No Longer Research About Us Without Us



A summer of book signing and guest appearances gave Patrick

Kearney top spot on Clare Champion's none fiction Best Seller list five weeks on the trot, heading the poll through November and on into December. "This Was My Life: I'm Here To Tell It" has sold three times as many copies as an average best seller according to a spokesman for the Ennis Bookshop. Following its enthusiastic reception at the Open University Social History conference in July Patrick's book has gone on to be widely guoted in Singapore, Canada and the States. At the books official launch in November Patrick met up with old friends from Clare Hurling matches, including the present P.R.O. for Clare G.A.A., Des Crowe. Flautist and story teller Des Mulcaire was also on hand and remembered Patrick well, "He was a legend at those games. He had us in stitches with his touch line commentary."

National Voluntary Bodies **Director John O'Dea** reflects on inclusive research presentations at the Radisson Hotel in July

C.I.R.G. Clare Inclusive **Research Group** Banner House Clare Rd, Ennis County Clare. *clare.brothersofcharity.ie* I did not know what to expect on the day and arrived with an open mind. I was very pleased and impressed by the positive and active engagement of all present and the absence of any segregated or unequal or contrived situation. The sense of empowerment of those present was obvious and the whole process has obviously increased the confidence and self-value of those who attend.

The concept of Service Users as researchers of people's satisfaction with their own life situations and also that of their friends and the quality of the supports they receive from services is spot on in the current environment and thinking.

How better could it be done? I found it very real and humbling for all of us.

It puts out the boat of the advocacy debate also and I believe challenges traditional concepts in this area. It also demands progress on the inclusion of the Service Users in Governance area and promotes the concept of equal citizenship in a meaningful way.







Best Seller



Grace and Ger

Lights! Camera!

Action Theatre!

"Talk to Joe"

About Employment

In this Annual Review of 2009 we're reporting on a number of successful ventures during this second year, of the Clare **Inclusive Research** Group.

Our Dramas made a major impact opening the year with a research performance to the Clare **Relationship Rights** Brothers of Charity Directorate. We toured Clare, adding a new Drama "Leaving Home" to our repertoire. We went on to perform at the Irish Research Network's "Galway Gathering", Cois na dAbhna, Ennis and in Garrihy's Pub Moyasta in the build up to our most

Nora Fry Institute, Roisin Dermody, U.C.D. researchers Sharon Foley, One-2-One Solutions) and learning disability presenters (ourselves and the ISEN spokespeople). We were delighted with the impact of our interactive

Comments and Recommendations:

Following Kelley Johnson's work setting up an inclusive research model in Clare in 2006/7 Trinity College commissioned Open University academic Jan Walmesley to assess our progress. We publish

here some of her comments followed by her recommendations. She spent a day and a half with us in March this year and attended our film, drama and power point presentation in Kilrush.





high profile event of the year, the Pavilion International Sexual Rights and Intellectual Disability Conference in Dublin.

Co-ordinated by our research compatriot Grace Kelly, this was a crossstake-holder gathering of government advisers (Dr Rosarie McCarthy from N.D.A.), academics (David Abbot, Kelley Johnson,



Kathleen and Trish: celebrating our Cork presentation success.

drama format and topped the poll in the Conference evaluation feedback in terms of content and delivery. A month later we rounded off a year of dramatic performances at the Cork National Advocacy Conference gathering (Continued on page 3)

Jan Walmesley: Clare Research Report

"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 (Continued on page 3)



No Longer Research About Us Without Us



have a disability."

