



All We Want To Say: Life in Ireland for People with Intellectual Disabilities



December 2009

National Institute for Intellectual Disability

School of Social Work and Social Policy

Trinity College Dublin

&

Co-Researchers with Intellectual Disabilities from Ireland

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ACKNOWLEDGEMENTS

Many people have contributed to this project. We would like to thank first, the people with intellectual disabilities that participated in the focus groups in the Republic of Ireland and Northern Ireland. We are also indebted to the organisations that hosted the focus groups. The research staff at the National Institute for Intellectual Disabilities also greatly contributed to make the research meetings possible. We would like to acknowledge the support of Sarah Jones, Ailish Kennedy, Minerva Rivas, and Zoe Hughes. We would also like to mention the support and guidance that the Transfer of Knowledge Advisory Committee and the Head of School, Professor Robbie Gilligan, have consistently provided to us.

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EXECUTIVE SUMMARY

This is the first national inclusive research project conducted in Ireland. This project aimed to find out what life is like for people with intellectual disabilities in Ireland and how the lives of people with intellectual disabilities could be better. This project was done in collaboration with the National Institute for Intellectual Disability (NIID), Trinity College Dublin, University of Ulster, co-researchers with intellectual disabilities (co-researchers) throughout Ireland, and supporters.

Co-researchers and supporters were trained in how to facilitate and run focus groups and they conducted 23 focus groups, 16 in the Republic of Ireland and 7 in Northern Ireland. We analysed what people told us in the focus groups and selected the themes that were most important for the focus groups participants. The main themes we found were that people with intellectual disabilities in Ireland wanted to have control, choice and support to become self-advocates, good communicators, paid employees, money managers, house owners and flat mates, partners in relationships, and overall, respected citizens.

We formed five groups of co-researchers and supporters and developed presentations of the findings. We put together these presentations into a DVD that we aim to present to staff in organisations, self-advocates, politicians, other people with disabilities, and the wider public. We have made this report and the DVD inclusively to advocate for change in the lives of people with intellectual disabilities in Ireland.

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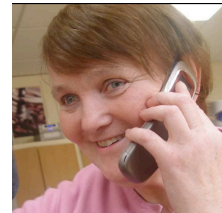
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INTRODUCTION

The All We Want to Say is an inclusive research project that started in 2008.

NATIONAL INSTITUTE FOR INTELLECTUAL DISABILITY
NIID
TRINITY COLLEGE DUBLIN



MARIE CURIE **ACTIONS**

- This project was done between the National Institute for Intellectual Disability and co-researchers from all over Ireland.
- The money came from the European Union. The idea was to get people with intellectual disabilities doing research that was important to them.

WHAT IS INCLUSIVE RESEARCH?

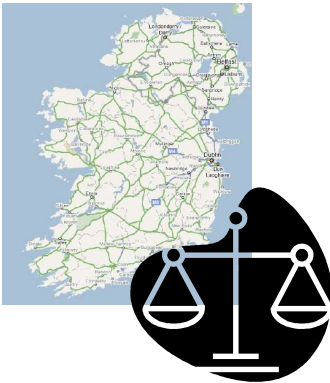
Inclusive research is research in which people with intellectual disabilities are active participants:



- Developing research questions.
- Selecting the methods.
- Collecting the data.
- Analysing and interpreting the data.
- Disseminating research.

WHAT IS THE POLICY IN IRELAND FOR DISABLED PEOPLE?

The Disability Act of 2005



The Disability Act aimed:

- To increase participation of people with disabilities in society.
- To increase access to public services.
- To make buildings and services accessible to disabled people.
- To increase employment for people with disabilities.

The United Nations Convention on the Rights of Persons with disabilities



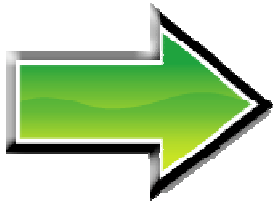
The United Nations Convention supports:

- People with disabilities claiming their rights.
- People with disabilities making decisions for their lives.
- People with disabilities being active members of society.

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RESEARCH AIMS

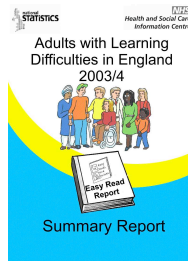
The research aims of this project were:



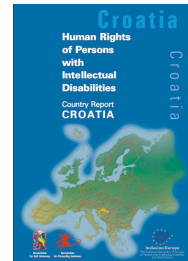
- To find out what life is like for people with intellectual disabilities in Ireland.
- To find out how their lives could be better.

