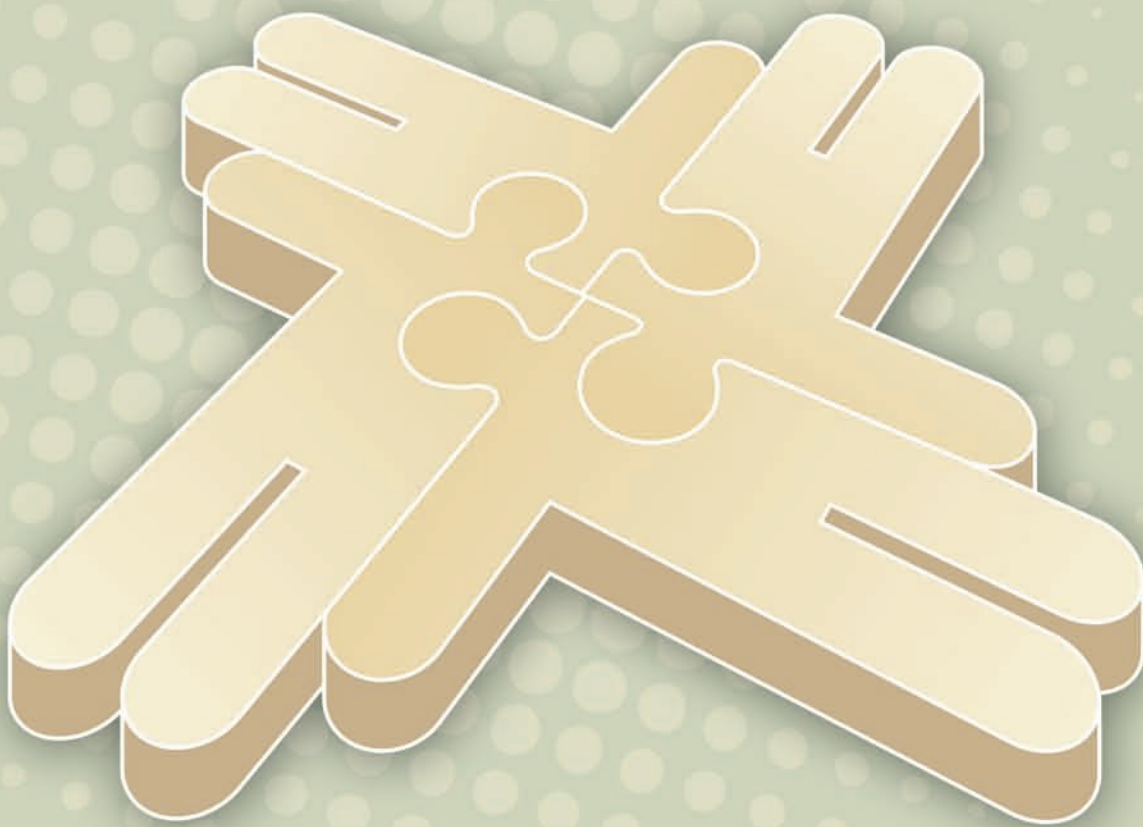

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

RESEARCH STRATEGY 2008-2013



AUGUST 2008

Foreword

The guiding principle which has underpinned the planning and delivery of services and supports to people with disabilities over the past 10 years in particular, is that people with disabilities 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 the life of 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 engendered much hope and expectation in people with disabilities, their families and friends and the organisations who support them. Of course, these expectations also create challenges for service providers. As a National Federation of Voluntary Bodies we acknowledge that to be truly person centred in our approach we need to recognise the imperative for us to transform the way we operate and develop more innovative and creative responses. Accordingly, we are in the process of developing a new strategic direction with the central objective of ensuring that we are fit for purpose, that what we provide is relevant and responsive to the needs of every individual we support.

Key to the achievement of this objective is an assurance that what we do is evidence based. In this regard, we recognise that appropriate high quality research is a necessary pre-requisite to ensuring best practice in service development and delivery, and in policy formulation. We have therefore developed a supporting research strategy which has been developed through extensive consultation with our member organisations and people who use our services, and which is outlined in the pages which follow.

In conclusion, I would like on behalf of the National Federation of Voluntary Bodies to convey my sincere gratitude to our excellent Research Sub-Committee, who have developed this strategy under the leadership of Dr. Brian McClean and supported by our Director of Research & Policy Development, Ms. Edel Tierney. I am confident that its contents will play a key role in ensuring that our overall objective of providing services and supports, which accord with or exceed best international practice, will be achieved.



Signed:

Brian O'Donnell,
Chief Executive

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Introduction

The objective of this Research Strategy is to set out a vision for the research activities of the National Federation of Voluntary Bodies for the next six years (2008-2013). The National Federation of Voluntary Bodies is committed to the dissemination of knowledge and the promotion of world class research. To provide high quality services to people with intellectual disabilities the field of intellectual disability must have a foundation of high quality research. The strategy aims to develop a positive environment of discovery and learning which will help people with intellectual disabilities, their families, the wider community, service managers, front-line staff, policy makers and researchers determine what is good practice. Above all, research should contribute to the quality of life available to people with intellectual disabilities.

Prior to the development of this research strategy, the opinions of member organisations were sought in a series of conferences on the relevance of research to them as services providers. In 2004 the value of research was examined and the ingredients of a good research strategy were explored; in 2006 specific research issues in mental health were examined and in 2007 innovative practices in services and supports were explored.

Following a series of meetings, the Research Sub-Committee of the National Federation of Voluntary Bodies agreed that the following principles underpinned the research strategy:

- To undertake research which will lead to a better quality of life for people with intellectual disabilities who use our services;
- To promote and disseminate research among member organisations;
- To focus on a number of relevant and timely themes to maximise the quality and impact of research projects. These themes will be interdisciplinary and inter-organisational to maximise the strength of the National Federation;
- To encourage research collaboration with academic and other research centres where appropriate;
- To conduct research which will drive national policy and respond to current key issues;
- To benchmark research conducted against a list of key outcome measures.

It was agreed to pursue an extensive consultation process throughout our member organisations. This meant consulting with people who use services, staff and management in service provider member organisations and people with a specific interest and working in intellectual disability research in member organisations.

The strategy which follows reflects a wide diversity of opinion and perspective. Yet it is a coherent vision for future research in Ireland because it recognises:

- The importance of advocacy and social inclusion in research activity and the need for inclusive and participatory research methods;
- That a strong evidence base is needed to understand the health, wellness and quality of life of persons with intellectual disability. This evidence base should drive policy and respond to issues and be used to benchmark ourselves internationally;
- That the National Federation has the potential and scope to promote world class research;
- That the research strategy should lead to a measurable increase in the quality and quantity of research conducted in Ireland;
- The need for people with intellectual disability to be included in any generic population studies.

Consultation with member organisations and people who use services included the following stages.

- Consultation 1: Research Sub-Committee consultation
- Consultation 2: Consultation with member organisations via email questionnaire
- Consultation 3: Consultation with Advocacy / Self-advocacy Groups
- Consultation 4: Consultation with the National Federation Secretariat
- Consultation 5: Consultation with the National Federation of Voluntary Bodies Board of Directors

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 partnerships/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.

An action plan was developed to achieve each of these Priorities in the timeframe 2008-2013.

These action plans are outlined in the following pages.

Priority 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*

Following extensive consultation with Chief Executive Officers, managers, frontline staff and people who use services and earlier consultations as outlined in Appendix VI, priority topics were identified for the Research Strategy. These themes are interdisciplinary and inter-organisational and will maximise on multiple resources and networks available to the National Federation of Voluntary Bodies.

The 11 priority topics of the National Federation of Voluntary Bodies Research Strategy are listed below:

- **Living options**
- **Quality of Service**
- **Community inclusion / integration**
- **Relationships**
- **Money**
- **Ageing**
- **Challenging behaviours**
- **Family Supports**
- **Staff resources**
- **Employment**
- **Early Intervention**

Action Plan to Achieve Priority 1:

1. The 11 topics identified through the various consultations are the priority areas for research in the National Federation of Voluntary Bodies for the period 2008 – 2013.
2. Following this identification of topics potential funding opportunities to pursue these priorities will be explored.
3. Research proposals will be developed as opportunities arise.
4. National Designated Experts (Priority 2) will support information on these key themes. Information will be posted to the National Federation of Voluntary Bodies website.
5. Priorities will be matched with expertise from a panel of research collaborators nationally and internationally as outlined in Priority 6.
6. National Designated Experts will continue to support development of knowledge and expertise in these key areas and advise on development of research proposals.
7. Raw data from this consultation process will be used again in the development of future research proposals and activities.

Priority 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 topics thus enhancing the knowledge base among members through the National Federation of Voluntary Bodies website*

Consultation through meetings and discussions with the Research Sub-Committee lead to the identification of key topics of interest to member organisations. Consultation with service user groups (Inclusive Research Network, Seasmh, and Community Participation & Inclusion Sub-Committee) identified topics relevant to people who use the services. These key topics were also drawn from the questionnaire analysis and consultation with people who use services/advocacy groups. These topics were deemed to be relevant to member organisations by the Research Sub-Committee for research and information purposes. A list of these topics was drawn up and key experts in Ireland were identified as '*National Designated Experts*' who would provide information on reading and assessment materials on these topics. These experts were contacted and invited to become National Federation of Voluntary Bodies National Designated Experts in these key areas for a period of one year.

Role of National Designated Expert:

- The role of the designated expert shall be to support member organisations (or researchers within organisations) develop their knowledge further on a particular topic of interest. Designated experts will also be asked to become an associate member of the Research Sub-Committee to advise the committee as occasion arises on issues arising in these areas of expertise.
- The tenure of the designated expert shall be initially for a period of one year and will be reviewed at the end of this period.
- Designated experts will be expected to provide an updated recommended reading list on their area of expertise and this will include a list of recommended assessment tools/research instruments in this area.
- This list of reading materials shall be made available through the National Federation of Voluntary Bodies website and will be updated at least biannually.
- Designated experts may choose to assign a PhD student or colleague to undertake the maintenance of this material under their supervision, or they may contact a network of people who are working in this area to support them in this role.
- In addition designated experts may recommend that certain tools or assessment materials be used in national studies across this area so that research comparisons may be made on a national level.

Action Plan to Achieve Priority 2:

A complete list of topics of expertise be drawn up and posted to the National Federation of Voluntary Bodies website.

1. Identify a list of topics relevant through consultations with the Research Sub-Committee and service user groups.
2. Identify National Experts in these areas.
3. Contact potential National Designated Experts to discuss their involvement.
4. A complete list of topics and designated experts be drawn up and posted to the National Federation of Voluntary Bodies website.
5. Each designated expert will draw up a list of recommended reading and assessment materials in their area of expertise and make these available through the National Federation of Voluntary Bodies website.
6. After a period of one year the role and tenure of the designated expert shall be revised in consultation with the experts at which time the topics may be expanded to include other areas of interest to members and experts may choose to continue in this role or an alternative expert may be chosen.
7. The topics of interest shall lead to the development of special interest groups (this may be a smaller list than the list of topics currently identified).

Priority 3: Develop quality indicators for research in intellectual disability and guidelines for evidence based practices

Early consultation prior to the development of the Research Strategy and the 5 stages of consultations in the development of the strategy both identified the need for evidence based practice and guidelines on developing quality indicators. This would enable services, researchers and people with disabilities assess the quality of research evidence. It was suggested that the most suitable way to assess quality of research was to develop a grading system or quality indicators for research methods.

High quality research should help managers, supervisors, front-line staff, parents, policy makers and researchers determine what is good research; i.e., separate practices that have a strong record of effectiveness from those practices that have little or no evidence. High quality intellectual disability research should provide an understanding of factors in services and society that influence how 'evidence-based' practices work in the real world. Intellectual disability research should contribute to the quality of life for individuals with intellectual disability and their families. Quality indicators will be particularly useful for individuals involved in research in intellectual disability in Ireland and for policy makers developing national policy.

The need for multiple research methodologies in intellectual disability research is imperative because of the heterogeneous characteristic of the population and the types and severity of disabilities among people in member services.

Research methodologies in intellectual disability could be organised in two categories that share common indicators of high quality e.g., experimental and quasi-experimental group designs, single subject designs, correlation designs, qualitative designs and participatory designs.

The process of creating quality indicators has been conducted by other professional organisations. However, these indicators whilst applicable to other fields of research will focus specifically on the methodologies used most often and most suitable to intellectual disability research.

Beyond identification of indicators of high quality research Priority 3 will propose how research findings can be used as evidence for effective practices. This has particular application for intellectual disability services and was mentioned repeatedly by respondents as an area they would like support with.

The development of indicators and guidelines will provoke discussion and foster reflective practices in professionals and research, practitioners and policy makers. Over time they may be developed and revised as more evidence and research emerges. These guidelines will provide a solid basis to examine evidence of best practice in Services.

Action Plan to Achieve Priority 3:

To support and promote high quality research in Intellectual Disability, the National Federation of Voluntary bodies will:

1. Establish a taskforce on quality indicators for research in intellectual disability;
2. Identify the types of research methodologies most commonly used in intellectual disability research;
3. Establish a set of quality indicators for these research methodologies;
4. Develop guidelines for identifying practices that are evidence based;
5. Position papers on quality indicators and guidelines using different research methodologies will be produced;
6. These will examine each methodology, its use in intellectual disability research,
 - its contribution to the understanding of specific topics in intellectual disability research,
 - its applicability,
 - the types of research methods within each category,
 - the contribution of this category of research to intellectual disability research using existing literature;
7. Each discussion paper will focus on the quality indicators for this type of research method e.g. qualitative research and the evidence for policy and practice.

Priority 4: Measure performance of research activities

There is a strong need to measure performance of research activity in order to evaluate how well research in the National Federation of Voluntary Bodies is performing. This may be done in collaboration with internationally recognised institutions to develop the National Federation's reputation e.g. collaboration with renowned universities, and researchers in order to evaluate how well research in the National Federation is performing.

The three key performance indicators will be:

- a) Publication in peer-reviewed journals, etc. – Whether or not the research undertaken is published will indicate the measure of performance of the research;
- b) Measurable impact on policy and practice – The relevance and impact of the research on policy and practice;
- c) Formal and informal feedback through service users on improvement of services etc.

Collaboration will take place with the Research Collaborators as explained in Priority 6 to measure our performance in comparison to other research centres.

Action Plan to Achieve Priority 4:

- 1. Consult with Research Collaborators on the development of Guidelines for Performance Measurement.
- 2. Review previous research completed to measure its performance in relation to the quality indicators outlined in Priority 3.
- 3. Develop Quality Research Proposals with National and International Centres, as outlined in Priorities 3 and 6.
- 4. Develop successful applications for funding.
- 5. Compare published research annually.
- 6. Increase the number of national research partnerships following the launch of the Research Strategy.
- 7. Develop a mechanism for feedback "How are we doing?" from services, service user groups and collaborators.

Priority 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*

The role of the Associate Member shall be to advise the Research Sub-Committee on areas or topics as occasion or circumstance arises. They may be chosen from the list of National Designated Experts or may be people interested in other areas. In addition when experts have agreed to become a National Designated Expert they also assume the role of associate member of the Research Sub-Committee. Other Associate Members may be identified as research projects or activities require.

Action plan to Achieve Priority 5:

1. The list of associate members will be drawn from the list of key designated experts in Priority 2.
2. Agreement will be sought from associated members/ experts on key topics for a period of one year as per Priority 2. During this year experts may be asked to advise the committee on their expert topics as occasion arises.
3. After a period of one year the role and tenure of the associate members shall be revised in consultation with them.
4. Additional Associate Members may be invited to the panel.
5. Associate members may also be asked to sit on advisory boards or scientific committees for research projects as proposals and projects are developed.

