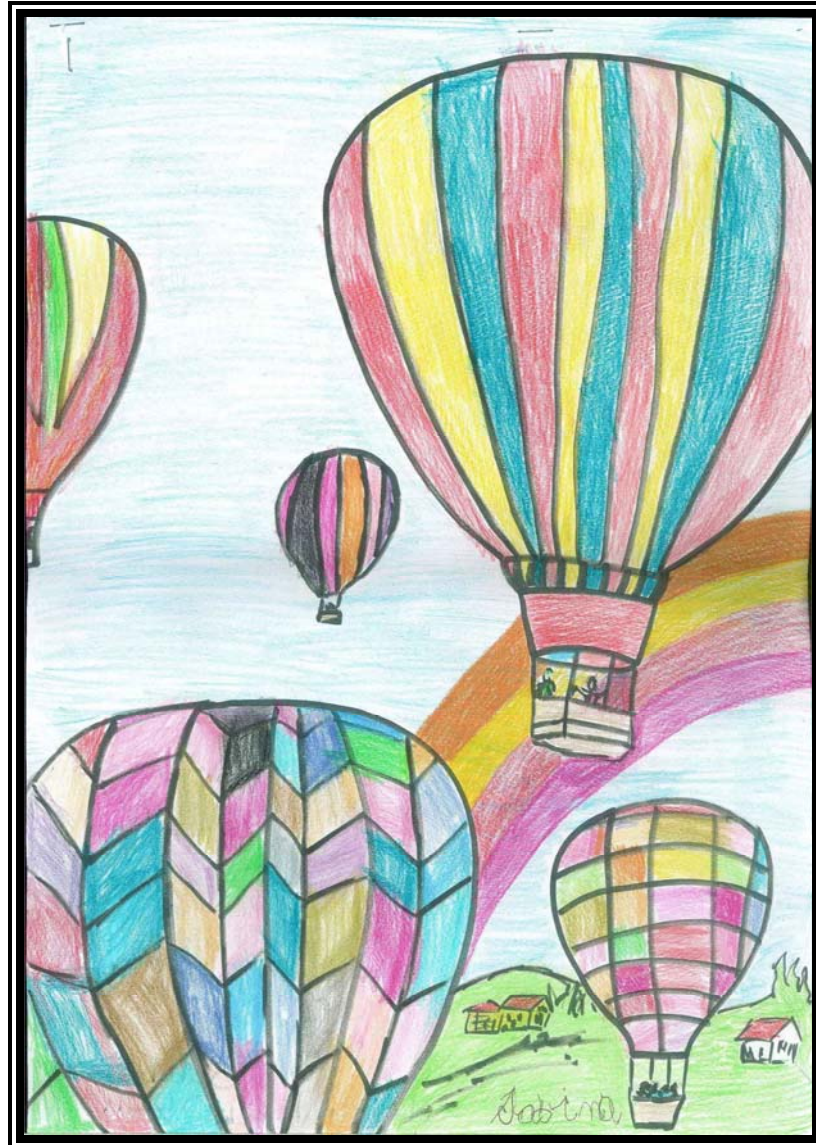

NATIONAL FEDERATION OF VOLUNTARY BODIES

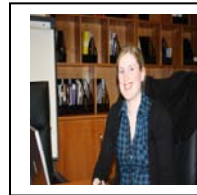
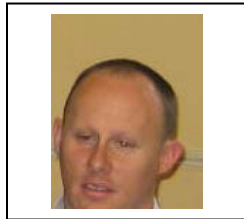
Providing Services to People with Intellectual Disability



The Inclusive Research Network A Participatory Action Research Project Easy-To-Read Version

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

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with support from Edurne Garcia Iriarte and Orla Kelly***



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Cover Art
***“Somewhere over the
Rainbow”***

**By Sabrina Staron,
The Nagle Centre, Cashel, Co Tipperary**



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1. Summary:

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 during 2008 & 2009. The workshops were held in Dublin and Galway. These workshops were to train people to do inclusive research and to help make services better for the people who use them by listening to people with disabilities.

This 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 shows 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 organisers
- The External Evaluator, an outside person, looked at how the workshops had been run and gave his opinion.
- The last part of the report makes suggestions for the future of the network.

2. Background of the 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

- There was no partnership work between people with intellectual disabilities, agencies and universities on research projects.
- There were no chances for people with intellectual disabilities to be co-researchers on projects;
- There was little or no involvement of people with intellectual disabilities in research done about them;
- There was a lot of research that did not look at the lives of people with disabilities;
- There were organisations doing the same type of research separately and not getting together to share information
- There were no chances for researchers to learn about doing inclusive research;
- There was no support for staff at their organisations to work with people with intellectual disabilities doing 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.



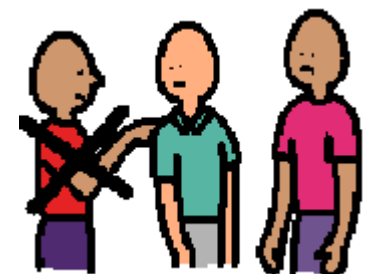
1. In October 2007, the National Federation held a national conference “*New Ideas New Approaches: Innovations in Services and Supports for people with intellectual disabilities*”.

