National Federation welcomes the development of National Standards and is represented on the NDA's Standards Advisory Committee by Mr. Brian O'Donnell, Chief Executive, National Federation Secretariat and Mr. Tom Hughes, Training and Evaluation Officer, Western Care Association.

During the last quarter of 2003, nine member organisations of the National Federation participated in piloting the implementation and monitoring of the

2nd Draft Standards. Arising from their participation in this pilot project, the service providers expressed serious concerns about the standards and the audit tool. On 17th December, 2003, a meeting was convened to share experiences between National Federation members. It was then agreed that a meeting of the wider disability sector, including the statutory service providers, would be convened again to share experiences after which time a communication would issue to the National Disability Authority and the Department of Health and Children.

■ European Affairs Sub-committee

2003 was designated European Year of People with Disabilities by the European Union. The aim of the year was to address disability within a citizenship framework and to promote equal opportunities for people with disabilities. The National Federation was represented on the National Co-ordinating Committee by Mr. Christy Lynch, KARE and Mr. Brian O'Donnell, National Federation Secretariat.

To mark the year, the National Federation's European Affairs Sub Committee submitted a project proposal for funding to the Health Services National Partnership Forum. The project involves a partnership approach between hospital, community services, intellectual disability services and parents, to develop, pilot and provide training on best practice guidelines on informing families of their child's disability.

The project was approved by the Health Services National Partnership Forum. Funding of €100,000 was allocated in Autumn 2003 and preparatory work on the project was carried out over the Autumn/Winter of 2003.

■ Vocational Training and Employment

The Vocational Training and Employment Sub Committee was busy preparing a detailed submission on behalf of the National Federation in relation to the Code of Practice in Sheltered Occupational Services. It also acted as the Irish Steering Group to the European Association of Service Providers for People with Disabilities (EASPD) LABOr Project of which the National Federation is a core partner. In recognition of its important contribution to this project it was invited by EASPD to host the concluding LABOr Conference in Ireland in 2004. Planning for this major conference by the Sub Committee commenced in the latter half of 2003.

In addition, the Committee made responses in relation to FAS Supported Employment Consortia and reviewed and proposed changes to the following documents:

- Review of Vocational Training Provision for People with Disabilities in Ireland;
- Sharing of Information on Workway Project

■ Freedom of Information

The National Federation was assigned responsibility by the Department of Health and Children to oversee implementation of the Freedom of Information Act 1997 in the Intellectual Disability Sector. Our work in this area during 2003 involved the following:

- Providing ongoing advice to the Local Area Networks;
- Providing support and advice to Decision Makers and Internal Reviewers in individual member organisations;
- Researching, drafting and circulating relevant information;
- Collecting and analysing statistical information and forwarding statistical data to the Information Commissioners Office.

■ National Federation of Voluntary Bodies Pension Scheme

The above pension scheme operates on a defined contribution basis. After intensive lobbying by the National Federation of Voluntary Bodies, the Department of Health and Children agreed to establish the Scheme in 1996 to provide retirement and life assurance benefits for its members who are those people employed in the sector not covered by the Nominated Health Services Superannuation Scheme (NHSSS).

During 2003, the Secretariat provided administrative services to the Trustees of the Scheme. In all, the Trustees met on five occasions during 2003 and entered into discussions with Irish Life regarding the Permanent Health Insurance element of the Scheme. In Autumn 2003, the Trustees engaged the services of Watson Wyatt to represent them in their discussion with Irish Life.

There were 1284 people from 21 different member organisations of the National Federation availing of the Scheme as at 31st December, 2003, and the value of the fund under management at this time was €19,154,700.

Research and Development

In our work we aim to be at the leading edge in promoting 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. We are therefore, committed to initiating and collaborating in relevant research. To this end, the National Federation of Voluntary Bodies set up a Research Sub Committee to:

- Advise the Board of the National Federation of Voluntary Bodies on research issues;
- Identify key areas of research for the National Federation of Voluntary Bodies and to exchange information and explore the potential of developing a cohesive plan of research actions;
- Assist the National Federation of Voluntary Bodies in developing research proposals for funded and non-funded research;
- Provide support for National Federation research projects through participation in project advisory committees;
- Disseminate the research undertaken by the National Federation and the member organisations, and to highlight the benefits for service users and their families;
- Encourage informal networking and to facilitate interagency cooperation on research projects among the member organisations;
- Highlight the research activities of the National Federation and its members with European Association of Service Providers to People with Disabilities (EASPD), International Association for the Scientific Study of Intellectual Disabilities (IASSID) and the National Disability Authority (NDA), and to encourage closer collaboration where appropriate;
- Debate best practice and develop guidelines in disability research based on national and international evidence.

