# NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability



Cover Art-"Somewhere over the Rainbow"

By Sabrina Staron, The Nagle Centre, Cashel, Co Tipperary The Inclusive Research Network



# A Participatory Action Research Project

A Joint Project of the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.

# Easy-To-Read Version

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#### Summary:

The Inclusive Research Network (IRN) is a joint project of the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.

The Inclusive Research Network was set up to teach people the different ways to do Inclusive research and to talk about research that will help change people's lives.

Three workshops were held between 2008-2009. Two sessions of each workshop were held in Dublin & Galway. These workshops were to train people to do inclusive research and too help make services better for the people who use them by listening to people with disabilities.

The report talks about the people who took part in the workshops and those who supported them. It talks about getting consent for the workshops and the research that was done during the workshops. The report showed how people were asked after each workshop if they thought the workshop had gone well or not. It gives a summary of what was said by people who took part in the workshops along with the opinions of the organizers and the External Evaluator who was an outside person who looked at how the workshops had been run and gave his opinion. The last part of the report looked at the work that the Inclusive Research Network has done until now and how it can keep going in the future with less money than before.

#### **Background of Inclusive Research Network:**

The Inclusive Research Network is a joint project between the National Federation of Voluntary Bodies and the National Institute for Intellectual disability.

This network was set up For a few reasons

- No partnership work between people with intellectual disabilities, agencies and Universities on research projects.
- No chances for people with intellectual disabilities to be coresearchers on projects;
- No involvement of people with intellectual disabilities in research done about them;
- Research that does not look at the lives of people with disabilities;
- Organizations doing the same type of research separately and not getting together to share information
- No chances for researchers to learn about doing inclusive research;
- No support for staff in organizations to support people with intellectual disabilities to do research.

#### Need for an Inclusive Research Network:

The need for inclusive research has come from the changes that Ireland is going through when it comes to providing services to people with intellectual disabilities.

 In October 2007, the National Federation held a national conference New Ideas New Approaches: Innovations in Services and Supports for people with intellectual disabilities. The conference involved working with people who use intellectual disability services and

included eight generating solutions sessions that looked at issues that affect people's lives.

- 2. A workshop was held in August 2007, the National Federation of Voluntary Bodies and the National Institute of Intellectual Disability, brought 33 people with an interest in doing inclusive research together. This group found the following topics as being important for national research in Ireland.
  - Bullying;
  - Access to primary education and mainstreaming;
  - Friendships, sexuality and relationships;
  - Community living;









- Individualized Funding;
- How to take part in local groups;
- People's experiences of getting a job;
- Older people with intellectual disability;
- Measuring lifestyle change;
- Developing idea of inclusion in funding or grant applications;
- Person Centred Planning;
- Involving people who cannot speak in research;
- Rights Issues;
- Our culture, our heritage.
- 3. The National Federation of Voluntary Bodies, when writing its Research Strategy 2008-2013, got opinions from advocacy Groups. Groups like the Seasamh Parliament & the Community Participation and Inclusion Sub-Committee. These groups said that they wanted to do research about: Community Participation, Independence & Choice, Friendship, Attitudes, Advocacy / Self-Advocacy, Accessible Information.

#### Aims of the Inclusive Research Network:

The aim of the Inclusive Research Network is to:

- 1. Show the different ways of doing research.
- 2. Give out the results from Inclusive Research nationally and internationally.



- 3. Talk to people with disabilities about research.
- 4. Guide National policy in Ireland through the voice of people with intellectual disability and their supporters

In 2008, the National Federation and the National Institute decided to look at the first aim and to hold inclusive research workshops. These workshops were set up to:

- Provide training on ways to do inclusive research;
- Support the improvement of disability services through good research which includes the voice of people with intellectual disabilities;
- Run workshops on inclusive research in Ireland.



# The IRN Workshops 2008-2009

#### The Three Workshops:

A series of workshops were organized during 2008-2009. Each workshop was held in 2 locations, Galway and



Dublin, because a lot of people wanted to come but some couldn't travel to Dublin.