Priority 6: Develop research partnerships/collaborations with national and international research centres

Consultation prior to and during the development of the research strategy identified collaboration as vital to the development of quality research initiatives. In its development of the Research Strategy, the Research Sub-Committee agreed that it would be beneficial to work in partnership/collaboration with research centres both nationally and internationally. It was felt that such partnerships could support the strategy by encouraging research collaboration on mutual topics of interest deemed relevant to member organisations. The purpose of these collaborations will be to share information and resources and engage in research activities such as advisory boards, ethics committees etc. Collaborations will also support applications for funding and ultimately develop world class research projects in the field of intellectual disability.

Action Plan to Achieve Priority 6:

1. Following the consultation process a number of research centres will be identified as potential collaborators for future research.
2. A list of these centres, in Ireland and internationally, will be drawn up and contacted regarding potential collaboration.
3. A letter of invitation will be issued to invite Research Partners to work in collaboration with the Research Sub-Committee initially for a period of one year and will be reviewed at the end of this period.
4. When collaboration has been agreed information regarding each research centre will be posted on the National Federation of Voluntary Bodies website.
5. Collaborators will meet regularly to discuss relevant ideas and goals and to discuss potential areas of collaboration.
6. Research proposals and applications for funding will be developed on agreed topics as occasion arises.

Priority 7: Develop a capacity to advise on how research could be funded in the future

One of the principles of the Research Strategy is to identify potential sources of funding for research projects and to develop a capacity to advise on research funding opportunities.

Action Plan to Achieve Priority 7:

1. Draw up a database of potential funders for research.
2. Identify funding opportunities which arise each year.
3. Match funding opportunities to priority research topics as identified in Priority 1.
4. Develop research proposals/applications for funding as opportunities arise as per Priority 1.
5. Funding opportunities for research will continue to be advertised and promoted through the National Federation of Voluntary Bodies' website and newsletters.
6. Training workshops for developing funding proposals will be promoted.

Priority 8: Develop a register of disability stakeholders

Early consultation and analysis of the questionnaire described the need for a national register of researchers in intellectual disability or the development of a disability stakeholders database. The disability stakeholders register will be established as part of this strategy. This will consist of organisations, government departments, statutory and non-statutory bodies, people with disabilities and family members. The purpose of this register is to identify people who may be consulted on disability research issues from time to time. People will be self selected or self-nominated to this register.

Action Plan to Achieve Priority 8:

1. In Consultation 2, Question 4 of the questionnaire asked for contact names in organisations. These names will form the basis of the researcher register.
2. An invitation to become a member of the stakeholders register will be issued on the National Federation of Voluntary Bodies website.
3. This register may include people who use the services, staff, management, family members, as well as researchers.
4. As members of the Disability Register, members will agree to be contacted as issues arise e.g. consultation groups, focus groups etc.
5. All Registers will comply with Data Protection Legislation.

Priority 9: Continue to develop a register of intellectual disability research as per National Federation of Voluntary Bodies website

As per early consultations, the Research Sub-Committee had previously developed a database of intellectual disability research undertaken by our member organisations. This database, which is a register of all known intellectual disability research projects undertaken in member organisations and dating back to 2000, is posted on the National Federation of Voluntary Bodies website www.fedvol.ie

This database will continue to be a priority of the research strategy 2008-2013 as a source of reporting what intellectual disability research has been carried out in Ireland.

The register has been updated to 2008 and this will be an annual activity of the Research Strategy.

Action Plan to Achieve Priority 9:

1. Template for submitting abstracts to the register will be developed which can be downloaded and completed
2. Using this template, reminders will be sent to organisations annually to return.
3. The database will be updated on an annual basis.
4. The database will be used as a reference tool for the Research Sub-Committee and for other researchers in the National Federation of Voluntary Bodies.
5. The database of research abstracts will be monitored to assess types of research and quality of research being conducted in Ireland in member organisations.
6. A system of quality assurance will be developed as outlined in Priority 3.

Priority 10: Develop a National Research Ethics Committee

Early consultations called for a national approach to dealing with ethical issues in Intellectual Disability research and guidelines in this area.

A National Research Ethics Committee will vet, overview and examine national research proposals to ensure the highest ethical standards are maintained in accordance with best international research practice and ensure the maximum benefit to the disability community from outcomes of the projects. Members of the National Research Ethics Committee will be drawn from representatives of 63 member organisations and the panel of National Designated Experts and /or Research Collaborators.

The function of the National Research Ethics Committee is not to replace or supplant any existing Ethical Committee of any member organisations. However it will be available to member organisations that do not have their own ethics committee and may be available as a single Ethics Committee where a research project is being conducted in multiple member organisations, should that be the wish of the member organisations.

The development of a National Ethics Committee will take cognisance of the national guidelines which exist on membership of ethics committees (for example, Operational Procedures for Research Ethics Committees: Guidance 2004, The Irish Council of Bioethics) and the procedures recommended in developing such a committee.

Action plan for Priority 10:

1. Terms of Reference of National Research Ethics Committee will be drawn up by Research Sub-Committee.
2. Role and Tenure will be approved by the National Federation of Voluntary Bodies Board of Directors.
3. Invitations will be issued to suitable candidates for a National Research Ethics Committee.
4. The Research Ethics Committee will vet and overview national research project applications for ethical approval.

Priority 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*

Early consultation and submissions received from service user groups called on the National Federation to encourage greater service user participation in research, there was also a consistent request for services to listen to people who use their services.

Issues of advocacy arose repeatedly in all submissions to the research strategy.

The Research Sub-Committee, in the development of the Research Strategy, saw an opportunity to work with the Inclusive Research Network (IRN) in developing expertise in finding out from people with disabilities the topics that they would like to have researched and to incorporate these choices into the Research Strategy as outlined in Appendix VI (iii).

Extensive consultation also took place in developing this strategy through consultation with the Community Participation and Inclusion Sub-Committee, and the Seasmh Parliament. (See Appendix VI (iii)) Development of these research approaches will ensure the participation of people with intellectual disability in research activities of relevance to them.

Priority 11 is an overarching priority. The process of listening to and consulting with people who use services is applicable across priorities 1 through to Priority 12.

Action Plan to Achieve Priority 11:

1. The National Federation of Voluntary Bodies will continue to work with the Inclusive Research Network in supporting research that includes people with intellectual disability. People with intellectual disabilities, as the researchers, will be given the opportunity to express their views and in so doing influence the types of research conducted within the National Federation.
2. The Inclusive Research Network will develop participatory research training through regular workshops.
3. Themes for workshops will be identified from Priority 1.
4. The National Federation will continue to support the Transfer of Knowledge (TOK) Project at the National Institute for Intellectual Disability, Trinity College Dublin (see Appendix IV (viii))
5. It will also continue to develop Participatory Research methodologies in national projects to enable participation of people with intellectual disabilities in research topics of interest.
6. There will be a commitment to developing 'easy to read' materials (for example, a version of this strategy in 'easy to read' format will be developed) as requested from service user consultation processes.
7. Over the next 6 years, we will continue to consult with people who use services on research topics and;
8. Encourage people who use services to register on disability stakeholder register as outlined in Priority 8.

Priority 12: Review the Research Strategy Annually

The role of the Research Sub-Committee will be to monitor and evaluate the research strategy. This may take several formats.

Action Plan to Achieve Priority 12:

1. The Research Sub-Committee will monitor the progress in implementing the strategy and in achieving its overall objectives on a regular basis.
2. It will review strategic actions annually.
3. It will monitor time lines of projects.
4. It will publish, annually, an update of research actions achieved.
5. It will measure quality of research as per Priority 3.
6. It will measure Performance as per Priority 4.

The Next Six Years – Challenges & Opportunities

This is the first National Intellectual Disability Research Strategy in Ireland. The object of the Research Strategy is to set out a vision for the research activities of the National Federation of Voluntary Bodies for the next 6 years (2008-2013). The Research Strategy, developed in consultation with the Research Sub-Committee, the member organisations and advocacy / self-advocacy groups, sets out 12 priorities or objectives to be developed over this time frame. These 12 priorities are interlinked and will be used together to drive research forward.

The National Federation of Voluntary Bodies will use the 11 priority topics as detailed in **Priority 1** as a basis for future research proposals both internally and in partnership with Research Collaborators. The National Designated Experts will be consulted on research proposals in their topic of expertise, and will be a source of information and advice to researchers and others interested in these topics (as per **Priority 2**). As occasion arises, they will be invited to Research Sub-Committee meetings as associate members to advise the committee on particular issues, as outlined in **Priority 5**. The table of National Designated Experts will be posted onto the National Federation website, and will be reviewed regularly by the Research Sub-Committee. These experts will provide researchers with an effective base from which to develop research proposals and will be a source of up-to-date information on topics that are important in Intellectual Disability Research. Researchers will also have a database of Intellectual Disability research available to them through the Intellectual Disability database available through the National Federation Website as outlined in **Priority 9**.

Research collaborations, as detailed in **Priority 6**, will also form a major part of the strategy. The purpose of these collaborations will be to share information and resources, support funding applications and engage in other research activities as the occasion arises to develop world class intellectual disability research. Such partnerships will increase the opportunities for funding of national projects as is envisaged by **Priority 7**. This priority also aims to develop the capacity to advise member organisations about opportunities that exist for them to pursue funding in their own right and an ability to advise on pursuance of funding.

The Research Strategy aims to have a foundation of high quality research in order to provide high quality services to people with intellectual disabilities. To this end, the Quality Indicators and Performance Measures as explained in **Priorities 3 and 4** provide a basis for measuring quality and performance of research, to assess research carried out. These priorities will also form the basis for research collaborations with other research centres to measure quality and performance of joint research proposals. The aim of these research collaborations is to ultimately develop world class research projects in the field of intellectual disability, and quality indicators and performance measures will help gauge the degree to which this aim is achieved.

The most important aspect of the National Federation of Voluntary Bodies Research Strategy 2008-2013 is that any research carried out will be done in consultation with the 63 member organisations of the National Federation, and in participation with people who use the services. **Priority 11** outlines some of the initiatives for listening to people, consulting with them and developing research proposals and projects based on the outcomes of participation and inclusion. A National Research Ethics Committee as envisaged in **Priority 10** will advise on national research projects and where the need arises will make available the opportunity to vet projects for ethical approval. The register of disability stakeholders outlined in **Priority 8** will support the development of the entire strategy by having available a stakeholders register whereby people with disabilities, researchers, service providers and families can be consulted on issues of importance and these people will act as a consultation group on topics under investigation.

Finally to evaluate how effective the Research strategy is and the goals achieved, the strategy will be reviewed on an annual basis (**Priority 12**). This review will form the basis for reflection on achievements to date but will also serve as an action plan for the years ahead and be a driver of the national research agenda for the next 6 years.

It is anticipated that the enactment of this research strategy will contribute greatly to our understanding of intellectual disability and will demonstrate the contribution that quality research can make to this knowledge. Such knowledge will result in a better quality of life for people who use services and enable providers of services to develop and enhance the delivery and quality of the services they provide.

Ultimately we envisage that the National Research Strategy such as the one outlined has the capacity to inform policy makers and government about issues of importance to people with intellectual disabilities and their families.

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Appendix 1 - Introduction

i. Who are the National Federation of Voluntary Bodies?

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability is a national umbrella organisation for voluntary/non-statutory agencies that provide direct services to people with intellectual disability in Ireland. The umbrella organisation is supported by a dedicated secretariat. In all, the National Federation comprises some 63 affiliated organisations who between them account for in excess of 85% of this country's direct service provision for people with intellectual disability. The National Federation's members employ approximately 15,500 staff covering a wide range of professional disciplines providing services and supports to over 22,000 people with 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.

ii. Historical Context

The National Federation of Voluntary Bodies traces its roots to the pioneering service-providers who responded to unmet need in the area of intellectual disability in the 19th Century – They were voluntary committees such as Stewarts Hospital and religious congregations like the St John of God Brothers and the Brothers of Charity. A second wave of development took place in the 1950s and 1960s, a period which witnessed the emergence of a number of voluntary Parents and Friends-governed organisations.

The National Federation of Voluntary Bodies was formally established in 1970 as a result of implications from the 1970 Health Bill. This bill proposed the setting up of Health Boards that service providers would be answerable to and funded by. The leaders of the service providers set up the National Federation to consider the implications of the Health Bill and to meet with the Department of Health to discuss these changes. The Federation met on a regular basis throughout the 1970's and 1980's, with no formal membership and no subscription. Federation meetings provided an ideal opportunity for the agencies to compare notes and share experiences of dealing with the different Health Boards throughout the country. In time Federation Sub-Committees were established to deal with issues such as Training, Human Resources, Education, Database and European Affairs and more recently Research.

Service provision within the intellectual disability community is distinctive in many respects against the backdrop of health and personal social services. Most significant in this regard has been the move from a medical-and-

therapy-focussed model to a social model. This change in orientation has been well embedded over the past 15-20 years. The National Federation of Voluntary Bodies construe their role as promoting inclusion, expanding and deepening participation in one's local community and society in general, safeguarding and reinforcing citizenship. Evidence based research on service issues, service development and the personal lives of people is one way to develop this sense of citizenship.

A strong partnership relationship with the statutory bodies has also been a prominent motif over the past 15-20 years. This partnership extends across the domains of mapping unmet need, reviewing service models, developing a working consensus around the allocation of finite resources. Research has been central to this mapping process.

Perhaps the most distinctive feature within our services has been the emergence and consolidation of the commitment to person-centeredness as a guiding principle. At the heart of this version of person-centeredness are the principles of sharing power and self-determination. Authority and expertise reside in the citizen with disability. Planning is done *with*, not *for* or not *to*, the consumer.

The National Federation of Voluntary Bodies has also had a long tradition of advocacy. Their origins were a concrete expression of advocacy – and for many decades they highlighted unaddressed need and the urgent need for quality enhancement. With the emergence of broad rights-based advocacy across a range of excluded groups, the National Federation, as an umbrella of service-providers, have come to recognise citizens with disability and their families as the primary and pre-eminent advocates.

Looking to the Future

The National Federation of Voluntary Bodies envisage a service-provision world unfolding over the next decade which is more complex, more differentiated. Service providers offering a standardised response will become outdated. Self-directed services will have a much larger presence. Configurations of support combining and blending informal supports, non-Department of Health statutory supports, generic primary care supports, and specialist-provider supports will be much more evident. A (hopefully significant) proportion of the population who are currently in situations of wraparound support will move to more mixed support arrangements. The presumption that the 4-or 5-bedded community group home will continue as the default residential option will be tested. A significant number of individualized residential options will have been developed. There will be a major transfer of power from the service provider to the citizen with disability. Research is central to this movement. Through evidence based research we can map these changes from standardised supports to individualised approaches, from a service provider approach to a person centred approach.

The future will be about extending choice and control. Control will ultimately reside with the fund holder. There will be a very significant increase in the numbers of citizens with disability who opt to control and direct their own

funding, many through family-governance mechanisms. We welcome such changes – confident of our capacity to meet this challenge and to retain relevance and value in this radically different world. (In fact many of these themes and challenges were grist for the mill at our recent annual conference as outlined in Appendix V (iii)) Research will assist us to meet this challenge in a coherent and appropriate fashion.

iii. Persons with Intellectual Disabilities in Ireland

The main sources of information on the incidence of intellectual disability in Ireland are the National Census 2006 and the National Intellectual Disability Database (NIDD). The National Intellectual Disability Database is maintained by the Health Research Board (HRB). There were 25,613 people registered on this database in April 2007. 24,898 people with intellectual disability were in receipt of services, representing 97% of the total population registered on the NIDD. This is the highest number of people recorded as in receipt of services since the database was established in 1995. In contrast with these figures, the National Census 2006 reported 70,869 persons with a learning or intellectual disability. This would suggest that there exists a large 'hidden' population of persons with intellectual disability who do not avail of a service and who have not registered on the National Intellectual Disability Database.

