NATIONAL INSTITUTE FOR INTELLECTUAL DISABILITY:

DOING DISABILITY RESEARCH

A place where people with intellectual disabilities, families, academics, professionals and service providers come together to promote full inclusion through education, research and advocacy.

ADVISORY COMMITTEE

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Dr. Nick Blitz - Camphill Communities of Ireland
Lizzie Breen - Moore Abbey
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Dr. Hasheem Mannan – NIID, TCD
Dr. Bob McCormack - Dara Services
Joe McGrath - Brothers of Charity, Ennis
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Dr. Patricia O'Brien – NIID, TCD
Molly O'Keeffe – NIID, TCD
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Karina Wallis - Moore Abbey
Professor Patricia Noonan Walsh – Centre for Disability Studies, UCD Ireland
Dr. Jan Walmsley – Disability Consultant, UK
Derek Watson – SOS Kilkenny
Marie Wolfe - Brothers of Charity, Galway

RESEARCH TEAM

Principal Investigator: Dr. Patricia O'Brien, Project Coordinator
Research Advisors: Professor Roy McConkey, Institute of Nursing Research, University of Ulster
Dr. Philip Curtis, School of Social Work and Social Policy, TCD

Marie Curie Post Doctoral Fellows:

2007- 2009	**2009- 2011**
Dr. Carol Hamilton, Coordinator, Story to Tell Project Stage 1	Dr. Darren Chadwick
Dr. Hasheem Mannan, Coordinator, Family Study Stage 1	Dr. Edurne Garcia Iriarte

Visiting Marie Curie Research Fellows for periods up to 6 months 2007- 2011

Professor Dorothy Atkinson, Open University, UK	Professor Barrie O'Connor, Griffith University, Australia
Deborah Espiner, University of Auckland, New Zealand	
Professor Tom Keating, Latrobe University, Victoria, Australia	Dr. Jan Walmsley, Disability Consultant, UK
Professor Roy McConkey, Institute of Nursing Research, University of Ulster	

Researchers

Zoë Hughes, IRCHSS PhD Scholar, A Story to Tell Project Coordinator Stage 1 (from Jan-2009)
Grace Kelly, Research Assistant, A Story to Tell Project, PhD Candidate UCC
Mary McNamee, Summer Research Intern, All We Want to Say Project 2008
Leah Quinlivan, Summer Research Intern, All We Want to Say Project 2008

Research Administrators: Stephen Curtis (2007- 2008) and Sarah Jones (from 2008)

BACKGROUND TO THE DOING DISABILITY RESEARCH PROJECT

In 2004, the National Institute for Intellectual Disability was launched with the mission of Inclusion through Education, Research and Advocacy.

In relation to research, it was important that an inclusive approach be taken where people with intellectual disabilities and their families were involved in all stages of the research project.

The Doing Disability Research project has provided such an opportunity where people with the lived experience of disability have ownership over the project through being involved in:

- an advisory committee;
- framing the research questions;
- collecting data, discussing, and disseminating the findings.

The European Union (EU) through a Marie Curie initiative has funded the project for four years in which four post doctoral fellows, and five visiting international researchers have joined the National Institute for Intellectual Disability (NIID) in working collaboratively with self advocates and family members to research:

What life is like for people with intellectual disabilities and their families in Ireland?

The overall project is aimed at building links within an Irish context between research, policy, and practice through the following projects:

- A Story to Tell: A Life Story project

- All We Want to Say: A National survey of people with Intellectual Disabilities

- A National survey of family members with a son or daughter with intellectual disabilities

ALL WE WANT TO SAY:

A NATIONAL SURVEY OF PEOPLE WITH INTELLECTUAL DISABILITIES

Why?

To find out what life is like for people with intellectual disabilities in Ireland.
To ensure that people with intellectual disabilities have an active voice in determining how they live their lives.

How?

▪ A core group of people with intellectual disabilities joined a NIID research advisory committee.

▪ The group decided on a set of questions about *What was life like in Ireland for people with intellectual disabilities* and what could be better.

▪ The core group with NIID researchers hosted a training day for people with intellectual disabilities on co-facilitating focus groups.

▪ People with intellectual disabilities co-facilitated 16 focus groups in the Republic and 7 in Northern Ireland.