SIMILAR STUDIES

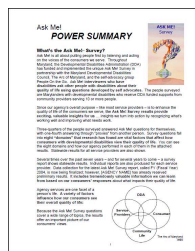
Other inclusive research studies have been done:



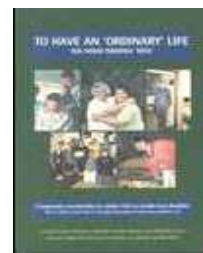
In the United Kingdom in 2003/4



In Croatia in 2007



In the United States in 2003



In New Zealand in 2003

This study in Ireland aims to add to the international picture of the lives of people with intellectual disabilities.

HOW DID WE DO INCLUSIVE RESEARCH?

We applied for ethical approval.

The project received ethical approval through the Research Ethics committee at Trinity College Dublin.

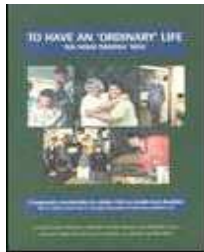
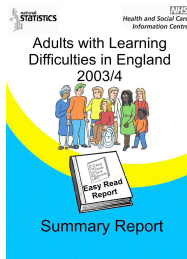
We set up a research advisory committee.



- We formed a core group of seven people.
- We were supported by two members from service agencies who had previously supported other self advocacy groups.
- Four of the members received support from services and three lived independently.
- The group met four times a year and were joined by a team of NIID researchers who facilitated the group.

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We identified the research questions.



- We invited a group of people with intellectual disabilities to run a pilot focus group on how life was for people with intellectual disabilities.
- We looked at the English and New Zealand studies to choose the questions.
- We presented a summary of the focus group discussion to an advisory committee meeting.
- The group decided on the questions to ask in the focus groups across the country.

We chose themes that:

- Were important in the lives of people with intellectual disabilities.
- Could be changed to make life better for people with intellectual disabilities.

We finalized the research questions:

- 1. Where and how people lived**
- 2. Where and how people worked**
- 3. Where and how people had friends**
- 4. Where and how people had relationships**
- 5. Where and how people gained an education**
- 6. Where and how people looked after their health**
- 7. Where and how people had a social life**



We identified the co-facilitators with intellectual disabilities and the supporters to run the focus groups around Ireland.



- The co-facilitators:
 - Would run the focus groups in the area that they lived in.
 - Would use their networks to ask others to come to the groups.

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- Two Trinity College research summer interns joined the project and became responsible for setting up the focus groups and also acted as supporters.

We conducted training for co-facilitators



- We decided that training would be held at the NIID for people interested in facilitating the focus groups.
- We advertised the training using:
 - The NIID web site
 - Telling other people about it.
- The programme was run at the NIID and up to 25 people attended each day including support staff.
- A similar training programme was run in Northern Ireland for seven co-facilitators.

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The training programme was facilitated by the NIID research team:

We trained people in:

- **Opening and closing a focus group.**
- **Using both open and closed questions.**
- **Handling difficulties in the group.**
- **Using technology to tape record the meeting.**
- **Making a summary of points made and checking these with the group.**

We used:

- **Action learning, people practiced the skills they were learning.**
- **Easy to read handouts and powerpoints.**

WHAT DID WE FIND OUT?