■ Research

Since the establishment of the Research Sub Committee in March 2003, the Sub Committee has been busy with a wide range of activities, including the review of three NDA publications, listed below, with the view to commenting on them from the perspective of their application to people with intellectual disability:

- Disability Research 1996-2001;
- Guideline for Including People with Disabilities in research;
- Public Attitudes to Disability in the Republic of Ireland

In addition, the Research Sub Committee work plan has included the review of the National Disability Authority / Economic Social and Research Institute (NDA/ESRI) National Disability Pilot Study, Research Ethical Guidelines and Guidelines for Interviewing.

POMONA Project

POMONA is an EU funded project which aims to identify health indicators for people with intellectual disability. The project was officially launched in November 2002 and is being co-ordinated by the Centre for Disability Studies, UCD, together with the University of Maastricht and the University of Wales College of Medicine. In September 2003, the Research Sub Committee devised a shortlist of indicators and continues to contribute to the compilation process.

It also commenced planning for a dedicated Research Seminar to be held in early 2004. The overall aim of this seminar will be to promote the value of research in intellectual disability services, promote the link between research and practice/procedures and legislation and give a formal opportunity to launch the ethical guidelines. The anticipated outcomes of the seminar at agency level are:

- Support the value of research;
- Strategy for National Federation Members to work together;
- Brainstorm ways that National Federation Members can further develop and support research.

Quality of Life

In early 2003, the National Federation of Voluntary Bodies commenced the second phase of our flagship research project "Quality of Life of Young People with an Intellectual Disability in Ireland". The aims of this project are:

- To consult directly with children and families in order to develop new approaches towards positive quality of life outcomes;
- To identify perceived supports to positive quality of life outcomes for young persons with a disability to live full and active lives;
- To identify perceived barriers to such outcomes for young persons;
- To highlight areas where change is required.

The second phase of the project involved the use of an in-depth qualitative multi-perspective approach, exploring all aspects of the quality of life of the teenagers. The three themes of self, friends and leisure provided the focus of in-depth interviews with a number of teenagers, parents, siblings and key workers.

The emphasis will continue to focus on identifying barriers and supports to quality of life in order that the completed study might inform policy to enhance the quality of life of young people with intellectual disabilities in Ireland. It is expected that the research project will be completed in April 2004 with a full report published later in the year.

■ European Association of Service Providers for Persons with Disabilities (EASPD)

Through our involvement in EASPD, we are actively involved as a project partner in a number of EASPD led research projects as follows:

a. Daphne

Under the auspices of the Daphne Programme of the European Commission, EASPD was given the opportunity to develop and launch a *“Knowledge Centre for the Prevention of and Response to Sexual Abuse of People with a Learning Disability”*. The outcomes from this project were highlighted in the National Federation of Voluntary Bodies Respect Symposium on 5th and 6th of November 2003.

b. Tolerance and Acceptance

The National Federation of Voluntary Bodies was a co-partner in the European Tolerance and Acceptance Project that was set up in 2002 and successfully completed in March 2003. In total nine European countries were involved in the research and three of the National Federation member organisations participated in this project: Daughters of Charity, Dublin; Brothers of Charity, Waterford and the Hospitaller Order of St. John of Gods, Celbridge, Co. Kildare. The core aim of the project was to carry out research at the member state level, to establish the key aspects that promote inclusion of people with disabilities in the community. Its objectives were to:

- Identify the implications of de-institutionalisation for people with disabilities and their families, their neighbourhood, and the professionals supporting them;
- To identify models of good practice to promote the participation of people with disabilities in the community and daily life activities.

Following the completion of this project, an on-line knowledge centre was established, which guides visitors through models of good practice in relation to the promotion of participation of people with disabilities in community activities. The closing conference of the Tolerance and Acceptance Project was held in Graz, Austria in March 2003. The conference report (A Life Like Everybody Else) offers some recommendations for service providers, which will be helpful to member organisations in setting up community based living arrangements and promoting inclusion of people with disabilities.