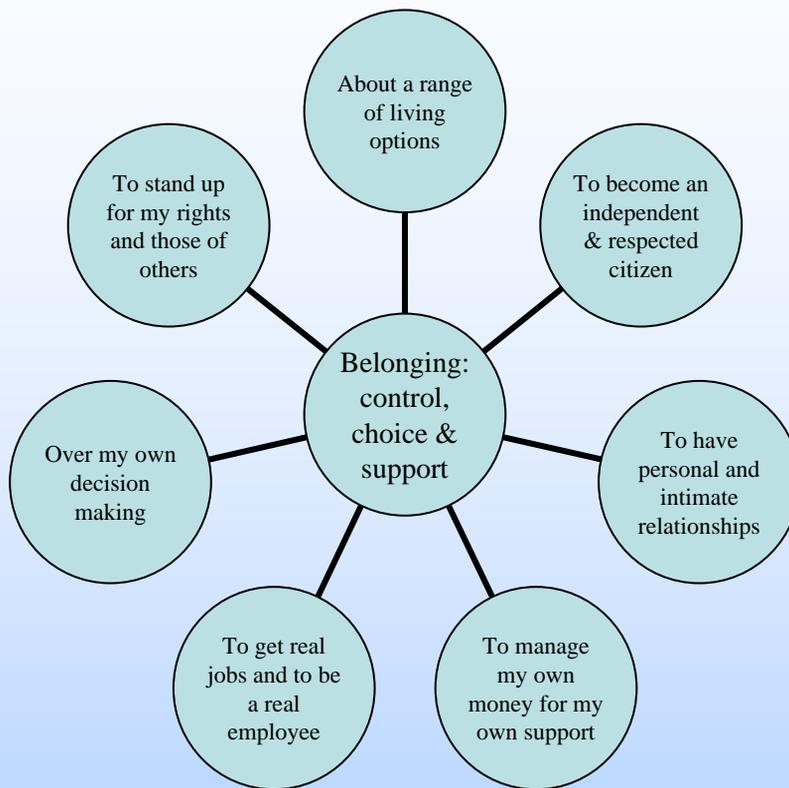▪ Facilitators of focus groups and NIID researchers identified and validated what people said in the focus groups.

So far- Emerging Themes
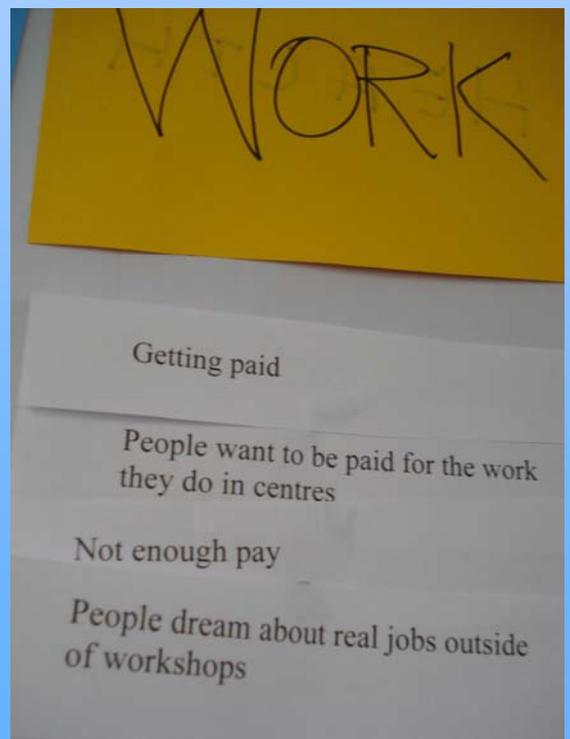

Across the country people talked about:
▪ How things could be different but how they, themselves, were no different.
▪ How they, like everyone else, needed to *belong through being…*
- … a paid employee
- … a decision maker
- … a self advocate
- … a partner in a relationship
- … a house owner, flat mate
- … a respected citizen
- … a money manager
- … a good communicator

People with intellectual disabilities were looking to a different future, a future where they could come in from the *outside* to take control and have choice over their own destinies so that they did not exist in two different worlds: the service world and that of the community, but rather their own world.

About a range of living options

To stand up for my rights and those of others

To become an independent & respected citizen

Belonging: control, choice & support

Over my own decision making

To have personal and intimate relationships

To get real jobs and to be a real employee

To manage my own money for my own support

What next?

▪The research team is planning to:
  ▪ Create a presentation to communicate these findings to advocacy groups, government officials and service agencies throughout Ireland.
  ▪ Ask these groups for their opinions on how they think things can change.
  ▪ Release an accessible report for all stakeholders that:
      ▪ outlines how to promote change for the better for people with intellectual disabilities.

