

**NATIONAL FEDERATION OF VOLUNTARY BODIES**

*Providing Services to People with Intellectual Disability*

# Research Strategy 2008-2013

Easy-To-Read Version



Produced by Brian Donohoe, National Federation of Voluntary Bodies

# **Research Strategy 2008-2013**

## **Foreword**

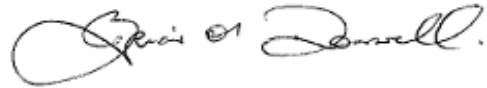
The most important part of providing services to people with disabilities is that people with disabilities get the chance to live good full lives by being supported to live with their families & be included in their communities.

In the last 10 years the Government's National Disability Strategy and the UN Convention on the Rights of People with Disabilities have both given a lot of hope to people with disabilities, their families and the services that support them.

As service providers the National Federation accepts that for services to be person centred we have to change the way we provide services by being more creative. We are now starting to look at the direction we need to be taking so we can meet the needs of those who use our services.

One of the ways that we provide the service people need is to know exactly what those needs are and that can only be done through high quality research into areas where more information is needed. So we have developed a research strategy after talking with all our member organisations and which is in the following pages.

I would like to thank our Research Sub Committee who have put the strategy together especially Brian McClean and Edel Tierney our Director of Research. I am sure that it will play a part in making services better for people with disabilities.

A handwritten signature in black ink that reads "Brian O'Donnell". The signature is written in a cursive style with a large initial 'B' and 'O'.

**Signed:** \_\_\_\_\_

**Brian O'Donnell,  
Chief Executive**

## Introduction

The main aim of the Research Strategy is to set out the research plans of the National Federation of Voluntary Bodies over the next six years (2008-2013).

The National Federation of Voluntary Bodies is committed to collecting and sharing information and to promoting high quality research.

To provide high quality services to people with disabilities those who are providing these services need to be involved in high quality research.

This strategy will support inclusive research which will help everyone including people with disabilities, their families, service providers & staff in services to find out what is best practice & should improve the quality of life of people with disabilities.

After a number of meetings the Research Sub-committee agreed the main aims of the research strategy

- To carry out research which will lead to a better quality of life for people who use services.
- To promote and share research among member services.
- To focus on areas which matter and will make the research real to people.
- To make links with research centres abroad.

- To carry out research which may change national policy on important issues.

It was also agreed by the committee to talk with member services at all levels including people using services, staff and managers in services as well as others with special interest in disability issues.

This strategy includes a wide variety of opinions and it is agreed vision for the future of research in Ireland.

## Research Priorities 2008-2013

1. Show the important areas for research that came up when talking with people who use services, management and staff.
2. Make a list of experts to support and share research in the Irish research community.
3. Find a way of knowing what is good research
4. Find out if research makes a difference
5. Find people who could advise the Research Sub-Committee on some issues.
6. Have links with research centres both in Ireland and abroad
7. Advise on how we could get money to do research in the future.
8. Make a list of people who are interested in disability research.
9. Make a list of research that is taking place and put it on National Federation website
10. Form a National Committee which would help with the rules of research and make sure people with disabilities benefit from it.
11. Continue to talk with people who use services through research projects such as the Inclusive Research Network and find ways to work together when doing research
12. Look at the research strategy at the end of every year to see if it is suitable.

## Priority Topics

The 11 topics below are the priority areas for research in the National Federation of Voluntary Bodies for the years 2008-2013:

- Living options
- Quality of Service
- Community Inclusion/Integration
- Relationships
- Money
- Ageing
- Challenging behaviours
- Family supports
- Staff Resources
- Employment
- Early intervention



After finding these 11 topics we will look at ways to fund them.

Research will be developed when opportunities arise.

National experts will support information on these important areas and the information will be available on NFVB website

[www.fedvol.ie](http://www.fedvol.ie)

**Priority 1: Show the important areas for research that came up when talking with people who use services, management and staff.**

**Action Plan to Achieve Priority 1:**

1. The 11 topics identified through talking with people are the main areas for research in the National Federation of Voluntary Bodies for the years 2008 – 2013.
2. Ways of funding research will have to be found.
3. Research projects will be started as opportunities arise.
4. Priorities will be matched with experts from a panel of national and international researchers.
5. National Experts will share their knowledge in these areas and advise on development of research projects.
6. Information from this consultation process will be used again in the development of future research projects and activities.

**Priority 2: Make a list of experts to support and share research in the Irish research community.**

Meetings with the Research Sub-Committee lead to a list of important topics of interest to member organisations. Talking with service user groups (Inclusive Research Network, Seasamh, and Community Participation & Inclusion Sub-Committee) identified topics relevant to people who use the services. These topics were found to be important 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 who are



called '*National Designated Experts*' provide information on these topics.