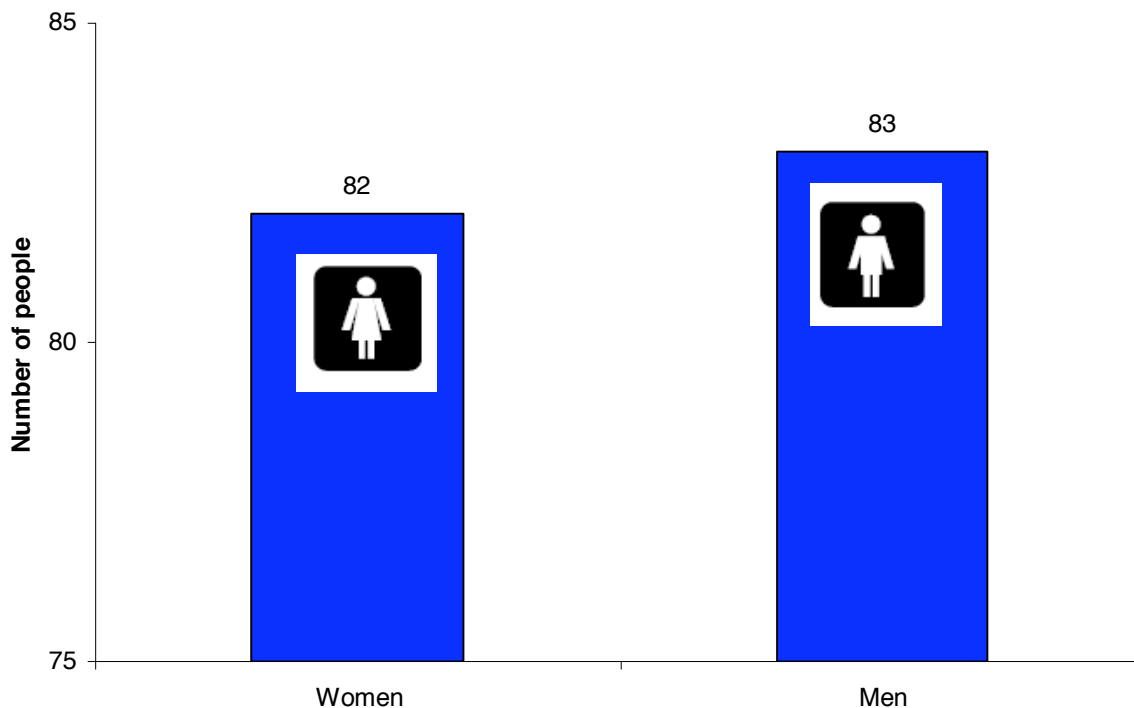
1. THE FOCUS GROUPS

The focus groups were run each with a facilitator with an intellectual disability and a supporter:



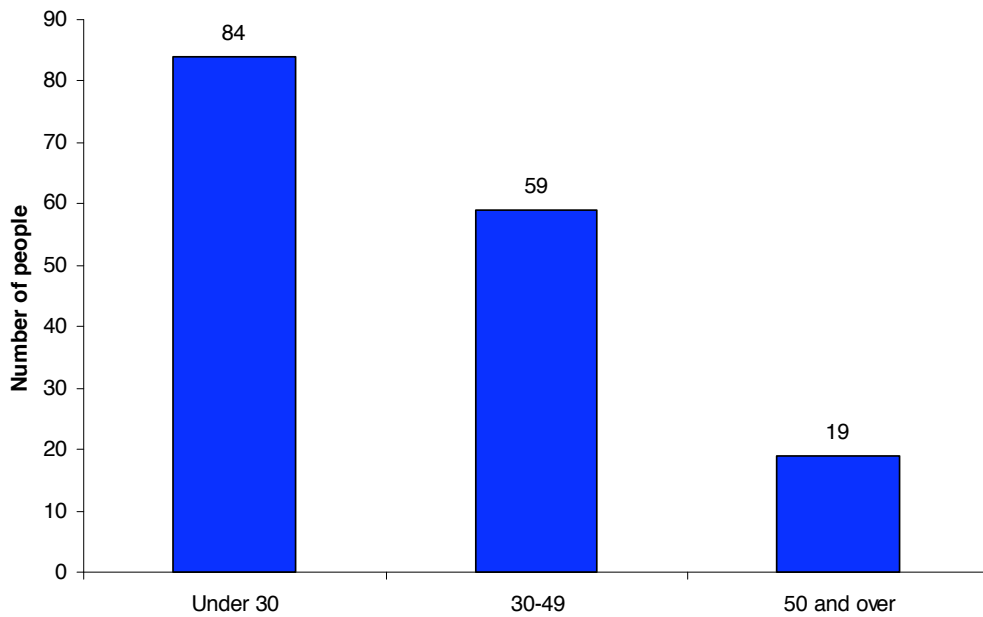
- 16 groups in the Republic of Ireland.
- 7 in Northern Ireland.
- In total, 168 people took part.

About the same number of men and women took part in the focus groups.

