



All We Want to Say – 2nd Part

People with Intellectual Disabilities Presenting Research Findings in Ireland

November 2010

**National Institute for Intellectual Disability
School of Social Work and Social Policy
Trinity College Dublin**

&

**Co-researchers with Intellectual Disabilities and
Supporters from Ireland**

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We would like to thank:



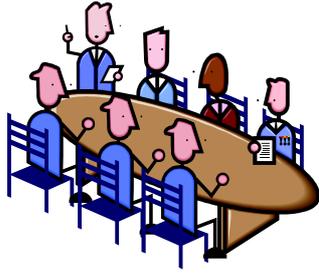
- the organisations that hosted the presentations: Clare Inclusive Research, DARA Residential, Galway Research into Action, and Walkinstown Association



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O'Doherty**



**Darren
Chadwick**



Roy McConkey



Patricia O'Brien

All members of the research team did this research.

We all had different roles doing the research.

We were all needed to do the research because:

- **We have different types of knowledge**
- **We have different experience**

Co – researchers with intellectual disabilities

have the knowledge and experience of:

- living with intellectual disabilities.

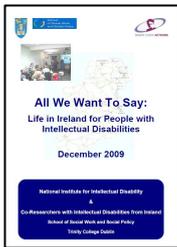
University co – researchers have the knowledge and experience of:

- research methods and doing research.

Supporters have the knowledge and experience of:

- helping people with intellectual disabilities do research.

EXECUTIVE SUMMARY



The **All We Want to Say-2** project is the second part of the **All We Want to Say** project.



The **All We Want to Say-2** was about:

- presenting research findings to other people
- working with committees to bring about change.

In the **All We Want to Say-2** project we presented these findings:

People with intellectual disabilities in Ireland wanted to have choice, control and support to become self-advocates, good communicators, paid employees, money managers, house owners and flatmates, partners in relationships, and overall, respected citizens (National Institute for Intellectual Disability, 2009).



We used a DVD to present the findings.



4 groups of co-researchers with intellectual disabilities and their supporters worked together on the project.



We did training workshops on how to:

- present the DVD
- work with committees

4

We did 4 presentations of the findings. Each group did one.



134

People in the audience joined committees to discuss the findings after each presentation.

In total, 134 people joined committees on home, money, relationships, work, advocacy, and respect issues.



The committees set goals to address the issues.



When we wrote this report, some committees had started to take action on the goals they set about home issues and advocacy issues.



The groups of co-researchers with intellectual disabilities talked to other self-advocacy groups, management at the organisations where they got services, and politicians to take action on the goals.

TIMELINE

2009

October We had a training day on how to present the “All We Want to Say” DVD and work with committees.

December We launched the “All We Want to Say” Report and DVD.

2010

February The DARA Residential Group and Galway Research into Action Group had training days to prepare for their presentation.

There was a Dublin Community Television broadcast of the DVD on Mondays and Fridays.

March The Clare Inclusive Research Group had a training day to prepare for their presentation.

April The Walkinstown Association Group had a training day to prepare for their presentation.

May The university co-researchers asked the ethics committee at Trinity College Dublin if it was ok to follow up with committees as part of the research project. The ethics committee said it was ok.

2010

June	<p>The DARA Residential Group did their presentation.</p> <p>The Galway Research into Action Group did their presentation.</p> <p>University co-researchers interviewed people in the audience after each presentation.</p>
July	<p>The Clare Inclusive Research Group did their presentation.</p> <p>The Walkinstown Association Group did their presentation.</p> <p>University co-researchers interviewed people in the audience after each presentation.</p>
July - September	<p>The Committees started to work on their goals.</p> <p>University co-researchers followed up with the committees on the goals they set.</p>
September	<p>We did 2 focus groups:</p> <ul style="list-style-type: none">• 1 group with co – researchers• 1 group with supporters <p>We talked about our experiences:</p> <ul style="list-style-type: none">• Doing the presentations• Working with the committees
October- November	<p>We wrote up this report.</p>

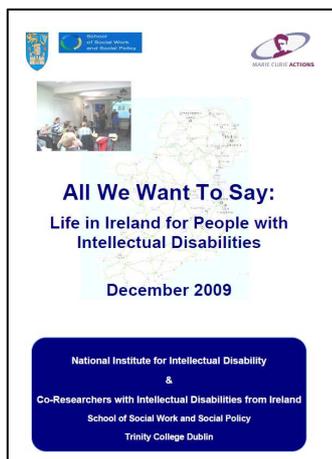
INTRODUCTION

- The **All We Want to Say-2** project is the second phase of the research project **All We Want to Say**.