WORK

Getting paid

People want to be paid for the work they do in centres

Not enough pay

People dream about real jobs outside of workshops

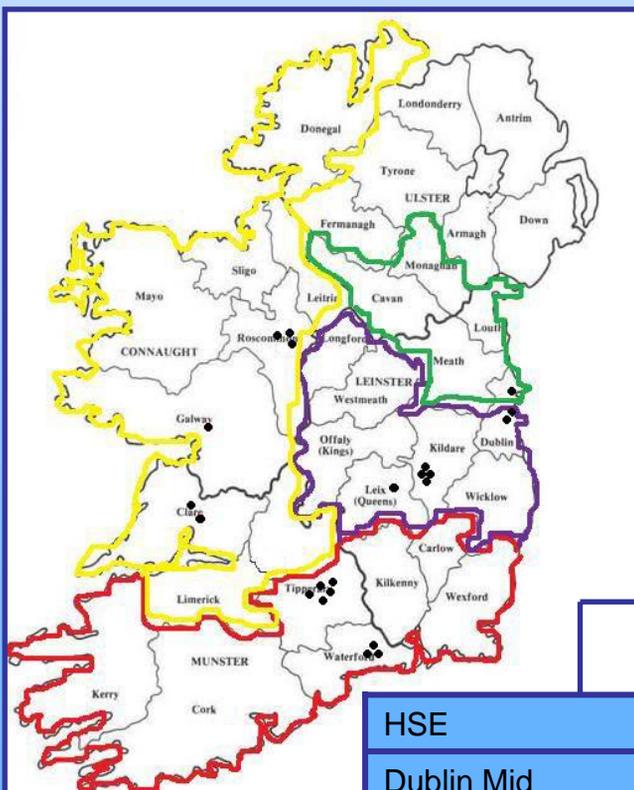# "A Story to Tell"- Lifestories of Older People with Intellectual Disabilities in Ireland

Why?

▪ Storytelling is a very important part of Irish history and culture. People identify with other people through the telling and hearing of stories that share commonalities, but also share differences.
▪ People with disabilities often have their stories told for them by other people- staff, family members and researchers.
▪ These stories are a source of great learning for frontline staff, researchers, people with disabilities and members of the general public. They are adding to the knowledge of Irish social history, and also to the history of people with intellectual disabilities in Ireland.

What?

▪ Support older people with intellectual disabilities to tell their life-stories.
▪ Develop a website to house these stories so they become a valuable social record of Irish history that is accessible to other people with intellectual disabilities, family members and supporters and members of the wider community.

How?

▪ We approached service providers and people with intellectual disabilities and made presentations on the project.
▪ Researchers talked to people about the issues, both the positive and negative around telling their story.
▪ People chose the sequence and the content of their stories.
▪ To finish the story took about 3 visits.
▪ The story was then made into a book, for the individual's own use, and in some cases into an audio or video record, for inclusion on the website/archive.

▪ We have worked with 22 people to help them tell their life story.
▪ These storytellers are spread over the four Health Service Executive (HSE) areas, from a mixture of service backgrounds.
▪ We are also working with over 10 services to support their service users and staff to undertake life story work.

HSE	
Dublin Mid Leinster	■ (dark blue)
Dublin North East	■ (green)
South	■ (red)
West	■ (yellow)

COUNTIES	STORIES •
DUBLIN	3
KILDARE	4
LAOIS	1
TIPPERARY	5
WATERFORD	3
ROSCOMMON	3
GALWAY	1
CLARE	2

So far- Emerging Themes

There are many themes that have emerged from the stories. A sample of these are below, using quotes from the stories that the storytellers have agreed to make available to the public.

Life in services

That was the sick ward. 'Take off your clothes', he said. 'I want you here for 3 nights only.' He told the lie. I'm still here.

I was talking to him, and he's from (county) now, and I said to him 'I'm never not to go home. I'd love to go home… pray for me, that was I'd go to it', I said.

Caring for others

My youngest brother was only 6 years of age when (my mother) died. I looked after him and I looked after the rest of the family. I got them out to school and got their dinners ready when they got home from school.

The rest of my brothers and sisters had all gone except me. I stopped back at my mothers'. I would never go away and leave her on her own.

Work

It wasn't like where you go to a job and work and get paid by the hour you know? It was like they made allowances for you being there.

Growing up in Ireland

We had cows and calves… the haymaking… bringing it on with the donkey and cart.

