



Inclusive research : An issue of ownership

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National Institute for Intellectual Disability

*Inclusion through
Education
Research
&
Advocacy*





Inclusive Research is where..

- People with the lived experience of disability have ownership over the research agenda through being involved in one or more of the following:
 - *Membership of an advisory committee;*
 - *Framing the research questions;*
 - *Collecting data;*
 - *Discussing and disseminating the findings.*



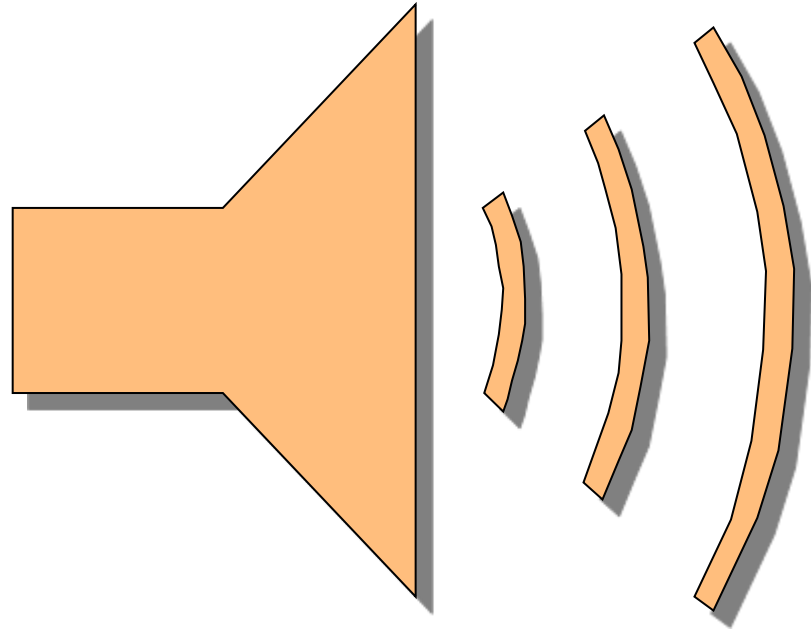


All we want to say

- Aim

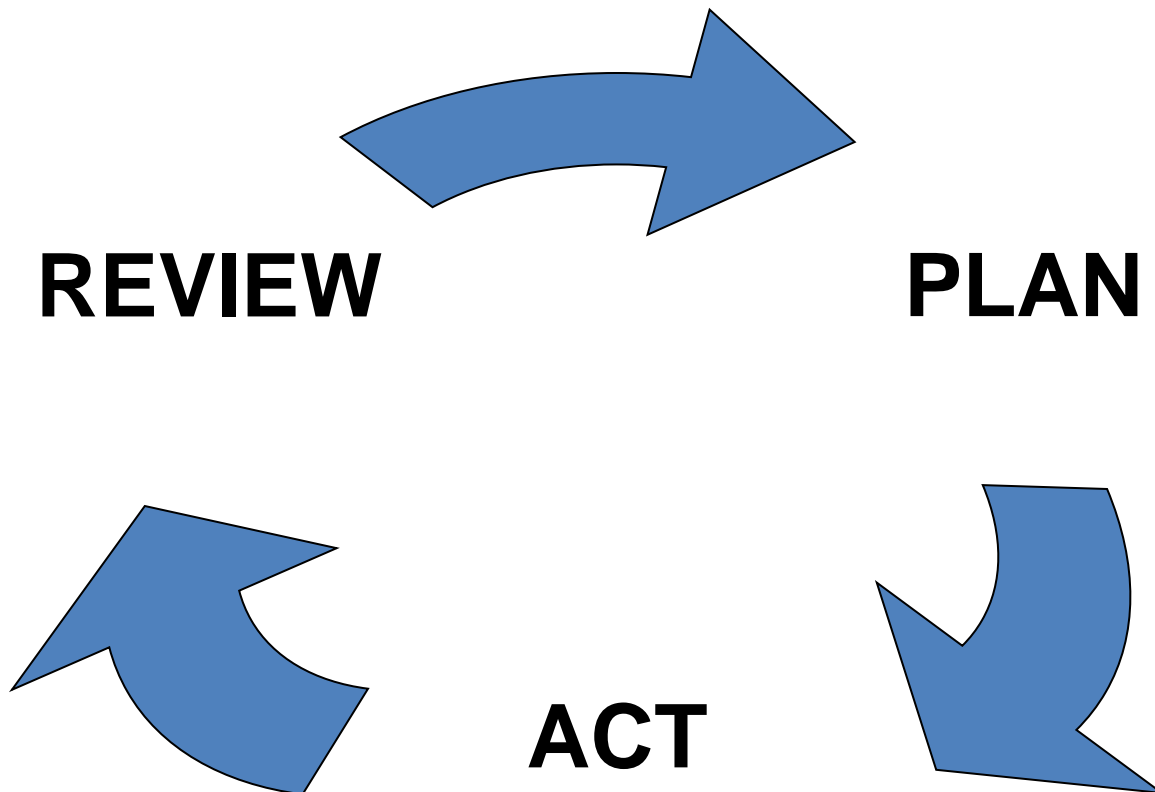
To find out what life was like for people with intellectual disabilities in Ireland