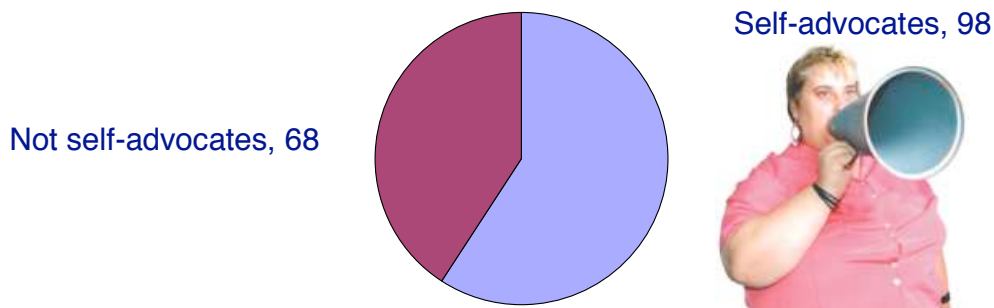


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- Most of the people that took part in the focus groups were under 30 years of age.
- Some were between 30 and 50 years of age.
- A few people were 50 years old and older.



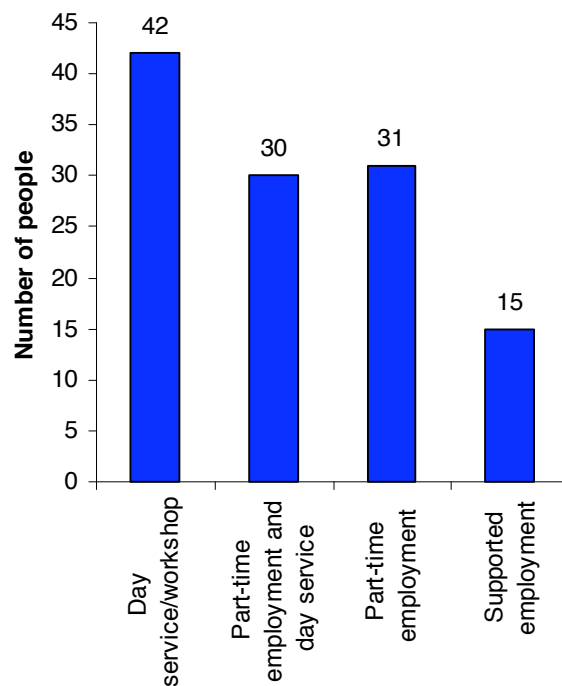
More than half of the people had experience of self-advocacy.



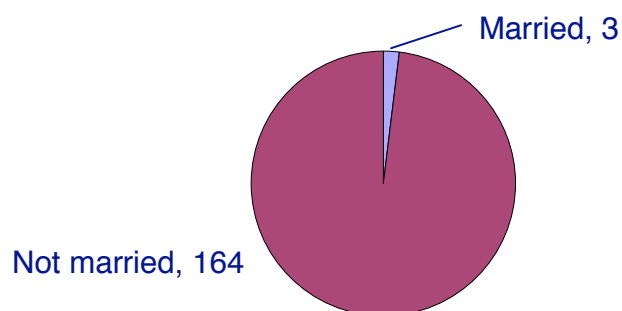
ALL WE WANT TO SAY, 2009

Of the people who took part in the focus groups:

- Only a few were in supported employment.
- Many were in a day service or workshop.
- Some were in part-time employment and a day service; about the same number were in part time employment.



Only three people out of 167 were married.



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Nearly everyone had something to say and they spoke about many different things.

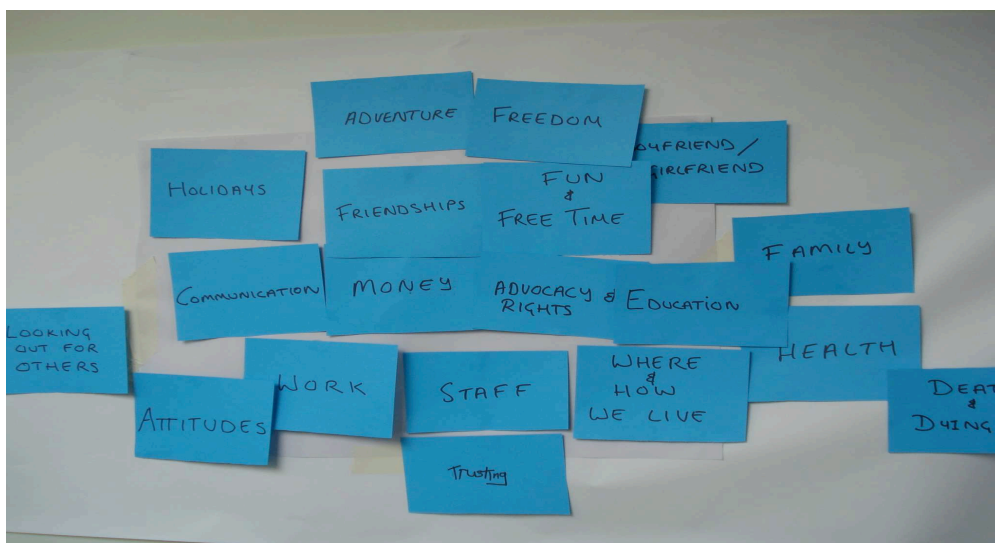


- We recorded everything that was said in the groups.
- We wrote it all down on a big sheet of paper.

