

# The Inclusive Research Network

## A Participatory Action Research Project



## Cover Art - "Somewhere over the Rainbow"

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Hello my name is Sabina Staron, I am 25 years old. I was born & brought up in Poland. I have lived in Cashel in Co. Tipperary for the past 3 years. I have met lots of great people. I have been attending the Nagle Centre two years, I adore dancing, music, painting, drawing & shopping. I love dressing up for a special occasion.



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**NATIONAL FEDERATION OF VOLUNTARY BODIES**

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*Providing Services to People with Intellectual Disability*

## **The Inclusive Research Network**

### **A Participatory Action Research Project**

**A Joint Initiative of the National Federation of Voluntary  
Bodies & the National Institute for Intellectual Disability**

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**December 2009**



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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 purpose of the Inclusive Research Network is to provide education and training in inclusive research methodologies, disseminate the findings from inclusive research nationally and internationally, provide a forum for dialogue and discussion among and with people with intellectual disability about research issues and provide a platform for influencing national policy in intellectual disability in Ireland through the voice of people with intellectual disability and their supporters.

A series of workshops were organised between 2008-2009. Each workshop was delivered in two geographical locations, Galway and Dublin. These workshops were designed specifically to provide training in relevant inclusive research techniques and support the enhancement of disability services through informed research which includes the voice of people with intellectual disabilities.

This report describes the workshop participants and their supporters, the significant role of supporters in the workshops, how the workshops dealt with the process of informed consent for the workshops and the research resulting from the Network. An evaluation of the network and the methodology employed is discussed along with some of the ethical issues encountered. In the evaluation of the Inclusive Research Network the views of the network members are described along with some reflections from the co-ordinators of the network and the external evaluator. Finally the report looks at the achievements of the Network to date; an action plan for the Network is outlined and considers what can be achieved with limited resources.

## **Background to the Development of an Inclusive Research Network**

**The Inclusive Research Network is an initiative of the National Federation of Voluntary Bodies and the National Institute for Intellectual disability.**

The origin of this network came about as a result of the identification of a number of anecdotal deficits which exist in the intellectual disability research arena in Ireland; for example:

- Lack of partnership work between people with intellectual disabilities, agencies and academic institutions on research projects about intellectual disability;
- Lack of opportunity for people with intellectual disabilities to be co-researchers on projects;
- Lack of involvement of people with intellectual disabilities in research undertaken about them;
- A strong emphasis on clinical research to date that does not incorporate the social model of research and life experiences of people with disabilities;
- Overlap with individual organisations doing similar projects but no strong co-ordination between them;
- Lack of opportunities for practitioners to learn about doing inclusive research;
- Lack of support for staff in organisations to support people with intellectual disabilities to do research.

### **Assessment of Need for an Inclusive Research Network:**

These needs reflect wider and deeper needs for inclusive research which have resulted from the changes that Ireland is currently experiencing in relation to the provision of services to people with intellectual disabilities. This project seeks to support current reforms and a more active citizenship model in relation to people with intellectual disabilities. Inclusive research and the proposed network will

both reflect and promote these changes. The development of an Inclusive Research Network also came about, more specifically, because of the issues identified by the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability in their respective roles. These issues are identified below from relevant inclusive work and research:

1. In October 2007, the National Federation held a national conference on the theme of *New Ideas New Approaches: Innovations in Services and Supports for people with intellectual disabilities*. The conference involved a very successful partnership with people who avail of intellectual disability services and included eight generating solutions sessions that dealt with issues that affect peoples lives such as managing your own money, working together creatively, health and well being, having your say, promoting best value, managing risks, benefits of technology, new ways of service delivery, providing choices, etc. Service users took us on journeys of transformation where they showed personal journeys of returning to their communities after many years of living in institutions. Some very clear proposals and recommendations emanated from the sessions and these were highlighted in our conference proceedings report, which has now been published and available on the National Federation website [www.fedvol.ie](http://www.fedvol.ie) under the publications section. In tandem with this, an easy-to-read conference report was also published to ensure that the outcomes from the conference were accessible to all the participants.
2. A workshop held in August 2007, auspiced jointly by 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 identified the following topics as being a priority for national research in intellectual disability services in Ireland. They also expressed their interest in being involved in the development of research proposals and the fieldwork to carry out this research:

- Bullying;
- Access to primary education and mainstreaming;
- Friendships, sexuality and relationships;
- Positive behaviour support;
- Community living;
- Individualised Funding;
- How to participate in local groups;
- People's experiences of getting a job;
- Cross disability inclusion power and control, choices;
- Older people with intellectual disability;
- Working and learning using multiple intelligences;
- Measuring lifestyle change;
- Developing concept of inclusiveness in funding or grant applications;
- Person Centred Planning;
- Involving people with complex needs who are nonverbal in research;
- Rights Issues;
- Our culture, our heritage.

3. The National Institute for Intellectual Disability (NIID) is currently involved in the **Marie Curie Transfer of Knowledge Project** which utilises participatory and inclusive methodologies in its national study on disability. The overall aim of the Marie Curie Programme is to transfer knowledge to the staff and associate members of the Institute so that, as researchers, they can become skilled in implementing and investigating the efficacy of the inclusive research paradigm for people with an intellectual disability within the Republic of Ireland. Six phases of work are planned over a four year period up to 2010.

1. The training of inclusive researchers – people with an intellectual disability and family carers.
2. The training of trainers in inclusive research

3. Implementation of a national life history project for people with intellectual disability within the Republic of Ireland.
4. Implementation of two national survey research projects; one for people with an intellectual disability and one with family members.
5. The writing of accessible publications.
6. Networking and setting up inclusive research projects across international boundaries.

As part of this work the National Institute for Intellectual Disability obtained funding for an international fellow to work with people with intellectual disabilities around Ireland for two years. During this time she has worked with a range of different service organisations and people with intellectual disabilities to produce 5 documented accounts of inclusive research. These are available from [www.tcd.ie/niid](http://www.tcd.ie/niid)

4. The National Federation of Voluntary Bodies, in developing its Research Strategy 2008-2013, sought submissions from service user groups and advocacy groups within its member organisations. Groups, such as the Seasamh Parliament, the Community Participation and Inclusion Subcommittee and the group who attended the Inclusive Research meeting above were consulted. In their submissions, these groups indicated that they wanted research to consult with people who use services and for topics such as: **Community Participation, Independence & Choice, Friendship, Attitudes, Advocacy / Self-Advocacy, Accessible Information, Transport and Disability Allowance** to be explored. For further information on the consultation process and the submissions see (National Federation Research Strategy 2008) [www.fedvol.ie/research/publications](http://www.fedvol.ie/research/publications). In developing its research strategy the National Federation has also committed itself to the development of inclusive and participatory research in exploring issues of relevance to people who use their services such as the issues outlined above. The Inclusive Research Network is one way to achieve this goal.

5. An event was held by the Brothers of Charity Clare (April 2008) showcasing the inclusive research projects currently underway in this organisation. The title of the event was *From Planning Peoples Lives to People Having Lives*. People who use the Brothers of Charity Services talked about the value of using life stories to tell their personal stories and plan services for the future.
6. Interest in inclusive research in intellectual disability has grown over recent years and projects have included a range of methodologies and participants and have sought to involve people with intellectual disabilities at many stages of the research process. Some examples illustrate this:
  - **The Rights Project** (Prosper Fingal/St. Michael's House). People with intellectual disabilities have been involved in designing and running focus groups and have used the information they gathered to develop training materials about the rights of service users. (McCormack and Buckley, 2006)
  - **The Garden Story** began with concerns of a group of people with intellectual disabilities about a garden attached to a sheltered workshop which was closing. As a result of their concerns they developed an oral history of the garden recording their memories of working there and using photographs to illustrate the stories. (Brothers of Charity Clare)
  - **Stop Bullying Working Group**. This began from concerns by people with intellectual disabilities about their experiences of bullying in a wide range of living and working environments. They researched the topic using the internet, shared their stories of bullying, gathered policies on bullying from agencies and facilitated a workshop on bullying.

[www.tcd.ie/niid/research/anti-bullying/](http://www.tcd.ie/niid/research/anti-bullying/)

- A series of topics have been explored by the Brothers of Charity Clare Inclusive Research Group including the topics of leaving home, sexuality, & relationships (see Brothers of Charity Clare website [www.brothersofcharityclare.ie](http://www.brothersofcharityclare.ie) ).

The interest in inclusive research had grown to an extent that there was a need to build on the interest and the capacity that had been developed in Ireland. Clearly there was a real need to bring people together who are involved in these types of projects to network, share ideas and resources, brainstorm and develop some national projects with participatory approaches and ethos at the core of their activities. The Inclusive Research Network was developed in response to these identified needs.

### **Aims and Objectives of the Inclusive Research Network**

The purpose of the Inclusive Research Network is to:

1. Provide education and training in Inclusive Research methodologies.
2. Disseminate the findings from Inclusive Research nationally and internationally.
3. Provide a forum for dialogue and discussion among and with people with intellectual disability about research issues.
4. Provide a forum for influencing national policy in intellectual disability in Ireland through the voice of people with intellectual disability and their supporters

In 2008, the National Federation and the National Institute decided to focus on the first objective and to develop inclusive research workshops accordingly.

These workshops were designed specifically to:

- Provide training in relevant inclusive research techniques;
- Support the enhancement of disability services through informed research which includes the voice of people with intellectual disabilities;
- Organise and run workshops on inclusive research in Ireland.

**The IRN Workshops 2008-2009**

**The Three Workshops:**

A series of workshops were organized between 2008-2009. (See Tables 1, 2 and 3 for workshop content). Each workshop was delivered in 2 geographical locations, Galway and Dublin, in response to the large numbers of people expressing interest and the difficulty associated for participants to travel long distances.