In what way? "In

the fact that people will see

ourselves"

prove an inspiration to the group, making

most recently the Western Region Autism

prominently in the public readings of the

Paddy Quinn, Kathleen

Patrick Kearney & the Book!

an impact through his presentations at

Training Group. His poetry has figured

'Three Legged Stool" poet's circle in

Autism Seminars around the country,

we can just be

Larry continues to

My tears are pouring out of me The sea of grief is deep How are we met in destiny You, me, our friends and hope

Jesters take the easy road Hoarders take the pain Gofers bear the fiddle Killers make the hell

Get me to Fair Erin It's where I must be Let me give my mind a rest Just so I can be well Larry O'Bryan



Pat Kenny signs up for Declan O'Dwyer

No Longer Research About Us Without Us



Its nice to have a job, and I'm aettina good wages but I still like to go to the workshop to meet a few friends

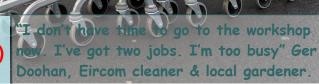


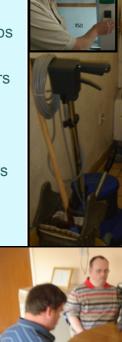
All We Want To Say 2009 **BECOMING** (All Ireland Research) A PAID EMPLOYEE

People said that they wanted to become paid employees. They said they liked:

- Getting well paid
- Getting support to get real jobs
- Friendly staff
- Getting to know the customers
- Making friends
- They said they didn't like:
- The level of pay
- Going for lots of job interviews and not getting any
- Feeling that employers don't want disabled people











6

7

0

11

12

Marie Deely in Cork

John Murphy with Joe Mc Grath

FORUM

BJLD

PAID

REPORT

Trinity "ALL WE

WANT TO SAY

EMPLOYMENT

CHAMPION

BOOKSELLER

THEATRE

Lynchs

I work 8-11 four days a week. I do the bailing of the boxes and plastics and sweep out the place clear out the shop, do the bins and wash the petrol pumps, pick up the papers and bring in the brickets to the shop. Kevin Lynch









I'm 5 years here, recycling, helping the customers. I love it -John Murphy

10

Inclusive Researchers in Action

Paid **Employment**

"Talk to Joe" **Mairead Moroney** talks to Joe McGrath about work

A Radio Programme "All We Want To Say About Employment" has been created of Clare Supported by Clare Inclusive Research Group to highlight the findings from the Trinity College "All We Want To Say" project . In it people talk of their experience of paid work. Four Ennis based people in open employment were interviewed by Joe McGrath with Ger Minogue and Rob Hopkins on sound and camera.

researchers take the lead He took a lead role deciding on the individual guestions and the priest newly returned from overall message of the programme. Joe has been in part time open employment for 8 years and has been supported you came to BOC. It's to manage his own business "Brian and Joe's Coffee Shop". He felt it was important to help people explain how they got their jobs, what support they received, what they did as



a result of earning their own money. He emphasised the role to pay my rent and helped in Employment. Mairead Moroney circle of friends and have my agreed, "The biggest challenge own house" was working without support but Mary Rowan (a former manager) was great help. She by example Joe quizzed gave great training and looked out for work for me... encouraged by others who It means a lot for me to have a job. I meet friends and I get paid." She went on I felt I wanted to do that to outline her work history; her too." jobs in catering, and

Peru.

"You've done an amazing amount of jobs even before important for people like you to have meaningful employment"

motivation

Organisations can promote inclusion through employment,



"Paid employment has helped a big way to improve my

leadership

Keen to emphasise leadership Mairead. Did she feel already had jobs? "When I saw people working

employers praised

hospitality, house keeping for a He made the same point in relation to employing organisations. Talking with John Murphy, at the recycling centre, he commented

> " Clare County Council have treated you well. It's nice to see a body like that taking on people with disabilities and leading by example."

(Continued from page 1) 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 where withal to pursue them. Also, make 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, it's been great for me too. It's shown me a different way to work with people' **Summary and Conclusions** If inclusive research is a success then local people with intellectual disabilities will have: 1. New skills and information 2. New friends and contacts 3. The chance to speak up about

what matters to

matters to other

4. And, sometimes,

(Continued on page 8)

more power, for

about what

people

them, and to learn

Inclusive Researchers' Highlights

C.I.R.G. researchers spelt out their highlights of the past year in two recorded programs to mark United Nations World Disability Day on Dec 2nd for Community broadcasters, Raidio Corca Baiscinn . Ger MacMahon was a revelation in the drama, with genuine comic presence. "I enjoyed the Cork Conference and the "Make a Will" (Don't Leave A Mess) presentation" from the Cork Advocates. "I also loved the band, Red Alert at



... the CIRG Year in View

(Continued from page 1) plaudits for raising for the first time in Ireland amongst in the Clare Champion, featured on

people with a learning disability the difficult topic of the legal prohibition of sexual relations.