I made home-made bread over a baker on a hearth fire. The baker was hanging on a crook, with the lid of the baker to take the bread.

Words of wisdom

The staff are telling me to talk to them. But how can I talk when I don't know what to say?

I am happy… there's enough nonsense going on in the world!

National Family Study: A Participatory Action Research (PAR) Initiative involving family members of people with intellectual disabilities in Ireland
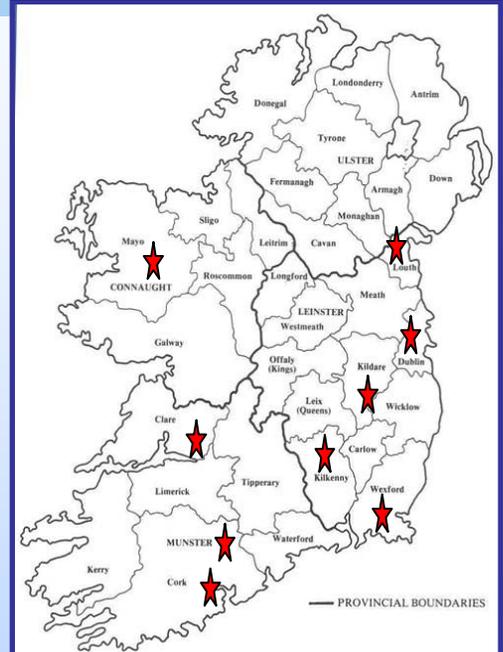
Why?

▪ To know what life is like for families of persons with intellectual disabilities.

▪ To enable human services to move *from giving service,* to *being of service to* families and persons with intellectual disabilities.

What?

▪ Documentation of what life is like for families across the life span.
▪ Recruitment and training of family members to be co-researchers.
  ▪ Collaborative process
  ▪ Filling the gap between researchers and people with intellectual disabilities and their families

How?

▪ 70 family members took part in focus groups.
▪ 44 family members participated in training workshops on how to facilitate a focus group as co-researchers.
▪ Four mothers and one father co-facilitated seven focus groups with NIID researchers

★	FOCUS GROUPS WERE HELD IN THE FOLLOWING CITIES & TOWNS:	
	Charleville	Ennis
	Clonakilty	Kildare
	Drogheda	Kilkenny
	Dublin	Rosslare
		Westport

So far- Emerging Themes

Family life is GOOD when:

▪ The family member with intellectual disabilities is in good health.
▪ There are opportunities for the family member to develop friendships and relationships.
▪ There is adequate support and intervention for the family member with challenging behaviours.
▪ The family member is achieving the best in life.

> We have just been a very fortunate family that his health is good. So we're blessed and fortunate (…).

> I felt it was important for her (daughter) to have friends with Down Syndrome as well.

But… family life is NOT SO GOOD when:

▪ Service providers and the wider community have negative attitudes, perceptions, and beliefs about disability.
▪ Families have negative experiences with service providers and service systems.
　▪ There is lack of adequate supports:
　　• Lack of information on entitlements.
　　• Inappropriate service settings.
　　• Lack of respite care.
　　• Reliance solely on informal parent networks having to continually advocate.

There is very little difference between children with learning disabilities, all children are the same. It's only as they become adults there is this huge difference

The biggest difficulty is the fact that you are thrown into this system when your child is born and nothing prepares you for the system (…).

Call for action in their words

Your time is taken up looking after the child and yet you have to go fight for every service you want.

2. Develop nationwide parent to parent networks

Down through the years I had the most extraordinary friends with people with disabilities and their families. They're absolutely marvellous.
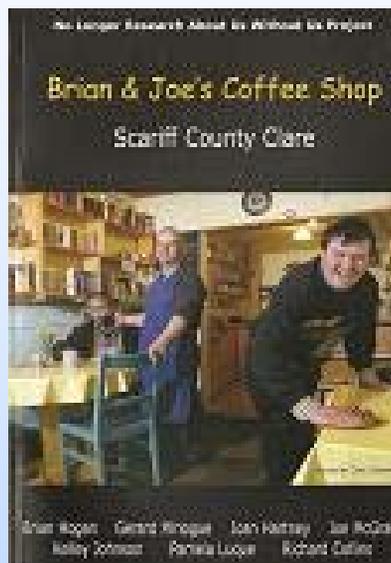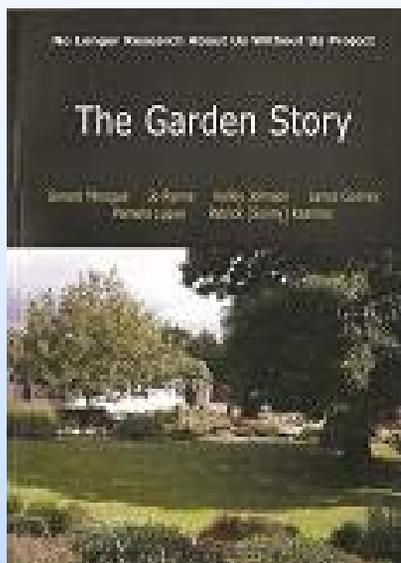
1. Empower parents to form reliable alliances with service professionals and service systems