The All We Want to Say Project (2009)

- We all did this project: university co-researchers from the National Institute for Intellectual Disability, co-researchers with intellectual disabilities and their supporters from all over Ireland.
- We asked people with intellectual disabilities in Ireland:
 - What life is like for them?
 - How could life be better?

They told us that life could be better being a:



- self advocate
- house owner
- paid employee
- good communicator
- partner in a relationship
- money manager
- respected citizen.

You can read the All We Want to Say Report and watch the DVD at <http://www.tcd.ie/niid/>.

The All We Want to Say-2 Project

- This project was about:
 - presenting the **All We Want to Say** research findings
 - working with committees to advocate for change.

This research project is also important because:



- the United Nations Convention on the Rights of Persons with Disabilities (the Convention) says that we need research to know what people with disabilities think (article 31) so we can change laws in Ireland
- there are more and more people with intellectual disabilities doing research (Dowse, 2009; Walmsley, 2001)
- But there are not many people with intellectual disabilities:
 - that use DVDs or drama to present the research findings (Garbutt, 2009)
 - that work with committees to address issues they have identified with the research.

In this report, we describe:



- how we presented the All We Want to Say DVD
- how we worked with committees
- what training we got for presenting the DVD and working with committees
- the goals the committees set
- what people thought about the presentations.

RESEARCH TRAINING

We did research training to develop skills:



- to present the research findings
- to work with committees to advocate for change.

We did training workshops in:



- Kildare
- County Dublin
- Galway
- County Clare.

Research Training to Present the All We Want to Say Results

We learned how to:

- get organised before the presentation
- present the DVD
- get our message across.

1) GET ORGANISED BEFORE THE PRESENTATION



We learned how to:

- choose the audience
- find an ally
- get in contact with the audience
- arrange a day for the presentation
- prepare the presentation.

2) PRESENT THE DVD



We learned how to:

- play the DVD and show the findings.

We needed help with three things:

- technical support to use the DVD and PowerPoint
- practising the presentation
- timing the presentation.

3) GET OUR MESSAGE ACROSS:



We learned how to:

- do a round on what people think
- summarise the DVD
- get the audience to focus on important findings for us
- repeat the findings
- answer questions.

Research Training to Work with Committees to Advocate for Change



We learned how to:

- ask for volunteers to join the committees
- review what people can do to make things better
- get people to agree to set goals to change things.

PRESENTATIONS

- We did 4 presentations of the “All We Want to Say” research findings.
- We showed the DVD in all the presentations.



Galway Research into Action & Clare Inclusive Research Group

We also did a play “Home Alone” to present on:

- home
- money
- relationships
- work.



DARA Residential Group

We also used PowerPoint to present on:

- advocacy
- respect
- money.



Walkinstown Association Group

We also did an interview & used PowerPoint to present on:

- home
- money
- respect
- work.



The DARA Residential Group Presentation



Who did the presentation?

- Derek Murphy
- Paul O'Neill
- Michael Ward.

Who was the supporter?

- Mary McNamee.

Where did we present?

- in DARA's main office in Celbridge.

What research findings did we present about?

- advocacy
- respect
- money.

How did we present the research findings?

- presented the All We Want to Say DVD
- used PowerPoint.

Who attended the presentation?

over 20 people attended including:

- family members
- staff
- CEO.

We set 3 committees after the presentation:



- advocacy committee: 4 people joined
- money committee: 7 people joined
- respect committee: 6 people joined.

In total, 12 people volunteered to work with the committees.

The Galway Research Into Action Group Presentation



Who did the presentation?

- Martin Dooher
- Ann Mahon
- Padraig McDonagh
- Marie Wolfe.



Who were the supporters?

- Geraldine Bane
- Josephine Flaherty.



Where did we present?

- In a hotel in Galway city.



What research findings did we present about?

- home
- money
- relationships
- work.

How did we present the research findings?

- presented the All We Want to Say DVD
- did a play - "Home Alone."



Who attended the presentation?

over 60 people attended including:

- politicians
- family members
- staff
- service users
- managers
- people with intellectual disabilities.