**Table 1: Workshop 1**

<b>Session</b>	<b>Topics Covered</b>
Getting to know each other	<ul style="list-style-type: none"> <li>• Introductions and ice breaker exercise</li> </ul>
Developing Listening skills	<ul style="list-style-type: none"> <li>• How to listen to people</li> <li>• How to know when people are listening.</li> <li>• Respectful listening.</li> </ul>
Asking questions How to ask the right questions	<ul style="list-style-type: none"> <li>• Finding out people’s views by asking questions.</li> <li>• Asking open and closed questions</li> <li>• How to ask the correct type of question to get information you need.</li> </ul>

	<ul style="list-style-type: none"> <li>• Checking with the person that you have understood them.</li> </ul>
Working in a group	<ul style="list-style-type: none"> <li>• Making sure everyone has a chance to speak</li> <li>• “Lets hear what others have to say”</li> <li>• Asking for people’s opinions</li> <li>• Developing group culture ‘the rules’</li> </ul>
Facilitation Skills	<ul style="list-style-type: none"> <li>• How to be a good facilitator</li> <li>• How to help a group to have meaningful discussion.</li> <li>• Making sure everyone takes part.</li> <li>• Everyone takes responsibility for group decisions.</li> <li>• ‘playing by the rules’ the culture of the group</li> </ul>
Looking for a question to research	<ul style="list-style-type: none"> <li>• Discussing and Recording ideas for research topics on flip charts</li> <li>• Reporting back to the group -one member of each group reports back to the main group.</li> </ul>
“How was the day?”	<ul style="list-style-type: none"> <li>• Evaluation of the day and feedback</li> </ul>

**Table 2: Workshop 2**

<b>Session</b>	<b>Topics Covered</b>
“What have we been doing?”	<ul style="list-style-type: none"> <li>• Renewing friendships</li> <li>• Revisiting and establishing group culture</li> </ul>
Presentation from Community	<ul style="list-style-type: none"> <li>• Presentations made to group by the</li> </ul>

<p>Participation &amp; Inclusion Working Group</p> <p>Consulting with people in research</p>	<p>Community Participation &amp; Inclusion Working Group which is made up of people who avail of services and of staff who provide the service. They explained how they had used consultation to identify ways to get involved in their own communities and examined the barriers that sometimes stops them doing this.</p>
<p>Interviewing People</p>	<ul style="list-style-type: none"> <li>• Looking at different ways to interview i.e. one-to-one, group interviews</li> <li>• Recording the interview</li> <li>• Preparing for the interview by selecting questions and candidates.</li> <li>• Explaining the purpose of the interview.</li> <li>• How to ask 'open' questions.</li> <li>• How to abstract main themes from the answers.</li> <li>• Mock interviews were performed by everyone in smaller groups with the aid of recorders.</li> <li>• Taking turns to interview</li> </ul>
<p>Research into Action</p> <p>Bothers of Charity Research into Action Group Galway</p>	<ul style="list-style-type: none"> <li>• Presentation made by the Brothers of Charity Galway on the findings of their Research into Action programme which was portrayed by a video.</li> <li>• This group used research to</li> </ul>

	<p>develop an induction programme for staff in their services</p>
Life Stories	<ul style="list-style-type: none"> <li>• What is a life story?</li> <li>• Using life stories as a research tool.</li> <li>• This was given by Carol Hamilton and Zoe Hughes NIID Trinity College Dublin based on the Life stories project underway there. These presentations focused on how people can tell their life story as a way to record their life and inform research on intellectual disability.</li> </ul>
Doing a survey	<ul style="list-style-type: none"> <li>• This presentation was given by Hashem Mannan from NIID Trinity College Dublin. He focused on</li> <li>• How to conduct a survey</li> <li>• Planning and developing questions.</li> <li>• Taking notes and observations.</li> <li>• Opportunity for practice session.</li> </ul>
Ethics	<ul style="list-style-type: none"> <li>• Introduction to the term ethics</li> <li>• What does this word mean?</li> <li>• What questions can and cannot be asked?</li> <li>• What to do with information gathered</li> <li>• How to store information confidentially.</li> <li>• Your responsibility as a researcher</li> </ul>

How was the day?	<ul style="list-style-type: none"> <li>• Evaluation sheets were collected on people's comments on the day.</li> </ul>
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**Table 3: Workshop 3**

<b>Session</b>	<b>Topics Covered</b>
"What have we learnt so far?"	<ul style="list-style-type: none"> <li>• This session took the form of a quiz with the questions based on workshops 1&amp;2 and some trivia questions thrown in.</li> <li>• The participants formed four teams which competed against each other to be quiz champions.</li> </ul>
Developing a Questionnaire How to design a questionnaire for a research study	<ul style="list-style-type: none"> <li>• This session was based on the common theme for research identified at workshop 1 on "where we live"-people identified topics such as independent living, choice about where to live, having my own home as topics they would like to research</li> <li>• Examples were given on how to develop questions and try them out</li> </ul>
Trying out the Questions. Piloting the questionnaire in session above	<ul style="list-style-type: none"> <li>• People were divided into groups</li> <li>• They worked in pairs and took turns both to ask questions and be the respondent. Everyone was given an opportunity to take part if they wished to do so.</li> </ul>

	<ul style="list-style-type: none"> <li>• This way people could test the questions</li> <li>• Afterwards a discussion took place about what we should do with the information gathered at this session as it was only meant as a pilot session</li> <li>• It was agreed that results would be compiled and distributed within the group only.</li> <li>• Participants who wanted to carry out their own research could use this as a training exercise as to what they would need to complete a piece of research.</li> </ul>
Celebration and presentation of certificates	<ul style="list-style-type: none"> <li>• This part of the programme was dedicated to the presentation of certificates to everyone who had taken part in the workshops.</li> </ul>
“How was the day?”	<ul style="list-style-type: none"> <li>• Evaluation of the workshop and feedback on the day.</li> </ul>

The three workshops were designed around developing and enhancing research skills and were delivered in a way that was accessible for all would-be researchers - those with a disability and those without.

Three workshops took place over a period of six months. The workshops were designed to give participants a rudimentary knowledge about research, the basic skills required, the different techniques or methods that can be used and some hands-on experience of conducting research. It also explored some of the wider

issues about the purpose of doing research, who can do it and why do it. Some issues around ethics and, in particular, around consent and getting consent were explored.

Topics were chosen to give participants as wide a range as possible of potential research methodologies which can be used in inclusive research. They were also chosen because inclusive research projects involving people with intellectual disabilities in Ireland were either underway or had been completed and these researchers (some of whom had an intellectual disability) were willing to be involved as presenters on the course. Participants had an active role in the workshops and this guided the content to some extent. Flexibility was built into the workshops to allow for discussion and reflection. This follows the nature of inclusive research and the need to be adaptive and flexible when considering the needs of people involved. Changes made to the programmes were done on the basis of the group's needs and the pace of learning. Materials were adapted to suit a range of literacy abilities and consider alternative communication systems where possible.

### **Common Elements across the three workshops:**

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

The workshops were paced with frequent breaks and refreshments to divide up the sessions and allow people to take a break. Each workshop started (from workshop 2 onwards) with a review of what had happened in the previous workshop and what we had learned. Input from participants was encouraged to reinforce learning at every this stage.

## **The Learning Method**

### *Learning method - a cognitive apprenticeship*

Collins et al (1989) put forward a model for teaching which they called a '*cognitive apprenticeship*'. Their model involved teachers working alongside learners, skilfully engaging them in scenarios where their understanding of the whole situation was incomplete. *Situated Cognition* implied that new skills be acquired through authentic contexts – actually doing real world tasks and not activities or problems devised by the teacher however similar to real world tasks they appeared to be. They discarded the model of active teacher and passive learner as this tended to accentuate the disparity in skill level between teacher and learner and led to low self esteem from those whose skill level was low. Instead, the teacher broke a complex problem into small parts and supported the learners to add to their skills until such a time as when they were able to understand and deal with the entire complex situation.

As learners gained in skill level and confidence, the teacher was able to reduce the support offered. A *scaffold* of support was created in which safe learning could take place. This scaffold also allowed learners to perform higher order reasoning and be relieved of lower order skills that they were still practising – making the global learning experience more varied and interesting.

### **Cognitive apprenticeship in the workshops**

This model was applied throughout the series of three learning workshops. At each stage, experts were brought in to demonstrate their skills (be they generic such as interviewing, facilitating, recording etc or specific, such as researching life stories, composing and conducting a survey etc.) and support the participants using their new skills in a graded sequence of tasks. In line with the agreed philosophy, the participants undertook real world activities which, in part, supported a research initiative of the group as a whole in addition to individually developed projects.

An example of learning and the reinforcement of skills:

One example of this type of approach used successfully in the workshops was learning how to conduct a focus group. The “experts” formed a small focus group and the learners sat in a wide circle all round them. The session facilitator was able to stop the focus group at any point to solicit comment from the observing learners. The experts took on pre-determined roles:

- the person conducting the focus group;

plus, for example,

- the silent person;
- the person who dominates the conversation;
- the person who feels they should respond on behalf of other people;
- the person who likes to move the discussion to their own different agenda;
- etc, etc.

The focus group was observed for a few minutes and then “paused”. At this point, the facilitator worked with the observers to come up with suggestions of what was inappropriate conduct and how the person conducting the group might handle things better. The group was then “rewound” and asked to repeat the discussion, taking onboard the comments from the observers.

The entire team was repeatedly impressed by the comments made and the insight shown by the observers. After what was always a very enjoyable session (with some quite outrageous behaviour from the “experts”!!) the learners were divided into groups to practise the skills for themselves. The practise groups always spent time reviewing their experiences and reporting back to the participants.

## **Transfer of skills**

Evidence from the participant feedback and the completed homework assignments suggests that this was an experience participants enjoyed and found useful. Informal feedback through a “pub quiz” (intended as a review session but indicated a large degree of retention of new skills) revision activity, indicated that learning had taken place over an extended period of time.

At the end of each workshop, a homework sheet was distributed and participants were invited (though this was not a requirement) to complete the homework sheet prior to the next workshop. In this way, skills learned at the workshop were reinforced and learning was reinforced between workshops. At the start of the next workshop homework sheets were returned to participants with comments and feedback.

Each workshop was designed to build on the skills learned at the previous workshops so that a process of reinforced learning took place. People were encouraged to recall and utilise learning from previous workshops to conduct exercises on the next one. For example the first workshop dealt with listening skills, how to listen attentively and how to show people that you are listening. For each exercise conducted in subsequent workshops participants were asked to recall this lesson on active listening. Likewise for group exercises participants were asked to recall the session of being part of a group and establish group culture etc.

Evaluation of workshops took place at the end of each workshop with an easy to read and easy to complete evaluation sheet. This asked participants for their comments and thoughts on the venue, catering and timing of the workshops and also for feedback on each session. This feedback, in part, influenced the delivery of content in further workshops. In this way, participants experienced ownership

of the workshops and validation of their opinions. Consent forms were also filled out for each workshop and this is discussed below.

### **The Workshop Participants**

This series of workshops were advertised as a package through the mailing list of the National Federation and its website and the National Institute mailing lists and website. Participants were asked to sign up for all three workshops and paid in advance. The workshops were run on a cost neutral basis. There was such a demand for these workshops that it was decided to run a series of two parallel sessions in Dublin and Galway and this would allow people from diverse locations across Ireland to attend.

Participants who attended the workshops fell into two somewhat distinct groups. Some were people with an intellectual disability who had been involved in the inclusive research projects mentioned earlier or who had been identified by their support worker as having an interest in inclusive research. Others were people who had an interest in inclusive research from a staff perspective and wished to support people to do research and yet others were family members who had heard of the workshops through the mailing shots and wished to attend with their family member and support them to conduct research on topics of interest to them.

The groups who attended the workshops can be divided into two discrete groups; people with an intellectual disability and supporters or staff members. Tables 4 and 5 below describe these two groups.

#### **Persons with intellectual disability**

Twelve people with intellectual disability attended the Galway workshops and ten attended the Dublin one. Typically, this group were adults between 20-59 years and were residing in different locations, i.e. with family, in a group home or in

their own apartment, over half were working in some kind of employment and the majority were involved in or were members of an advocacy group.