LIFE STORIES

Patrick Kearney took his book "This Is My Life I'm Here To Tell It" to the Open University in July in the U.K. and received acclaim from "Social History Conference" director, Dorothy Atkinson for "raising the bar in content and presentation" for books of this kind. He won over hearts and minds in Ennis,

John Cook's "Morning Focus" (on the day the of the book's official launch) and ended up on the best seller book list topping the Champion Sales Poll for "None Fiction" for five consecutive weeks throughout November to

No Longer Research About Us Without Us 3

the social. I don't think they were expecting it

when I got to the mike and belted out 'Ring Of Fire'!" Ger Minoque picked out our presentation at the Pavilion Relationships

there was to be a knock at the door but "no knock



Fair City's Vinny McCabe Ken and Declan

Conference. "I think Grace Kelly (who we first got to know at the Cape Town Conference in 2008) was a bit surprised with the presentation of flowers I made for all the great work she put in organizing the conference."

Kathleen Ryan grew in stature as an actress through the year, improvising to great effect. In the drama

came ... I had to bang my walking stick on the floor." She picked out meeting Pat Kenny in March as the highlight, "I could not believe it. My family heard me all over the country. Its our right to have relationships. I'm glad I said that."

Kenneth Meade and Declan O'Dwyer enjoyed being involved in our dramas and the appearance of Fair City

(Continued on page 5)

Moyasta and the aforementioned Cork Conference, head lined twice



Celebration: Patrick Kearney with Rob Hopkins and Ger Minogue

December 9th.

"ALL WE WANT TO SAY" We've also been proud to be associated with Trinity College's "All we Want To Say" All Ireland inclusive research project for people with a learning disability, the first of its kind.

Asking the basic question "What was life like for people with intellectual disabilities and what could be better?" key themes of Control, Choice and Support began to emerge. We're now at the "How We Want To Say It" phase, promoting three of the nine areas of action identified by the report.

(Continued on page 4)

No Longer Research About Us Without Us

No Longer Research About Us Without Us 4

Continued from page 3) THE YEAR IN VIEW.

Sections are highlighted in **red** throughout this review.

Ger Minogue conducted a workshop among researchers asking "What Is A Disability"?

Kathleen Ryan made an effective presentation introducing our Forum Theatre work along with her own testimony on the "All We Want Say" DVD.

And Joe McGrath fronted the "Paid Employment" section with a series of radio interviews with people in paid employment. This featured Kevin Lynch, Ger Doohan, John Murphy and Mairead Moroney employees supported by Ennis services.

Congratulations to all those involved.

A paper that caught my eye in a recent *Inclusion in Mainstream Community* Module I undertook (part of my Nora Fry Institute study) spoke of the danger of inclusive research being either *"professionally stage managed or"* veering towards trivia" (Riddell et al (1998) From emancipatory research to focus groups: people with learning difficulties and the research process, in P.CLOUGH & L. BARTON (Eds)

Articulating with Difficulty: research voices in inclusive education (London, Paul Chapman Publishing).

Jan Walmesley also spoke of the difficulty of Learning Disability participants "exercising decision making influence in the research process".

This is something we in the CIRG Group continue to struggle with. Who is saying what? Who is pleasing who? I feel the Forum 👋 Theatre work, which has given us a way of generating discussion between people with a learning disability (and other none

disabled participants) has given us a sense of genuine engagement, in situations where people are commonly felt to be easily led into agreeing with support staff or family members.

We look forward to 2010 with optimism and expectation. Helena Mac Inerney has suggested an access research project in Shannon. We are set to work through the Respond Family Resource Centre with other community groups, (a mother and toddler group, a physically disabled and active age group) to promote awareness and access in the area.