**Action Plan to Achieve Priority 2:**

1. Identify a list of topics important to member organisations through consultations with the Research Sub-Committee and service user groups & staff and management in services.
2. Identify National Experts in these areas.
3. Contact Experts to talk about their involvement.
4. Each expert will make up a list of reading materials in their area of knowledge and put them on the National Federation of Voluntary Bodies website.
5. 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: Find a way of knowing what is good research.**

In talking to different groups including people with disabilities and service providers it was agreed that ways of measuring the quality of research done by the National Federation would have to be looked at. It was agreed that a system showing the quality of different methods of research should be set up

High quality research should help managers, supervisors, front-line staff, parents, policy makers and researchers know what is good research i.e., Different methods are better for different projects.

Intellectual disability research should lead to a good quality of life for people with intellectual disability and their families.

### **Action Plan to Achieve Priority 3:**

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

1. Set up a group to look at quality issues for research in intellectual disability;
2. Talk about research methods in intellectual disability research;
3. Develop a set of rules for these research methods;
4. Look at ways of knowing what practices are research based;



### **Priority 4: Find out if research makes a difference**

There is a need to measure performance of research in order to know how well research is being done in the National Federation of Voluntary Bodies. This may be done by joining up with well known universities and researchers.

The three best ways to measure performance of research are listed below

- Publication in journals, etc. – Whether or not the research undertaken is published will indicate the measure of performance of the research;
- Impact on policy and practice – Does the research effect government policy
- Asking what is working in services



Information will be shared with the Research partners as explained in Priority 6 to measure our performance in comparison to other research centres.



#### **Action Plan to Achieve Priority 4**

1. Talk with Research Collaborators on the development of Guidelines to see if the research we are doing is good research.
2. Look back over research that has been completed to measure its it's quality
3. Develop Quality Research Projects with National and International Centres,
4. Develop successful applications for funding.
5. Count the number of projects that appear in journals.
6. Increase the number of national research partnerships following the launch of the Research Strategy.



7. Develop a way of asking people “How are we doing?” from services, service user groups and partners.

**Priority 5: Find people who may be called upon to advise the Research Sub-Committee on some matters.**

**Action plan to Achieve Priority 5:**

1. The list of advisors will be drawn from the list of key designated experts in Priority 2.
2. Agreement will be got from these experts on key topics.
3. During this year experts may be asked to advise the committee on their expert topics as occasion arises.
4. After a period of one year the role of the advisors shall be looked while talking with them.
5. Other advisors may be invited to the panel.
6. Advisors may also be asked to sit on boards or committees for research projects as projects and projects are developed.

**Priority 6: Have links with research centres both in Ireland and abroad**

Talking to people before and during the development of the research strategy showed that working in partnership was important to the development of quality research projects. The Research Sub-Committee agreed that it would be good to work with research centres both nationally and abroad. It was felt that

such partnerships could support the strategy by doing research together.

### **Action Plan to Achieve Priority 6**

1. A number of research centres will be found to help us with future research.
2. A list of these centres, in Ireland and abroad, will be drawn up and asked about working together.
3. A letter of invitation will be sent to invite Research Partners to work with the Research Sub-Committee for one year. Information about each research centre will be posted on the National Federation of Voluntary Bodies website.
4. Research partners will meet to talk about ideas and goals and to discuss potential areas of collaboration.
5. Research projects and applications for funding will be developed on agreed topics as occasion arises.

### **Priority 7: Advise on how we could get money to do research in the future**

One of the principles of the Research Strategy is to find money for research projects.



### **Action Plan to Achieve Priority 7:**

1. Draw up a database of organisations who have money for research.
2. Look at this every year.

3. Apply for funding on some of the 11 priority topics.
4. Tell researchers about the funding that is available

**Priority 8: Make a list of people who are interested in disability research.**

Analysis of the questionnaire described the need for a national register of researchers in intellectual disability or the development of a list of people interested in disability research. This will consist of organisations, government departments, people with disabilities and family members. The purpose of this register is to identify people who will be spoken to about disability research issues from time to time.

**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: Find out the research that is taking place and put it on National Federation website**

The Research Sub-Committee has already set up a list of intellectual disability research done by our member organisations since 2000 and is on the National Federation of Voluntary Bodies website [www.fedvol.ie](http://www.fedvol.ie)



This list of research will continue to be a priority of the research strategy 2008-2013 as a way of reporting what intellectual disability research has been done in Ireland.

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

**Action Plan to Achieve Priority 9:**

1. The list will be updated every year.
2. The database will be used to know what research has been done.
3. The list of research abstracts will be looked at to see the types of research and quality of research being done in Ireland in member organisations.