**Table 4: Participants with intellectual disability who attended the IRN Workshops**

		Galway	Dublin	Total
Age	Under 20	0	1	1
	20-39	3	5	8
	40-59	9	3	12
	60+	0	1	1
Gender	Male	4	7	11
	Female	8	2	10
Where do you live?	Living with family	3	4	7
	Living an a group home	5	0	5
	In a residential centre	0	2	2
	Living in your own house or apartment	4	1	5
	Living with other people	0	1	1
	No response	1	1	1
Job?	Yes	8	6	14
	No	4	4	8
Type of Job	Unpaid		1	3
	Part-Time Paid	1	3	4
	Full-Time Paid	4	0	4
	No Response	5	6	11
Involved in an advocacy group?	Yes	9	10	19
	No	2	0	2
	No Response	1	0	2
Member of an advocacy group?	Yes	9	6	15
	No Response	3	4	7
Total participants:	Total number of people in each group	12	10	22

**On advocacy:**

19 of 22 participants in total indicated that they were involved with an advocacy group. 15 indicated that they were a member of an advocacy group. Some examples of groups given by the delegates were: Malta Advocacy, Anti Bullying group, Newbridge Pantomime, Newbridge Musical Society, Self Advocacy group, Client Representative Group, National Service Users Council, Brothers of Charity Advocacy etc. Many of the groups meet every month and some meet three or four times a year with the director of services of their organisation. One group in particular has carried out research and put their findings into action, i.e. a staff induction programme. The implications of participants having experience in being part of an advocacy group or movement will be discussed later.



*Workshop 2: Dublin participants share their ideas*

## Supporter Participants

**Table 5: Supporter Participants who attended the IRN Workshops:**

		Galway	Dublin	Total
Age	Under 20	0	0	0
	20-39	1	5	6
	40-59	7	4	11
	Over 60	1	0	1
Gender	Male	1	1	2
	Female	8	8	16
Employed	Yes	6	7	13
	No	3	2	5
Type of employment	Unpaid	1	1	2
	Part-Time Paid	4	0	4
	Full-Time Paid	3	7	10
	No Response	1	1	2
Qualification (Certificate, Diploma, Degree, and Masters)	Qualification	6	8	14
Member of Advocacy	Yes	4	5	9
	No	4	0	4
	No Response	1	2	3
Supporting Member	Yes	3	1	4
	No	2	6	8
	No Response	4	9	13
Have you research experience?	Research Experience	6	9	15
	Total	9	9	*18

\*Information is not available on all support workers who attended as some did not fill out questions to collect this data. In addition some supporters changed throughout the 3 workshops and this related to shift work, holidays etc.

Typically, supporters who attended the workshops were paid staff members who accompanied people to the workshops or family members who had an interest in

inclusive research. In some instances, staff members attended the workshops to learn about inclusive research and how to do similar training with people with intellectual disabilities in their own organisations.

For paid staff, examples of job titles included Research and Development Officers, Training Officers, or Instructors e.g. Community Integration Instructor, Advocacy Co-ordinator, Research & Communication Officer, Home support worker, Social Care worker, PHD student, Home maker – Carer, Care Assistant, Quality systems Co-ordinator i.e. person centred planning.

Their research experience was varied and included academic training to Masters and degree level at academic institutions and direct experience with inclusive research projects within services

### **Advocacy groups**

Half of the supporters reported that they are members of advocacy groups. The groups included Anti-Bullying group, A “People First” group, National Advocacy Committee, A “Speak Up”, Outreach group, and members of a Research Into Action Group. Again this experience will be discussed later in the report.

13 of 18 supporters were paid supporters, 10 were in full-time employment and four in part-time employment. 15 of 18 supporters recorded that they had a qualification at Certificate, Degree or Masters Level in areas such as social work, Diploma in Education and Training, Psychotherapy & Learning Disability and Registered Nurse for Intellectual Disability. Support workers had spent between 5 and 30, (with a mean of 16 years working in the area of intellectual disability and also supporting people with intellectual disability in their own homes, i.e. supporting a child or sibling, or volunteering in their communities where they supported people with intellectual disabilities in an unpaid capacity.

## **Role of Supporters and their Engagement in the Process**

The role of supporters in the inclusive research network workshops was two-fold. The supporters, in the main, came to support the person with disability attend the workshops. Support included accompanying them on the journey to the venue and physical and moral support during the workshops. In addition, the role of the supporter was to facilitate ease of communication (as most communication regarding the workshops and materials etc was done via email). In addition, some staff members from disability organisations attended. They expressed an interest in developing skills in inclusive research and perhaps teaching the skills to people with disability in their own organisations.

### **Feedback from a supporter in the Network:**

#### **Supporting People to Carry Out Research By Emer Keenan**

The following are some suggestions, based on first hand experience, that might help a staff member to better support a person with an intellectual disability who is undertaking a piece of research:

- Before starting the project it is important for the support person and researcher to have some time to get to know one another and each other's expectations for the project. It might be worthwhile discussing the role each person will have in the project and agreeing some ground rules – these might be in relation to confidentiality, making decisions together, when they will work on the project together, contacting one another etc. The support person should make it clear where their responsibilities to the researcher start and end; the difference between a staff member offering support for a research project and support for personal issues may have to be explored.

- It is important that the support person has some knowledge of the research process from the outset. They should at least know about the different ways of carrying out research and be able to explain these to the researcher in a way that they will understand. The support person may have to take a lead role in determining what would be the best research methodology to apply, taking into consideration the research topic, resources and the researcher's strengths, abilities and preferences.
- Two areas for careful consideration in research are confidentiality and consent. It would be worthwhile for the support person to discuss these two ethical areas with the researcher before the project begins. Both parties need to agree exactly what they are asking respondent's consent for – is it to be interviewed only or does it include putting their responses in a report, their photograph on a website or videoing them to show at a conference? The support person and researcher cannot assume that someone's signature gives blanket consent to use the information they give them in whatever way they choose unless it is clearly stated on the consent form what their information / image may be used for. Similarly, respondents may reveal personal or sensitive information that is or is not in relation to the topic. While it is fine to record this information in a report where the anonymity of the person can be guaranteed, showing a video clip or voice recording of the person speaking about the issue might be very detrimental to the person and / or others spoken about or related to / associated with the person. The support person must use their discretion in this regard when showing video clips or using voice recordings where anonymity for the person is not guaranteed. This should be explained to the researcher because a situation may arise where the researcher, or indeed the support person, may think because the person gave their consent to be videoed / taped that the clip / recording can be used regardless. Discretion is certainly advised!

Both the researcher and support person should have copies of all correspondence, action plans, forms etc. in a suitable folder. However, keep in mind that there may be some materials that the support person might have to retain only, such as consent forms or receipts. Both parties must take responsibility for their own folder and bring it to meetings with them. This helps the researcher to take ownership of the project and ensures that both parties are prepared when they come to meetings and have anything they might need to hand.

- If the support person and researcher attend workshops together, the support person should be attentive to the needs of the researcher. They should check that the researcher can follow what's going on and make a note of concepts / activities that the researcher appears to have difficulties with for follow up later. The support person should encourage the person to speak up, ask questions, actively participate in the activities and engage with others. The support person should always go back over workshop material with the researcher to check understanding. This may require simplifying course material or presenting it in another format. They should encourage and support the researcher to complete and submit any course work required.
- When working together it is very important that the support person checks the researcher's interpretation of concepts and conversations with others, and is very clear about the agreements or commitments they make. This is vital to progressing the project, getting work completed accurately and on time and managing additional work or responding to new opportunities that arise as a result of the research project.
- Although the project is ultimately the researcher's piece of work, it is good practice for the researcher and support person to work as a team. It is helpful if they make agreements and decisions together as opposed to one member of the team making a commitment/s without consulting the other. This is

important because it gives both members an opportunity to discuss the consequences / pros and cons / impact of the commitment / decision on the project, researcher, support person or respondents before taking action.

- It may be helpful to work to an agreed action plan that sets out the tasks to be achieved, broad timeframes for task completion and names who is responsible for carrying out each task. The action plan can be broken into different phases, just like the different steps of the research process is itself. For example, advertising the research, practising, getting consent, collecting information etc. There must be agreement and commitment by the researcher and support person about who will carry out what task and what tasks will be carried out together. There may be definite tasks for each person according to the role they are carrying out or agreements made before the project started. Each party must be clear about the task they are responsible for and the support person should discuss with the researcher the consequences if either party fails to carry out their tasks. It is imperative that the support person encourages the researcher to take on as much as they can and are comfortable with – this will help them to take ownership of the project and to understand and remember more readily what they did and why.
- When meeting with the researcher, the support person should keep in mind how long the researcher can concentrate on the project. It is probably better for the researcher if they can meet the support person for several sessions of one hour duration rather than sitting and doing three or four hours in one sitting. It would be worth discussing the researcher's preference with them. Also discuss with the researcher their ideas around the research project and what they think might work well for themselves and the respondents. There may be particular supports that the researcher finds more beneficial than others and it would be important for the support person to be aware of these.

It is probably better if the support person and researcher meet in the same place at the same time on the same day, if possible. This makes a clear diary entry for both parties and means the researcher doesn't have to learn different journey routes.

- As the project progresses it is important to make a record of activities and achievements and keep evidence. This might include taking photographs, using video or keeping notes. This will be helpful when the support person and researcher start to formulate the research report. Together they should choose an appropriate way to present the information; it may involve some imagination and creativity! Some ideas might be a scrapbook, poster, video, oral recording, diary or book. The information needs to be in the researcher's own words and in a format that they can follow and explain to others. The use of pictures (for example Clipart, Boardmaker symbols) might be useful.
- Don't forget to thank the respondents and anyone else who assisted with the research project. It is important to go back to the respondents and tell them about the findings so that they have an opportunity to add more information or clarify something that has been misinterpreted by the support person and researcher.
- Finally, celebrate the completion of the project. Don't under-estimate what an achievement such a piece of work is for anyone!!

***Written by Emer Keenan 2009***

***Supporter at the Inclusive Research Workshops***

## Process of Informed Consent

At the start of each workshop all participants were asked to sign a consent form. This consent form asked people if they were happy for photographs to be taken during the workshop to be used in promotion and dissemination of information of the Inclusive Research Network. The consent was not considered a once off event but rather was a process of consent whereby participants could change their minds from one workshop to the next.

For workshop2 the consent process differed slightly. At this workshop interviews and a survey were conducted as live examples of doing research and how to conduct research. This information was used to collect participant's thoughts on the workshops and some demographic details about participants (see workshop 2). The consent form therefore included consent to have photographs taken but also sought consent to use survey and interview data in this report of the workshops. No personal data would be revealed in the report.

Workshop 3 sought photo consent only. Again participants were asked if they were happy for photographs to be taken at the workshop and for these to be used in a report or on the website to highlight the work of the network.

In line with the guidelines of assessing capacity, each sheet was dated and was specific to the workshop and the process was explained in each workshop

### **Photographs**

The use of photos for the three workshops was educative in purpose. It allowed the participants to see the Inclusive Research Network as a real network of people who came together to talk about real issues. This process was seen and understood by participants and acted as a modelling exercise for what was necessary in their own research.

## Evaluation of the Network and Methodology Employed

As this was a new initiative of the National Federation and the National Institute, an evaluation of the workshops and the network was built in from its inception. The purpose of this evaluation was two-fold, it allowed the organisations to understand the process of setting up a network such as this and gave them an opportunity to record the developments and roll out of such a network. It also allowed for learning to occur in the development of the network so that facilitators could adapt and amend teaching and course requirements as the need arose. In addition, the project was supervised by an external evaluator, Prof. Roy McConkey from the University of Ulster. Prof. McConkey's role was to supervise the methodology of developing the network and to advise where appropriate on programme content, teaching methods employed and evaluation of the network.