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, organised by the National Federation of Voluntary Bodies and the National Institute of Intellectual Disability. 33 people attended. This group found the following topics as being important for national research in Ireland:

- Bullying;
- Access to primary education
- Friendships, sexuality and relationships;
- Community living;
- Individualised Funding;
- How to take part in local groups;
- People’s experiences of getting a job;



- Older people with intellectual disability;
- Measuring lifestyle change;
- 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 Seasmh 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.

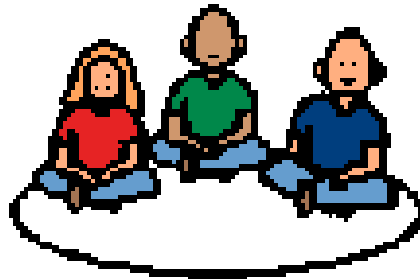
3. Aims of the Inclusive Research Network:

The aims of the Inclusive Research Network are:

1. To show the different ways of doing research.
2. To share the results from Inclusive Research nationally and internationally.
3. To talk to people with disabilities about research.
4. To guide National policy in Ireland through the voice of people with intellectual disability and their supporters

In 2008, the National Federation of Voluntary Bodies and the National Institute of Intellectual Disability 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;



4. 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 from the West and East of Ireland wanted to come.



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 teach those taking part training in many research methods that can be used in inclusive research. People taking part in the workshops had an active role in the workshops and this helped to decide on what was done during the workshops.

In workshop 1 people learned how to develop listening skills, how to ask questions and the difference between open and closed questions. They also learned how to be part of a group and facilitate a group. In workshop 1 we also talked about what is a good topic to research.

In workshop 2 people learned about different ways to do research, there were presentations on consultation groups, interviews, life

stories, doing a survey and using drama in research. We also talked about ethics –the right and wrong ways to do research

In workshop 3 people learned how to think of questions to ask in a research study, we tried out the questions in small groups. Everybody got a certificate for attending 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.



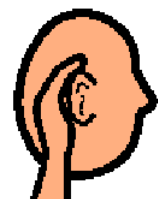
The workshops had lots of breaks. Except for workshop 1 each workshop started with a look back at what happened in the previous workshop and what we had learned.

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. This was to allow for 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. Including questions on the venue, catering and timing of the workshops and also for feedback on each session.

5. The People who went to the Workshops



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”, group on outreach, and members of a Research Into Action group.

6. Getting 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.

7. What did people think of the workshops?



A number of methods were used to look at the work of the IRN.

Method 1 We interviewed people

Method 2 We did a survey

We also looked at feedback from all the workshops. People gave their feedback by filling in a form at the end of each workshop and we looked at what people thought was good and not so good about each workshop.

Method 1: Interviewing People



Interviews were done in the workshop 2 to find out what people thought about the workshops.

Thirty two interviews in total were done in the workshops. Sixteen interviews were in Dublin and sixteen interviews were done in Galway. The answers to questions in the interviews can be seen below.

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 their lives.



What have you learnt from coming to the workshops?

- People learned how to speak for themselves.
- People learned how to listen & respect other people’s opinions.

- People learned about open & closed questions.
- People learned the importance of asking direct questions.
- People learned 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 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 these skills into practice through group work. In this way they gained confidence to use the skills once the workshops have been completed.



What 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:

- *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



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.

The survey asked questions about people's age, where they lived, what kind transport they used and if they were part of an advocacy group. This gave us information about the people who came to the workshops.

We then looked at all the feedback forms and found out what people thought about the workshops.

Workshop 1 Feedback:

The first workshop, both in Dublin and Galway, got positive feedback 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: Feedback:

Overall comments from Workshop 2 in Dublin 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. 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.

We put all the information from the interviews, and the survey together with the feedback from the workshops.



8. Summary

We can say that the Inclusive Research Network gave people the chance to come together and learn research skills

The Network gave people a chance to get together to socialise and to learn. There are not many opportunities for people to do this at the moment.

People who came to the workshops became more confident and began to do their own research.

People used different ways to do their research and in a follow up event there were presentations from people using drama, power-point and life-stories. This showed that there are many ways to present inclusive research.

People who were involved in advocacy groups got involved in the Inclusive Research Network.

The skills they used in advocacy groups were useful for getting involved in research.

Having support to do research is very important. The role of the supporter is very important in doing inclusive research.

There were some things that were difficult about setting up the Inclusive Research Network.

We had to learn to adapt the material for the workshops to make them more accessible. It was difficult for people to have the same support person at each of the workshops. Travel and expenses were an issue for some people. Trying to get in touch

with people by email was not always the best way to communicate.

It was important to have facilitators to organise and lead the workshops. It was difficult sometimes to make the workshops suitable for everybody.

The network is important as it listens to the experiences of people with an intellectual disability and tries to be a more inclusive way of truly listening to people.

The external evaluator also gave his thoughts about the Network and we have included these in the conclusion.

9. Conclusion

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

We need to show how this network adds to equality and social inclusion.

There has to be a role for services in the network

We need to decide how the network will be kept going. Is it better to start smaller networks?

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

The real strength of any 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.

9. 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
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John Doyle
Edurne Garcia Iriarte
Darren Chadwick*