**Priority 10: Form a National Committee which would help with the rights and regulations of doing research and make sure people with disabilities benefit from it.**

There is a need for rules to deal with people's rights when taking part in Intellectual Disability research.

A Committee will help with the rules and regulations and make sure that people with disabilities benefit from the projects and are not upset by any research that is done.

it will be there for member organisations that do not have their own committee or where a research project is being done in a few member organisations.

The development of a National Ethics Committee will look at the proper ways to set up an ethics committee

**Action plan for Priority 10:**

1. The role 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 people to be a part of National Research Ethics Committee.





4. The Research Ethics Committee will look and examine national research project applications to see if they follow the right rules.

**Priority 11: Continue to talk with people who use services through research projects such as the Inclusive Research Network and find ways to work together when doing research.**

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 often 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 include these choices into the Research Strategy.

Talking also took place in developing this strategy with the Community Participation and Inclusion Sub-Committee, and the Seasmh Parliament. Development of these research approaches will ensure the participation of people with intellectual disability in research activities that are important to them.

Priority 11 is very important. The process of listening to and talking with people who use services will be done across priorities 1 through to Priority 10.

**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.
5. It will also continue to develop Participatory Research methods 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 as asked to by people who use services
7. Over the next 6 years, we will continue to talk with people who use services on research topics.

**Priority 12: Look at the research strategy every year to see if it is still suitable.**

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

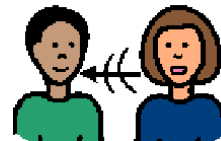
**Action Plan to Achieve Priority 12:**

1. The Research Sub-Committee will look at the progress of the strategy.
2. It will review the action plans every year
3. It will look at how long the projects are.
4. It will publish, annually, an update of research actions achieved.
5. 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 aim of the Research Strategy is to make a plan of research activities of the National Federation of Voluntary Bodies for the next 6 years (2008-2013).

The most important part of the National Federation of Voluntary Bodies Research



Strategy 2008-2013 is that any research carried out will be done by talking with the 63 member organisations of the National Federation, and with people who use the services.

The Research strategy will be looked at every year. This will be to look at our achievements to date but will also serve as an action plan for the years ahead and be a driver of the national research plan for the next 6 years.

It is hoped that this research strategy will help us to understand intellectual disability and will show how research can make a difference. This would give a better quality of life for people who use services and will help service providers to provide a better service.

**Research Activities in  
the National Federation of Voluntary Bodies  
- Past & Present**

Research has always been important to the National Federation of Voluntary Bodies. The research carried out both at national and European level has led to the development of national and European policy.

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 centre of European research and policy developments. The projects listed below are examples of research that has been done up to now.

## National Federation of Voluntary Bodies Projects:

- Volunteering in disability services in Ireland 2008
- Informing Families of their Child's Disability-best practice guidelines 2007
- People Connecting-inclusive research 2007
- Person Centred Medication Management (ongoing)
- Education survey 2006
- Analysis of need project 2005-2008
- Guidelines for researchers interviewing people with Intellectual Disability 2005
- Research projects done in Partnership
- TILDA Irish Long-Term Study on Ageing (Disability included) 2008
- Inclusive Research Network 2007
- EASPD LABOr Project
- EASPD Conversion Project (moving from institutions) 2005
- EASPD Tolerance & Acceptance Project (inclusion in the community) 2003

### **Research Strategy Consultations 2008**

Early consultations took place between 2004 and 2007 at National Federation of Voluntary Bodies Conferences & the information gathered has been included. Consultation also took place in 2008 to develop research priority topics for the Research strategy.

#### **Consultation 1: Consultation with the Research Sub-Committee**

**Consultation 2:** An email consultation with staff and management in the 63 member organisations.

**Consultation 3:** Advocacy / Self advocacy Groups

- Community Participation and Inclusion Sub-Committee
- Submission from the Inclusive Research Network
- Submission from Seasamh Parliament

**Consultation 4:** National Federation Secretariat Team

**Consultation 5:** Board of Directors of the National Federation of Voluntary Bodies

**National Federation of Voluntary Bodies**  
**Board of Directors, Secretariat Team & Research Sub-Committee**

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Brendan Broderick, Sisters of Charity of Jesus & Mary

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

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Patricia Lee, Sisters of La Sagesse

Vincent Millet, Irish Sisters of Charity

Maura Nash, COPE Foundation

Michael Noone, Sunbeam House Services

Winifred O’Hanrahan, Brothers of Charity Service

**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)

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

**Research Sub-Committee**

Aine Kelly, St John of God Hospitaller Services

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 Galway

Kay Downey-Ennis, Daughters of Charity Dublin

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Mary McCarron, Trinity College

Nick Blitz, Camphill Communities of Ireland