The facilitators of the Inclusive Research Network kept a journal of how the Inclusive Research Network evolved during its implementation in 2008 and 2009.

This journal was useful in a number of ways:

- It highlighted the changes and adaptations that were made from the original conceptions and allow for the facilitators to reflect on the reasons for these;
- It enabled the facilitators to share with one another their reflections on the impact which the process had on them personally as well as the participants and the services represented in the process;
- It was used to record impressions of the training events and issues that arose during them;
- It gave the external evaluator a better understanding of the evolution of the Network and the facilitators' perceptions on a longitudinal basis;
- It will support the roll out of a national network for the future

As part of the delivery of the workshops, evaluation was built in to help the facilitators to plan and deliver training. It also gave the facilitators the opportunity to get feedback from participants and to incorporate this feedback into future sessions. Feedback sheets examined at the end of each workshop were analysed and participant comments and suggestions were taken on board. Some examples included where participants asked for materials to be in a more accessible format, for the sessions to be shorter and for the food to be better. These methods for evaluations are discussed below and fall into four methods:

- The evaluation forms at the end of each workshop;
- The survey which was conducted in workshop 2;
- The interviews which were conducted in workshop 2;
- Final evaluation at the end of workshop 3.

This methodology gave an action research approach to the project and allowed for the development of a participatory action research project to emerge. The facilitators were open to learning and adapting material and teaching methods given the feedback received from participants throughout the three workshops.

## Ethical Issues

**Ethical issues were considered in the development of the network and in the evaluation of the network and the workshops.** As mentioned above, this project was supervised by an external evaluator Prof. Roy McConkey from the University of Ulster. Prof. McConkey's role was to supervise the methodology of developing the network and to advise, where appropriate, on programme content, teaching methods employed and evaluation of the network. Prof McConkey also advised re ethical issues which arose during the course of this project development.

### **Ethical Approval for Evaluation of the workshops:**

#### **Note on ethical approval from evaluator Prof. Roy McConkey**

Formal ethical approval was not sought for the evaluation of the workshops for the following reasons:

- This is essentially a training and development activity that includes an element of formative evaluation to make it a better experience for the participants;
- There was little or no risk to the health and wellbeing of the participants;
- All participants were fully informed about what their participation would entail and they gave consent to their involvement;
- People with intellectual disabilities would be supported by a staff member or advocate of their choosing.

This is keeping with rulings given by the NI Office for Research Ethics with respect to the distinction between research and service audits (Prof. Roy McConkey 2008).

## Methods Employed in Developing the Network Workshops

The methodology chosen to evaluate the workshops was a Participatory Action Research Model.

Each activity of the Inclusive Research Network workshops was based on an action research model. Modelling was used as a research and evaluation tool. To evaluate the workshops and the network, the methods employed were part of the research training which participants received. This was explained to participants and, at each stage, participants were informed that the results of the evaluation forms, the interviews and the surveys would be used to evaluate the network and results would be fed back to them when the workshops were finished. Signed consent forms were gathered to this effect and each participant had the opportunity to be excluded from these exercises or withhold their interview survey, etc. if they did not wish it to be included in the analysis of the network.

## Evaluation of the Inclusive Research Network

A triangulation of methodologies was used to evaluate the network and the workshops.

**Method 1** involved interviewing people about the Network.

**Method 2** involved conducting a survey with participants to seek their opinions and feedback about the Network workshop.

**Method 3** Analysis of the evaluation sheets distributed after each workshop and Analysis of the final evaluation sheet distributed in workshop 3.

## **Method 1: Interviews with People**

This session employed in workshop 2 used modelling as a way to demonstrate interviewing as a research method. It became obvious that participants were confusing interviews with job interviews – this needed to be clarified before the session proceeded.

During modelling of the interviews the idea of a ‘right’ answer and the ‘right’ questions was prevalent, reinforcing skills learned in the previous workshop.

Participants were numbered off in fours then they were given an audio recorder. The facilitators modelled the first interview on the questions provided about the workshop series. Then, whoever was interviewed became the interviewer for the second go ... and so on.

This was demonstrating a real life method of research - collecting information on what people say. The interviews were recorded and formed part of the evaluation of the Inclusive Research network. This session encountered two difficulties and took longer in the workshop than anticipated due to having to discuss two issues – the job interview as opposed to research interview – and what to do if someone discloses something that indicates that they are at risk (either from self or others), this required a lengthy discussion on responsibilities as interviewer. This is an example of how the facilitators had to amend and tailor the workshops to issues that arose unexpectedly and without having planned for them.

Thirty two interviews in total were conducted at the two workshops - sixteen interviews were conducted at the Dublin workshop 2, sixteen interviews were conducted at the Galway workshop. The responses to questions in the interviews are analysed separately.

## **Interview questions:**

### **Why did you want to come to these workshops?**

When asked why they had decided to attend the workshop one of the most common responses was that many felt it would be an opportunity to meet new people and make new friends while at the same time learning something new. People also said they had attended because they were interested in learning how to do research as they saw research as a way to influence future policy and “change services”. Inclusive research had the added benefit of involving people who use the service themselves and participants felt this workshop would enable them to participate in future research projects which would be pertinent to them.



*Workshop 3: Dublin participants practicing interview skills they have learnt*

Some people had already experienced at first hand the benefits of doing research from projects they had been involved in their own organisations but *“wanted to learn more information on research”* and in this way *“help change the services for the future”*. Many of the support workers in attendance felt that by attending the workshops it would help them to do their job better in the future. *“I want to gain more knowledge so that I can be a good support for people”*.

Another staff member indicated that in order to be a good support worker she needed to learn about Ethics. *“I am interested in Ethics and also have a great interest in consent, I want to be sure it’s done properly before I do any work with people telling their stories”*

Some people indicated that they wanted *“to see what it is like in other organisations”*. Equally, learning about inclusive research was something everyone was interested in. One of the reasons given for their interest in research was that they saw research as a tool they could use to make changes in their life - *“in my life there are lots of things that bug me from time to time and I really would like to get things sorted out a bit and I thought coming along here might be an opportunity to find out how to go about doing some research to help change things”*.

Some of the participants had experienced the positive benefits of research through programmes already in existence in their own organisations and as a result felt that they would like to become directly involved in research themselves....*“Well when I heard about this workshop I heard the word ‘research’ and I work with a service user who is doing a job for 25 years and has never got paid. She goes to work every day to a day centre, to a laundry, and she would like to get paid. So I thought this would be an ideal opportunity to learn how to assert to get pay for her and that was the main reason but also to learn anything else I can learn as well”*. Most of the participants saw research as a way to change policy for the benefit of those using the service. They also felt that

everyone had something to contribute as *“we all have abilities and have something to contribute”*



*Workshop 3: Trish O'Brien, Marie Wolfe and Rob Hopkins take turns at interviewing and recording at the Galway workshop*

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

One of the common answers to this question from participants was that the workshops helped people gain confidence in interacting with people by giving them the opportunity to meet new people from other agencies and work together as a group and participate in discussions. People learned to *“speak up for themselves”* but also developed valuable listening skills and how to *“value other people’s opinions”*. They also learned the difference between open and closed questions, the importance of asking directed questions, thereby getting the most information from the questions asked. The importance of confidentiality, how to structure an interview and how to facilitate a group were also given as important and useful topics learnt.

Many people reported learning about the importance of research, the different types of research and that research was a process that had different stages, however, research was “*not a guaranteed way to make change happen*”.

Participants reported they were enjoying learning new things, meeting new people and learning how to interact with others while still having fun. A lot of people said that getting the opportunity to work in groups was great for people’s confidence and was a morale boost. Many people stated that they had also learned how the art of listening and “*giving everyone a chance to speak*” is such an important part of good communication and were made aware that communication is an essential tool in conducting research. “*I think I have learnt how to listen a bit better to people and really hear what they are saying*”. People stated that through the workshops they were shown that research is a process that involves many stages and that while it may take time it can be an enjoyable and fruitful experience and “*can make a difference*”.



*Workshop 2 Galway – Participants hard at work practising interviewing skills*

### **What is good about the workshops?**

One of main themes from the answers given to this question was that *“People are listened to”* and *“everyone had the opportunity to speak”* which people felt was very important. Different ideas and opinions from different perspectives *“and not just from one organisation”* were good for everyone to hear. Points such as *“you can listen to people, talk to people, and get to know about their life as well”* were echoed through the group.

One of the other benefits of attending the workshops, according to many of the participants, was learning about the art of listening and how it was such an important component in good communication. People were shown how to *“listen to others’ ideas”* and how to ensure that people are given time to speak and put their point across. As research is based on information gathering, people felt it was very beneficial to be shown how to ask directed or open questions in order to get an informative answer.

Another theme that came across was the social aspect attached to attending the workshops. Most comments were very positive with many people 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. Comments like *“there are a few things I am taking from this that will help us do our own research”* and *“I know it is going to make me want to do some research”* reinforced this. 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. *“The workshops give people with a learning disability a chance to take part whereas they might not get opportunities when they are back in the services”*.

### **What is not so good – could be done better?**

This question was designed to provide feedback to the organisers of the workshops to help them find ways to improve the way the workshops are presented so that everyone gets the most from them. At the Dublin workshop the delegate's answers were mostly positive stating everything was "*going well so far*" and that they found the workshops informative and enjoyable. There were some constructive comments made indicating that perhaps "*some of the words used may be difficult for some people to understand*" and that possibly "*more visual material*" could be used to combat this problem. One person asked if some music could be included as the day was long and a lot of information was given and this could be a way of breaking up the day.

Another suggestion was made that it may have help to have more role play involving moving around and being more active as "*sometimes it hard to sit for half an hour just listening*".

Another suggestion was to make the writing bigger and therefore making it easier to read the presentations. Everyone acknowledged that efforts were being made to improve the format and that "*we are learning from each other*" and previous comments on the quality of the lunch on Workshop 1 were taken on board and improved upon for workshop 2.



*Workshop 3: Galway participants practice their interviewing skills*

### **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?*

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### **Method 2: Doing a Survey**

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

was explained to everyone as part of the session and the purpose for collecting data about people was explained as part of the evaluation of the network. Again it was used to model a real-life example of doing research. Consent was discussed and participants were informed that they did not have to complete the survey if they did not wish to.

Results from the survey were used to compile the information on participants in table 4 and 5.

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### **Method 3: Analysis of Evaluation forms distributed at each workshop:**

Evaluation forms (see appendix 1 for sample) were distributed at the start of the workshop and the participants were asked to rate each presentation immediately after watching them while it was fresh in their minds. In this way they could give an accurate assessment of what they had just seen. There were also questions on the topics of venue, time and participant's overall impressions of the workshop.

The evaluation forms were designed with pictures and symbols which assisted people to understand the questions more easily. The objective of asking people to fill out the evaluation sheets was to provide the organizers of the workshops with feedback which was then taken on board and any suggested adjustments could be made to the subsequent workshops.