Appendix II - Current Disability Climate

What are the values and current climates that are changing the way in which services are delivered in Ireland? What are the policy initiatives which are the drivers of force in Ireland? What are the ongoing developments at Irish and world wide level which influence the development of this strategy?

A more person-centred approach to how people with disabilities are viewed and treated in Ireland and world wide is evident in the trend of Irish and world legislation in recent years. People with disabilities are no longer seen as 'objects' or 'subjects' to be pitied but rather as a person first who have the same rights as every other Irish citizen. The disability rather than been seen as central to the person themselves as in the 'medical model of disability' has shifted to be a problem of society as in the 'social model of disability'. The core values of dignity, autonomy and equality underlie these changed views.

The recent Irish legislation is in place to protect and promote these core values.

i. National Disability Strategy

The National Disability Strategy, which underpins the participation of people with disabilities in society, was launched by the Government on 21 September, 2004. The Strategy builds on existing policy and legislation including:

- Employment Equality Act 1998;
- Equal Status Act 2000;
- Equality Act 2004;
- Education of Persons with Special Educational Needs Act 2004;

And on the policy of mainstreaming services for people with disabilities within the State agencies that provide the service to citizens generally. The Strategy is comprised of 4 elements:

1. Disability Act 2005
2. Citizens Information Bill 2006
3. Government Sectoral Plans
4. Multi-Annual Investment Programme

This legislation was an indication that Ireland was moving away from simple non-discrimination legislation to a more comprehensive approach to disability legislation which will become the major driver for change to benefit

people with disabilities in Ireland. It has been described as 'sitting half way between the US civil rights model (with its traditional emphasis and perhaps over dependence on non-discrimination law) and a new European social model in the disability context' (Centre for Disability Law and Policy Strategic Plan page 14).

The disability strategy outlines a wide variety of positive action measures which support people on a statutory footing.

1. Disability Act 2005

The Disability Act 2005 establishes a basis for:

- An independent assessment of individual needs, a related service statement and independent redress and enforcement for persons with disabilities. Part 2 of the Act refers to Assessment of Need together with Service Statements which set out which of the identified needs can be met and how this will be affected. An appeals mechanism is in place which is largely administrative. The success of this new system is crucial and will require monitoring and research to determine success or failure;
- Access to public buildings, services and information;
- Sectoral plans for six key departments which will ensure that access for people with disabilities will become an integral part of service planning and provision;
- An obligation on public bodies to be pro-active in employing people with disabilities;
- Restricting the use of information from genetic testing for employment, mortgage and insurance purposes; and
- A Centre for Excellence in Universal Design.

The Disability Act was enacted by the Houses of the Oireachtas in September 2005. Moreover, the Act also placed the process of mainstreaming on a solid legislative footing by specifically requiring six key government departments to take an active approach and produce sectoral plans to ensure maximum and efficient delivery of services to people with disabilities across these government departments.

2. Citizens Information Bill 2006

The Citizens Information Bill 2006 was launched on 13 October 2006 by the then Minister for Social and Family Affairs, Seamus Brennan, T.D. (R.I.P.) The Bill, formerly known as the Comhairle (Amendment) Bill 2004, is a key element for the Government's legislative programme for improving services for people with disabilities and will facilitate the introduction of a new Personal Advocacy Service. The Bill also facilitates a change of name for Comhairle. It is now known as the "Citizens Information Board".

3. Sectoral Plans & Code of Practice

As provided for under the Disability Act 2005, Sectoral Plans have been published by six Government Departments which set out programmes for action to improve service provision and access to infrastructure for people with disabilities.

- Communications, Marine & Natural Resources: The Sectoral Plan of the Minister for Communications, Marine and Natural Resources is focused on the broadcasting and energy supply sectors, including the Broadcasting Commission of Ireland.
- Enterprise, Trade and Employment: The Sectoral Plan of the Minister for Enterprise, Trade and Employment includes proposals for a Comprehensive Employment Strategy for persons with disabilities. A key aim is the promotion of equal opportunities for people with disabilities in the open labour market supported by enhanced vocational training and employment programmes and the further development of supports to the open market employment of persons with disabilities.
- Environment, Heritage & Local Government: The Sectoral Plan of the Minister for the Environment, Heritage and Local Government is aimed at promoting and proactively encouraging equal opportunities for persons with disabilities to participate in the economic, social and cultural life of the community and also a housing strategy for people with disabilities.
- Health & Children: The Sectoral Plan of the Minister for Health and Children includes plans for delivery of services by the Health Service Executive and the arrangements for the implementation of Part 2 of the Disability Act 2005 and Multi Annual Investment programme underpinning expenditure on services for persons with disabilities. The Department of Health & Children reviewed its sectoral plan at the end of 2007 and plans to review it annually.
- Social & Family Affairs: The Sectoral Plan of the Minister for Social and Family Affairs is geared towards developing services that give persons with disabilities financial security and encourage maximum participation in society. Initiatives include the transfer of income maintenance payments from the Health Service Executive as well as a Service Delivery Modernisation programme. The Plan identifies the key actions which will be underpinned by cooperation across agencies to develop service provision for persons with disabilities.
- Transport: The Sectoral Plan of the Minister for Transport addresses the accessibility needs of people with disabilities by putting in place a comprehensive programme of accessible transport across the transport modes.

The Sectoral Plans were drawn up in December 2006. Progress reports will be prepared on the Sectoral Plans after 3 years and the Disability Act will be reviewed after 5 years.

Code of Practice on Accessible Public Services

In conjunction with the Sectoral Plans, the Government also launched a Code of Practice on Accessible Public Services. Under the Disability Act, all public bodies, subject to certain considerations provided for in the Act, are required to ensure that access to services is integrated and to provide assistance to people accessing services. Services and goods supplied to all public bodies are required to be accessible and communications and information provided by public bodies must be accessible. The Code of Practice, prepared by the National Disability Authority, offers advice to those organisations on how to meet their obligations in this regard.

4. Multi-Annual Investment Programme

The final element of the National Disability Strategy is the Multi-Annual Investment Programme for high priority disability support services. This outlines the Government's commitment to a programme of revenue and capital expenditure, amounting in total to around €900m, on specific disability support services.

Implementation of the Disability Strategy is now monitored by the National Disability Strategy Stakeholders Monitoring Group.

ii. Disability Strategy Stakeholders Monitoring Group

Under the new Social Partnership Agreement Towards 2016 a commitment was made regarding monitoring progress on the implementation of the National Disability Strategy. This led to the establishment of the National Disability Strategy Stakeholders Monitoring Group. The purpose of this group is to monitor progress on the overall implementation of the strategy, building on the monitoring and review procedures already in place in each of the six sectoral plans. The group contains representatives from key departments as well as from the intellectual disability services and the NGO community. Mr. Brian O'Donnell represents the National Federation on this monitoring group. This group is chaired by the Department of An Taoiseach.

The Act will be reviewed after 5 years and this review offers a good opportunity to the National Federation of Voluntary Bodies to ensure that research priorities identified in this strategy will form part of the overall national disability agenda.

Further to this, in 2008 the government formally announced the establishment of the Office for Disability & Mental Health. One of this office's primary responsibilities is to support implementation of the Health Sectoral Plan under the Disability Act.

iii. Office for Disability and Mental Health

In January 2008, the Government announced the establishment of the Office for Disability and Mental Health to support the Minister for Disability & Mental Health in exercising their responsibilities across four Government Departments: Health & Children, Education & Science, Enterprise, Trade & Employment and Justice, Equality & Law Reform. This reflects the Government's commitment to developing a more coherent and integrated response to the needs of people with disabilities and mental health issues and recognises that service users need to be at the centre of service delivery.

The new office brings together responsibility for a range of different policy areas and State services which directly impact on the lives of people with a disability and people with mental health issues. The Office will aim to bring about improvements in the manner in which services respond to the needs of people with disabilities and mental health issues, by working to develop person-centred services, focussing on the holistic needs of service users and actively involving them in their own care and support.

The key priorities for the Office for Disability and Mental Health are:

- Supporting the implementation of the Health Sectoral Plan under the Disability Act 2005. The Office will focus in particular on facilitating the delivery of integrated health and education support services for children with special needs, by further developing existing mechanisms for co-operation and co-ordination between the health and education sectors, both at national and local level;
- Developing an appropriate continuum of training and employment support services for people with a disability by working together with the Dept. of Enterprise, Trade and Employment, FAS and the HSE;
- Bringing a new impetus to the implementation of A Vision for Change, working in partnership with the HSE and other stakeholders to achieve implementation of agreed targets;
- Achieving greater cooperation between the health and justice sectors on matters relating to people with mental illness who come before the Courts, who are in the prison system or in the Central Mental Hospital.

The Director of the Office is a member of the Senior Officials Group on Social Inclusion, which monitors progress on the Government's commitments in relation to social policy. Meetings will be held on a quarterly basis between the Minister for Disability and Mental Health, the four Secretary Generals of the relevant Departments and the Director of the new Office, to review progress in the priority areas.

iv. Other Relevant Legislation

Other pieces of Irish legislation are relevant to the Disability Act.

- **Employment Equality Act 1998**

The purpose of the Employment Equality Act 1998 is to make provision for the promotion of equality between employed persons and to outlaw discrimination in relation to employment. The scope of the Act is comprehensive and prohibits direct and indirect discrimination, victimisation, dismissal, harassment and sexual harassment on nine grounds, including gender, marital status and disability.

- **Equal Status Act 2000**

The Equal Status Act 2000 promotes equality and prohibits discrimination in the provision of goods, services and facilities. These include access to a publicly available place, transport, accommodation, refreshment, entertainment, banking, insurance, grants, loans, credit, education and professional services – including those provided to members by trade unions. The act also prohibits sexual harassment and victimisation. The Equal Status Act 2000 came into force on 25 October, 2000. It does not cover events which took place before 25 October, 2000.

- **Equality Act 2004**

The Equality Act 2004 amends the Employment Equality Act 1998 and the Equal Status Act 2000. It broadens the scope of claims based on unequal treatment in the workplace and elsewhere on the ground of age, gender, disability, race etc. In particular it provides as follows:

- A person employed in another person's home will henceforth be covered by the equality legislation.
- Setting a minimum age of greater than 18 years for job applicants is now deemed discriminatory.
- The self-employed and partners now have rights under the employment equality legislation.
- The definition of what constitutes sexual harassment has been broadened.
- An employer must provide facilities for disabled employees unless the cost to him would be unreasonable given his means.
- Where there are reasonable grounds for delay in bringing a claim, the time for bringing it may be extended to 12 months, instead of 6 (previously there had to be exceptional grounds).

- **Education of Persons with Special Educational Needs (ESPEN) Act 2004**

The Education of Persons With Special Educational Needs Act 2004 was passed to ensure that persons with special educational needs can be educated where possible in a inclusive environment, that they can have the same rights to education as persons who do not have special educational needs, and to ensure that such persons are equipped by the education system with the skills they need to participate in society and to live independent and fulfilled lives. The aims of the Act are:

- to make further provision for the education of people with special educational needs;
- to provide that their education takes place, as far as possible, in an inclusive environment;

- to provide that they have the same right as everyone else to avail of, and benefit from, appropriate education;
- to help children with special educational needs to leave school with the skills necessary to participate, to the level of their capacity, in an inclusive way in the social and economic activities of society and to live independent and fulfilled lives;
- to provide for the greater involvement of parents of children with special educational needs in relation to the education of their children;
- to establish the National Council for Special Education (this Council has already been set up and the Act gives it a statutory basis);
- to confer certain functions on HSE areas in relation to the education of people with special educational needs;
- To establish an independent appeals system - the Special Education Appeals Board.

- **The Health Act (2007)**

The Health Act 2007 established the Health Information and Quality Authority (HIQA). One of its functions is to set and monitor standards in the health care sector which includes service providing organisations for people with disabilities. It will play a vital role in the year ahead ensuring high quality delivery of services. It also includes the office of the Chief Inspector of Social Services whose remit it is to inspect residential settings/homes for people with disabilities.

v. Mental Capacity and Guardianship Bill (2008)

The Mental Capacity and Guardianship Bill (2008) was introduced as a private members Bill in the Seanad in February 2007 and completed its first stage through the Seanad in February 2008. This Bill replicates the principles set out in the Law Reform Commission report - Vulnerable Adults and the Law (2006). The key recommendation from Vulnerable Adults and the Law is that the law on capacity should reflect an emphasis on capacity rather than lack of capacity and should be enabling rather than restrictive in nature, thus ensuring that it complies with relevant constitutional and human rights standards.

The Mental Capacity and Guardianship Bill provides for reform of the law concerning mental capacity, provides for informal decision-making on behalf of adult persons who lack capacity in certain circumstances, establishes a guardianship board which may appoint personal guardians to deal with the property, financial matters and welfare of adult persons who lack capacity, confers jurisdiction on the high court in certain matters, provides for the establishment of the office of public guardian and sets out the functions and powers of the public guardian. It is expected that this legislation will be published by the end of 2008.

vi. Towards 2016-Ten Year Framework Social Partnership Agreement

Underpinning all of these pieces of Irish legislation is Social Partnership. The latest partnership agreement- **'Towards 2016-Ten Year Framework Social Partnership Agreement'** endorses a lifecycle approach to social planning for the challenges individuals face at each stage of their lives - from childhood to old age and including disability. Although provision is made at each of the life-cycle stages for people with disability, 'Towards 2016' also deals with specific issues of disability in section 33.

Section 33: People with Disabilities

The parties to this agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of their local community, free from discrimination.

To achieve this vision, the Government and the social partners will work together over the next ten years towards the following long-term goals with a view to continued improvements in the quality of life of people with disabilities:

- Every person with a disability would have access to an income which is sufficient to sustain an acceptable standard of living;
- Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services;
- Every person with a disability would have access to public spaces, buildings, transport, information, advocacy and other public services and appropriate housing;
- Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential, and;
- Carers would be acknowledged and supported in their caring role.

(Towards 2016 - 'Ten Year Framework Social Partnership Agreement')

Summary

In summary these are the domestic drivers for change in the current disability climate. With such legislation in place, Ireland is fast moving from a traditional medical model of disability to the more appropriate social model of disability. The principle of change is not enough. With the statutory requirements in place mainstreaming and the life cycle approach together with modernisation and improvements of service will all create new opportunities for change. Evidence based research will support this drive for change.

vii. The Wider Context - UN Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities received its 20th ratification on 3 April 2008, triggering the entry into force of the Convention and its Optional Protocol on 3rd May 2008. This marks a major milestone in

the effort to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of persons with disabilities, and to promote respect for their inherent dignity. The Convention and its Optional Protocol do not create new rights but aim to ensure that the benefits of existing rights are fully extended and guaranteed to the estimated 650 million people with disabilities around the world.

The convention contains both a mix of both civil and political rights as well as economic social and cultural rights. The convention asserts the rights of people with disabilities to education, health, work, adequate living conditions, freedom of movement, freedom from exploitation and equal recognition before the law for persons with disabilities. It also addresses the need for persons with disabilities to have access to public transport, buildings and other facilities and recognises their capacity to make decisions for themselves. The Convention's Optional Protocol allows individuals to petition an international expert body with grievances.

Obligations are undertaken by States who sign the convention and these include the introduction of new legislative measures to achieve these principles, the obligation to repeal inconsistent existing laws and the obligation to mainstream disability into all relevant policies and programmes to eliminate discrimination and to promote research (Article 4).