The three workshops were set up to improve research skills and were given in a way that was easy for all would-be researchers - those with a disability and those without.

Three workshops took place over a period of six months.

Topics were chosen to give those taking part as many research methods as can be used in inclusive research. They were also chosen because inclusive research projects involving people with intellectual disabilities in Ireland were either being done or finished. People taking part had an active role in the workshops and this helped to decide on what was done during the workshops.

#### Common Elements of the three workshops:

Each workshop started with tea/coffee and biscuits on arrival and gave people a chance to meet, chat and get to know each other.

The workshops had breaks to break up the sessions and allow people to take a break. Each

workshop started (from workshop 2) with a look back at what happened in the previous workshop and what we had learned.

At the end of each workshop, a homework sheet was given out and people were asked to fill the sheet before the next workshop. At the start of





the next workshop homework sheets were returned with comments and feedback.

Each workshop was designed to build on the skills learned at the last workshop so that a process of learning took place. For example the first workshop dealt with listening skills, how to listen better and how to show people that you are listening.



Feedback on workshops took place at the end of each workshop with an easy to read and easy to complete sheet. This asked people for their comments and thoughts on the venue, catering and timing of the workshops and also for feedback on each session.

# The People who attended

People who came to the workshops fell into two groups. Some were people with an intellectual disability who had been involved in other research projects. Others were staff who wanted to support people to do research.

Supporters who came to the workshops were paid staff members who came with people to the workshops or family members who had an interest in inclusive research.

#### Advocacy groups

Half of the supporters said that they are members of advocacy groups. The groups included Anti-Bullying group, A "People First"

group, A "Speak Up", Outreach group, and members of a Research Into Action Group.

#### The way to get Consent

At the start of each workshop everyone was asked to sign a consent form. This form asked people if they were happy for photographs to be taken during the workshop to be used in giving out information about the Inclusive Research Network. This was done at all three workshops so people could change their minds if they wanted to.

## What did people think about the workshops?

A number of methods were used to assess the network and the workshops.

Method 1 We interviewed people

Method 2 We did a survey

Method 3 We got feedback after each workshop

Method 4 We looked at the feedback sheets given at the workshops

#### Method 1: Interviews with People

Thirty two interviews in total were done at the two workshops - sixteen interviews were done at the Dublin workshop 2, sixteen interviews were done at the Galway workshop. The answers to questions in the interviews were looked at separately.



# Interview questions: Why did you want to come to these workshops?

People said they had come because it was a chance to make new friends and learn something new. Other people said they were interested in learning how to do research because it's the way to change policy & change services".



Some people had already seen the

benefits of doing research projects in their own organizations & "wanted to learn more about research" and "help change the services for the future.

A staff member said that to be a good support worker she needed to learn about Ethics. "I am interested in Ethics and consent; I want to be sure it's done properly before I do any work with people telling their stories"

Some people said that they wanted *"to see what it is like in other organisations".* Learning about inclusive research was something everyone was interested in. They had an interest in research because they saw research as a way to change in their lives.



#### What have you learnt from coming to the workshops?

- People learned how to speak for themselves.
- Learned how to listen & respect other people's opinions.
- Learned the difference between open & closed questions.
- The importance of asking direct questions.
- To keep information confidential.



#### What is good about the workshops?

People were listened to. Everyone got the chance to speak. We heard different opinions. We heard about other people's lives

One of the other benefits of going to

the workshops was learning about the art of listening and how it was an important part of good communication. People were shown how to "*listen to others' ideas*" and how to make sure that people are given time to speak and put their point across.

Most people were happy with the opportunity to be part of a something where people with disabilities are getting together to share experiences and problems as well as getting trained in how to do research.

People were also getting the chance to put this training into practice through group work and in this way gain confidence and develop skills which will encourage people to put this training into practice once the workshops have been completed.