### **Workshop 1 Feedback:**

The first workshop, both in Dublin and Galway, achieved an excellent response overall to the modules presented and "*Everyone really enjoyed the workshop*". The comments on the catering at the Galway workshop was taken on board and different caterers were used for workshop 2. Some other comments from Workshop 1 participants included:

- *Self-esteem got a great boost by being allowed to facilitate a group;*
- *Everyone's contributions were heard respectfully;*
- *On the journey home plans for documentaries and other innovations were being suggested;*
- *Felt it could have been one hour shorter, possibly too much to take in a short time;*
- *A very good workshop look forward to the results;*
- *Many issues were discussed which opened up the topic of research;*
- *"presenters are brilliant" and "very professional";*
- *The workshop was a great opportunity to meet new people;*
- *Found group work a little difficult at first;*
- *Workshop was a little long, especially for people who had to travel long distances;*
- *Lunch was 'poor quality'.*

## **Workshop 2:**

Overall comments from Workshop 2 were positive stating that it was a *"very informative and well structured session"*. However feedback included the suggestion that there should have been more time for discussion on research topics, that the some of the presentations were too long and that possibly more group work should be included.

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

- *Lots of food for thought*
- *Great day. Sessions improved as the day progressed.*

- *For the first workshop I would have liked to spend more time discussing research topics*
- *Thank you for very interesting day.*
- *Broad topic - not sure if everyone ended up knowing what ethics were.*
- *Really Super! Thank you very much*
- *The cartoons on evaluation sheet are not treating us like an adult. Use photographs instead*
- *Ethics needed more time spent on it.*
- *Keep up the work! We want more!*
- *We would like more of these kind of days.*
- *We'll put together and good division of presenters.*

### **Workshop 3**

As with the previous two workshops evaluation forms were distributed and the following questions were asked which were based on the modules being presented on the day and again the most common response was 'excellent' for all of the modules.

This workshop also included a 'celebration' where certificates were handed out to all the delegates that had attended the workshops.

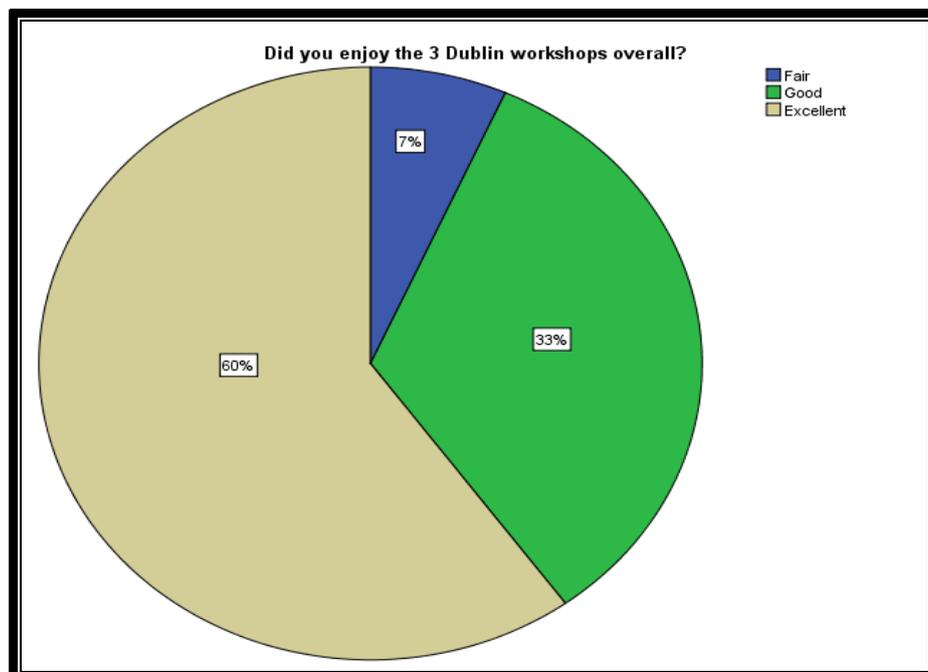
Some other comments from workshop 3 were as follows:

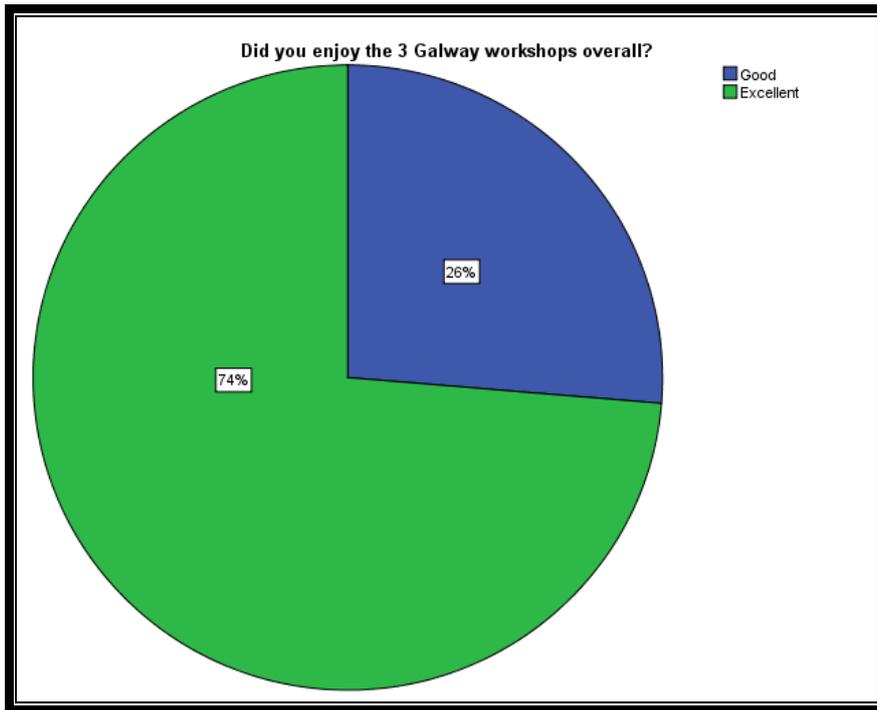
- *I enjoyed the workshops but I would like more practical instruction;*
- *Possibly delivering training at a local level to service users would be helpful;*
- *Excellent, very productive and great for networking;*
- *Overall it was good. However a joint survey/ research project could have been done and then findings could have been for June and expanded to all for next year;*
- *Very good ratio between different kinds of people from a wide base;*
- *Very good I'm impressed;*

- *Maybe try and cover less, but spend more time on them. More homework to practice with;*
- *I think the work should be more visual.*
- *I acquired a lot of skills;*
- *Presenters very competent;*
- *Good structure. There is a need for reinforcing links with research buddies? We've made the link but we need on-going contact and expertise;*
- *I think it is the beginning of something that can help change lives;*
- *It was great to hear what people with disabilities talking about research that will affect them.*

**Overall comparison between Dublin & Galway feedback:**

This evaluation form included a question “*did you enjoy the 3 workshops overall*” When comparing the feedback to this question between the two venues both the Dublin and Galway workshops scored a high satisfaction rating – this is outlined in the graphs below:





Overall, at the end of the three workshops the feedback was very positive with everyone feeling a great sense of achievement. However, it was also felt that it was just the beginning of an important piece of work that had the potential, if continued, to impact greatly on people's lives as is demonstrated in the comment from one participant "*I think it is the beginning of something that can help change lives*".

## Reflections from the Co-coordinators

Throughout the three workshops the facilitators kept a journal and shared reflections with each other following each workshop. The purpose was to gather and record information about the process of setting up the network, the difficulties and challenges encountered and to develop a method of recording the process to enable similar networks to be established and the benefits and challenges be discussed. These reflections are set out below under the following headings:

- The achievements
- Observations
- The challenges
- The trainers/facilitators
- Group dynamics, participation and levels of understanding
- The external evaluator
- Advocacy
- Combating exclusion
- The role of the supporter

Finally some conclusions are drawn about the value of the Network and the future of the Network

## **The Achievements**

The Inclusive Research Network gave people, both with and without an intellectual disability, the chance to learn valuable research skills together. The programme that was developed was relevant and respectful to all participants.

The Inclusive Research Network gave people from a range of agencies/services an opportunity to come together and socialise together. It would appear that there are few opportunities for that currently.

The IRN gave people with intellectual disability a chance to participate and this participation was treated with respect.

The IRN created a profile for Inclusive Research in Ireland and put into practice the principle of inclusive research

There was an obvious growth in confidence of people who took part indicating transference of new skills from the research environment into everyday life.

There was a growth in the number of inclusive research projects with people with intellectual disabilities as researchers now underway as evidenced by the get together event held in June.

## **Observations**

The following are some observations made by the facilitators during the course of the workshops which may help to develop future activities of the IRN

- The media and methods used by people to report research findings was mixed and varied from person to person and topic to topic.
- In a follow-up event to hear about the research activities of members it was noteworthy that some presentations took the form of a short drama, others a role play of how the interviews were conducted, others choose to tell their life story through video and song and some used the more

'traditional' research method of a power point presentation to report their findings. This indicates the need for people to be supported flexibly to allow researchers to report in ways they themselves value as powerful and appropriate. This may well include many non-traditional formats.

- In addition to this the use of multi-modal methods to teach the research workshops was useful in that it allowed for learning to occur in a relaxed and enjoyable environment using methods which were well suited to the participants abilities
- Involvement in advocacy was a strong influencing factor in the workshops both for people with disability and their supporters. It was obvious to the facilitators from the start that participants who had indicated that they had been involved in advocacy groups were more vocal, more confident and had clearer and definite ideas about what topics they would like to research and how research could help them to bring about change.
- In addition for supporters who were members of advocacy groups they appeared to be more tuned in to their role as supporter and the ways in which the role of the supporter was vital for the person to learn and participate in the workshops.
- The importance of supporters and consistency in support across workshops was vital for the success of these workshops. As mentioned earlier the role of the supporter was varied and "support" included both physical assistance and moral encouragement. The role of the supporter at the workshops was two-fold. It was a supportive role on the day of the workshop but also a continuing role between workshops for course work to be completed or for the person to pursue their research ideas. In some cases this role was not clearly understood (and this was not defined at the outset). In some cases the support person varied from workshop to workshop and was not aware of the activities and work of earlier workshops. In some cases the supporter required their role to be supported back at organisational level and this was an issue that needed careful consideration. In other cases staff members attended the

workshops without a person with disability. This was noted at the start of the workshops but it was felt that this would encourage staff to adopt more inclusive approaches in their own organisation through the work of the Inclusive Research Network.

### **The Challenges**

- Adapting materials constantly and according to learning styles of individuals and the flexibility required of facilitators proved to be a consistent challenge.
- The difficulty of having a consistent support person with each person at the three workshops despite the fact that dates were put in well in advance was noted
- Staff members reported that it was a difficulty for them to be released for a day to accompany people to the workshops and this often meant that others were left unsupported in their organisations in their absence.
- The issue of travel and expenses to travel was also cited by some participants as problematic
- All communication regarding the workshops was via email. This included reminders, updates, homework sheets and course material (though all material was also made available to course participants in hard copy). This meant that most participants with a disability were reliant on the supporters to check emails on their behalf or with them and update them re the activities and the workshop dates etc.