We grouped the things that went together in what we call themes.



- We wrote the 19 themes on cards.
- We asked our co-researchers to identify those they thought went together.
- They also picked out the really important themes for the people who had come to the focus groups.



2. THE MAIN THEMES WE FOUND

BECOMING A PAID EMPLOYEE

People with intellectual disabilities said that they were not happy with employment and things could be better.



They said they were not happy because:

- The level of pay was low.
- They were going for lots of job interviews and not getting any jobs.
- They felt that employers don't want disabled people.
- There were centre rules about coming and going to work.

They said employment could be better if they:

- Are well paid.
- Have support to get real jobs.
- Have friendly co-workers.
- Get to know the customers.
- Can make friends at work.

People wanted to be paid more for the work they did in the centres and to be supported to get real paid employment.

BECOMING A MONEY MANAGER

People said that they were not happy with the management of their own money and that things could be better.



They said they were not happy with the money because:

- They were not able to manage their own money.
- They struggled to pay bills.
- The disability allowance was not enough for a good weekend.
- They did not have enough money to live independently.

They said things could be better if they:

- Are paid like other people and not disabled people.
- Are supported to learn how to manage their own money.

They said politicians need to know about how low pay affects disabled peoples' lives.

BECOMING A PARTNER IN RELATIONSHIPS

People with intellectual disabilities had different opinions about relationships and they wanted to have choice.



People said:

- 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.

They said:

- It's the person's own choice.
- People start slowly and get to know the person before seeing them as boyfriend/girlfriend.

The views of people in Ireland were similar to those found in other research in England, New Zealand, Croatia and United States. People with intellectual disabilities wanted to have a fuller life in Ireland. They wanted more control over their lives. They did not want to be outsiders.

BECOMING A SELF-ADVOCATE

People with intellectual disabilities said that they wanted to become self-advocates.



In the focus groups, they said they wanted to advocate for:

- Having their rights recognized.
- Their right to be respected.
- Their right to speak up for themselves.
- Their right to be asked.
- Their responsibilities.
- Their right to have a house.
- Their right not to be bullied.

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.

BECOMING A RESPECTED CITIZEN

People with intellectual disabilities said that they wanted to become respected citizens.



They said that they wanted the public to know that:

- They no longer want to be treated badly.
- They want to stop putting themselves down.
- They want to set up anti-bullying groups.

BECOMING A HOUSE OWNER, FLATMATE

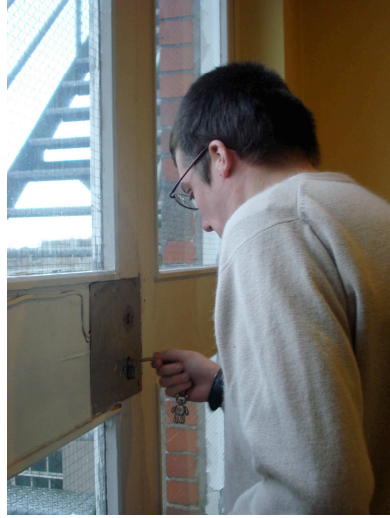
People with intellectual disabilities said that they wanted to become house owners and flatmates.



They said that they wanted:

- More choice to live more independently.
- To gain skills such as cooking and budgeting.
- To change from living in large groups, with people with different interests and abilities.

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- Better transport to places.
- More things to do in small towns and villages.
- To have their names put down on housing lists.

Our research shows that:

- People with intellectual disabilities can be involved in doing research.
- People enjoyed coming to the groups and sharing their views.
- People wanted things to change.
- People wanted to be involved in bringing about change. They did not want to leave it to others.

TELLING OTHERS ABOUT OUR FINDINGS

We decided to create a presentation to show the results of this project to different groups of people.



- The presentation could be used with advocacy groups, government officials and service agencies throughout Ireland to tell them about the findings.
- After the presentation, these groups would be asked for their opinions on how things could change.
- We could then prepare a report that outlined how to promote change for the better for people with intellectual disabilities.