International monitoring of the Convention will be achieved via:

- The Conference of States Parties which will be made up of signatories to the Convention, and will have the authority to consider any matter with regard to implementation of the Convention. The first meeting of the Conference of States Parties will be convened no later than six months after the entry into force on 3 May 2008 of the Convention. The Conference will elect members of The Committee on the Rights of Persons with Disabilities.
- The Committee on the Rights of Persons with Disabilities will have a membership of 18 experts, who will serve in their individual capacities rather than as government representatives. States Parties will provide reports to the Committee every two years after the Convention has entered into force. The reports will provide a comprehensive explanation on the progress made towards implementation of the Convention.

Research will place a crucial role in this monitoring process. Of particular relevance in the context of services and service provision is Article 19 which deals with the right to live independently and be included in the community *'Persons with disabilities shall have access to a range of in-home, residential and other community support services including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community'* (Article 19.b).

On a world wide level the UN Convention will be the driver for change in disability legislation and the way in which people with disabilities are viewed in our society. Whilst not a binding legal document in Ireland as yet it is a powerful moral persuader to underpin the Disability Agenda currently underway.

viii. Summary

The role of research in implementing, monitoring and evaluating the effect of the Irish legislation is invaluable. Through research we shall be able to monitor the transitions that are currently underway.

Research can and will play a useful role in the reform underway. Research can identify the range of practical solutions that may be needed to implement policy based on evidence based practice on the ground. Such research will be of a broad range and should include social policy research, baseline data approaches, service evaluations and models of service delivery, and participatory research methodologies.

The solutions identified by employing a multi-faceted research approach will enable us to identify best fit models for driving the disability agenda. Research will be evidence based and informed by users of services, families, staff, service provider organisations and policy makers. Such a comprehensive programme of research and inclusive approach will enable us to ensure that national policy and guidelines has a solid evidence base with a grounding in the lives of people with disabilities themselves.

Appendix III - Research in the National Federation of Voluntary Bodies: Past & Present

Research has always been at the heart of the activities of the National Federation of Voluntary Bodies. This research has been in the main multi- and cross-disciplinary in nature and of national relevance. The research conducted both at national and European level has led to the development of national and European policy. The examples below illustrate the potential for the National Federation of Voluntary Bodies to expand its research horizons and outline its position as a national umbrella body to take the role in directing and leading national research priorities.

Much of the research conducted has been funded by external bodies and the ability of the National Federation of Voluntary Bodies to attract such funding is an impetus for driving the research agenda forward.

In addition the position of the National Federation of Voluntary Bodies as a member of European Association of Service Providers for Persons with Disabilities (EASPD) has placed it at the heart of European research and policy developments. The contribution that the National Federation of Voluntary Bodies has made to research initiatives in Europe has been wide and varied.

i. Informing Families of their Child's Disability: Development of National Best Practice Guidelines

The aim of the Informing families project was to develop evidence-based National Best Practice Guidelines, education, and training; on appropriate procedures to inform families of their child's disability (or suspected disability). The aims of implementing the Guidelines are to:

1. Ensure improved outcomes at disclosure for families;
2. Provide improved support, guidance, education and training for professionals communicating the news.

The Guidelines relate to intellectual, physical, sensory disabilities or autistic spectrum disorders, and concerns raised during pregnancy, at birth and evolving diagnoses. It is intended that the Guidelines will form operational policy within hospital, community and disability service settings.

Qualitative data was collected from seven focus groups with parents of children with disabilities in Ireland, and 15 focus groups with disciplines of professionals involved in disclosure or supporting parents immediately thereafter. Quantitative data was collected through a national postal questionnaire survey of 584 parents and 1588 professionals. (Sampling made use of the National Intellectual Disability Database).

Overall satisfaction with disclosure was comparable with previous studies. Deficits were identified in the settings for disclosure (lack of privacy), in the information provided to parents, in communication skills, and in continuity of care. Recommendations for practice were identified in the following areas: the physical and social setting for disclosure; communication; information and support, culture and language, referral, organisation and planning; training, education, and support for professionals.

Using a triangulation of the results of the literature review, the focus groups and the questionnaire survey, the recommendations flowing from the findings were collated to produce the National Guidelines (Harnett et al, 2007).

ii. People Connecting – Participatory Research

Through the Community Participation & Inclusion Sub-Committee, whose representation includes people with intellectual disability, discussions have been facilitated on identifying the barriers, incentives and solutions to community participation and inclusion of people with intellectual disability. In order to widen its understanding, the sub-committee decided to undertake some participatory research and a Consultative Workshop was facilitated, with people with intellectual disability, to explore their interpretation and meaning of the words community, participation and inclusion. The findings from this workshop were presented to the Board of the National Federation, together with supporting recommendations from the Community Participation & Inclusion Sub-Committee, for their consideration. The findings, plus the supporting recommendations, have now been published in an “easy to read” document titled “People Connecting” and this is being disseminated throughout our member organisations, advocacy groups and other disability stakeholders.

iii. Volunteering in Intellectual Disability Services in Ireland - *Supporting People to Live the Life of their own Choice in their own Community*

In 2006 the National Federation Volunteering Sub-Committee identified the need to collate reliable data on volunteering within member organisations. The purpose of collating this data was to enable the National Federation to plan and prioritise responses to the volunteering needs identified by member organisations, and inform the Board of Directors on priority issues, key challenges and recommendations in respect of volunteering at a local & national level. Volunteering activities support people to develop new skills and reduce the levels of social isolation and exclusion often experienced by people with intellectual disabilities within the community. This survey was the first national study on volunteering to be conducted within the intellectual disability services in Ireland. The survey findings will enable the National Federation Volunteering Sub-Committee to put volunteering on the agenda of the National Federation, Government Departments and other public authorities and national bodies. The survey findings are now complete and the report will be published in August 2008.

iv. Person Centred Medication Management (PCMM)

Person Centred Medication Management Policy Guidelines (PCMMP)

In February 2003, following a survey of all National Federation member organisations, a Working Group was established to examine how best practice could be supported in the area of Person Centred Medication Management, 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 UCD and the Department of Health & Children's Nursing Advisor in Intellectual Disability, as well as representation from member organisations of the National Federation of Voluntary Bodies.

There are two phases to the work of this project group:

- *Phase 1 - Guideline Document:* The first phase involved developing policy guidelines and necessitated extensive research along with consultation and dialogue with a wide variety of key stakeholders, to include people with intellectual disabilities and their families, professionals such as pharmacists, nurses and medical practitioners.

It is intended that the 'Person Centred Medication Management Policy Guideline Document' will be launched in 2008.

- *Phase 2 - Training Programme:* The second phase of the project is the development of a national accredited training programme in person centred medication management for staff members within the member organisations of the National Federation of Voluntary Bodies.

The working group has reviewed national and international training programmes and a draft document has now been developed which it is hoped will inform the structure and content of this programme.

Nurse Prescribing

This year (for the first time) seven Nurses from the Intellectual Disability Sector are undertaking the Certificate in Nursing (Nurse & Midwife Prescribing) course with either University College Cork or the Royal College of Surgeons Ireland (RCSI), Dublin. Prescribing Site Coordinators have been identified at each service site, to develop structures to support Nurse & Midwifery prescribing in their respective Organisations.

The National Federation of Voluntary Bodies is supportive of the Nurse & Midwife prescribing initiative and is pleased to work in collaboration with the HSE Office of Nursing Services Director to ensure that the introduction

of Nurse Prescribing to Intellectual Disability Services will facilitate and support the further enhancement of ordinary lifestyles for people with Intellectual Disability, in line with the purpose of the National PCMMP Guidelines.

v. Education Survey 2006

The National Federation of Voluntary Bodies carried out an extensive survey with its member organisations that provide educational services and supports to people with Intellectual disability. The findings of this survey were captured in a report entitled *“Report to the National Council for Special Education’s Consultation on the Implementation of the Education for Persons with Special Educational Needs (EPSEN) Act 2004”*.

This report:

- Clarified and quantified the role of National Federation of Voluntary Bodies Member Organisations (n=31) in the provision of education,
- Highlighted significant areas in the implementation of EPSEN Act 2004 and Disability Act 2005,
- Detailed the National Federation of Voluntary Bodies recommendations in relation to all sections of the EPSEN Act 2004,
- Suggested a prioritised approach to the implementation of the EPSEN Act 2004 and Disability Act 2005 which illustrate the vision of the National Federation of Voluntary Bodies to the future of education services to people with intellectual disability in Ireland.

This Report was then presented to the Joint Oireachtas Committee on Education & Science in February 2006.

The Education for Persons with Special Educational Needs Act 2004 and the recently published National Disability Strategy which, inter alia, provides for a statutory right to an independent assessment of need, together with the soon to be launched National Standards in Disability Services, present unprecedented opportunities for people with disabilities and their families. They also present significant challenges and opportunities for service providers and will have profound implications in terms of how services are designed and delivered in the future.

vi. Analysis of Need Project

In 2004 the National Federation of Voluntary Bodies published a report on the Analysis of Need for Services and Supports for People with Intellectual Disability over the period 2005 – 2008. This document gave accurate information on the services being provided and on the levels of unmet need. For people with intellectual disability and their families the publication of this information represented a recognition of their needs. For Government and for service providers, both statutory and voluntary, it was an essential planning tool and gave focus to the planning and development of services and supports in the immediate years ahead.

In this context, the availability of accurate information on the services being provided and on the levels of unmet need is crucial. The basis of this analysis is the 2004 Annual Report of the National Intellectual Disability Database and we are indebted to the Health Research Board for the quality of the information provided.

vii. Guidelines for Researchers when Interviewing People with an Intellectual Disability

In 2005 the Research Sub-Committee of the National Federation published a document entitled 'Guidelines for Researchers when Interviewing People with an Intellectual Disability'. This document was intended as a guide for anyone conducting interviews with people with an intellectual disability. The guidelines were based on an extensive literature review in the area. These guidelines have highlighted and discussed a wide range of issues to be considered by interviewers. In particular, these guidelines identified some of the practicalities interviewers need to consider on the day of the interview, including dealing with abstract concepts, the wording and/or redesign of questions, avoiding response bias and/or induced acquiescence, and asking about satisfaction levels. These guidelines have also explored who should interview, the use of proxies and/or interpreters, and methods for enhancing communication. People with an intellectual disability should be treated with respect and dignity, and in a manner appropriate to their age before, during and after interviews. Other considerations such as language, allocation of time, disclosure, refusal to participate and the venue of the interview are highlighted and discussed. A copy of the guidelines is available from www.fedvol.ie/publications.

Appendix IV - Collaborative Research Activities and Projects

i. EASPD LABOr Project

The LABOr project was financed by the Leonardo da Vinci programme of the European Union and run by European Association of Service Providers for Persons with Disabilities (EASPD) and sixteen other partners throughout Europe, including the National Federation of Voluntary Bodies. The central aim of the project was the collection of material on training and employment measures for people with intellectual disability throughout Europe and the dissemination of this information through the development of a web-based Knowledge Centre. The LABOr partners collected information on legislation, labour market policies, methods and approaches, case studies, good practice measures and individual success stories. All material was then made available to the Knowledge Centre.

The Knowledge Centre is a web-based centre offering information that is tailored to the needs of different stakeholders and is based on the material gathered by the LABOr Partners and on scientific review of good practice. A summary of the main findings of the LABOr project is available in a Good Practice Guide entitled “From Disability to Ability - A Pathway to Equal Employment of People with Intellectual Disabilities” and is available in the Knowledge Centre. Information is added and updated regularly. The knowledge centre can be used to support providers in fine-tuning their training and employment services and to advise the local, regional, national and European authorities in order to increase the employment opportunities for people with intellectual disabilities. The Knowledge Centre can be accessed at www.start-labor.org.

The National Federation of Voluntary Bodies, in partnership with The Irish Council for Training, Development & Employment for Persons with Disabilities (CNEASTA) and the Irish Association of Supported Employment (IASE) hosted the final LABOr project conference in the Royal Hospital Kilmainham, in Dublin, in October 2004. This conference provided a forum to consider the findings of the LABOr project and provided an opportunity for discussion on current EU policies regarding disability and employment. Over 50 speakers and 320 delegates from 21 countries participated in the conference - representing service users, service providers, employers and legislators.

ii. EASPD Conversion Project

The National Federation of Voluntary Bodies was involved in a ‘Pilot Project to Develop and Test a Comprehensive Programme on Conversion from Segregated Settings to Inclusive Employment Services’ under the Leonardo da Vinci programme, in 2005.

Partners in this project included: EASPD, Belgium; La Fédération Médico-Sociale des Vosges (FMS), France; European University College from Brussels (EHSAL), Belgium; National Federation of Voluntary Bodies (NFVB), Ireland; The Polish Association (PAPMH), Poland; BAG:WfB, Germany. The project is based on the findings emerging from the previous LABOr project.

The specific aim of this project was to pilot a comprehensive training programme targeted at managers and front line staff in agencies wishing to convert from sheltered employment to employment on the open labour market of persons with disabilities.

The project will improve the skills and competencies of managers and staff who pilot the training materials in different agencies as well as the quality and access to continuing vocational training focused on the open labour market by equipping front line staff in agencies with the knowledge and skills needed to adapt a high quality client centred approach.

iii. EASPD Daphne Project

The National Federation of Voluntary Bodies was involved in the Daphne Programme of the European Commission, EASPD which developed and launched a Knowledge Centre for the "Prevention of and Response to Sexual Abuse of People with a Learning Disability" (see www.stoppingabuse.org) It enables easy access, with the possibility of gaining information about the prevention of/and response to sexual abuse. It offers information about key issues and findings and creates the opportunity to exchange ideas and develop networks of advice and support.

This Knowledge Centre is updated on a regular basis by EASPD and all policy changes in the 25 member states of the EU are reflected in that update with information being provided by 25 member states of the EU.

iv. EASPD Tolerance or Acceptance Project

The National Federation of Voluntary Bodies was a co-partner in the European Tolerance or Acceptance Project that was set up in 2002 and successfully completed in March 2003. In total 9 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 St. John of God Hospitaller Services, 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.

Following the completion of this project, a Knowledge Centre was established, which guides visitors through models of good practice in relation to promoting the participation of people with disabilities in community activities (See www.community-lives.org) The Closing 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 all together can combat discrimination in European community based settings.

v. TILDA ID - The 'Intellectual Disability Supplement to TILDA' (The Irish Longitudinal Study on Ageing)

Including People with an Intellectual Disability in The Irish Longitudinal Study on Ageing (TILDA)

An '*Intellectual Disability (ID) Supplement*' to the '*Irish Longitudinal Study on Ageing (TILDA)*' will be launched on the International Day of Persons with Disabilities, Wednesday, 3rd December 2008, at Trinity College Dublin.

This will be the first longitudinal study of ageing in persons with intellectual disability in Ireland and the European Union and the only study with the potential to compare the ageing of people with intellectual disabilities with other population groups.

Almost half of people with a moderate, severe, or profound intellectual disability living in Ireland are aged 35 years or over; the numbers are growing and longevity is increasing. A great achievement, the realities of ageing also present new challenges:

As the carers of adults with intellectual disability also age beyond their caring capacity, additional formal supervised living arrangements will need to be established

Increased pressure for the creation and support of residential placements is already being experienced by residential services

There is evidence that rates of chronic illness are higher in old age and average age of death is lower for people with intellectual disability (when compared to the general ageing population) while access to services and health promotion is poorer and quality of life is often compromised.

This supplement is designed to gather data to support finding answers to these challenges. We also wish to highlight the need for such studies in other countries too; hence the launching of the Supplement on the International Day of Persons with Disabilities.