You do just find it randomly you know … when under severe pressure ..you're told that you could have this or you could have that.

3. Streamline dissemination of information on entitlements

NIID RESEARCH DISSEMINATION

LIFESTORIES PROJECT

The Garden Story and **Brian and Joe's Coffee Shop** are available for purchase at €6 each or €10 for both from the Research Office, NIID.

The Anti-Bullying Group

People with intellectual disabilities talk about bullying behaviour

'RESPECT FOR ALL – THE WAY WE WORK'
"People feel listened to…it's user led. Disabled people helping as opposed to 'experts'. We provide a place for people to truly express themselves. A 'safe place' because the group is not attached to a service.

Anti-Bullying Group Wins Poster Prize at the IASSID World Congress in Cape Town

Announcing
A 3-Day Summer School
Inclusion through Education, Research and Advocacy

Hosted by

The National Institute for Intellectual Disability (NIID) & NIID Alumni

Trinity College Dublin

9.30am to 4.30pm, from Monday 27th to Wednesday 29th July 2009

Arts Building, Trinity College Dublin

Keep these dates free

The *Three Day Summer School* is aimed at providing a forum where issues of inclusion can be discussed, Â debated and experienced with the support of facilitators who are open to share their experience on:

professionals partnering with families

school based inclusion and transition strategies from school to community

early childhood intervention, specifically associated with social competence and literacy

expressive arts k

mass media k

sports activities k

The Summer School is a series of three day workshops. Participants will spend three days with the same facilitators to deepen their knowledge and skills in a particular area. Accommodation is available at Trinity College.

k Past and present students of the Certificate in Contemporary Living (CCL) would welcome community members to these workshops.

Facilitators of the 3 Day Workshops

Professors Rud and Ann Turnbull from the Beach Centre, University of Kansas, Laurence will describe how alliances between individuals with disabilities, their families, and their service providers can facilitate adult lives characterised by valued relationships, economic control over resources, and self-determination.

John Kubiak, NIID, Trinity College Dublin will present a variety of **workshops** on the **expressive arts.** k

Professor Mary Falvey and Dr Richard Rosenberg, California State University, Los Angeles will present on **school based inclusion** and **transition strategies.**

Niamh Lally, NIID, Trinity College Dublin will introduce participants to a range of **Gaelic sports activities.**

Professor Susan Ryan, University of Vermont will focus on early intervention as it relates to **social emotional competency** and **literacy** for children with developmental delays in the early years.
.
Irene Clark, Artist, Melbourne, Australia will provide **an introduction to portrait painting** and **other forms of expression in painting.**

Deborah Espiner, University of Auckland and Ray Murray, NIID, Trinity College Dublin will present on what constitutes **personalisation** and its implications for **person centred planning** and **practice.** Â A variety of planning strategies will be demonstrated.

Minerva Rivas, NIID, Trinity College Dublin will present on **how to communicate with the media** when **advocating for change.** k

The programme will be available in mid April with more information
Each day will begin with a plenary session from one of the International Presenters

Cost for the 3 day workshop is **E250.** Students or those in receipt of benefits /Disability Allowance is E**150**

For further information please contact: Ailish Kennedy, NIID. Ph: +353 (0)1 896 3885 or akenned@tcd.ie

AN INVITATION TO YOU

We would like YOU to participate in Inclusive Research.

If you would like to participate in any of the following activities with us,

- Being part of a focus group

- Attending discussion forums

- Giving your input on research results

- Drawing recommendations for the future

Please contact:
Sarah Jones, Research Administrator
National Institute for Intellectual Disability
Phone: 8962174
E-mail: sarah.jones@tcd.ie

For further information on any of these projects,

we invite you to visit our website:

www.tcd.ie/niid

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