We set 5 committees after the presentation:



- home committee: 12 people joined
- money committee: 7 people joined
- relationships committees: we set 2 and 21 people joined
- work committee: 8 people joined.

In total, 34 people volunteered to work with the committees.

The Clare Inclusive Research Group Presentation



Who did the presentation?

- Marie Deely
- Ger Minogue
- Mairead Moroney
- Kathleen Ryan.

Who was the supporter?

- Rob Hopkins.

Where did we present?

- in a hotel in Ennis



What research findings did we present about?

- home
- money
- relationships
- work.



How did we present the research findings?

- presented the “All We Want to Say” DVD
- did a play - “Home Alone.”



Who attended the presentation?

over 75 people attended including:

- politicians
- family members
- staff
- researchers
- service users
- managers
- other people with intellectual disabilities.

We set 4 committees after the presentation:



- money committee: 10 people joined
- home committee: 15 people joined
- relationships committee: 10 people joined
- work committee: 11 people joined.

In total, 20 people volunteered to work with the committees.

The Walkinstown Association Group Presentation



Who did the presentation?

- Darren Broderick
- Paul Duff
- Margaret Keogh
- Jacinta Moran.

Who was the supporter?

- Susan Wade.

Where did we present the research findings?

- in Walkinstown Association

What research findings did we present about?

- home
- money
- respect
- work.

How did we present the research findings?

- presented the "All We Want to Say" DVD
- used PowerPoint
- did an interview.





Who attended the presentation?

over 40 people attended the presentation including:

- service users
- staff
- management.

We set four committees after the presentation:



- money committee: 5 people joined
- respect committee: 5 people joined
- home committee: 7 people joined
- work committee: 6 people joined.

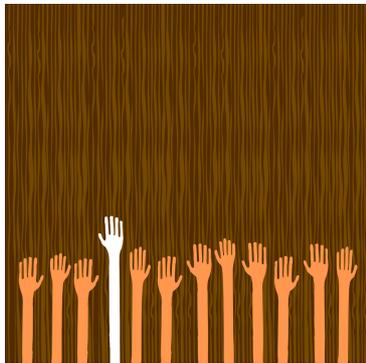
In total, 9 people volunteered to work with the committees.

COMMITTEES

We set up committees after the presentations of the research findings.

Here we describe the work we did with the committees, the agenda for change that we set up, and the follow up that we did.

We set up 1 committee for each finding we presented.



- We asked people in the audience to join 1 of the committees.
- We reviewed with the committee members:
 - what people had told us could be better
 - what they could do to make the situation better.
- We asked committee members if they wanted to work with us after the presentation.
- We asked them to put their names on a “sign-in” sheet.

People joined the committees that were more interesting for them.



- 1 of the co-researchers with intellectual disabilities and a supporter or a university co-researcher facilitated the discussion.
- We asked other people in the committees to be the chair of the committee.
- We wrote minutes of the discussion with each committee.

We wrote the minutes in plain language and using pictures. Each of us took on a different role:

University co – researchers:

- sent the minutes and sign-in sheets to each group of co-researchers with intellectual disabilities
- followed up with each group of co-researchers with intellectual disabilities.

Co-researchers with intellectual disabilities and their supporters:

- identified which goal was most important and urgent to take action.

Agenda for Change

These are the goals that committees set to address the issues with money, employment, relationships, housing, advocacy, and respect.

Money

There were a total of 4 committees on money.

25 people joined these committees.



We set goals on:

- information and education about money
- decisions about how to use money
- advocacy on how to handle money
- working to get money.

Information and education about money



Goals:

- to know what our money is spent on
- to learn how to use the cash machine
- to get more education about how to handle money
- to show the “All We Want to Say” DVD to more people.

Decisions on how to use money



Goal:

- to make decisions about what to spend the money on.

Advocacy to handle money



Goals:

- to go on strike to get better pay
- to encourage the use of laser cards (debit cards) for people who want them
- to get support using laser cards
- to set up a support group:
 - on handling money
 - with peers that had control of their money to help others handle money.

Work to get money



Goals:

- to become friends with employers in the same area as:
 - our associations
 - our services
- to offer help in stores to get work experience.

Employment

There were a total of 3 committees on employment.
23 people joined these committees.



We set goals on:

- starting a business
- transport for people with intellectual disabilities
- community
- attitudes.

Starting a business



Goal:

- to support people with intellectual disabilities to start up small business enterprises.