### **The Trainers/Facilitators**

It was evident from the outset that the success of the workshops depended on many factors one of these was the need for a facilitator or coordinator to drive the work of the network. In the case of this pilot study this network and the workshops were organised and co-ordinated by two facilitators. These two facilitators came from a teaching and a research background but the skills required to run the workshops required a much broader skill base.

The facilitators drew on a wide range of skills and experience in both the National Federation of Voluntary Bodies and the National Institute of Intellectual Disability to fulfil this broad skill base. Presenters for the workshops were drawn from a range of researchers and professionals in both organisations to conduct demonstrate real life example of research as examples of research methods which can be used.

- The importance of flexibility and matching course material to suit participant abilities was evident throughout. Often facilitators came to the workshop with material prepared in advance only to find that as the workshop progressed a different method was required, a different pace, more role play, less text etc. This required enormous flexibility and confidence on behalf of the facilitators to adapt the programme and be tuned in to participants, their abilities, tiredness levels, literacy levels, communication skills etc.
- The skills required to deliver the workshops in this manner are broad and cannot be defined within the role of teacher, researcher or support worker, rather a careful mix of each of these roles is required

### **Group Dynamics, Participation and Levels of Understanding**

Throughout the workshops it was a constant challenge to determine whether all participants fully understood the content and the purpose of the workshop. Each workshop had on average 30 people in attendance and it was difficult to always determine if all participants were engaged all the time.

Opportunity was built into the workshops for socializing and get togethers. This was reported by all participants to be one of the most important elements of the workshop. In evaluation of each workshop participants asked that more time be allowed for the social aspect.

Despite the varying abilities of group members and variety of combination methods they employed there was a significant level of participation from most group members. One aspect of the workshops which really helped this participation was the small group work and the opportunity to do role play etc within these small groups. This also helped participants get to know one another better.

### **Advocacy**

People came to the network with advocacy experience. However the network reframed advocacy and went beyond advocacy as it is traditionally known. Some participants came to the workshops with experience of being involved in advocacy groups. There was a marked difference in those who had this experience and those who did not in their ability to be able to speak up and engage in discussions about topics of interest to them and undertake research of their own. This would suggest that this type of network is particularly useful for people who have had experience of advocacy but would like to put move this to a more action based level of advocacy.

The network had a much more systematic approach to advocacy in that it is based on evidence and the analysis of evidence.

This type of analysis leads to policy decisions and change ....an aspect that truly goes beyond the realm of advocacy known as participatory action research. This is what is required in the future to progress Inclusive research and bring about change in people's lives.

### **Combating exclusion**

This acted as a central theme from the network. The network listened to the experiences of people and their social conditions. Rather than expecting people to fit in with societal norms it addressed issues of how society needs to fit or change to accommodate different needs and abilities. This is a move to more

control for people with disabilities. The social inclusion agenda has been addressed and we now need to ask how we shift cultural expectations and attitudes through a network such as this.

### **The role of the supporter**

The role of the supporter or staff member in this area is vital. One observation was that as already mentioned staff members who supported people at the workshop often changed from one workshop to the next. This had the effect that there was often little consistency between workshops or little follow up on the work being done by the network. This was particularly evident when it came to the National study on 'where we live' (see Appendix 2). People who had indicated that they would like to participate were unable to do so because of the lack of staff support to carry out interviews etc.

The success of an Inclusive Research network and the growth of Inclusive Research Network will depend very strongly on the support that people receive. In the future it may be necessary for staff to commit to three workshops in advance and that the specification be that the same supporter should accompany the person to all related events. This would bring with it a sense of cohesion as well as having the supports in place outside of network organised activities.

The feedback received from one supporter who attended all three workshops could well act as the basis for a job description when attending or supporting somebody to conduct research.

### **Reflections from the External Evaluator Prof. Roy McConkey:**

An external evaluator was invited to oversee the development of the network and the roll out the workshops. Prof. Roy McConkey attended one of the series of three workshops and corresponded with the facilitators on the workshop content and the evaluation of the workshops. He also served as adviser throughout and this was a valued role for the facilitators when they struggled with some of the challenges which are outlined above.

Prof McConkey also met with the Facilitators following the network to give some formal feedback and discuss the development of the network into the future.

The independence of the external evaluator was important and this was vital in determining the value of the network and the outcomes of the workshops.

## **Feedback from External Evaluator:**

### **Reflections from Roy McConkey on the Inclusive Research Network**

#### **Aims**

I was pleased to be asked to act as external evaluator for the Inclusive Research Network. This linked with my involvement as a Visiting Scholar with the National Institute of Intellectual Disability (NIID) at Trinity College Dublin. My primary role was to assess the achievements of the Network and to advise on the next steps. Hence these reflections are intended to:

- Synthesise the main lessons emerging from the experiences of the Inclusive Research Network as perceived by the external evaluator.
- Identify key issues that should be considered in taking forward the Inclusive Research under the aegis of National Federation and its partners.
- Make recommendations for further actions in support of inclusive research.

#### **Evidence base used**

These reflections are based on the following sources, details of which are available in accompanying documentation.

- The compilation of information contained in the draft report which encompassed the Journal kept by the Network facilitators and the feedback received from participants.
- The meetings and discussions held with the facilitators since the project's inception.
- Direct participation and observation of Network training and meetings on 6 February, 2009 in Dublin and 11 June, 2009 in Galway.
- Discussion and comments from other critical friends of the Network such as Patricia O'Brien (National Institute of Intellectual Disability, TCD) and Errol Cocks (Perth, Australia).

#### **Achievements and lessons of the Network**

There are a number of well-attested achievements:

- People from a range of agencies have come and stayed together.
- People with intellectual disabilities have been active participants who were respectfully listened to and the meetings have been responsive to their needs.

- The profile of Inclusive Research has been heightened within the Federation and some of the member organisations.
- The confidence of participants has increased along with their capacity to be active contributors to all aspects of the meetings.
- Many of the participants had prior experience of advocacy and this is likely to be an important foundation for building a Network such as this.
- The meetings have been thoughtfully planned and required a sustained struggle to ensure that the content and method of presentation were attuned to the needs of participants.
- Two facilitators were appointed to ensure that the vision and values of the Network were maintained and that the programme of work was undertaken. Without them it is unlikely that the Network would have continued and the programme of work completed.
- Alliances were formed with other agencies and people (notably the National Institute of Intellectual Disability, TCD) who could assist practically and financially, as well as offering advice and guidance.

In sum, the feasibility of recruiting and supporting people with intellectual disabilities to undertake inclusive research has been demonstrated and the value of this endeavour is already attested for the participants. Resource materials are now available along with a facilitation process that would enable similar networks to be developed elsewhere in Ireland and beyond.

### **Future challenges**

To my mind, three main challenges emerge from this experience which I have framed as three questions. No doubt implicit consideration has been given to them but the coming months may be an opportune time to address them more explicitly.

#### **1. Why have an Inclusive Research Network? What are its likely *unique* contributions?**

The answers to these and similar questions are likely to be couched in terms of a better deal for people with intellectual disability in Ireland. But the analysis probably needs to go somewhat deeper and attempt to address the unique contribution that *inclusive research* can make to this endeavour, which other forms of advocacy and even research may not. However it is likely that these answers will emerge through the ongoing activities of the Network especially if these 'why' questions are made explicit and answers sought to them through experiences of undertaking research and in monitoring its impact. This might be most pertinently done through an ongoing evaluation of the Network's aims and activities. However this presumes that the Network does continue.

## **2. What are the risks associated with the Network's activities and public statements?**

This links with the above point. As long as the Network remains a small, almost private endeavour, then there is little risk that it poses any significance challenge to the status quo with respect to services and funding policies. However there are indications already in some quarters of a wish to exert some control the Network's activities. This may be accentuated as the 'research' outcomes are disseminated, especially if they challenge existing practices. Hence there is risk for the inclusive researchers that their efforts will be devalued - possibly derided - and this could be compounded by a realisation that the high goals they have set themselves may not be achieved in the short-term. Equally the facilitators' motives and competence may be called into question. These scenarios are raised not to discourage but rather to stimulate some advance planning and exploration of contingencies. The continuing support and commitment from the NFVB would be a major component in this.

## **3. How does inclusive research fit with other forms of empowerment of people with intellectual disability in Ireland?**

Inclusive research shares common aims and outcomes with other efforts to empower persons with intellectual disability in Ireland: examples include advocacy initiatives, service-users committees, courses in third level Colleges, the Ambassador programme of Down Syndrome Ireland and the leadership programme of Special Olympics. Indeed it could be that Inclusive Research becomes a component within these broader programmes and hence the training materials produced in this project should be shared with other programmes. Equally, it could be that representatives from the different empowerment programmes noted above, come together to provide a new form of Inclusive Research Network. Neither of these initiatives will come to fruition without suitable leadership.

### **Recommendations for consideration**

There are a number of practical steps that might help to address the above challenges but also have a wider applicability. These are grouped into those that: 1) sustain and develop inclusive research as a process, and 2) a national strategy for Inclusive research.

#### **1. Sustaining and developing inclusive research**

**1.1 Promoting Participatory Action Research/Emancipatory Research.** The work of the Network could be explicitly presented within a Participatory Action Research Framework. The goal is to involve marginalised people and their local supporters in a series of action research cycles to address key issues of concern to them. Arguably the first action cycle is complete; i.e. sharing knowledge

about specific research techniques and procedures, and a second cycle has commenced on research into people's views on living arrangements which has involved data gathering and analysis, and presentation of findings at a major national conference (NDA: 6<sup>th</sup> October, 2009). However this cycle may continue with further interviews being conducted and reports prepared for publication. Moreover a third action cycle might commence, such as the implementation of change within services. This is a theme currently being pursued by the NIID as part of their 'All We Want to Say' Project.

**1.2 Role of supporters.** In future, more attention might be paid to recruiting, training and supporting the local service personnel who have acted as supporters to the Inclusive Research Process. They will be a crucial element in ensuring local action but they are also likely to be the people who can lead the Network in the future. I wonder if they were aware of what was being expected of them when they come along to Network meetings? Also there could be personnel within services and organisations who are better placed and equipped to support inclusive research. Indeed it might be helpful to document the person specification and 'job' description of staff who act as supporters of Inclusive Research. Opportunities for training might be also be offered.

**1.3 Having fun.** Keeping alive a spirit of fun and celebration when people come together is essential to maintaining the Network. Given the limited time available for meetings it can be tempting to overload the programme with business and squeeze out the time for making learning fun. The development of 'Take-home' materials that local supporters can further work through with co-researchers could help free up time in the programme.

**1.4 Spreading the word.** The longer-term future of the Network is probably dependent on widening the membership. Hence opportunities to publicise the Network locally, regionally and nationally should be sought and taken, for example articles in magazines and media.

## **2. A national strategy for Inclusive Research**

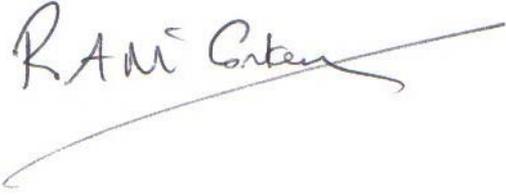
**2.1 Research Strategy.** The National Federation is well placed to provide the leadership required to ensure that Inclusive Research is located within a broad research and development strategy in the area of intellectual disability. Their existing Research Strategy 2008-2013 is a good example of the overarching programme in which Inclusive Research can find a home. This could also serve as an example to other agencies and organisations who may undertake research in intellectual disabilities such as Inclusion Ireland, HQIA, NDA and HSE.