Throughout this project EASPD was interested in the degree to which people with disabilities, service providers and authorities working together can combat discrimination in European community based settings.

c. LABOR

The National Federation of Voluntary Bodies is a co-partner in the LABOR Project, which is a project financed by the Leonardo da Vinci programme of the European Commission and run by EASPD, together with sixteen service providers and research institutions throughout Europe. This project grew out of the need to bring together materials on training and employment measures for people with intellectual disabilities and to improve the flow of this information throughout Europe. Its central objective is to establish a Knowledge Centre to enhance the information flow and exchange of good practice in the area of

improving vocational training and employment opportunities for people with intellectual disability throughout Europe. The concrete output of LABOr is a website (www.start-labor.org) with database and helpdesk.

During 2003, under the auspices of our Vocational Training and Employment Sub Committee, we continued to survey member organisations and other key stakeholders with a view to identifying models of good practice for consideration in the context of the European Project.

At the invitation of EASPD, the National Federation has agreed to host the LABOr Project final conference in 2004. This leading European Conference will provide a forum to consider the findings of the project and examine current EU policies regarding disability and employment.

d. Europe, a Place to Live

This project, in light of the European Year of People with Disabilities, started from the principle that all European citizens should be listened to, and specifically aimed at giving a voice to people with a more serious intellectual disability. A seminar was organised in Belgium to celebrate the European year involving participants from a broad range of countries.

■ Person Centred Medication Management

In April 2002, following the expressed interest by member organisations, the National Federation of Voluntary Bodies issued a questionnaire to all member organisations with the purpose of gathering information on practice and discussion on the development of policy guidelines in the area of medication administration. In response to the results of this survey, the National Federation of Voluntary Bodies established a Working Group in February 2003 to examine how best to support practice in this area having regard to best practice both in Ireland and internationally. The Working Group has a wide range of professional representation, including significant nursing representation and specific representation from An Bord Altranais, the National Council for the Professional Development of Nursing and Midwifery, Centre for Disability Studies (University College Dublin) and the Department of Health and Children's Nursing Advisor in Intellectual Disability, as well as representation from member organisations of the National Federation of Voluntary Bodies.

During the course of 2003, the first phase of this project, which involved developing Person Centred Medication Management Policy Guidelines, progressed to an advanced stage and by end of December 2003 the Working Group had signed off on 80% of the policy guidelines document. In 2004, it is our intention to enter into a wider consultation on its contents with the key stakeholders, including people with intellectual disabilities and their families, pharmacists, medical practitioners and organisations such as the Irish Nurses Organisation, Irish Medical Council and NAMHI.

In the latter part of 2003, the Working Group commenced the second phase of this project, which explored the potential for developing a national accredited training programme for people with intellectual disability, organisation delegated staff members and significant others, e.g., parents, within the member organisations of the National Federation of Voluntary Bodies. To date, the Person Centred Medication Management Working Group has reviewed both

national and international training programmes and is currently in the process of formulating key proposals for the development of a national accredited training programme.

We would like to take this opportunity to thank all the member organisations for the information and support provided to date. This continued support has enabled us to respond to the expressed interest in facing the challenges of developing best practice in medication management in the context of promoting inclusion, participation and contribution of people with intellectual disability.

Person Centred Medication Management Working Group Members:

Mr. Peter Boland, St. Ita's, Portrane
Ms. Brigid Bulter, St. John of Gods Services
Ms. Carmel Byrne, St. Michael's House
Ms. Hilary Coates, Beaumont Hospital
Ms. Deirdre Fay, Brothers of Charity Limerick
Ms. Marie Grimes McGrath, St. Anne's Services
Ms. Heather Hogan, Sisters of Charity of Jesus and Mary
Ms. Christine Hughes, National Council for Nursing and Midwifery
Mr. David Kieran, St. Anne's Roscrea
Ms. Christine Linehan, UCD
Ms. Sheila Macken, Brothers of Charity Roscommon
Ms. Audrey Mee, St. Hilda's, Athlone
Mr. Richard Morton, Co-Action West Cork
Ms. Mary McArdle, Department of Health and Children
Ms. Una Nagle, Brothers of Charity, Cork
Ms. Linda O'Leary, Dara Residential
Ms. Anna Plunkett, St. John of God, Drumcar
Ms. Janet Swinburne, National Federation of Voluntary Bodies
Ms. Luck van Erwegen, Sisters of Charity of Jesus and Mary
Ms. Kathleen Walsh, An Bord Altranais
Mr. Joe Wolfe, Joe Wolfe and Associates
Ms. Maria Walls, National Federation of Voluntary Bodies