Transport for people with intellectual disabilities



Goal:

- to encourage better transport services so people with intellectual disabilities get better jobs.

Community



Goal:

- to make links with the community:
 - to promote work opportunities for people with intellectual disabilities
 - to offer more hands on training for people with intellectual disabilities.

Attitudes



Goals:

- to challenge 'old fashioned' ideas about people with intellectual disabilities not being able to work
- to make people see that people with intellectual disabilities can do things for ourselves.

Relationships

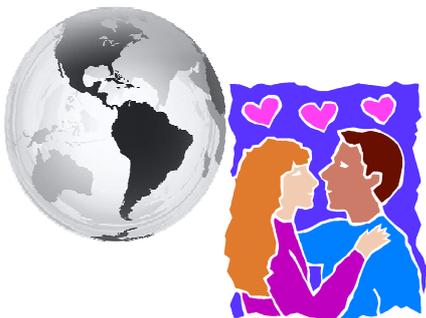
There were a total of 3 committees on relationships.
30 people joined these committees.



They set goals about:

- getting more information
- educating people
- services.

Getting more information



Goals:

- to have more discussions like at the “All We Want to Say” presentation
- to find out about what makes a relationship work, ask people in a relationship what it’s like and what makes it difficult
- to look at how people with intellectual disabilities in other countries
 - have been helped to have friendships
 - have been helped to have relationships.

Educating people



Goals:

- to have more family training about relationships
 - they could come to more discussions like at the “All We Want to Say” presentation
- to make people aware of old laws that make sex for people with intellectual disabilities illegal
- to do the drama we did in schools or send the All We Want to Say DVD there
 - to help reduce fear and change attitudes.

Services



Goals:

- to have more discos in different counties
- to send policy on relationships and sexuality rights to organisations for people with intellectual disabilities.

Housing

There were a total of 3 committees on housing.
30 people joined these committees.



We set goals about:

- creating groups
- getting more information
- educating politicians and the public.

Creating Groups



Goals:

- to set up a support group:
 - to help people move house
 - to find flat sharers
 - to talk about home issues and invite families to talk with us.

Getting More Information



Goals:

- to find out about:
 - what is in the reports on living options for people with intellectual disabilities
 - research on homes for people with intellectual disabilities
- to review what goals we have achieved in a year's time.

Educating Politicians and the Public



Goals:

- to show the All We Want to Say DVD to politicians
- to educate the public: people with intellectual disabilities are capable.

Advocacy

There was 1 committee on advocacy.

5 people joined this committee.



We set goals about:

- creating groups
- getting more information
- being involved in decision making.

Creating groups

M	T	W	T	F	S	S
X						
X						
X						
X						

Goal:

- to plan and organize an advocacy meeting in the service every week.

Getting more information



Goal:

- to learn more about self – advocacy.

Being involved in decision making



Goal:

- to be on interview panels when services are interviewing staff.

Respect

There were 2 committees on respect.

8 people joined these committees.



We set goals about:

- community
- government.

Community



Goals:

- to be respected and have friends outside the centre or services
- to be listened to when speaking
- to talk to people to understand why they are not respecting people with intellectual disabilities.

Government



Goals:

- to ask the government to change policies and services so we can meet our needs.

Follow up with Committees

DARA Residential Group



- we are working on meeting every week with our self – advocacy group in DARA residential.

Clare Inclusive Research Group



- we are giving this agenda to other self-advocacy groups in County Clare.
- we are telling them “these are the goals that people with intellectual disabilities set to have better lives in Clare and in Ireland.”

Galway Research into Action Group



- we are making links with the person who wrote the report on Congregated Living Settings
 - we want him to present to our group in an accessible way
 - a researcher from NUI Galway is helping us.
- we are also talking to the management team in our organisation to prioritize goals.

Walkinstown Association Group



- we have met and decided we want to present the DVD to local politicians.

WHAT DID PEOPLE THINK ABOUT THE PRESENTATIONS?

We wanted to reflect on the process of presenting research findings and we also wanted to know what people thought about the presentations. We did focus groups and interviews.

Co-researchers with intellectual disabilities and supporters



2

- we came together in focus groups and talked about doing presentations of research findings.
- we did 2 focus groups: 1 for co-researchers with intellectual disabilities and 1 for supporters.