The Supplement project will collect data from 800 people with intellectual disability (over age 40) on physical and psychosocial health, living situations, social networks and quality of life. Supplement findings on ageing will also be compared with the findings for the general population being collected in The Irish Longitudinal Study on Ageing (TILDA) led by Professor Rosanne Kenny.

Funded by the Health Research Board and led by Professor Mary McCarron of the School of Nursing and Midwifery at Trinity College Dublin, collaborators include the National Federation of Voluntary Bodies, Inclusion Ireland, the National Intellectual Disability Database, and an international advisory committee comprised of nurses, psychologists, psychiatrists, social workers, physicians, family members, providers and advocates including collaborators from Northern Ireland and the U.S.

What a great day December 3rd 2008 will be for people with intellectual disability in Ireland; unknown to many of them at the moment this project will represent the first national inclusive venture, which will hopefully improve/enhance their lives in the future and ensure that their ageing years are ones to remember for both themselves and their families.

vi. Audit by Research of Abuse in Disability Services - A joint project by the Health Service Executive (HSE) & the National Federation of Voluntary Bodies

In December 2007, the Health Service Executive published the Report of Dr. Kevin McCoy on the Western Health Board inquiry requested by the Brothers of Charity Services in Galway. This inquiry was into historical allegations of abuse. The period covered by the inquiry was 1965 to 1998. The report is available on www.hse.ie under news and events.

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 service in the period 2007;
- Review Policies and Procedures currently in use for the protection of service users;
- Identify good practices;
- Provide information that will assist in developing national policy;
- Identify training needs, and good current training practices for service users, families and staff.

The methodology will include an audit of all Federation Member organisations and HSE intellectual disability service providers (this is approximately 70 service providing organisations to people with intellectual disabilities) 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.

vii. Inclusive Research Network

The idea for an Inclusive Research Network emerged in 2007 as a joint venture between the National Federation of Voluntary Bodies and the National Institute of Intellectual Disability, Trinity College Dublin.

The network consists of a group of people who come together to do research or talk about research that is about people with intellectual disabilities. e.g., people from services, self-advocacy groups, organisations, researchers from universities and services and community groups.

This network is for anyone who is interested in this type of research e.g., people with intellectual and/or multiple disabilities, people with an interest in inclusive research, university researchers, staff and members of services, and members of self-advocacy groups.

The Goals of the network are:

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

Members will meet on a regular basis and share research knowledge and skills. They will develop partnerships together on common research interests and could develop joint proposals. Members can be part of a discussion

forum for researchers in Ireland and get training in research methods. The network will provide a list of all inclusive disability research in Ireland and will share research findings with all members.

All members are equal

Inclusive Research will address issues which are important to people with intellectual disability and which will lead to better lives for them. It will express the views and experiences of people with intellectual disabilities. Research findings will be used to make real changes where needed in peoples lives. The network will involve people with intellectual disability at all stages of research projects, i.e. as researchers, advisors, committee members, network members etc. It will look at new ways of doing research and a variety of ways will be considered. Research findings will be shared with all members and the research will be written in accessible formats.

For more information, log on to www.fedvol.ie/research or <http://www.tcd.ie/niid/research/irn/>

viii. National Institute of Intellectual Disability (NIID) - Transfer of Knowledge Project- Doing Disability Research

Dr Patricia O'Brien is co-coordinating 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 research methods and practices.

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.

The project is supported by a national advisory committee and Ms. Edel Tierney, Director of Research and Policy Development at the National Federation of Voluntary Bodies, is a member of this advisory committee.

For more information see www.tcd.ie/niid/research

ix. Database of Research on National Federation Website

The Research Sub-Committee of the National Federation of Voluntary Bodies has developed a database of intellectual disability research. This database is a register of all the intellectual disability research projects which have been completed in member organisations since 2000.

Details of the authors and abstracts are provided for each project.

For anyone wishing to access this database, it can be done through the National Federation website www.fedvol.ie/research/.

This database will continue to be a priority of the research strategy 2008-2013. A comprehensive database of research abstracts can then be examined to monitor types of research and quality of research being conducted in Ireland in member organisations.

Appendix V - Early Consultations on Research Priorities

Prior to the development of this research strategy the opinions of member organisations were sought in a series of conferences on the relevance of research to them as services providers. Two key questions explored were: (1) how can research promote the activities of services? and (2) how can research promote evidence based practice in the delivery of services? Opportunity arose at the National Federation of Voluntary Bodies conferences in 2004, 2006 and 2007 to consult with member organisations on particular research issues. In 2004 the value of research was examined and the ingredients of a good research strategy explored, in 2006 the specific issues of research in mental health were examined and in 2007 innovative practices in services and supports were explored. Participants were also asked which topics they would like future conferences to explore.

i. National Federation of Voluntary Bodies Research Seminar – May 2004

The value of research has always been recognised within the National Federation of Voluntary Bodies members and with this in mind the Research Sub-Committee organised a Research Seminar in May 2004. The purpose of the seminar was to be a showcase for research from the intellectual disability services sharing “what is happening” and to provide encouragement to those who are carrying out research. It also promoted the value of research and collaboration within the member organisations.

A series of roundtable discussions took place during this seminar on the value of research to member organisations. Responses were collated from the delegates and are summarised below.

Q. What is the value of research?

During the seminar, round table discussions took place and it was agreed that evidence based research can validate and increase the knowledge base leading to finding new ways to improve current practices thus improving the quality of service and resulting in effective policy making. By providing evidence based material the results of research can be a useful tool when making funding requests.

Q. How is research currently promoted within your organisation?

Methods of research vary within the organisations with some organisations having a research officer with a specific role dedicated to research whereas others have incorporated research as part of contract or included in their job description with only minimal time to dedicate directly to research. Affiliations between the organisation and the National Federation of Voluntary Bodies and the National Disability Authority also help promote research. Organisations sometimes have research committees or research centres with specific objectives and policy guidelines to better support research. Training workshops, presentations to staff, and third level training often endorse research within an organisation.

Q. What are the key challenges for the development of research?

Challenges faced in research development include time constraints, lack of support from senior staff, and differing levels of expertise between those involved in the research. The development of an ethical basis for research projects is another important challenge to researchers. There is also the issue of ownership for researchers and so co-operation is required between agencies.

Q. What could support the development of research?

To support the development of research projects within an organisation, it was suggested that there should be more awareness of research undertaken, and a greater level of information sharing between agencies. Research development could be greater served by promoting the participation of service users as researchers and as participants. Funding and resources available must also be taken into account.

Q. How can we work more effectively together as a National Federation in the development of research?

The National Federation must pool its resources to be effective in the development of research. This could be done by encouraging collaborative research, by establishing communications systems and through co-operation and information sharing. To better disperse information, the National Federation could set up a register of researchers within Intellectual Disability Services; they could publish a research review; and they could set up a database of research projects. The National Federation should also encourage a partnership or person-centred approach to research.

Q. What next steps can you take to further develop this in your organisation?

Organisations should use their own websites to log research undertaken that they are involved in. Another suggestion from the round-table discussion was that a mission statement on research be drawn up by organisations, with the aims and objectives clearly stated. Annual reports could include research projects undertaken, and a database of researchers could be set up within the organisation.

Q. What Particular actions do you recommend the National Federation initiate?

Suggestions were made that the National Federation of Voluntary Bodies should use their website as a tool for research promotion. A database should be setup online with topics currently being researched, and a list of researchers in the field of Intellectual Disability along with their contact details. There could be a section in the National Federation's newsletter dealing with research currently being undertaken. The National Federation could also establish guidelines on areas of research, e.g. how to access funding, how to get published, etc, and provide training on how to do research. The National Federation should be involved in supporting smaller agencies that do not have the facilities for their own research department.

ii. Symposium on Mental Health Services October 2006 entitled “*Meeting the Challenge of Building a Person Centred Mental Health Service for People with Intellectual Disabilities*”

The National Federation of Voluntary Bodies in association with the Health Service Executive and in consultation with key stakeholders hosted this symposium on how to best meet the mental health needs of people with an intellectual disability. The key objectives of the symposium were to promote positive mental health approaches for people with an intellectual disability, expand and empower the service user perspective, raise awareness and critically appraise relevant policy and legislation. In addition the symposium provided debate around person centred service models to best meet the needs of this population, examined capacity within the context of the Mental Health Act 2001 and the Law Reform’s *Consultation Paper on Vulnerable Adults and the Law* (2005) and reviewed support and response systems for people with a dual diagnosis.

Key Points raised during the symposium were:

- Too much bureaucracy in the system needs to be taken on board. The person with an intellectual disability needs to be in the centre of the debate rather than joined on to the service;
- We need to think strategically about how we can provide children with disabilities a better start. The *Vision for Change* document makes very good statements. We need to identify the specific things we need to do;
- All service users say to us that we must listen to them and start responding. The Mental Health Act gives positive signals. It is a journey towards the delivery of good quality mental health services;
- Local services are what people with disabilities are looking for. We need to deliver these services in accordance with best practice. We need to develop specialist services in accordance with the legislation. The HSE will work to coordinate and integrate the elements of the service. There will be access to and information on local services as far as possible;
- The quality of what we do is important, the Disability Act, HIQA, the Vision for Change document and the Inspectorate. We must fund in accordance with the legislation. Good progress has been made;
- Person centeredness is the key. There must be flexibility in building teams. Appropriate staff training is vital. There is a major difference between teams of specialists and specialist teams;
- There are very few choices. If there were more choices, there would be fewer mental health problems;
- If we ask the service users what they need and base our services on the answers we get, then there will be more choice;
- There is an accountability issue. A specific example of waiting for 5 hours to see a consultant was given;
- There is a need to promote, encourage and foster good practice. A quality service must be accessible;
- There are people living in old inappropriate facilities. The existing manner of allocating resources (day, residential or respite places) will not address this problem.

iii. ***“New Ideas – New Approaches – Supporting Innovation in Services and Supports to People with Intellectual Disability” - National Federation of Voluntary Bodies Conference, October 2007***

The National Federation of Voluntary Bodies' most recent conference was based on the theme of innovation. In organising this conference the National Federation took a somewhat different approach to previous years, and with the theme of innovation in mind, decided to give top priority to audience participation. Each of the 8 parallel sessions of the conference dealt with a different issue. After speakers' presentations, a solutions generating session began, wherein the issues raised by the speakers were discussed between all participants at that workshop. Common themes emerged from these sessions, which could be summarised into 7 key actions for moving forward, as outlined below:

- Develop partnership;
- Shift culture;
- Shift power;
- Develop listening skills;
- Share decision making;
- Examine how to move towards individualised services;
- Empower people with intellectual disabilities to have control over their money.

It was suggested that further research needed to be undertaken on these core issues, and so these actions helped shape and influence the Research Strategy.

For more information, there is a downloadable version of the Conference Proceedings Report available from the conference website: <http://conference.fedvol.ie/> An easy-to-read version is also available.

iv. **Summary of Early Consultations**

Early consultations on the development of a research strategy and the value of research to member organisations indicated the need for evidence based research and developing best practice. Developing quality services based on this evidence and the need to collaborate to develop national best practice guidelines and have national baselines on research issues was a common theme which emerged. Consultations also indicated the need for more information around particular topics and the need to share this information among member organisations.

There was also a repeated need for identifying funding for projects and how collaborations or partnerships may make funding opportunities more viable and more attractive to funders. Research projects would also benefit from a national rather than a local approach or methodology. Listening to people with intellectual disabilities and

sharing the decision making and power would support a more person centred approach and shift the culture of services to be at the heart of the issues. Partnership was cited as central to these themes.

The areas the participants requested research to be carried out in were:

- staff training;
- ethical procedures;
- service user participation and listening to service users;
- developing a register of Irish researchers;
- developing a data base of research;
- developing guidelines for conducting research;
- developing research proposals on person centred approaches including looking at choices, issues of power and empowerment and decision making;
- In addition participants repeatedly called for research on models of services with particular reference to individualised services.

Many of these topics were reiterated in the round of consultations which took place to develop the research strategy 2008-2013. The overlap is clear and obvious. Early identification of these topics was important as they were considered and incorporated into the action plan as outlined in Priority 1.

It was also important to consider that consultation was not simply a one off event but rather a culmination of consultations over the past number of years.

Appendix VI - Research Strategy Consultations 2008

Early consultations took place between 2004 and 2007 as outlined in Appendix V at National Federation of Voluntary Bodies Conferences. A series of further consultation took place in 2008 to develop research priority topics for the Research strategy.

- Consultation 1:** Consultation and discussion with the Research Sub-Committee (for membership of this committee see Addendum B)
- Consultation 2:** An extensive email consultation sought the opinions of staff and management in the 63 member organisations (for a list of member organisations, see Addendum A)
- Consultation 3:** Presentation and Submissions from Advocacy / Self advocacy Groups to the Research Sub-Committee:
- Presentation to the Research Presentation to the Research Sub-Committee and written submission from the Community Participation and Inclusion Sub-Committee (for membership of this committee see Addendum C)
 - Submission from the Inclusive Research Network (for membership of this network see Addendum C)
 - Submission from Seasamh Parliament (for membership see Addendum C)
- Consultation 4:** Consultation with the National Federation Secretariat Team (For a list of current staff, see Addendum A)
- Consultation 5:** Presentation to the Board of Directors of the National Federation of Voluntary Bodies (For current membership of the Board, see Addendum A)

i. Consultation 1: Research Sub-Committee Consultation

This research strategy was driven by the expertise of the National Federation of Voluntary Bodies Research Sub-Committee. The Research Sub-Committee was set up in February 2003, and has been extremely active, responding to a wide variety of issues on research on behalf of National Federation Members. The Research Sub -Committee is comprised of representatives of member organisations many of whom have particular interest and expertise in research. For a full list of current members, see Addendum B. Consultations took place with the National Federation Research Sub-Committee at the committee meetings and by email. From this consultation, a list of key topics were identified as areas in need of research. The Research Sub-Committee was also involved in the other stages of development of the Strategy.

ii. Consultation 2: Consultation with Member Organisations

Through a process of meetings with the Research Sub-Committee, methodology for the process of consultation with member organisations was agreed. The email consultation was agreed by Sub-Committee members to be the most suitable technique for an exercise of this type.

An email questionnaire was the method of communicating with Chief Executive Officers, management and staff of member organisations. The email outlined the purpose of the research strategy and what it was hoping to achieve. A brief questionnaire was attached to this email which entailed four questions.

- Q1. How would you like research to help in the field of Intellectual Disability with particular reference to your service?
- Q2. What are the main issues you feel need to be researched in your service?
- Q3. What areas do you think people who use your service would like researched?
- Q4. As we continue to build a network of contacts, who should we contact in your organisation for issues relating to research? (Please provide names and contact details)

This email was sent to the Chief Executive Officers of the 63 member organisations, the mailing list of the National Federation Newsletter recipients (management, front line staff etc), and all sub-committees of the National Federation of Voluntary Bodies (See Addendum B for membership of these sub-committees), known researchers in the member organisations and the Research Sub-Committee. In total the email was sent to approximately 200 individuals. The email also encouraged people to forward the email to people in their organisation or to consult as widely as possible when completing the questionnaire. As replies were returned question no. 4 served to develop a database of people interested in intellectual disability research. The email was also forwarded to the named contacts in organisations if they were not already on one of the above mailing lists. Reminder emails were also sent over a six week period.

In total 39 responses were received from this process. One response was not recorded as the person did not work in any of the member organisations and was connected through her role with the service provider sector generally. Responses were made by individuals on their own behalf or by consulting with other members of staff or people who use their services. Some respondents indicated that they were not responding on behalf of their organisation but rather were making a statement based on their personal opinions.

