

# **Inclusive Research in County Clare, Ireland: 'No longer researching about us without us'**

## **Report of Evaluation Visit, March 12<sup>th</sup> 2009**

This Report was written following an evaluation visit to The Brothers of Charity Services in Ennis, County Clare, on March 12<sup>th</sup> 2009. The Visit was hosted by Rob Hopkins, Inclusive Research Officer.

The visit comprised:

- Visit to Training Centre, Kilrush, County Clare
- Attendance at researchers' networking lunch
- Attendance at Presentation of Research findings, Kilrush
- Interview with Journalist

Its purpose was to assess the impact of inclusive research in Clare on giving people who use Brothers of Charity Services:

- New skills and information
- New friends and contacts
- The chance to speak up about what matters to them, and to learn about what matters to other people
- And, sometimes, more power, for example to undertake campaigns and make changes in their lives.

## **Background to Inclusive Research: Researching Together**

Researching Together was developed by Kelley Johnson, Visiting Marie Curie Research Fellow, NIID, Trinity College, Dublin 2006/7 to be used with groups of people with learning difficulties working with supporters who are interested in knowing more about research, and how they might use research to improve their and other people's lives.

### *The Aims of researching Together are to:*

Help people to identify why research is important to them

How research can be used to improve their lives

Encourage people to become researchers, and

Help people undertake projects which are important to them.

If researching together is a success people with intellectual disabilities who take part will have

- New skills and information
- New friends and contacts

- The chance to speak up about what matters to them, and to learn about what matters to other people
- And, sometimes, more power, for example to undertake campaigns and make changes in their lives.

Working alongside people with learning difficulties as they learn about research can give staff and supporters:

- Greater insight into what matters to the people they work with
- New ideas about projects and activities they can undertake with service users
- Information about what happens in other service settings
- Skills in supporting self advocacy and person centred planning
  - And add to the quality of the research that is done.

## **Inclusive Research in County Clare**

The Brothers of Charity who provide services in County Clare, Ireland, chose to use Researching Together to embed inclusive research following a visit by KJ in 2007. At this time, the service has been committed to a programme of resettlement from group homes to smaller units of accommodation, to give people their own home, and to maximize their independence. Researching Together has accompanied this process

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- To show how people can have more control over their own lives
- To ensure that people have the power to make changes.
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There have been two phases of research teams at work in County Clare. The first phase was inaugurated by Kelley Johnson and led to a group being set up to work in East Clare and Ennis. The core group of people were:

Gerard (Ger) Minogue Jo Rynne Lance Cooney Pamela Luque, Patrick (Sonny) Kearney, Joe McGrath.

However a number of other people were involved in different parts of the projects including doing interviews, sharing life stories and taking photographs.

The group raised a number of issues that they were interested to explore through research including:

- Housing
- Bullying
- Evaluating Joe and Bryan's coffee shop
- Recording the work done in the garden attached to the training centre in Ennis.

The bullying issue was raised with the national advisory group for Kelley's project which met in Dublin and which included Ger Minogue and Pamela Luque (as support person). The national advisory group established an anti bullying working group and has since run a number of very successful workshops around Ireland on bullying.

The group in Clare decided to work on two projects:

- **Coffee Shop**-The research group worked to look at the place of the coffee shop in the small town in which it was located. They developed questions for a questionnaire for the customers, did some observation in the coffee shop, interviewed staff and customers and took photographs of the coffee shop and the town.

A poster presentation was later made the NNDR conference in Sweden which won the conference competition for posters. Joe McGrath presented at both national and international conferences on the project.

- **The Garden Story** preserving the memory of a Garden where people had worked in words and pictures. The Garden story involved those people who had worked in the garden or had used it for recreation. Old documents and photos were found which showed the beginnings of the garden, a group of people used cameras and interviews to document how people saw their work and the place of the garden at the training centre. The document ended with a plea for the garden to be retained after the training centre closed.

Ger Minogue presented this work and the other projects developed the Clare research group in Cape Town South Africa in 2008.

In addition to these projects a life history was developed with Patrick Kearney and this has since been published by the Brothers of Charity.

## Lance Cooney's Story 'I'll come back here again'



*Lance in the garden*

I was one of the very first ones here when they first built [the workshop]. None of you were around that time. I think none of you existed that time. Another thing, Danny Montgomery is my best friend. He is the very first one I met here. And Mark White. Ger Doohan, Martin O'Connell. All the others. There was a lot of us. [Now] most of the fella's

have left.