**2.2 Finding Allies.** Like much other research, inclusive research is likely to be undertaken by interested parties in their own locality. National projects are relatively rare. Hence it is crucial that the existing Network finds local allies to support and extend its work. Again the Federation is well placed to do this through its membership but also by linking with comparable organisations with similar interests such as Special Olympics and Inclusion Ireland.

**2.3 Reconceptualising research.** Underpinning the above strategies is the need to build a new understanding of what constitutes research and of the methodologies that can be deployed. At one level this can be achieved through the training materials that are produced for participants in Inclusive Research as noted above – including supporters. But more broadly, the training in research that is offered in professional training courses within Universities should also cover inclusive/participatory research methods. Likewise, grant-awarding bodies might specifically encourage inclusive research as appropriate in their calls for research. These latter two initiatives are more likely to come about in Ireland when Inclusive research has a proven track-record and local personnel with expertise in it.

## **Conclusions**

As often happens, small-scale innovative projects such as the Inclusive Research Network raise some very fundamental issues around the role of research within services, the people who need to be involved in it, the methods used and how the outcomes of research influence practice. Arguably the gains from establishing an Inclusive Research Network are more to do with forcing a re-evaluation of long-held beliefs and priorities rather than the production of research findings. I hope this learning is not prematurely ended with the completion of this phase of the Inclusive Research Network.

A handwritten signature in black ink, appearing to read 'R. A. M. Carter', with a long horizontal flourish extending to the right.

**14<sup>th</sup> October, 2009**

## Conclusion

Now may be the time to consider the role of Participatory Action Research or emancipatory model of research in this network rather than focusing further on research methodologies. We need to ask how we translate the message of the Inclusive Research network via the methods that people used in the workshops e.g., film drama, life stories are telling mechanisms.

Research methodologies are only a means to an end and the question now is how to get the message across in relevant media....an empiricist methodology as traditional methods suggest is not necessarily the best method.

We need to be technique oriented and outcomes driven....rather than focusing on research methods per se and we need to consider the larger picture. How does a network such as this contribute to equality and social inclusion for people with intellectual disability in Ireland?

This begs the question about what is the role for services and voluntary organisations in the network.

It appears that buy -in from agencies is important to sustain an ongoing network. However, there has to be congruency of thought and purpose both from management and from practitioners and participants.

We need to build a situation where agencies and the people in them want to align themselves with the Network and come to the Network for advice.

Two issues raised by participants were related to continuity and sustainability. These two issues require careful attention.

What will be the mechanism to sustain the network and how will it be maintained. Is it a better approach to try to seed smaller networks? If the network becomes too big then it loses the essence of what makes its ability to connect meaningfully with people.

Its success was in its size and the aspect of social supports and contacts. The real strength of research produced by a network such as this lies on the wealth of knowledge that can be gleaned from the researchers- the people with disability. This adds a note of credibility to the research; the credibility lies in collecting people's voices and hearing the first hand experiences of people with a disability. The true picture of the research includes the voices of people themselves. This in essence requires a reliance on qualitative research rather than a traditional empiricist method of research.

The Inclusive Research Network is based on an ideology; the ideology of people doing their own research and presenting their own research. This ideology involves a process. This is a process which requires first listening to what people say are important research topics to research, second, supporting people to pursue research in this area and third implementing change based on these research findings. Without a doubt this 3<sup>rd</sup> stage is both the most difficult and most important to implement. It may be that the Inclusive Research Network needs allies to implement this third stage of the Inclusive Research Process. These allies include the member organisations, HSE, funders of research, University Departments and graduates of university programmes as potential champions of this research.

The role of the support person in the process is vital and as already outlined, this needs careful consideration. It may be that anyone interested in pursuing a cycle or process of Inclusive Research would first define the role of the supporter in the process. This needs as much planning as the research project itself.

The Inclusive Research Network fits with the National Federation Research Strategy and in fact complements the overarching principles of including people's voices in a national Strategy and being guided by what people say is important to them.

The National Federation Research Strategy also commits to using and adopting inclusive and participatory approaches in its work plan and this is one demonstration of this commitment. In going forward the Inclusive Research network may need to consider where it fits with other National Frameworks and National Policy and how it can address national policy which relates to intellectual disability. E.g., HSE, HIQA, National Disability Strategy, National Social Inclusion Strategies etc.

One mechanism may be to influence the research programmes and training programmes of local universities and have inclusive researchers present findings from their research to undergraduate and post graduates programmes. This would influence the practice and research methods employed by the clinicians and staff members of the future.

Some work has already been done with aligning the work of the Inclusive Research Network to various University Departments not least its partnership with the National Institute for Intellectual Disability at Trinity College Dublin and its natural alliances with other university Department e.g., the Child and Family Research Centre based at NUI Galway and indeed some of the researchers on the network independent of the Network provide training on the NUI Galway psychology and related training programmes.

### ***Fun Fun Fun!***

Repeatedly the participants on the Inclusive Research network told us of the importance of the social activities and the opportunities to come together to have fun. This is vital to the development and the roll out of the Network. For many the

sole purpose of attending network meetings was the opportunity to socialise and have a bit of fun. The future of the network should not lose this as a driving force and remember that for many this is the only chance they got to come together and meet other people outside of the their own organisations. The importance of the fun element cannot be underestimated. In coming together people also get the opportunity to share their thoughts about research and plan research projects together of national significance whilst having some fun.

## So Where to from Here?

The following is an action plan for the Network based on the lack of funding available but also considers what can be done with limited resources.

### **Action Plan for the future of the Inclusive Research Network**

- Existing members on the mailing base will be kept up to date about the Network, about research projects happening via web and email;
- This report will be launched to the members of the Network at a get-together event;
- This final report will be circulated to network members and the National Federation Member organisations;
- The Research Unit of the National Federation will continue to support and promote the work of the Inclusive Research Network albeit on a scaled down basis until such as time as funding is sought to develop the work of the network further;
- Training materials for Inclusive Research Workshops will be put together in downloadable format. This will support the supporters to deliver similar training to people at local level;
- This report will be circulated to trainers in university departments;
- Every effort will be made to promote inclusive research as a legitimate research methodology;
- We will continue to present the findings of inclusive research projects at national events and opportunities that arise.

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## **Appendices: Outcomes of the Inclusive Research Network**

### **Appendix 1: Inclusive Research Get-together June 11<sup>th</sup> 2009**

This day was organised to bring the two geographically separated groups who had been attending the Inclusive Research Network Workshops together, to talk about what they have been doing since the workshops and to celebrate and socialise.

#### **Description of the day:**

The day started with tea and coffee on arrival and registration.

The Introductions were done by Prof. Roy McConkey. Five minutes were spent on meet and greet. People were asked to go to somebody they did not know and introduce themselves.

Roy then introduced the activities of the day by talking about what is meant by research. He talked about how research is now moving in a different direction. Instead of research being about people, research is being done with people and for people. Research is about finding out about peoples lives and how it could be better, and about how research can make a difference. Research can bring about change at a local, service and a national level. Therefore research is important. Government want to know what research is telling us. As researchers, it is our job to get the message across to Government. People need support to do this. The purpose of the Inclusive Research Network is also about helping supporters to learn about supporting people to do research. The role of the supporter is crucial and it is important that they share this learning with their colleagues.

Research is about more than our own ideas and experiences. We need to listen to other people and find out what they think. This needs to be done at local level in peoples own services and communities.

Research can also be fun and it can be exciting to meet new people and work with them and exchange ideas with them.

This event was designed to be fun and have a chance to meet other people who are also interested in doing research and in supporting people to do research.

Next the facilitators gave a presentation on the Inclusive Research Network workshops held over the past year and the evaluation of the workshops fulfilling the commitment to provide feedback to participants on their opinions and evaluation of the three workshops. This presentation looked at what had been achieved so far, what people thought of the workshops, who attended the workshops and what people had to say about research and the benefits of doing research.

Following this presentation there was opportunity for members of the Inclusive Research Network to present on research that they had been carrying out since the workshops finished.

## **Appendix 2: Inclusive Research Projects Underway following Attendance at the Network Workshops**

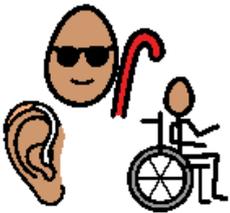
- Sandra Corr and her supporter Emer presented on their study Attitudes to People with Disability
- The Clare Inclusive Research Group presented on three aspects of their research which has been ongoing entitled the travel challenge, leaving home and moving to independent living. They used a mixture of drama; film and presentation to show case their research.
- Dawn Lonergan and Nicola Carroll presented on their involvement in conducting interviews with people about their life styles. Dawn and Nicola role played one aspect of this questionnaire on what supports a person might need to live independently.
- Ann Mahon and Geraldine Bane presented a piece on their research to date on transport challenges for people with disability.
- Carmel Carpenter presented her life-story through film and also treated us to a few well known songs to get the group in the mood for the work of the afternoon session.
- The afternoon session of this day focused on the development of the methodology and training for the national study of the where we live a National Study conducted through peer-to-peer interviews.

## 1. 'Attitudes' towards People with Disabilities

**Researcher: Sandra Corr**

**Supporter: Emer Keenan**

disabilities



I did my research on attitudes towards people with disabilities. I picked this issue because I have a disability and I don't think I am always treated as I should be and I wanted to see how other people with disabilities were treated. I am hoping if people read this they will treat people with disabilities better.

group work



I used focus groups to find out if people with disabilities are treated fairly or unfairly. Altogether I did 7 focus groups. I did them in Portmarnock, Seatown Road and Rush in Prosper Fingal. Altogether 41 people took part. If people wanted to take part I had them fill in a consent form to give me permission to tape and video record our conversations and to use their answers in my final report

tape recorder



video camera



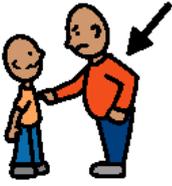
Emer had to put on paper what was recorded on the tapes, but she didn't include anybody's names. Emer put all the answers from every group under the 10 questions I had asked. She was looking for answers that were the same and different. This was called the findings.

I was not happy with the findings, for example:

- Some people were not aware they had a disability. I think it should have been explained to them so they could better understand themselves
- I was shocked to hear that some people with disabilities were treated disgracefully on public transport. Some buses refused to put the wheelchair ramp down, other passengers can be very mean and hurtful and even the drivers can be very disrespectful



bully



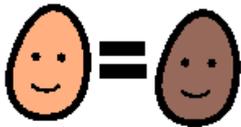
- Lots of people have been treated unfairly. They have been bullied, shouted at, refused jobs and made to feel ashamed of themselves, which is a total disregard of their human rights
- I myself have never been refused service in a shop, but I was appalled to learn that some people have been given the wrong change and some have a very, very hard time when they try to go out and socialise, like in discos

disco ball



Finally, I think people with disabilities should be treated the same as people without disabilities, if not with more respect because they take what life has given them and make it a plus side. They still lead a normal life and have their own responsibilities and independence despite what their disability is. I would like to be given the chance to help people be treated better and I think I would be good at giving them advice as I have experience. I am very proud of myself - this was a big thing for me to do because I have never done anything like this before and it is a subject I feel very strongly about and an issue that people should know about!

equality



## **2. The Clare Inclusive Research Group**

The Clare Inclusive Research Group presented on three aspects of their research which has been ongoing entitled the travel challenge, leaving home and moving to independent living. They used a mixture of drama, film and presentation to show case their research. Below is a letter from their group facilitator on their experience of being involved with Inclusive Research group and outcomes of their work written to Patricia O'Brien.