Finally I'd like to thank the Brothers of Charity Services in Clare for supporting our projects, both financially and with their help and interest in our work; in particular Shannon Services for their support in the person of the open, questioning and positive presence of Research Supporter Trish Dillon, but also through other members who've given of their time where more high support situations required it.

The work we do has the potential to affect the way services are provided to people with a learning disability; supporting people to find and express an effective voice. In the words of researcher, Larry O'Bryan, to "change the perception of people in services"

This "shift" was reflected by John O'Dea, (National Federation of Voluntary Bodies' Director at the Galway Gathering of Researchers in July. An excerpt of his letter can be found on the back page. Rob Hopkins, CIRG Coordinator

> *Footnote* Thanks to Nuala Coghlan for her input while she was in the group. She gave great assistance to us in talking up about relationships.

PRESS COVERAGE- Clare Inclusive Research Group have maintained positive press coverage through the year in the local press and on local, national and community radio. They also earned praise internationally through their conference



presentations. Kathleen Ryan and Ger Minogue ioined Inclusion



Ireland's Aine Ni Aileagain and parent Freda Findlay on a panel with Pat Kenny discussing sexuality and learning disability relationships on RTE's Kenny Live. As Kathleen pointed out, "people want the chance to live

Kathleen Ryan, Pat Kenny, Ger Minogue, Declan **O'Dwyer and Kenneth Meade**

RTE Studio One: I to r Trish Dillon, Rob Hopkins, together and get married like anyone else."



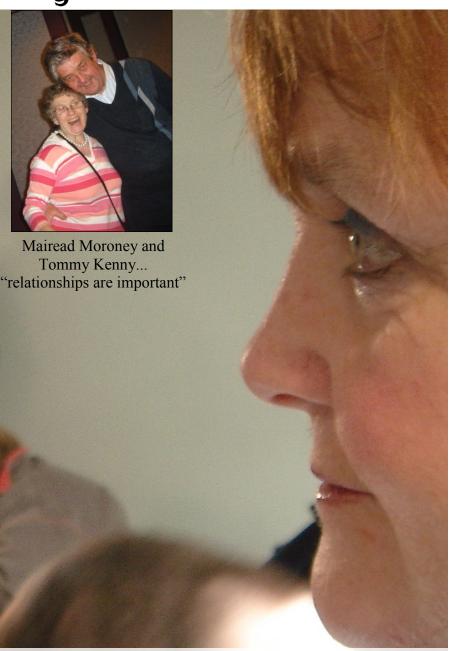
"Making Research Live!" (cont.)

program 'Kenny Live'. The following comments are from those who took part in the radio programme-It was great to meet the man (Pat Kenny). It was a challenge, (and) gave people lots of ideas. Lots of people with learning disability (can gain) confidence to talk to people like I was able to do on the interview we did, promoting inclusive research for people with a learning disability. There's still a lot of work to be done so that people can have more control over their lives. There's a lot of good research being done, but it has to be put into practice not just on paper, and actually see services changing. People in the research group were particularly concerned about Criminal Law (Sexual Offences) Act (1993) which makes it illegal for people with intellectual disabilities to have sex outside of marriage. They have commented: You see this is ... what the problem is. Can we talk to people about it? And ask people why? Is it because I'm Down syndrome no one's told me about this before? The last time we met with the Irish Sex Education Network. **** wanted to take his girlfriend out and not get into trouble.

People should be told about this law. We're leaving people vulnerable to breaking the law by mistake. **CONCLUSION**

Over its short life-time, the C.I.R.G has achieved not only the identification of a range of research topics, but also the dramatisation of its relationships and access research using the social action drama approach. The work of the group has received media attention, and two members represented the group on national radio. The group's membership are clear that much work remains to be done in terms of assuring the rights of people with intellectual disabilities, and their views concerning the importance of relationships are acknowledged, respected and reflected in the new legislation that is being proposed in the Irish Republic. Rob Hopkins

9



I.R.N. training in action.