## What is not so good - could be done better?

This question was to give feedback to the organisers of the workshops to help them find ways to improve how the workshops are presented so that everyone gets the most out of them.

At the Dublin workshop the answers were mainly positive saying everything was *"going well so far"* and that they found the workshops interesting and enjoyable.

Some people said that maybe "some of the words used may be difficult for some people to understand" and that possibly "more pictures" could be used to solve this problem.



#### Is there anything else you want to tell me?

A lot of people declined to answer this but some of the comments were as follows:

- o I am just having a great time
- I will come again.
- I would like to see another workshop done on accessibility.
- If I get on doing the research is there anybody who can help me?

## Method 2: Doing a Survey

As an example of finishing a survey having learned about surveys as a research method in workshop 2 people then had the chance to do a survey about the Inclusive Research Network. There were two different versions, one for people with intellectual disabilities and one for supporters.

# Method 3: Looking at the feedback forms given out at each workshop:

As forms were given out at the start of the workshop and the people were asked to rate each presentation just after watching them while it was fresh in their minds.

#### Workshop 1 Feedback:

The first workshop, both in Dublin and Galway, got a great response overall and "Everyone really enjoyed the workshop". The comments on the catering at the Galway workshop were listened to and different caterers were used for workshop 2. Some other comments from Workshop 1 included:

- Self-confidence got a boost by being able to lead a group;
- On the way home plans for documentaries and other ideas were being suggested;
- It could have been shorter, too much to take in a short time;
- A very good workshop look forward to the results;
- Many issues were talked about which opened up the topic of research;
- The "presenters are brilliant" and "very professional";

- The workshop was a great opportunity to meet new people;
- Other points made were that some felt the workshop was a little long, especially for people who had to travel long distances;
- They also felt the lunch was 'poor quality' and that the question on age was a bit too personal.

#### Workshop2:

Overall comments from Workshop 2 were positive stating that it was a "very informative and well structured session". People did say that some presentations were too long.



In Workshop 2 in Galway most comments were positive but it was felt by some that the *"Ethics module needed more time and it was possible that not everyone understood it at the end of the session."* Other comments included:

- Lots of food for thought
- Great day. Sessions got better as the day went on.
- Thank you for very interesting day.
- Really Super! Thank you very much
- Ethics needed more time spent on it.
- Keep up the work! We want more!



## Workshop 3

As with the previous two workshops feedback forms were given out to look back on the workshop. This workshop also included a 'celebration' where certificates were handed out to everyone that had attended the workshops.

## Method 4: What did people think of the workshops?

The form included a question "did you enjoy the 3 workshops overall" The Dublin and Galway workshops scored a high satisfaction rating – this is shown in the graphs below:



At the end of the three workshops the feedback was very good with everyone feeling they had done well. However, it was just the beginning of an important piece of work that would, if continued, have a great effect on people's lives.



## **Conclusion:**

We need to get the message of the Inclusive Research network out using film, drama, life stories etc.

How does this network add to equality and social inclusion?

What is the role for services in the network?

How will the network be kept going.

Is it better to start smaller networks?

If the network becomes too big it may loose its ability to connect with people.

The real strength of research done by a network like this is based on the knowledge that can be got from the researchers- the people with disabilities. This makes the research stronger by collecting people's voices and hearing the experiences of people with a disability.



Presenters at the IRN Workshops

# Thank You to all the Presenters at the Workshops

Edel Tierney Stephen Curtis Patricia O'Brien Ray Murray Mary Gavin Aine Kerr Bernadette Casey Mary Lannon Mary Lucey Breda Casey Brian Donohoe Roy McConkey Hasheem Mannan Carol Hamilton & Zoe Hughes Josephine Flaherty & BOC Galway Team, Marie Wolfe, Martin Dooher, Paul Dunne, Vanessa Delle-Vedove, Ann Mahon, Geraldine Bane, Padraic McDonagh John Doyle Edurne Garcia Iriarte Darren Chadwick