### **CLARE INCLUSIVE RESEARCH GROUP BROTHERS OF CHARITY SERVICES CLARE**

T: 065 6849400 F: 065 6869769



06 / 11 / 09

Dear Patricia,

I know I can speak for our CEO Mary Kealy and our own group members who participated in the training, Ger Minogue, Kathleen Ryan, Marie Deeley, Nuala Coghlan and myself, along with the rest of the C.I.R.G. researchers thanking you for all the support, help and guidance you have given to services in Ireland, particularly in the research field, in your time at Trinity. We wish you all the very best in your new undertakings "Down Under"!

The following represents a summary of our work since becoming involved with IRN in September 2008 following our spell binding experience in Cape Town!

We presented our first drama to the ISEN 2008 AGM and made a series of presentations from Jan to March 09 around Clare promoting our research. This featured the three aspects of our Research Programme, 2 Dramas, one on Relationships "No Kissing" and one on Wheelchair Access "The Travel Challenge" alongside our film about people moving into their own homes "No Place Like Home".

This culminated in our being asked onto RTE Radio's flagship Current Affairs Magazine Programme "Kenny Live" opening the debate nationally about the law and prohibition of sexual relationships for people with a learning disability.

In June we presented our new relationships drama "Leaving Home" at the Galway Gathering alongside a film of the group in action "My Life My Research" which was also presented to government policy advisers at Cois na dAbhna in Ennis.

In July the autobiography, "This Was My Life I'm Here To Tell It: *The Life and Times of Patrick Kearney* was launched at the Open University Social History Conference in Milton Keynes UK. Patrick has sold over €600 worth of the book with Ennis bookshop twice selling out of its allocation since August. Dorothy Atkinson, Head of Social History Dept O.U. said "This book has raised the standard in terms of content and production for the publication of social histories."

In September we were invited to present at the "Human Rights and Sexuality" International Conference in Dublin to a cross section of voluntary organisations, health trust officials, family members and people with a disability and came top in the evaluation presenters feedback summary for both content and delivery for our Forum Theatre interactive drama presentation. Most recently we presented to the Brothers of Charity National Advocacy Conference in Cork and were similarly received.

The training, support and contacts we enjoyed through the IRN Research Programme were thoroughly appreciated by the Clare group and the event at the Radisson was a major highlight in our year.

We are continuing to work with the Trinity College "All We Want To Say" National Research Project covering the areas of relationships, paid employment and public speaking for a conference for people with a learning disability, policy makers and service providers set for autumn 2010. We are also looking to establish an access project with Shannon town family resource centre in a partnership with Young Mothers with Buggies, the Elderly and People with Physical Disability in the new year.

These undertakings would not have been contemplated without the grounding, support and training we received from yourself, Edel Tierney and Steve Curtis during the IRN programme.

Many thanks once again,  
Rob Hopkins

## Appendix 3: Where we Live Survey

***A national study of where people with intellectual disability live conducted through peer-to-peer interviews***

### What IRN members were interested in?

- During the workshops the IRN members said that the following topics should be researched or would make a good research project: *choice about who to live with, freedom to be independent, moving into my own house – independent living, privacy – my rights and alternatives to group housing*  
As a result, the Inclusive Research Network decided with the support of the facilitators of the network to undertake a study about '**where we live**'.

### The National Survey

- This study looked at where people with intellectual disabilities live, what they like or do not like, what supports they need and what they would like to change about where they live.
- The survey was a way to use and transfer the skills learned and developed in the inclusive research workshops.

### Developing the Survey

- A group from the NFVB and the NIID supported this project.
- Members of the IRN developed the questions for the survey over the first two workshops and tested the survey. Changes were made to the wording of questions, order of questions in the survey, and pictures.
- The support group developed a co-researcher and a supporters' manual with instructions to administer the survey, and an answer booklet.
- The survey, manuals of instructions, and the answer booklet were pilot-tested four times and changes were made to the survey following the pilot interviews. The final version of the 'Where We Live' National Survey is available online at [www.fedvol.ie](http://www.fedvol.ie).
- The project received ethical approval through School of Social Work and Social Policy Ethical Approval Committee, Trinity College Dublin.

### How we conducted the survey

#### Training:

- The support group provided training on how to use the survey as an interview tool at a get-together event in June 2009.
- IRN members also learned about basic sampling including people of different gender, age groups over 18 years, and different housing situations (e.g., group homes, independent living, living with family, residential institutions, etc.).

### **The interviewers:**

- A total of 11 co-researchers interviewed 43 people. The co-researchers were based in Clare, Cork, Dublin, Galway, Monasterevin, Roscommon, and Waterford.

### **Support:**

- To take part in the national study each person had to identify a supporter who would help them to conduct the interviews.
- Two members of the support group, one from the National Federation and one from the NIID, provided support to the co-researchers during the months of July and August of 2009.

### **What did we find out?**

- The co-researchers who conducted the interviews were invited to a session to analyze the results. The results were presented using bar charts and graphics and in a way that was easy to understand for everyone. At that session, we concluded that:
  - 16 males and 27 females responded the survey. 41.5% of the respondents were between 20-35 years, 36.6% were between 36-50, 19.5% were between 51-65 and 2.4% under 20 years.
  - Most people who were interviewed reported living with their families (42.86%), some lived in group homes (21.43%), and a few in independent living apartments (4.76%).
  - People who lived in group homes said that, on average, ten people lived with them. In contrast, people who lived with their families said that they lived with three people.
  - People who lived with their families and in group homes, had lived there for about 9 years, however, people who lived in semi-independent apartments said that they have lived there for only about three years. Most people interviewed said that they were able to use the kitchen when they wanted. Almost all people said that they had their own bedroom but only a few had a key to their bedroom.
  - A lot of people lived in a town (46.6%), many in the countryside (40.5%), and only a few in the city (11.9%). Most people had access to transport-taxi (94.7%), and bus (90%). Many had access to trains (69%).
  - In general, most people liked where they lived and they said that they liked where they lived when it was a nice house or flat and when it was near things that were important to them, or when they could be independent, had privacy, and they liked the people they lived with.
  - Only half of the people chose where they lived and more than half did not choose who they lived with.
  - About half of the people (48.8%) said that they would change things about their homes including wanting their own homes, their own rooms, or changing room or house. Some people had problems with their landlords/landladies and neighbours, some people said they wanted to

change who they lived with. A few people wanted to do more around their home and have their houses kept better.

- *Examples of what people said:*
  - *I would like to live in my own house*
  - *I'd like a new house. I would like to move, live with girls.*
  - *Its too quiet. I would like to do more things.*
  - *Landlord should look after the house more*
  
- Only a few (16.2%) said that they would change something about the people they live with including having more choice about who they live with and the independence they had. Finally, some people (34.1%) said that they would change things about the support they get.
- As a final reflection on independent living, the group who were involved in analyzing the results said that there is lack of services for individuals to seek independent living including resources, funding, and money. In addition, individual needs have to be considered and that there are few choices for people. The group said that some people would like more choice about where they live and who they live with. Some of the group felt that attitudes should change for families to allow their family member to be more independent. The group concluded that supports need to be in place so that it is less frightening for people to be independent and that they don't have enough forums to be heard.

**The Inclusive Research Network would like to thank all those people who took part in the study.**

## **RESEARCH ON: WHERE WE LIVE**

By: Pauline O'Meara and Michael Freiberg Co-researchers on the 'where we live project'

We did a piece of research as part of the Inclusive Research Network. The Inclusion Research Network is looking at how people with disabilities can do research about issues that are important to them.

We need to do research about where people live because it will tell us what people like and don't like about where they live, and how people can live in a place of their choice.

We interviewed some people from our community with intellectual disabilities. We explained that the Research was about living options and that peoples ideas are important. We would be asking questions about living situations. The answers would be kept confidential and private. People could stop at any time. When they understood this we asked them to sign a consent form. One of us asked questions about where they lived using pictures and the other one recorded the answers. At the end of the questions we asked the person if there is anything else they would like to add. Then we said Thank you. We met with other researchers from the Inclusive Research Net-work in NIID at Trinity College to analyse the nation survey. The results were presented to the National Disability Authority Conference on the 6thOctober2009.



*Co-researchers Sarah Flynn, Simon Buggy, Edurne Garcia (supporter), Michael Freiberg and Pauline O'Meara at the NDA conference in October 2009*

**Appendix 4: Workshop Evaluation Form for IRN Members**

**How was the day? Galway November 17<sup>th</sup> 2008**



**Tell us what you think...  
Please take a few minutes to fill out this form.  
Circle the best emotion.  
This will help us to do better when we run the next workshop  
Thank you!**

**Q1: How did you find the session about;**

**(a) What have we been doing?**

**Introduction: Renewing Friendships ... warming up**



**EXCELLENT**



**GOOD**



**FAIR**

**POOR**

**(b) Session 1: Consultation Focus Groups**



**EXCELLENT**



**GOOD**



**FAIR**



**POOR**

**(c) Session 2: Interviewing People**



**EXCELLENT**



**GOOD**



**FAIR**



**POOR**

**(d) Session 3: Research into Action**



**EXCELLENT**



**GOOD**



**FAIR**



**POOR**

**(e) Session 4: Life Stories**



**EXCELLENT**



**GOOD**



**FAIR**

**POOR**

**(f) Session 5: Doing a Survey**



**EXCELLENT**



**GOOD**



**FAIR**

**POOR**

**(g) Ethics – What is it all about?**



**EXCELLENT**

**GOOD**

**FAIR**

**POOR**

**Q2: What did you think of the venue?**



**EXCELLENT**



**GOOD**



**FAIR**



**POOR**

**Q3: What did you think of the time of the workshop?**



**EXCELLENT**



**GOOD**



**FAIR**



**POOR**

**Q4: Did you enjoy the workshop overall?**



**EXCELLENT**



**GOOD**



**FAIR**



**POOR**

**Q5: Is there anything else you want to say?**

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## **Appendix 5: Presenters at the IRN Workshops**

The Inclusive Research Network would like to thank all presenters who came to the workshops and presented free of charge!

**Edel Tierney**

**Stephen Curtis**

**Patricia O'Brien**

**Ray Murray**

**Mary Gavin**

**Aine Kerr**

**Bernadette Casey**

**Mary Lannon**

**Mary Lucey**

**Breda Casey**

**Brian Donohue**

**Roy McConkey**

**Hasheem Mannan**

**Carol Hamilton and Zoe Hughes**

**Josephine Flaherty & BOC Galway Team, Marie Wolfe, Martin**

**Dooher, Paul Dunne, Vanessa Delle-Vedove, Ann Mahon, Geraldine**

**Bane, Pdraic McDonagh**

**John Doyle**

**Edurne Garcia Iriarte**

**Darren Chadwick**