Researchers, Ger Minogue, Kathleen Ryan, Marie Deeley, respond to questions from Gort's Anne Mahon, while supporter Geraldine Bane looks on

Clare Inclusive Research—Jan's Report



example to undertake campaigns and make changes in their lives. Overall, I found that the initiative has met its objectives, but that there consultative structure remain challenges in some areas where progress requires more than enabling people to 'find a voice'

More Power It is in this respect that less has been achieved to the service is delivered. date. Where implementation is relatively straight forward Team involved in (for example recording memories of The Garden), there has been significant change. However, researchers have put more controversial issues, such prohibitive legislation. as relationships, firmly on Jan Walmesley

to services to consider how to respond. At a time of financial stringency this will be a challenge. However, following the round of Presentations earlier in the year Brothers of Charity, Clare Directorate have agreed to the Researcher's request for a joint made up of Learning Disabled Representatives and Management to agree on future research projects and identify ways in which research might influence the way Joint Consultation

the agenda. It is now up

Members of the Research **Relationships Research** are working together with other Learning Disabled members of the ISEN Peer Support Group to challenge current

The C.I.R.G. Research Action Plan 2010 made in consultation with the joint Advisory Group uses the four criteria Jan identifies as a strategic framework. View it on brothersofcharityclare.ie/inclusiveresearch

"Making Research Live!"

(Continued from page 6)

Irish Sex Education Network to Government advisers; disabilities specific centres; open public performances in village pub function rooms and traditional culture venues. Our most recent experience came at an international conference sponsored by Pavilion, 'Sexual rights and Intellectual Disability' to families, health care professionals, legislators and people with intellectual disabilities, in Dublin. This then in their own words is the experience of the relationship researchers and the work they've been doing, taken from live recordings I made, and an interview with an intellectual disabilities magazine program 'Now We're Talking' on Raidió Corca Baiscinn, the West Clare Community Station.

The group's presentations have generated a series of local press stories and attracted national media attention. Two of the researchers were asked to take part in a discussion on Sexuality and Learning Disability on national radio for R.T.E.'s flag-ship magazine

All We Want To Say 2009 (All Ireland Research) BECOMING A PARTNER IN RELATIONSHIPS

People with intellectual disabilities said that they wanted to become partners in relationships.

People said that:

•Most people saw themselves as single •Some people hoped for a relationship in the future while some people said they were OK the way they were •Having a relationship must be the person's own choice •It's better to start small and get to know the person before seeing them as boyfriend/girlfriend

No Longer Research About Us Without Us

All We Want To Say Inclusive Researchers' Highlights continued... **2009** (All Ireland Research)

BECOMING A GOOD COMMUNICATOR

People with intellectual disabilities said that they wanted to become good

- communicators.
- They said they wanted to:
- Explain what disability is
- Be good listeners
- Have good verbal
- conversational skills • Have support to explain

things

Ger Minogue followed up his outstanding presentation in Cape Town's IASSID Congress, and responded to Professor Roy McConkey's invitation to demonstrate the "Good



(Continued from page 3)

Actor Vinny McCabe at the Pavilion Conference during the "Leaving Home" role play.

Both men spoke of their visit to the RTE studios during the Pat Kenny broadcast, where the group met a host of TV personalities. Colm Murray (inset with Kathleen Ryan above) the sports broadcaster, echoed many others on the day, amazed that

Communicator" section. He conducted a discussion "What is a Disability?" amongst the researchers and has grown in confidence and stature as chief presenter for the group.

Inclusive Research **Network Training**

Joint Inclusive Research training from Voluntary Bodies' Research coordinator Edel Tierney and Trinity College's Steve Curtis and Prof Patricia O'Brien (pictured middle and right above) led up to "The Galway Gathering" a series of presentations which drew a positive response from N.V.B. director, John O'Dea (see back page)



sexual relations were barred to people with a leaning disability in Ireland.