In total there was at least one entry from 32 member organisations. There was a spread of occupations of respondents, with Chief Executives, Directors, Managers, Social Workers and Psychologists being among those who responded. For a full list of the respondents' organisations and job titles, see Addendum D.

Method of Analysis

To analyse responses to the email questionnaire *Burnard's Method of analysing interview transcripts in qualitative research* was applied (Burnard, 1991):

Three researchers undertook the task of analysing the data:

- Stage 1:** All responses were read through and notes made throughout the reading on general themes which emerged in the response sheets.
- Stage 2:** Responses (transcripts) were read through again and as many headings as necessary were written down to describe all aspects of participant's responses. Then headings or category system called 'open coding' was generated.
- Stage 3:** The list of all the categories was looked at in detail by the three researchers and they were grouped together under higher order headings. The aim was to reduce the categories by collapsing some ones that were similar into broader headings.
- Stage 4:** A new list of categories and sub headings was formulated by looking at issues which came up repeatedly and very similar headings were removed to produce a final list.
- Stage 5:** The three researchers generated category systems, independently of each other. Then these categories were compared, discussed and adjustments made. The aim here was to enhance the validity of the categorising method and prevent bias.
- Stage 6:** Responses were re read alongside the finally agreed list of categories and sub-headings to establish the degree to which the categories generated, reflected and covered all aspects of the responses. Adjustments were made as necessary.
- Stage 7:** Each response sheet was examined in detail with the list of categories and sub-headings and coded accorded to the list of category headings.
- Stage 8:** Each coded section of the response sheets were put together, and from this the major themes were drawn together.
- Stage 9:** Members of the rating team were asked to check the appropriateness or otherwise of the themes which emerged against the raw data. Adjustments were made as necessary.

Analysis and Consensus

Three researchers coded the information/data presented as described. They analysed the information independently and developed categories for the information.

When discussion took place regarding categorisation there was general agreement on categories. Where disagreement emerged each category was examined and discussed. Through analysing the content or topics which comprised the categories a consensus was formed on what the category should be called. It should be noted that many categories naturally overlap, so when some respondents mentioned more than one category in

their response, e.g. Health and Education, then that response was entered into 2 categories, Ageing & health and Education.

Q1: How would you like research to help in the field of Intellectual Disability with particular reference to your service?

Consensus on Categorisation of open coding

There was agreement among the 3 researchers on 14 of 17 categories. There was discussion about the remaining three categories:

- **Research methods** was a new category agreed to account for responses which mentioned participatory /action research, policy, literature reviews etc;
- **Consultation with service users and families** became a new category to take account of specific issues around consultation; and,
- **Understanding Intellectual Disability** was created to take account of miscellaneous topics which were considered to deal with types of disability and more specific topics such as genetics.

It should be noted that some respondents did not answer this question fully, in that they focussed more on specific issues that needed addressing, rather than how research should help overall .

Categories	N	Other terms used	Examples of responses
Best Practice	18	<ul style="list-style-type: none"> Identifying best practice Sharing Best practice Evaluation Evidence based practice Policy Bench marking National and international trends Quality in service provision Holistic Approach 	<ul style="list-style-type: none"> <i>Highlight and share good practice initiatives</i> <i>Identify areas of best practice particularly around ageing and dementia</i> <i>To evaluate the quality of services, and thereby help set benchmarks</i> <i>Evaluation of service delivery</i> <i>To promote and enhance a high quality service that is evidenced based.</i>
Organisational Development and Management	18	<ul style="list-style-type: none"> Service models Culture Organisational issues Service planning Quality of service Service issues Staff Issues Management Issues Risk Management Bullying Innovation Service Delivery 	<ul style="list-style-type: none"> <i>We would like research to inform how we develop the service.</i> <i>Research would help by having a direct impact on service delivery, in terms 'what works'</i> <i>Development of models of service</i> <i>To address further service planning</i> <i>To guide/ inform our practice/ future planning of Services</i>

Research Methods	8	<ul style="list-style-type: none"> • Participatory /action research • Policy • Literature review • Story gathering • R&D approach • Intervention based research 	<ul style="list-style-type: none"> • <i>For us to engage with the researchers to deepen our contribution and our responsibilities</i> • <i>Policy focused research</i> • <i>I would like to see a lot more action research that truly involves service users and those important to them</i>
Community Inclusion	6	<ul style="list-style-type: none"> • Social inclusion • Mainstreaming 	<ul style="list-style-type: none"> • <i>Community resources that prove most rewarding to people</i> • <i>effects of mainstreaming on long term placement in integrated settings as opposed to special adult services</i> • <i>Family service and societal attitudes that are barriers to inclusion</i>
Quality of Life	6	<ul style="list-style-type: none"> • Leisure • Loneliness • Positive outcomes 	<ul style="list-style-type: none"> • <i>Research into peoples lives outside of the service. Are they lonely at home?</i> • <i>Supports that ensure practice rather than rhetoric in achieving real unique lives and lifestyles</i> • <i>By informing what are the most important factors that contribute to positive quality of life outcomes</i>
Understanding Intellectual Disability	6	<ul style="list-style-type: none"> • Severe and Profound disability • Mild Intellectual Disability • Dysphasia • Attitudes • Challenging Behaviours • Autism • Multiple sensory/motor disability 	<ul style="list-style-type: none"> • <i>I would like some research specific to Autism to be carried out</i> • <i>Inform and keep current with national and international trends in the area of children with severe and profound Intellectual Disability</i> • <i>Gain a deeper knowledge of the people we work for – how responsive / meaningful our interaction is</i>
Consultation with service users and their families	5	<ul style="list-style-type: none"> • Service users voice, views • Service user research includes advocacy, changing needs, service users views • Issues of relevance to service users 	<ul style="list-style-type: none"> • <i>To address further service planning by having a voice from the families who are depending on our services and interventions</i> • <i>Give parents and family members a real voice</i>
Living Options	5	<ul style="list-style-type: none"> • Housing • Communal Living • Mixed housing • Cost effectiveness of models 	<ul style="list-style-type: none"> • <i>Communal living and mixed housing</i> • <i>By examining the cost effectiveness of supporting certain adults and enabling them to continue to live in their own homes rather than being admitted to residential care</i>
Therapeutic Interventions	4	<ul style="list-style-type: none"> • Medication • Alternative therapies, e.g., aromatherapy, speech and language therapy 	<ul style="list-style-type: none"> • <i>To address quality of interventions by consumers</i> • <i>To increase awareness of aromatherapy for service users and staff</i>
Individual Supports/ Person Centred Planning	4	<ul style="list-style-type: none"> • Person-Centred Plans 	<ul style="list-style-type: none"> • <i>To help inform Individual programme plan and individual management plan for front-line staff (all disciplines)</i>
Ageing & Health	3	<ul style="list-style-type: none"> • Dementia • Aging population 	<ul style="list-style-type: none"> • <i>Identify areas of best practice particularly around ageing and</i>

			<i>dementia</i>
Family supports	3	<ul style="list-style-type: none"> Family Issues Family involvement Respite 	<ul style="list-style-type: none"> <i>Respite models for charities like CASA where 99% of the members are voluntary</i> <i>The research to inform our practice to ensure our role is meaningful now and into the future for families and their natural supports.</i>
Volunteering	2	<ul style="list-style-type: none"> Vetting issues Development and retention of volunteers 	<ul style="list-style-type: none"> <i>Developing smaller roles for volunteers to open up access to assisting the service would be good</i>
Rights and Equality	2	<ul style="list-style-type: none"> Freedom of movement Citizenship 	<ul style="list-style-type: none"> <i>How to move from congregate care to contributing citizenship</i>
Training and staff support in research	2	<ul style="list-style-type: none"> Transfer of learning Identifying best practice methods Monitoring and feedback Supervision Recruitment 	<ul style="list-style-type: none"> <i>Transfer of learning from staff training initiatives</i>
Education	1	<ul style="list-style-type: none"> Meeting ongoing needs Educational models Students with mild intellectual disability 	<ul style="list-style-type: none"> <i>To explore pre and ongoing educational requirements of service users</i>
Communication	1	<ul style="list-style-type: none"> Easy to read literature Accessible information 	

Q2. What are the main issues you feel need to be researched in your service?

Consensus on Categorisation of open coding

There was consensus among researchers on 13 of 16 categories.

New categories discussed and added were:

- **Supports**, which included advocacy, therapeutic interventions and children's services; and,
- **Health & Mental Health;**
- **Quality of Service** was also added to take account of issues around delivery of a quality service and evaluation of a quality service and service models not included in Living Options;
- Originally recorded as two categories, Sexuality and Relationships became one category called **Relationships** but included topics on sexuality, friendships etc.

Categories	N	Other terms used	Examples of responses
Supports	20	<ul style="list-style-type: none"> • Therapeutic interventions • Medication • Evidence based interventions • Family supports • Family needs • Respite • Bereavement • Assistive technology • Social and communication skills • Volunteering • Changing needs/transitions 	<ul style="list-style-type: none"> • <i>Dealing with change e.g. changes in living circumstances, changes in staffing</i> • <i>Better ways to support families to support their child or adult in the home environment.</i> • <i>Aromatherapy in relation to Palliative Care</i> • <i>School leavers and those who need support for further training or work</i> • <i>Supporting people in a changing cultural / ethnic profile of service users, staff & families</i> • <i>Research covering the essential and absolute supports that families in similar circumstances feel would be most meaningful</i> • <i>Multi-Disciplinary Supports and linking to Mainstream Generic Services</i>
Quality of Service	17	<ul style="list-style-type: none"> • Service models • Evaluation of services including respite, transitions • Organisational Development including culture partnership, resources, service developments, recruitment • Evidence based practice • Early intervention • Rostering • HSE restructuring • Service user governance • Flexible supports 	<ul style="list-style-type: none"> • <i>Impact of the HSE restructuring for service delivery (what are the outcomes?)</i> • <i>quality and relevance of services within social inclusion models</i> • <i>Effective Planning</i> • <i>Effective practices and models of service delivery, with regard to children services</i> • <i>What makes a good manager in our services – from different perspectives i.e. service users, families, staff?</i> • <i>9-5 service vs. supporting a 24hr lifestyle with people</i>
Living Options	14	<ul style="list-style-type: none"> • Models of living • Deinstitutionalisation, Residential services for people with severe or profound intellectual disability • Living supports 	<ul style="list-style-type: none"> • <i>Ordinary Living Models</i> • <i>Impact of deinstitutionalisation on lives of service users</i> • <i>Future Service provision in regard to semi-independent Living Models of Service</i> • <i>different type of housing/accommodation needed for older people as opposed to younger persons</i> • <i>Congregate service models – large day centres, group homes</i>
Community Integration and Inclusion	11	<ul style="list-style-type: none"> • Mainstreaming • Social networks • Barriers • Participation 	<ul style="list-style-type: none"> • <i>Community Tourism or Citizenship? How people can be present in their community and make their presence valuable</i>

			<ul style="list-style-type: none"> • The possibility of forming a Community workforce or a community support service to provide for continued normal living • Identifying and overcoming barriers to community inclusion • Real engagement with local communities • Best practice in community integration (e.g. community resources that prove most rewarding to people)
Training and Staff Development	10	<ul style="list-style-type: none"> • Staff roles and responsibilities • Staff training • Staff awareness and skills 	<ul style="list-style-type: none"> • Best use of staff resources in various settings (e.g. rostering in community houses) • How much does staff training impact on quality of life outcomes? • Staff awareness /skills in areas of social and emotional intelligence • Research into staff roles and responsibilities in a changed work environment
Ageing	10	<ul style="list-style-type: none"> • Dementia • Autism • Alzheimer's • Changing needs 	<ul style="list-style-type: none"> • Ageing a new phenomena • The changing supports required for the older person with Autism e.g. cognitive, physical, etc. • Ageing & dementia • Changing Needs owing to the aging profile of Service Users
Quality of Life	8	<ul style="list-style-type: none"> • Contributing factors • Profound Intellectual Disability 	<ul style="list-style-type: none"> • Provision of a human rights based approach increasing quality of life for service users • Impact of quality initiatives on the lives of service users • How can we support people to have more involved and meaningful lives • What factors contribute most to positive quality of life outcomes?
Health and Mental Health	8	<ul style="list-style-type: none"> • Severe and Profound Intellectual Disability • Dysphasia 	<ul style="list-style-type: none"> • Collaboration between Health and Education, as in the wider context and the need for recognition of the benefits of very close collaboration nationally. • Issues pertaining to mental health interventions • General health and people with disability • Health & Education working as a complementary unit of support
Advocacy	7	<ul style="list-style-type: none"> • Supported Decision-Making • Choice 	<ul style="list-style-type: none"> • Research on Supported Decision-making • Development of Advocacy Services • Advocating on behalf of people with intellectual disability with their family • Personal choice

Challenging Behaviour	7	<ul style="list-style-type: none"> • Offenders • Supporting people with challenging behaviour • Evaluation of high intensity services • Genetics 	<ul style="list-style-type: none"> • <i>Evaluation of high intensity services for people with behavioural challenges</i> • <i>Self harming amongst people with intellectual disability</i> • <i>Research into the contribution of genetics to intellectual disability, with particular reference to those with behaviours that challenge</i> • <i>positive effects of a low arousal non aversive model of care</i>
Relationships	7	<ul style="list-style-type: none"> • Sexuality • Friendships 	<ul style="list-style-type: none"> • <i>Sexuality and Autism</i> • <i>Sexuality and Relationships</i> • <i>Supporting people to develop friendships and social networks</i> • <i>Sexuality...Restrict protocols and legal issues in relation to this</i>
Equality and Rights	6	<ul style="list-style-type: none"> • Entitlements • Service user rights • Respect 	<ul style="list-style-type: none"> • <i>Arrangements in relation to Service User Wills & Voting rights</i> • <i>Rights based provision beyond education</i> • <i>Research on Service Users Rights and the issues / dilemmas this raises for service providers, and how these dilemmas may be resolved</i>
Money	6	<ul style="list-style-type: none"> • Individualised funding • Direct payments 	<ul style="list-style-type: none"> • <i>How service users can have more direct control over their own money, including people with limited understanding of money.</i> • <i>The application within services of Social Welfare entitlements</i> • <i>Service User Monies and Utilisation towards holidays & wishes where additional staff supports required</i>
Person Centred Planning	6	<ul style="list-style-type: none"> • Personal outcomes • Participatory research 	<ul style="list-style-type: none"> • <i>Person centred planning and the community context.</i> • <i>Quality Systems, Person Centred</i> • <i>Evaluations of person centred planning</i>
Education	6	<ul style="list-style-type: none"> • Mainstreaming education and inclusive education • Severe and Profound Intellectual Disability 	<ul style="list-style-type: none"> • <i>The significance of and the creation of a therapeutic classroom environment to facilitate the education process</i> • <i>Supporting people with significant disabilities in education</i> • <i>Health & Education working as a complimentary unit of support.</i>
Employment	5	<ul style="list-style-type: none"> • Evaluation • Employee training 	<ul style="list-style-type: none"> • <i>Marketing the Irish employer: what they know/ Experiences of employing people with a disability/ what is/isn't working for employer and employee</i> • <i>The world of work</i>

Q3. What areas do you think people who use your service would like researched?

Consensus Categorisation of open coding

As part of the consultation process it was imperative that we take account of research topics of interest to people who use services. In the process described above we asked respondents to identify topics they thought were of interest to the people who use the services. We also asked that people completing the questionnaire would do this by consulting with people with disabilities in their service. This was done in some but not all cases.