To ensure that people with intellectual disabilities had an active voice in the process of finding out





Action based





Stages of the project

- **Stage 1:** Inviting a core group of people with intellectual disabilities to join a NIID research advisory committee
- **Stage 2:** Working with the group to decide on a set of questions and pilot them
- **Stage 3:** Setting up a training session on how to facilitate a focus group for people with intellectual disabilities



Stages of the project

- **Stage 4:** Running the focus groups across multiple research hubs with people with intellectual disabilities as co-facilitators
- **Stage 5:** Working together to identify and validate what people said in the focus groups
- **Stage 6:** Deciding together where to go next



Questions

- Where and how people lived
- Where and how people worked
- Where and how people had friends
- Where and how people had relationships
- Where and how people gained an education
- Where and how people looked after their health
- Where and how people had a social life



Tell me about where you live ?



What do you like about where you live?





What don't you like about
where you live?



Is there anything you would
change about where you live?





Probes



Things that you do ?



Staff ? ----- staff that work there?



People you live with?



Friendships

- Who are your friends?



- Tell me about them?



- What do you like most about having friends?



- What things do you like doing together?



PROBES



Things that you
do ?



Staff? -----
spend time with
staff ?



Friends? -----
spend time with
friends





Focus groups	23 across All Ireland
Gender	82 women 83 men = 168 (3 missing)
Age	Majority between 30 – 49
Working situation	Majority day service /workshop Closely followed by part time employment
Self advocates	Over half involved in advocacy
Status	164 single
Living situation	Majority living in family home



Coding: Stage 1

- Two NIID researchers read all transcripts
- Coded same three into open codes for comparison
- One researcher then proceeded to manually open code verbal responses on side of transcript
- Two researchers then worked together to move all codes into categories



Coded thematically

- Where we live
- Money
- Fun and free time
- Staff
- Death and dying
- Education
- Health
- Families
- Adventure

- Holidays
- Boyfriends/girlfriend
- Freedom
- Communication
- Attitudes
- Looking out for others
- Friendship
- Advocacy and Rights
- Being wise