Audience



- we also asked the people who came to the presentations what they thought about them. We interviewed:
 - 2 people with intellectual disabilities
 - 2 family members
 - 3 staff from organizations
 - 4 managers from organizations
 - 1 politician
 - 2 university researchers.

The co-researchers with intellectual disabilities said...



- Research is good, we meet other people, make new friends, and we take part.

- Drama is a good way of telling our stories and talking about rights.

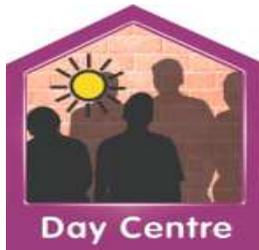
- We get good support but we need more support from our services.

But, what happens next?

- We need to show the findings on TV.

- Services need to change. We need more control and consultation.

The supporters said...



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- It was a positive and interesting experience being part of the research.
- Inclusion is a challenge because of the time and different levels of understanding.
- We, supporters, feel isolated in our services but feel we are part of a team with other groups and the university.
- The presentations gave us credibility with our managers and organisations.
- Some co-researchers with intellectual disabilities were checking in on us, keeping us on track.
- Individual support from the university was good.
- Goals are very important but who is taking the lead now?

People in the audience said...

Good things about the presentation



Showing the DVD at the presentation

'I think the video was quite useful. It's people's opportunity to speak or being able to do something without having to do it live.' (CEO)



Seeing people with intellectual disabilities do this presentation

'I thought the play was outstanding because I think there is something very powerful for people to see, the depth of understanding where people are playing different roles.' (Researcher)

'I found them interesting, the different ones telling their stories and that.'
(Person with an intellectual disability)



Good Work of the co-researchers with intellectual disabilities

'The co-researchers seemed to know exactly where they were at in introducing each other and there was great linkage between one part of the presentation and the next.'
(Manager)



Support

‘Support people have gotten clearer about being more invisible. Making sure that the researchers with intellectual disabilities led the discussion is good for people to see.’ (Researcher)

‘The role of the supporter is to find an ability that the lads can convey their point of view in such a way that the essence of what they want to say comes across.’ (Support staff)



Expectations

‘I didn’t think people like myself could do something like that.’ (Person with an intellectual disability)

‘I thought they were quite good, better than I had expected, I’ll tell you.’ (Family member)

Things that could improve in the presentations



Audience

‘I really found the drama very powerful and I would love for more audiences to have the opportunity to see it.’ (Researcher)



Work with Committees

‘From the leaflet that went out I didn’t know that the discussion was going to be part of it and I think it would have been good to know that in advance.’

(Researcher)

‘I wasn’t aware at all at the end of the discussion what the goals were from the other committees. There should be a round of feedback on the overall goals.’

(Researcher)

Reading

‘One of the things I have seen work fairly well including at a conference is almost someone being interviewed so they don’t have to remember or read.’

(CEO)



‘Well in a lot of the presentation there are some people that can’t read stuff in a particular format. I have to say that I have done a few interviews now.’ (Person with an intellectual disability)

The work of the committees



Impact

'I would like it to have more of an impact than I think it probably will.' (Staff)

Empowerment

'The challenge for her to speak in front of a senior manager in her organisation and I was struck by the speed and force by which she came to the challenge.' (Researcher)



'I think it's great to see them actually being at a 3rd level institute, do you know what I mean? And you're also, you're giving them ownership of their own life if you like. They're able to act for themselves.' (Family member)



Resources

'I suppose I am more cynical at the moment about the resources issue.' (Manager)

'Throwing money at it isn't the solution. It's coming up with a proper structured plan.' (Politician)

CONCLUSION

This project was about involving co-researchers with intellectual disabilities in:

- the presentation of the “All We Want to Say” research findings
- using the “All We Want to Say” results to work with committees.

We showed in this report how co-researchers with intellectual disabilities presented research findings using DVD and drama and how we worked with committees with training and support. The DVD and the drama were useful to do these presentations. Also, the message was more powerful because co-researchers with intellectual disabilities were the ones presenting the findings.

As a result of these presentations around Ireland and work with the committees, we now have a national agenda for change. This agenda includes goals on money, employment, relationships, housing, advocacy, and respect.

Co-researchers with intellectual disabilities developed this agenda in collaboration with university co-researchers, supporters, policy makers, staff and management of disability organisations, and family members.

We still need more support to change things. We also need more research like this to make sure that change is happening, as article 31 of the Convention says.

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