In the questionnaire analysis there was agreement on 12/16 categories. New categories suggested were:

- **Recruitment, choice and social life** to take account of other submissions from SU groups;
- A category called communication became **accessible information** to include the more specific topics such as easy to read information, understanding Person Centred Plans, etc;
- Issues around causes of learning disability, challenging behaviour and attitudes were discussed and a category of **Disability Awareness** was discussed and agreed;
- The category of **Supports** was agreed as suitable for topics such as volunteering, bereavement, therapeutic interventions, etc.

Categories	n	Other terms used	Examples of responses
Supports	13	<ul style="list-style-type: none"> • Bereavement • Respite • Therapeutic interventions • Transport • Volunteering and vetting of volunteers • Bullying • Key-worker • Dealing with change • Family involvement and supports 	<ul style="list-style-type: none"> • <i>Dealing with change e.g. changes in living circumstances, changes in staffing.</i> • <i>If the interventions they are being offered are the best ones</i> • <i>Real and meaningful bereavement support</i> • <i>Am I getting the right support at the right time...from the right person</i> • <i>More respite care – needs driven</i> • <i>Bullying (particularly in relation to their experience out in the wider community)</i>
Advocacy	12	<ul style="list-style-type: none"> • Having a say • Consent • Power • Change • Equality • Opportunities • Independence • Decision making • Governance • Consultation 	<ul style="list-style-type: none"> • <i>How to get your voice heard within an organisation</i> • <i>Advocacy and what this means in people's lives</i> • <i>Advocacy and service planning</i> • <i>Development of self-advocacy</i>

Service planning, Provision and Evaluation	11	<ul style="list-style-type: none"> • Service developments management • Risk management • Age appropriate supports • Alternatives to traditional day services • Home support • Person centred planning 	<ul style="list-style-type: none"> • <i>Service development</i> • <i>How service users can participate at Board level – what preparation, supports they need, etc.</i> • <i>Are services age-appropriate?</i> • <i>More networking between services and with other services to access community based activities</i>
Living Options	11	<ul style="list-style-type: none"> • Models of living • Housing • Semi-independent living • Out of hours support 	<ul style="list-style-type: none"> • <i>Residential care for all categories of disability</i> • <i>Being supported to have own home, alternative to traditional model of day services.</i> • <i>Alternative living arrangements</i> • <i>Living environments</i> • <i>Support for living – particularly outside of ‘service’ hours</i>
Community Inclusion and Integration	10	<ul style="list-style-type: none"> • Social supports • Social inclusion • Partnerships in the community • Networks 	<ul style="list-style-type: none"> • <i>Community integration of people with significant Intellectual Disability, how much has it really improved in past ten years</i> • <i>Innovative partnerships with community organisations</i> • <i>Social support networks</i> • <i>How to become a valued member of my local community</i>
Relationships	8	<ul style="list-style-type: none"> • Family Relationships • Parents • Sexuality and friendships 	<ul style="list-style-type: none"> • <i>Support in the area of sexuality and developing relationships</i> • <i>How to succeed in having friendships and relationships</i> • <i>Relationships, Friendships & Inclusion</i>
Employment	7	<ul style="list-style-type: none"> • Supported employment 	<ul style="list-style-type: none"> • <i>Work and pay opportunities</i> • <i>Future prospects (career/placement options) for children with Mild Intellectual Disability</i> • <i>Supported Employment –current position re numbers involved, difficulties in accessing jobs, resources required to support those in jobs</i>
Quality of Life	7	<ul style="list-style-type: none"> • Opportunity • Health • Meaningful lives 	<ul style="list-style-type: none"> • <i>Quality of life initiatives</i> • <i>Quality of Life- what does it mean for someone (adult with Intellectual Disability)</i> • <i>How to have a life that is meaningful to them</i> • <i>“For staff to show us the way to a normal young adult life”</i>
Inclusive Education	6	<ul style="list-style-type: none"> • Mild Intellectual Disability • Mainstream Inclusion • Specialist Schools 	<ul style="list-style-type: none"> • <i>Participation in continuing education in main stream colleges</i> • <i>The numbers of children with Intellectual Disabilities particularly Mild, who are attending mainstream schools and are not recorded on the NIDD System</i> • <i>Supports for mainstream inclusion in</i>

			<i>schools (especially the social and peer support needs)</i>
Choices	6	<ul style="list-style-type: none"> Control over destiny Opportunity 	<ul style="list-style-type: none"> <i>Increased Control over own destiny</i> <i>Real opportunity</i> <i>Risk management – the extent to which services allow people freedom of choice</i> <i>What choice do I have?</i>
Social Life	5	<ul style="list-style-type: none"> Free time Leisure Holidays Recreation Loneliness Autonomy 	<ul style="list-style-type: none"> <i>Supported leisure – how services can overcome social isolation and loneliness</i> <i>Variety of activities</i> <i>Social and Relationship Opportunities</i>
Money	5	<ul style="list-style-type: none"> Managing money Spending money 	<ul style="list-style-type: none"> <i>Access to money & holidays</i> <i>How service users can have more direct control over their own money, including people with limited understanding of money.</i> <i>Managing my own money – spending my money</i>
Accessible Information	4	<ul style="list-style-type: none"> Information National Intellectual Disability Database system Easy to read Health promotion Understanding Person Centred Planning 	<ul style="list-style-type: none"> <i>What are the priority areas for provision of accessible information, to allow me to access community supports?</i> <i>Availability of information re service and schools and the effects that can have</i>
Equality and Rights	3	<ul style="list-style-type: none"> Balancing power Education 	<ul style="list-style-type: none"> <i>The area of rights education has been approached by many organisations using different strategies. It would be useful to establish what fits best in the Irish context and which educational and organisational strategies are the most effective</i>
Recruitment	3	<ul style="list-style-type: none"> Involvement of Service User 	<ul style="list-style-type: none"> <i>How service users can be involved in the recruitment of their own direct support staff</i> <i>How to recruit the right staff</i>
Disability Awareness	3	<ul style="list-style-type: none"> Causes of learning disability Challenging behaviour Attitudes 	<ul style="list-style-type: none"> <i>Focus on educating the general public regarding the needs of persons with a disability</i> <i>understanding the cause of learning disabilities</i>
Ageing	2	<ul style="list-style-type: none"> Changing Needs 	<ul style="list-style-type: none"> <i>The changing supports required for the older person with Autism e.g. cognitive, physical, etc.</i>

Q4. As we continue to build a network of contacts who should we contact in your organisation for issues relating to research? (Please provide names and contact details)

This part of the questionnaire was included to develop a list of people, and their contact details, who were interested in intellectual disability research, from the member organisations. Early consultations, as outlined in Appendix VI, highlighted the need for a Register of Disability Stakeholders (see Priority 8). As part of this, there should be a subgroup of the register that would be made up of all those with an interest in Intellectual Disability Research. This list of people retrieved from the questionnaire responses, will be used as a basis for the Intellectual Disability Researcher Database.

iii. Consultation 3: Consultation with Advocacy / Self-advocacy Groups

In addition to these consultations with the Research Sub-Committee and the member organisations, we asked that presentations be made to the Research Sub-Committee by people who use services. Submissions were sought from the Community Participation and Inclusion Sub-Committee, Seasamh Parliament and the Inclusive Research Network.

The submissions from each of these groups are outlined below.

- **Presentation from Community Participation & Inclusion Sub-Committee to the Research Sub-Committee - 31st March 2008**

Brian Donohoe made a presentation on behalf of the Community Participation & Inclusion Sub-Committee. His presentation was based on the views and interests of the members of the Community Participation & Inclusion Sub-Committee and, in particular, their recent publication "People Connecting". The overall aim of this Sub-Committee is to look at how people who avail of intellectual disability services can live full active lives, of their own choice, within their own communities, and to look at the best ways of making this happen. "People Connecting" includes the findings from a consultative workshop - involving people who avail of services and staff from services - on the barriers, incentives and solutions to community participation & inclusion of people with intellectual disability, together with recommendations to the Board of Directors of the National Federation. A copy of this publication was circulated to everyone at the meeting.

The main points from the presentation can be summarised into 7 broad themes:

1. Independence & Choice
2. Friendship
3. Attitudes
4. Advocacy / Self-Advocacy

5. Accessible Information
6. Transport
7. Disability Allowance

The specific topics under each of these themes are outlined below. People who avail of intellectual disability services would like:

- Independence & Choice - We would like to live and work in the place of our choice, make our own decisions, and ask you to support us to take risks like everybody else.
- Friendship - We would like to meet and spend time with friends who share common interests.
- Change Attitudes - We would like to get help to change the negative attitudes of people around us towards people with a disability.
- Advocacy / Self-Advocacy - We would like to speak up for ourselves or have someone to support us to do this.
- Accessible Information - We would like to access information that's easy to read and understand.
- Transport - We would like to have transport available to us, especially in rural areas, so that we are not isolated from everyone
- Disability Allowance - We would like to get more money from the Department of Social & Family Affairs so that we can do the things we want to do

The group also emphasised the importance of national and international evidence based best practice that will enable people who avail of services to live full active lives, of their own choice, in their own communities, including the following:

- Examine ways of fostering and maintaining good community connections and social networks so that people can develop real, meaningful, long lasting and freely chosen relationships
- Develop short and long-term strategies to support people to live, work and spend time in ordinary community settings
- Develop strategies to support people's right to independence and the right to make their own decisions, including managing their own money
- Develop strategies to raise awareness and challenge assumptions of disability in communities, within services and in the media
- Look at how "day services" are traditionally provided and examine ways of providing more holistic person centred services e.g. outside of the 9 to 5 model.
- Examine best practice in managing change to facilitate the smooth transition of change within organisations

Brian also highlighted that people who avail of services should also be involved in some of this research – “nothing about us without us”. He finished his presentation by thanking the sub-committee for giving the Community Participation & Inclusion group a chance to have their say and for listening to their opinions.

Following the presentation the Research Sub-Committee thanked Brian Donohoe and commented that the presentation was helpful and insightful. Brian McClean acknowledged that we may need to revisit our table of National Designated Experts to include topics of friendships and accessibility of information (e.g. easy to read documents). This table of topics was updated to reflect the Presentation from the Community Participation and Inclusion Sub-Committee

The group discussed with Brian ideas around how best to include the views of people with intellectual disabilities in research for the future and the following suggestions were made:

- Holding consultation days or focus groups with people who avail of services;
- Use the recommendations in “People Connecting” and include them in the research strategy;
- Encourage people to focus their research in the areas raised in the “People Connecting” document e.g. friendships, etc;
- Invite a representative from the Community Participation & Inclusion sub-committee to become a member or an associate member of the Research Sub-Committee.

These suggestions were incorporated into the strategy action plan outlined at the end of this document.

- **Submission from the Inclusive Research Network (IRN) to the National Federation of Voluntary Bodies Research Sub-Committee for Inclusion in the Research Strategy**

This submission was made by Derek Watson, a Public Relations Officer in Seasamh, Kilkenny and a member of the IRN. Derek compiled the views of the IRN into this submission, as outlined below, which summarises the main issues identified by the network.

Setting up a Research Network

- We are working in a new ‘network’ for all Ireland
- We have been meeting in Dublin in Trinity College
- The network is for people who access intellectual disability services
- Members come directly from service centres, from ‘National’ organisation like the Federation of Voluntary Bodies; representative organisations like ‘Seasamh’, we asked our forum to get involved and they said ‘yes’ so we aim to hold one of the research workshops in Kilkenny
- Because there is no one better to talk about such things than the people themselves; ‘advocacy’ is the only way to improve quality-of-life.

- The network aims to make a 'picture' in Ireland of what life is like for people facing the challenges entailed by Intellectual Disability
- We are going to hold 'workshops' through the whole island of Ireland and to make the findings available to everyone

Some things people in the network have already said

People attending network meetings have already pointed out some things that they are concerned about:

- Ways to communicate, i.e. through using computers,
- The need for clear communication – no jargon
- Making sure that people have all their entitlements
- Better pay and conditions; for work done in centres
- Being involved in staff recruitment
- Being part of statutory evaluation of services
- More independence for service users – less changes to be decided solely by management
- Close all institutions and end institutional practices

Social Inclusion:

- Deal with 'Bullying'
- Rights to 'Privacy'
- Access to mainstream education
- Sexuality and Relationships, education and support
- Community Living
- Employment
- Support for non-verbal persons

- **Submission from Seasamh Parliament to the National Federation of Voluntary Bodies Research Sub-Committee for inclusion in the Research Strategy**

Seasamh is an open forum lead by a peer-elected leadership-team operating on a parliamentary basis working to improve quality of life for persons who access intellectual disability services in partnership with providers. Their submission to the National Federation outlines research priorities as identified by Seasamh.

Agenda Areas of Interest or Difficulty:

- Leadership Course in Galway Called for at Exchange Day
- Health Care for persons with disabilities
 - Routine Care
 - Consent
 - Communications with Health Professionals
- Bereavement Counselling Services

- To help people cope with loss
- Access to Public Buildings
- Better and safer pedestrian crossings for people, outside of their workplace
- Better pay and conditions in centres
- Have Service users on interview boards for new staff
- Introduce Forklift driving courses
- Service users to have the right to be employed in their services as supervisors
- More independence for service users – less changes to be decided solely by supervisors and management
- Close all institutions
- Improve recycling in services
- Put our committee on a national level
- Invite people to have meetings in the West of Ireland, Roscommon and Mayo
- Rotate meetings, like a league of “home and away” matches
- Visiting centres in different regions
- Fair pay – minimum wage
- Employment in the open labour market
- Social clubs – new friends
- Better transport, especially for people living in rural areas with passes but no buses
- More independence
- Better communication – understanding people as they are and why
- Care for people who cannot read or write – literacy training
- ‘Stamp’ out bullying
- Independent housing – support for independent living single and partnerships
- Relationships
- Community network – teamwork, working as a group together
- Training must lead to employment not more training

Conclusions & Recommendations

- More training courses in colleges
- People in centres to be paid properly and fairly for work done, the Government to increase wages to the minimum wage of 8.50 or increase by 120.00 per week WITHOUT losing Disability Allowance, to ensure a fair standard of living
- Investment in development of workshops
- Improved levels of support for people working
- People to receive sick benefit if not working
- Have a person with a disability stand for next Government elections
- Learning how to cook, shop, manage money and doing everyday things for yourself

- Living in your own house, within a community – a move from full-time residential to semi-independent living
- Provide training to enable a move out into the community
- Sharing with another person of YOUR CHOICE
- It will be less expensive in the long term for the government to support people living in their own homes
- Active socialising – enable people to build relationships and receive support to get out with friends
- Make own choices – not be bossed about by staff. No decisions about us to be made WITHOUT us
- Seasamh members should organise a protest by placing pickets outside SOS, about lack of a safe pedestrian crossing and reducing the speed limit
- Better road signs that are disability friendly
- Better transport facilities in taxis, trains and buses for those with travel passes in rural areas
- There should be better ramps on buses
- Improved foot paths

For more information on the Seasamh Parliament, please contact: seasamh@eircom.net

iv. Consultation 4: Consultation with the National Federation Secretariat Team

The National Federation Secretariat team, having reviewed the research strategy document and the topics in Priority 1 requested that **Early Intervention** be included as a priority topic. They felt that including Early Intervention would advocate for a life cycle approach to research as per the structure of Towards 2016 National Partnership agreement. In addition they cited the National Economic and Social Development Office Report (2006) which stated an earlier cost benefit analysis NESF Report 31 (July 2005) showed that there was a return of 7 euro for every 1 euro invested in early childhood care and education (NESF, 2006).