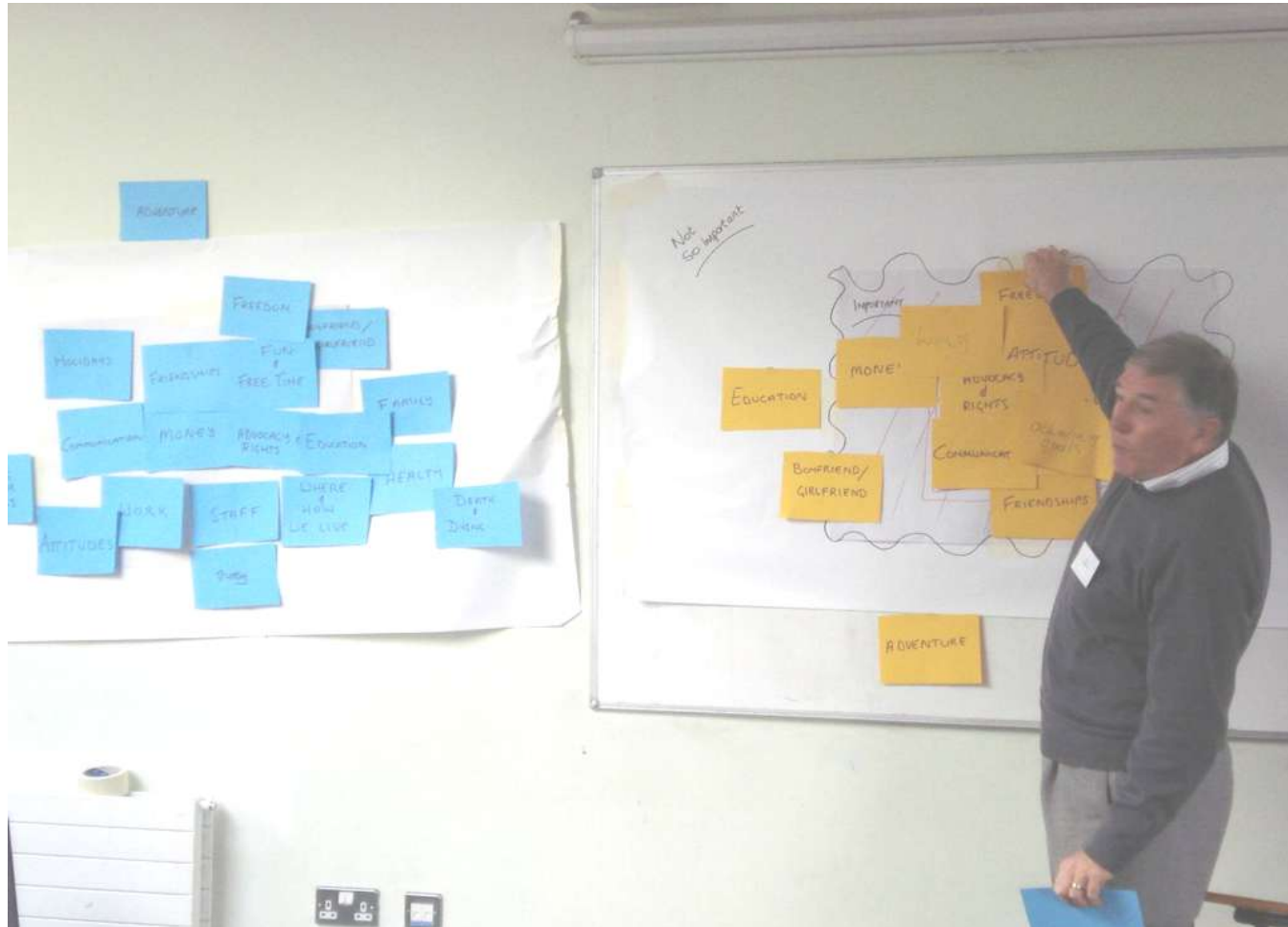
Coding: Stage 2

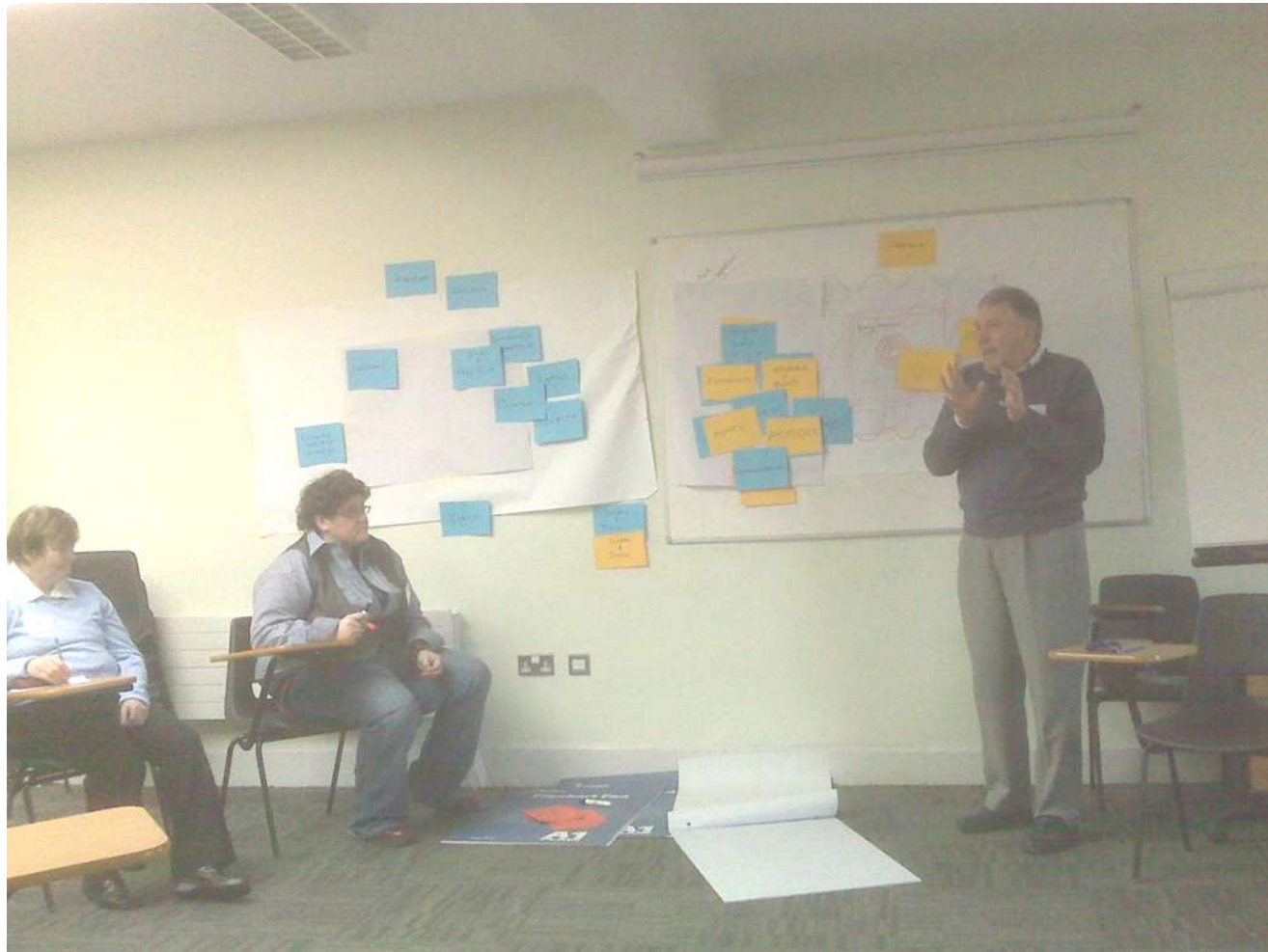
- Co researchers with intellectual disability invited to workshop to verify themes
- Two groups each given 19 themes on flip cards and one of NIID researchers discussed where the themes fitted
- Inner circle; middle circle; outer circle in terms of importance from what they had heard at the workshop they co-facilitated