Kathleen O'Leary's



highlight came when Clare People feature writer Claire Gallagher (inset) interviewed her at her

Kilrush apartment about her work as a researcher. Claire

recognized Kathleen from a campaign she

waged for a road crossing. Finally two members looked to the future with Marie Deeley speaking of her new Tidy Town's community job, soon to feature in our "Employment Research 2010" Program and Helena MacInerny who outlined her Shannon Access Research idea involving the "Respond" Family Resource Centre and other "access challenged" groups, mothers and toddlers & the physically disabled.





Forum Theatre ...discussion through role play

We've been using social dramatist, Augusto Boal's, interactive Forum Theatre. It gives audiences chance to step into the role play, suggest

ways of tackling difficult issues. The drama, "Leaving Home" came from discussions at the Dublin peer support group. People had experienced difficulties with over protective parents & social workers. They were worried about where they stood regarding the law...



"Mum, I love you, but I want to live with my girl"

"Just because I've got a disability doesn't mean I don't have feelings and I

See if he's fit for the job."

"In the eyes of God we're not criminals. We're



people with a earning disability. We want to get nto relationships, not go to gaol."



"I did a personal development course. I'm ready to have a relationship"



"Give us a chance Mrs Sullivan."

Fair City's Vinny McCabe and Clare Mayor Tony I've a got a learning disability?" Mulcahy joined in.

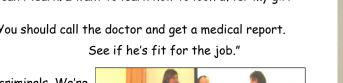
Critical Acclaim

"... an amazing drama ... which highlighted the problems facing people... when they want to leave home and ... have a relationship." I.R.N. Website 'Forum Theatre should be further explored ... this was really powerful.' Pavilion Relationship Conference, (evaluation summary extracts) C.I.R.G. topped the conference evaluation poll





can't learn. I want to learn how to look after my girl"





The October 2009 edition of the BJLD carries a special feature on Inclusive Research in Ireland. It carries the following article on C.I.R.G. **INTRODUCTION**

C.I.R.G. (Clare Inclusive Research Group) started up in March 2008 with the appointment of a Research and Communications Officer for the Clare region of Brothers of Charity, Ireland: the largest single provider of intellectual disabilities support in the Republic of Ireland. In order to identify issues that they wanted to research the group had a series of 'thinking together' meetings with the focus of 'what matters to you'. This paper describes some of the work that the group has done over the past twelve months. Each section includes comments from group members. Relationships was identified as one of their main areas of investigation, alongside Homes and Housing ('A Place of My Own'), Transport and Holiday Breaks ('The Travel Challenge') and Personal Social Histories ('Life Story Work'). **RELATIONSHIPS**

I want to have my own life and for the other people and for the disability people as well.

It's not easy for me to get married or the other people. But if they want to get married they can. It's very important for everybody and myself to have a good relationship. In the new future we hope we'll keep it up ... for the rest of our lives. People want to find out more about marriage, living together, having their own homes. It's their choice but I wouldn't move in ... to the same room unless I was married.

This is important for me because we're learning (about) talking about relationships, talking about friendship, boyfriend, girlfriends... We made up a story out of everything everybody said (from the Irish Sex Education peer support group)



Communicating though drama with Family, Friends, Service Providers and Government Decision Makers



Dublin Community TV Filming "All We Want To Say" Research at N.I.I.D.

Some members conducted a focus group on relationships with the rest of the group and went on to collaborate, as respondents and co-facilitators, with a national inclusive research project 'All We Want To Say' coordinated by The National Institute for Intellectual Disability (NIID) at Trinity College. The Relationship Research was transformed into a drama by the group's membership. This dramatisation of the research came about through a number of factors. The interest and experience of members using drama to tell stories; several of the group had worked before on films and role plays. Also as coordinator, I was mindful, through my own training as post graduate distance learning student on the Bristol University Nora Fry Institute M. Sc course in Inclusive Research, to make our process as engaging and accessible as possible. C.I.R.G. have performed three dramas to date; two about relationships 'No Kissing' and 'Leaving Home', and one on access and hotels 'The Travel Challenge' to a broad spectrum of audiences. Performances have taken place at the peer support group of the



(Continued on Page 8)