In Clare, inclusive research is a tool to foster empowerment. In the second phase of the research following the appointment of Rob Hopkins to the newly created post of Research and Communications Officer to the Clare Brothers of Charity staff team, The Clare Inclusive Research Group developed from the work and ethos of Kelley Johnson's work to pursue ~~has produced~~ three main areas of enquiry-

- Researching the Travel Challenge
- Researching Relationships
- A Place of My Own – Living Independently

Marie (Helena) took on the travel challenge. She researched into a journey to a hotel, and then did the trip with friends and a staff member. She reported 'my first trip on public transport since 1992, 17 years. My parents didn't think it was doable enough for me, and I didn't think it was either'

'It was great'.

The Inclusive Research Group use drama, power point presentations, documentary films and a news letter to present their research findings:



*Marie (Helena) presents findings to an audience of fellow students, families and staff, Kilrush, March 13<sup>th</sup> 2009*

The differences between travel training, familiar in services, and researching one's own travel needs may be semantic, but they are also significant. Travel training implies the role of a recipient of information, a student role, all too familiar to people with intellectual disabilities, and to staff. A researcher is an active role, defining one's own travel needs, and gaining the wherewithal to pursue them. Also, make some mistakes on the way .... And learn from them.

Possibly equally important was the response of the worker who supported this adventure- 'it is the first time I have ever done anything like this. It's been great for the lads clients, it's been great for me too. It's shown me a different way to work with people' (Personal communication 2009)

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Relationships

The Clare Group also presented..... 'you can its your choice' Kathleen Ryan

The Clare Research Group Researchers have used a range of methods to present their findings and promote their work:

#### Local Newspaper Features

- Clare Champion (Features on the Cape Town Congress – Sept 08 & Publicity Feature March 09)

#### National Radio:

- RTE Current Affairs Magazine Prog “Kenny Live” – Relationships and Sex Education (April 09)

#### Booklets:

- The Garden Story (2007)
- Brian and Joe’s Coffee Shop (2007)
- This Was My Life. I’m Here To Tell It. (To be Published July, 2009) An Individual Life Story

#### Newsletter:

- C.I.R.G 2008

#### Conferences:

- The IASSID International Congress, 2008, Cape Town, South Africa,
- Brothers of Charity National Advocacy Conference (Athlone) 2008,
- “One Person at a Time” (Clare Castle) Individualising Services National Conference

#### Networks:

- I.R.N. (Inclusive Research Network) Joint National Federation of Voluntary Bodies & Trinity College Sponsored training programme and affiliation of researchers
- I.S.E.N. (Irish Sex Education Network) Peer Support Group

#### Documentary Films:

- “A Place Of My Own” Video Presented by and featuring people with a learning disability moving into living arrangements of their own choosing
- Work in Progress – collaboration with Galway Film Maker Paddy O’Connor on project, covering the experience of three individuals doing research in Clare (due to screen June 2009)

#### Power Point Presentations with Drama

- “No Longer Research About Us Without Us” – Testimonies from the Research Group members, their roles and why the work is important to them, followed by two role plays
1. “No Kissing” (Relationship Research)
  2. “The Travel Challenge” (Access Research)

## Summary and Conclusions

If inclusive research is a success then local people with intellectual disabilities will have:

- New skills and information
- New friends and contacts
- The chance to speak up about what matters to them, and to learn about what matters to other people
- And, sometimes, more power, for example to undertake campaigns and make changes in their lives.

Overall, I found that the initiative has met its objectives, but that there remain challenges in some areas where progress requires more than enabling people to 'find a voice'.

### *New Skills and Information*

Undoubtedly it has contributed to people developing new skills-asking questions, gathering information, finding ways to share it

### *New Friends and Contacts*

Much of the research is undertaken with familiar people, staff and fellow service users. However, in sharing the results people have the opportunity to travel and meet others.

### *The chance to speak up about what really matters*

This has been achieved, although undoubtedly more can be done (and is being done). Relationships, travel, recording memories of places as they close, all these have been identified as important

### *More Power*

It is in this respect that less has been achieved to date. Where implementation is relatively straightforward (for example recording memories of The Garden), there has been significant change. However, researchers have put more controversial issues, such as relationships, firmly on the agenda. It is now up to services to consider how to respond. At a time of financial stringency this will be a challenge. However, following the round Presentations earlier in the year Brothers of Charity, Clare Directorate have agreed to the Researcher's request for a joint consultative structure made up of Learning Disabled Representative and Management to agree on future research projects and identify ways in which research might influence the way the service is delivered.

Members of the Research Team involved in Relationships Research are working together with other Learning Disabled members of the ISEN Peer Support Group to challenge current prohibitive legislation on relationships.

Professor Jan Walmsley

29<sup>th</sup> May 2009

### **Acknowledgments**

I would like to thank

Rob Hopkins and the Inclusive Researchers in Ennis and County Clare for a very warm welcome, and a memorable and inspiring visit

Kelley Johnson, friend and colleague, for blazing the trail

Trinity College Dublin for funding the evaluation