Advocacy, Respect, Money



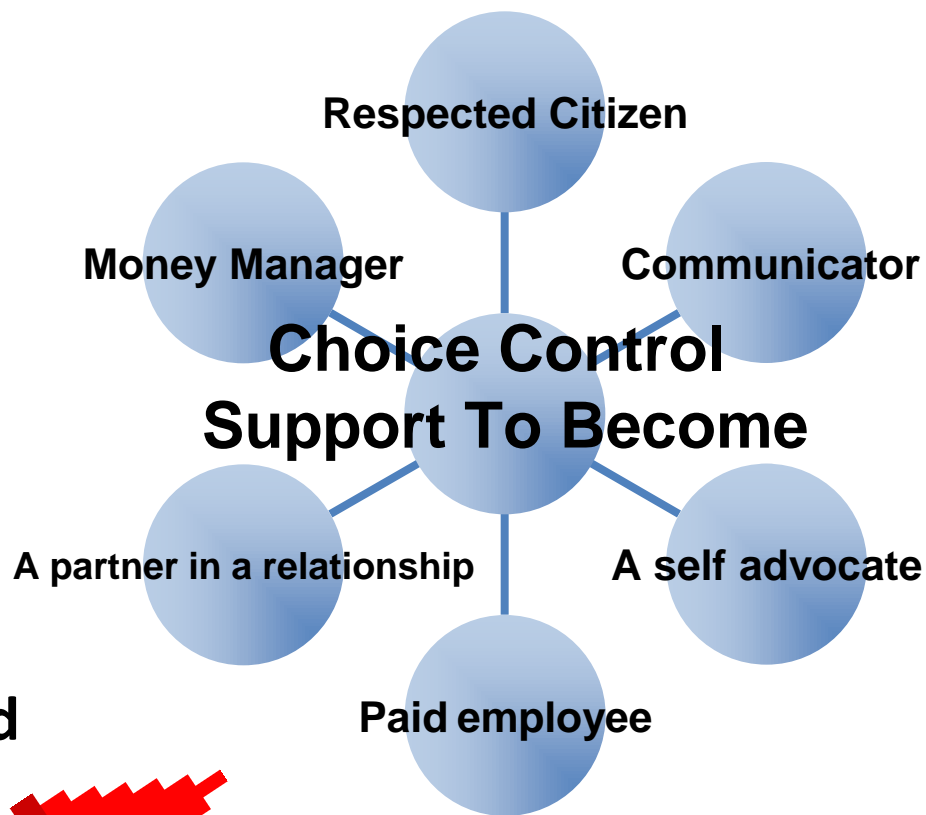




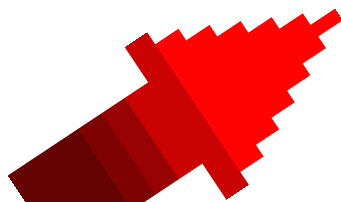


Choice through Voice & Control

- The findings of this study show that people with intellectual disabilities do not want to be treated as outsiders. They want to have fuller lives and the same opportunities as other citizens:



- They said that they needed





Moving forward

- Create a presentation to talk about these findings to advocacy groups, government officials and service agencies throughout Ireland.
- Ask YOU for your opinions on how you think things can change.
- Release a report for all stakeholders that outlines how to promote change for the better for people with intellectual disabilities.





Dissemination

What themes do we want to present? Pick 2



a self advocate



a house owner, flatmate



a paid employee



a person who enjoys leisure time



a money manager



a respected citizen



a partner in a relationship



a good communicator

- We formed 5 groups of people
- Each group picked from 1 to 3 themes to present:
 - Money manager: 2 groups
 - Self-advocate: 2 groups
 - Paid employee: 1 group
 - Partner in relationships: 1 group
 - Good communicator: 2 groups
 - House owner: 3 groups



Dissemination

What format do we want to use?

Video



Art



Photography



Graffiti



Power Point



Collage



Audio



Drama



Newspaper article




- Video: 3 groups
- Collage: 1 group
- Drama: 1 group
- Power Point: 2 groups



All We Want To Say

A collaboration between the National Institute for Intellectual Disability, Trinity College Dublin, co-researchers with intellectual disabilities, and supporters.

	16:9 subtitles for the hearing impaired	ENG creative commons	21:34
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Advocacy, Respect, Money

- **June and July 2010**
- We became 4 groups of co-researchers and supporters
 - Galway (4 co-researchers & 2 supporters)
 - Clare (2 co-researchers & 1 supporter)
 - Dublin –Walkinstown Association
 - (4 co-researchers & 1 supporter)
 - Dublin –Dara Residential
 - (3 co-researchers & 1 supporter)