In July of 2009,



- 21 co-researchers and 6 supporters consented to participate in this new phase.
- 5 groups from different places in Ireland were formed.

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Each group picked from 1 to 3 themes and made these into a presentation



- Money manager: 2 groups
- Self-advocate: 2 groups
- Paid employee: 1 group
- Partner in relationships: 1 group
- Good communicator: 2 groups
- House owner, flatmate: 3 groups

Each group selected the media to do their presentations



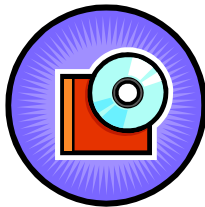
- Video: 3 groups
- Collage: 1 group
- Drama: 1 group
- PowerPoint: 2 groups

Each group added in their own experiences or experiences at their organizations to describe the findings from the focus groups

- Personal Experience
- Experience at the Organization or Home
- Results from the All We Want to Say

- People's own experiences: 4 groups
- Experiences at their organizations: 1 group

We decided to make a video with all the presentations of the findings.



We partnered with Dublin Community TV.

- We asked them to film our presentations.
- We had an editorial workshop where we made decisions about what would be in the DVD.
- When the DVD was finished, we checked it to make sure we were happy with it.
- This DVD can be seen:
 - On TV-DCTV (available by cable)
 - On the Internet
 - As a DVD for people to view at home or in groups.
- People can show it and use it to tell others what is important to people with disabilities and to advocate for change.

CONCLUSION

This study included people with intellectual disabilities in all the research phases:



- Developing the research questions.
- Gathering the data.
- Analysing the data.
- Developing presentations of the findings.

Inclusion required two way communication between co-researchers with intellectual disabilities and other team members:



- To develop easy to read materials.
- To develop training workshops.
- To prepare the presentations and the DVD.

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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:

What themes do we want to present? Pick 2



People with intellectual disabilities said that they need choice, control, and support to become:

- Self-advocates and good communicators.
- Money managers.
- Paid employees.
- Partners in relationships.
- House owners and flatmates.
- Respected citizens.

This inclusive research study can benefit co-researchers through:



- Active participation in looking at issues of concern to them.
- Getting more research knowledge and skills.
- Getting more awareness of their personal and collective situation.

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- Providing evidence that people can share at public forums.
- Networking with potential allies.
- Providing opportunities for people to take on new roles.

This inclusive research study can benefit the research community because:



- It offers a response to the UN call for full participation of persons with disabilities.
- It demonstrates that people with intellectual disabilities can be active participants.
- It identifies issues of concern to people in Ireland in 2009.
- It adds to the findings of other inclusive research projects conducted in other countries.

WHAT HAPPENS NEXT?

We are planning to use this report and the DVD to:



- Advocate for positive change in the lives of people with intellectual disabilities.
- Develop local committees to work on making change. This will mean training co-researchers in how to:
 - Present the DVD.
 - Form committees.
 - Work with committees on plans.
 - Manage committees.
- Present the results of our research to a wider audience, including politicians, general public, other people with disabilities.

We will evaluate how our work has an impact on the lives of people with intellectual disabilities in Ireland.

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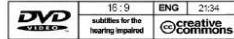
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All We Want To Say

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



All We Want To Say

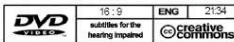
All We Want To Say

This DVD presents the results of the first national inclusive research study conducted in Ireland. This study was done in collaboration between the National Institute for Intellectual Disability, Trinity College Dublin, co-researchers with intellectual disabilities, and supporters. We conducted focus groups and asked people with intellectual disabilities in Ireland, "What is life like for you?" and "How could life be better for you?" People with intellectual disabilities told us that they wanted choice, control, and support to become self-advocates, paid employees, partners in relationships, money managers, house owners and flatmates, good communicators, and overall, respected citizens. This DVD brings together the presentations that we developed to show the findings of this study and make the voices of Irish people with intellectual disabilities heard. We have made this DVD inclusively to advocate for change in our lives.

We aim at living meaningful lives in which *nothing* is done about us without us.

Filmed and edited with the support of Dublin Community Television, Digital Hub, 101 - 103 James St, Dublin 8 Telephone: +353 1 511209

www.tcd.ie/niid/
www.dctv.ie



DC TV



All We Want To Say

"This DVD presents the results of the first national inclusive research study conducted in Ireland with people with intellectual disabilities"