The Research Sub-Committee agreed to include this as a priority topic for research and it was included in the final 11 topics outlined in Priority 1.

v. Consultation 5: Consultation with the National Federation Board of Directors

A final consultation with the Board of Directors included a presentation on the Research Strategy. The Strategy was endorsed and approved by the Board in July 2008.

vi. Summary of Research Strategy Consultations

Through these processes of consultation with our Research Sub-Committee, member organisations and advocacy / self-advocacy groups, 11 issues could be seen as priority areas for Intellectual Disability research in the future. These 11 issues are listed below:

- Living options
- Service Models
- Community inclusion / integration
- Relationships
- Money
- Ageing
- Challenging behaviours
- Family Supports
- Staff resources
- Employment
- Early Intervention

Research proposals developed by the National Federation of Voluntary Bodies will use these 11 topics as guidelines when deciding on future research proposals, both within the National Federation of Voluntary Bodies and with the Research Collaborators (see Priority 6). These topics will be considered in relation to best practice guidelines (as stressed in the three consultations) and compiled where possible in easy-to-read format (as requested by people who use services).

Addenda

• Addendum A - National Federation of Voluntary Bodies Board of Directors, Secretariat Team & Member Organisations

Board of Directors

Brendan Broderick, Sisters of Charity of Jesus & Mary (Chairperson)
 Tony Darmody, Kerry Parents & Friends Association
 Maura Donovan, Stewarts Hospital
 Wally Freyne, Daughters of Charity Services
 Mary Kealy, Brothers of Charity Services Clare
 Laurence Kearns, St. John of God Hospitaller Services
 Edith Kennedy, MIDWAY
 Christy Lynch, KARE
 Paul Ledwidge, St. Michael's House
 Patricia Lee, Sisters of La Sagesse
 Vincent Millet, Irish Sisters of Charity
 Maura Nash, COPE Foundation
 Michael Noone, Sunbeam House Services
 John O'Dea, Western Care Association
 Winifred O'Hanrahan, Brothers of Charity Services

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, Clerical Officer (Fixed Term Contract)
 Brian Donohoe, Clerical Officer (1 day per week)
 Jillian Sexton, HR & Training & Development Co-ordinator
 Alison Harnett, Informing Families Project Co-ordinator
 Breda Casey, Policy Development Co-ordinator

Member Organisations

- Ability West, Blackrock House, Salthill, Galway
- 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, Bawnmore, 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
- 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, Unit F12, Maynooth Business Campus, Maynooth, 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, Lower Eyre Street, 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, Industrial Estate, Donore Road, Drogheda
- 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, 138 Hillside, Greystones, Co. Wicklow
- Peamount, Newcastle, County Dublin
- Prosper Fingal, Vocational Training Centre, Piercetown, 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. Anne's Service, Sean Ross Abbey, Roscrea, Co. Tipperary
- 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, 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, Drangan, Thurles, Co. Tipperary
- Walkinstown Association, 1 Longmile Road, Dublin 12
- Waterford Intellectual Disability Association, Ashley Drive, Spring Garden, Cherrymount, Waterford
- Western Care Association, Pool Road, Castlebar, Co. Mayo
- Windmill Therapeutic Training Unit, Larkins Lane, South Main Street, Wexford

• Addendum B - List and members of National Federation of Voluntary Bodies Sub-Committees (as of July 2008)

Research Sub-Committee

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

Early Intervention Sub-Committee

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

Education Sub-Committee

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

Human Resources Sub-Committee

Shona Boyne, Rehabcare
 Pauline Brennan, Western Care Association
 Eileen Carr, Malta Services Drogheda
 Anne Coffey, KARE
 Francis Coughlan, SOS Kilkenny Ltd.
 Paul Egan, Sisters of La Sagesse
 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
 John Pepper, Hosp. Order of St. John of God
 Eileen Skehan, Carriglea Cairde Services
 Jillian Sexton, 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, Limerick
 Jillian Sexton, National Federation of Voluntary Bodies Services

Quality Sub-Committee

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

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

Vocational Training & Employment Sub-Committee

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

Volunteering Sub-Committee

Anne Byrne, KARE
 Roisin Deery, Midway Services
 Rosemarie Kearns, Brothers of Charity Services Galway
 Rhoda Judge, Daughters of Charity Services
 Linda Keane, Ability West
 Noreen McGarry, Western Care
 Peter McKevitt, RehabCare
 Gerry McLaughlin, Sisters of Charity of Jesus & Mary
 Susan McGill, Brothers of Charity, South Eastern Region
 Jerry Mullane, COPE Foundation
 Mary O'Connell, Brothers of Charity, Limerick
 Saretta O'Mahony, St. Joseph's Foundation
 Martina Rynne, Brothers of Charity Clare
 Kathleen Sherry, SOS Kilkenny Ltd
 Breda Casey, National Federation of Voluntary Bodies

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

• Addendum C - Members of Advocacy / Self Advocacy Groups who made Submissions

Name	Organisation
Aine Ní Aileagain	Inclusion Ireland
Anna Nolan	Roscommon Brothers of Charity
Anna O'Callaghan	St. Josephs Foundation
Anne Keenan	CWCW Wexford
Brian Donohoe	National Federation of Voluntary Bodies
Carol Hamilton	NIID TCD
Caroline Dalton	University College Cork
Caroline Hart	Rehab Care
Christina Doody	St. John of Gods
Darach Murphy	Trinity College Dublin
Edel Tierney	National Federation of Voluntary Bodies
Eibhlin Clifford	Mountmellick Development
Frances Hannon	NDA
Gerard Quinn	NUI Galway
Gillian Martin	St. John of Gods
Hasheem Mannan	NIID TCD
Janice Hyde	St. Michaels House
Jean Ware	Dublin City University
Joan Lalor	Trinity College Dublin
John Sweeney	University College Dublin
Karina Wallis	Sisters of Charity of Jesus and Mary Services
Kathleen Lynch	University College Dublin
Kay Downey-Ennis	Daughters of Charity Services
Kay O'Shea	Parent of son with a disability
Kelley Johnson	Norah Fry Research Centre Bristol
Leah Quinlivan	NIID TCD
Liza Kelly	Inclusion Ireland
Lyn Farelly	Dara Residential Services
Martha McGinn	Inclusive researcher with special interest in sexuality and relationships
Mary Comiskey	Headway
Mary Kelly	NIID Student
Joe McGrath	Inclusive Researcher
Brian Hogan	Inclusive Researcher
Maria Wolfe	Inclusive Researcher
Mary McCarron	Trinity College Dublin
Maureen O'Connor	University of Limerick
Michael O'Keeffe	Dublin City University
Neil Morris	Radish
Nick Blitz	Camphill Services
Nina Cohen	Former student NIID TCD
Patsy King	St. Cronan's Service
Paul Keenan	Trinity College Dublin
Rachel Stevens	NUI Galway
Richard Collins	East Clare Project
Rob Hopkins	Brothers of Charity Clare
Robin Toner	Researcher
Sheelah Watson	NUI Maynooth
Simon Foley	University College Dublin School of Sociology
Stephani Bonar	Researcher
Stephen Curtis	NIID TCD
Susan Carton	Researcher
Suzanne Little	Researcher
Teresa Ryan	Limerick Brothers of Charity
Tim O'Connell	Seasamh Parliament / SOS Kilkenny
Derek Watson	Seasamh Parliament / SOS Kilkenny

Members of Community Participation & Inclusion Sub-Committee

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

Members of Seasamh Parliament as at June 2008

Alma Breen	Anna Foley	Simon Minihan
Carol Browne	David Fraughan	Helen Moore
Ger Byrne	Mandy Gahan	Thomas Mullane
Margaret Carey	Andrew Gallagher	Kevin Murphy
Martin Carroll	Kathleen Gittens	Raymond O'Brien
Nicola Carroll	Thomas Harding	Anita O'Connor
Louise Coleman	Michael Hearne	Joanne O'Shea
Sally Ann Conway	Eleanor Hickey	Helen O'Shea
Paul Crilly	Christopher Hurley	Maria Phelan
Thomas Daniels	Kathleen Johnston	Claire Power
Dermot Darcy	Brigid Keane	Patrick Roche
Paul Deacon	Liam Kiely	Veronica Rossiter
Ann Dillon	Gerri Kinsella	Marian Ryan
David Dobbyn	Tomas Kinsella	Conor Ryan
Jonathan Douglas	Mary Ledwell	Michelle Ryan
Brendan Downes	Richard Lennon	Martin James Scanllan
Brendan Doyle	Barry Lonergan	Mary Shanahan
Emily Dunbar	Claire Maher	Pamela Travers
Sylvia Dunphy	Paula McCarthy	Deborah Tyrell
Michelle Finn	Sean McDonald	John Walsh
Sharon Fitzgerald	Stephen McDonnell	John Walsh
Alan Fitzpatrick	Carol Melbourne	Brian Waters
		Derek Watson
		James Whelan

- Addendum D - List of Member Organisations and occupations of questionnaire respondents

Organisations
Ability West
Ard Aoibhinn
Brothers of Charity Clare
Brothers of Charity Galway
Brothers of Charity Roscommon
Brothers of Charity Services
Brothers of Charity Services, Limerick
Camphill
Carriglea Services
CASA
Cheeverstown House
Cope Foundation
Cork Association for Autism
Dara Residential
KARE
Kerry Parents and Friends Association
Peamount
Rehab Care
Sisters of Charity of Jesus and Mary
Sisters of La Sagesse Services, Cregg House, Sligo
St. John of God Services
St. Joseph's Foundation
St. Michael's House
St. Patricks Centre (Kilkenny) Ltd., Kilkenny
Walkinstown Association
Western Care Association

Range of Occupations
Asst. Programme Manager
CEO
CNM 2
Co Worker
Development Officer
Director
Head of Evaluation and Training
Housing Officer
Manager
Medical Officer
Psychologist
Research and Communications Officer
Research Officer
Social Worker

- **Addendum E - Letters to National Designated Experts & Research Collaborators**

Letter to National Designated Experts

May 2008

RE: National Designated Experts

Dear

As you may be aware, the National Federation of Voluntary Bodies is currently developing a National Research Strategy for 2008- 2013. This is being developed with the support of the Federation Research sub-committee.

As a priority of the strategy we are committed to making more resources and materials available to our members. This information will help to develop knowledge in key areas as identified through our consultation process.

At a recent meeting of the Research Sub-Committee we decided that one way to do this would be to develop a database of National Designated Experts on key research issues. You were identified as a national expert in the area of _____. I am writing to ask if you are willing to become our nominated expert in this area.

The role of the designated expert shall be to support member organisations (or researchers within organisations) develop their knowledge further on this particular topic. We would also like for you to become an associate member of the Research Sub-Committee to advise us as occasion arises on issues arising in your expert area.

We anticipate that the role of the designated expert shall be initially for a period of one year and will be reviewed at the end of this period. Designated experts will be expected to provide an updated recommended reading list on their area of expertise and this will include a list of recommended assessment tools/research instruments in this area. The list of reading materials shall be made available through the NFVB website and shall be updated quarterly. You may choose to assign a PhD student or colleague of yours to undertake the maintenance of this material under your supervision, or you may contact a network of people who are working in this area to support you in this role.

In addition you may recommend that certain tools assessment materials be used in national studies across this area so that research comparisons may be made on a national level.

I trust that this will not involve much extra work on your behalf outside of your usual day-to day activities. I know that the expertise that you can share with our member organisations in contributing to the national agenda will be much appreciated by people who work in this area.

Please do not hesitate to contact me should you have any further queries regarding your role as National Designated Expert.

Yours truly,

Edel Tierney
Director of Research and Policy Development

Letter to Research Partners/Collaborators

May 2008

Re: Research Partnerships

Dear

As you may be aware, the National Federation of Voluntary Bodies is currently developing a National Research Strategy for 2008- 2013. This is being developed with the support of the Federation Research Sub-Committee.

In order to do this we are committed to working in partnership with the key disability stakeholders and research centres nationally and internationally. We believe that such partnership can support the strategy by encouraging research collaboration on topics of interest. Such partnership may also support applications for funding, and develop world class research projects which can contribute widely to our knowledge base of intellectual disability, its causes, life span development and the delivery of services.

We believe that such partnership working will be mutually beneficial and will contribute to the development of national and international policy.

At a recent meeting of the Research Sub-Committee we identified your research centre as a potential partner for future research. This would mean continuing the type of collaboration we have already engaged in thus far and may include in the future the development of research proposals for funding where appropriate, the sharing of information and resources and engagement in research activities such as advisory boards, ethics committees etc. We envisage that the partnership will be a flexible one whereby each partner may engage at a variety of levels on an ongoing basis.

We look forward to a fruitful research partnership in the years ahead. If you agree to be cited as a research partner can you please complete the table below and email to us at your convenience?

Please do not hesitate to contact me should you have any further queries regarding your centres role as a Research Partner

Yours truly,

Edel Tierney

Director of Research and Policy Development

- Addendum F - Template for Research Collaborators

Centre Name:

Address:

Website address:

Director/CEO/Chair

Information about Centre:

References

- A life Like Everybody Else Conference Report (2003) European Association of Service Providers for Persons with Disabilities (EASPD) Available at www.community-lives.org
- Analysis of Need for Services and Supports for People with Intellectual Disability (2004) National Federation of Voluntary Bodies, Available at www.fedvol.ie/publications
- Burnard, P. (1991) A method of analysing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461-466.
- Centre for Disability Law and Policy (2007) Strategic Plan 2008-2012.
- Education for Persons with Special Educational Needs Act EPSEN (2004) Available at www.ncse.ie
- Employment Equality Act (1998) Available at www.equality.ie
- Equal Status Act (2000) Available at www.equality.ie
- Equality Act (2004) Available at www.oireachtas.ie
- From Disability to Ability - A Pathway to Equal Employment of People with Intellectual Disabilities (2004) European Knowledge Centre on Vocational Training and Employment for People with Intellectual Disabilities, Available at www.start-labor.org
- Harnett, A., Dolan, B., Guerin, S., Tierney, E. & Walls, M. (2007) *Informing families of their child's disability: National best practice guidelines consultation and research report*. National Federation of Voluntary Bodies, Galway, Ireland. www.fedvol.ie/publications
- Health Act (2007) Available at www.oireachtas.ie
- The Irish Council of Bioethics (2004) *Operational Procedures For Research Ethics Committees: Guidance 2004* www.bioethics.ie/pdfs/guide.pdf
- Mental Capacity and Guardianship Bill (2008) Available at www.oireachtas.ie
- National Disability Strategy (2004) Available at www.justice.ie
- National Economic and Social Forum (2006) NESF Report 34; Improving the Delivery of Quality Public Services. www.nesf.ie/publications.asp
- National Federation of Voluntary Bodies (2005) Guidelines for Researchers when Interviewing People with an Intellectual Disability. NFVB; Galway. www.fedvol.ie/publications
- National Federation of Voluntary Bodies (2008), *Volunteering in Intellectual Disability Services in Ireland - Supporting People to Live the Life of their own Choice in their own Community*. www.fedvol.ie/publications

- O'Brien, J. & O'Brien, C. (Eds) (1997) *A Little Book of Person-Centred Planning*. Inclusion Press.
- Odom, S.L., Brantlinger, E., Gersten, R., Horner, R.D., Thompson, B. & Harris, K. (2004) *Quality Indicators for Research in Special Education and Guidelines for Evidence Based Practices*. Division for Research Council for Exceptional Children. www.cecdr.org
- People Connecting (2007) National Federation of Voluntary Bodies, Available at www.fedvol.ie/publications
- Report to the National Council for Special Education's Consultation on the Implementation of the Education for Persons with Special Educational Needs (EPSEN) Act 2004 (2006) Available at www.fedvol.ie/publications
- Towards 2016, Ten-Year Framework Social Partnership Agreement 2006-2015 (2006) Department of the Taoiseach, Government Buildings, Upper Merrion Street, Dublin 2
- UN Convention on the Rights of People with Disabilities (2008) Available at www.un.org/esa/socdev/enable/rights