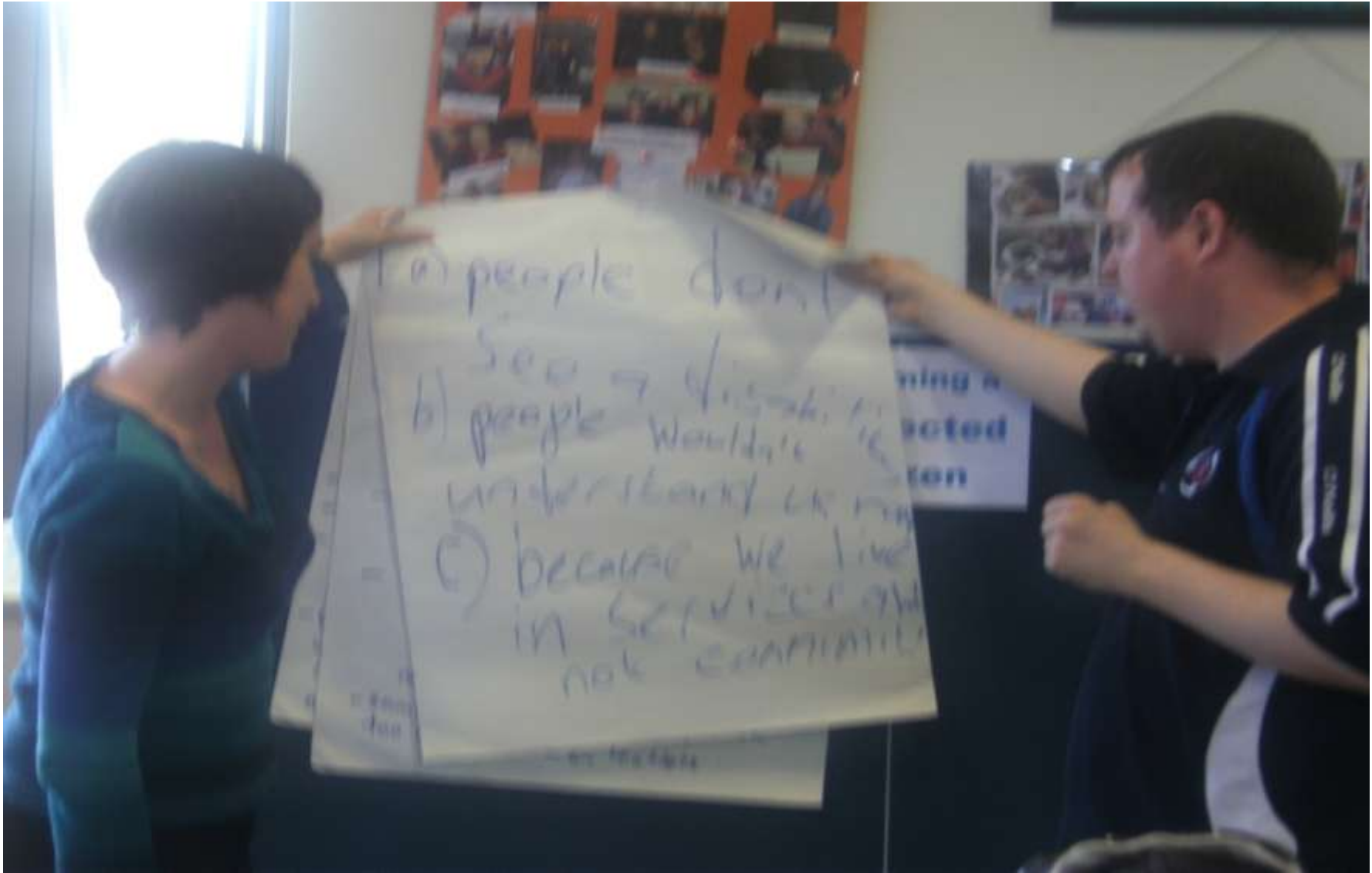
Each Presentation

Our home towns	Themes & Committees	Presentation
Galway	Home, money, relationships and work	DVD & Drama
Clare	Home, money, relationships and work	DVD & Drama
Dublin – Walkinstown	Home, money, respect, & work	DVD, Interview & Power Point
Dublin –Dara	Advocacy, Respect, Money	DVD and Power Point

Walkinstown: Home, money, respect, & work



Galway: Home, money, relationships and work



Clare: Home, money, relationships and work



Clare: Right to relationships



Dublin: Advocacy, Respect, Money






Work with Committees

Examples of Goals

Home	To organize group discussions to talk about home issues and invite families.
Money	To set up a peer support group with people who had already a bank link card and people who wanted a bank link card. They could help each other.
Respect	Go to Inclusion Ireland march to Dail on 7th April. Watch the march on TV if you can't go. Write a paper about the March and give it to the newspaper.
Work	Make links with community –be seen and heard.
Advocacy	To get better at speaking up for our rights and the rights of others. Bringing any concerns to staff/ managers on a regular basis. Getting the skills to someday be on a interview panel.

Committee membership promoted

Committee: Work	
	Co – researcher: Paul Duff and Jacinta Moran
	Facilitator: Paul Duff and Jacinta Moran



Make links with community –**be seen and heard**



The committee set a goal:
To promote the use of pass cards and laser cards for people who want them.
To find out what support they would need.



Challenge old fashioned ideas.
Make people see that people with an intellectual disability can do lots of things.

Follow up

- All goals written in accessible format and committee members' contact details emailed to groups of co-researchers (July)
- 1 Group has a meeting on advocacy in October.
- 1 Group is organising the presentation of a report on living options by the author of the report at their local agency in an accessible way.
- 2 Groups haven't started to follow up with their committees.
- University researchers following up/supporting the groups to take action.

Data collection on efficacy of dissemination of findings

Accessible dissemination and work with committees: data collection

- Audience interviews: family member, person with ID, manager/staff, politician at each presentation
 - Purpose: impact of the presentation
 - June & July
- 2 Focus groups: co-researchers and supporters
 - Purpose: experience on the process
 - September
- Field notes of each presentation
 - Purpose: explore supports and barriers to accessible dissemination
 - Retrospective field notes (June & July)
- In the process of analysing data and writing the report

- Slides available on CDS, University of Sydney website as well as DVD
- <http://www.cds.med.usyd.edu.au>
patricia.obrien@med.usyd.edu.au
- More information about the project on the NIID, Trinity College Dublin website
- www.tcd.ie/niid
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