How We Work:

The Inclusive Research Network's way of doing projects

IRN Authors

The IRN is made up of over 40 people. There was a smaller group who worked on this easy read report. Their names are on this page.

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Note on the Words We Use in this Report
The Inclusive Research Network has talked a lot about the words we use to tell people about our work.
One of the terms that is used often in Ireland is 'people with intellectual disability.' This phrase is not easy to say or easy to read.
In talks by the IRN we often say 'IRN members' or 'self-advocates' when we refer to the people who are part of the IRN. In this report we agreed to use the term 'self-advocates' when we are talking about the IRN members with disabilities.
Many services in Ireland have agreed on new terms to use. For example, some services now say 'people supported' and others say 'people with extra support needs.'
When the IRN is applying for funding we have to explain who is part of the team in a way that is easy for review panels to grasp.
We came up with four options of words we could use to describe who we are: 1. People with intellectual disabilities   2. People with learning difficulties   3. People with cognitive impairments   4. People with learning disabilities
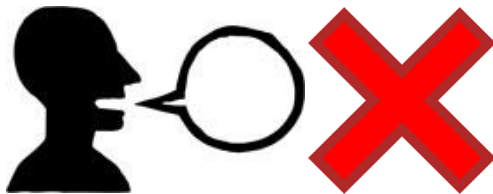
	We said 'no' to the use of 'people with intellectual disabilities' because everyone in the IRN cannot say this easily.
	We said 'no' to the use of 'people with learning difficulties' because members of the IRN did not want to be linked to the term 'difficult'. That term is always used in a bad way.
	We said 'no' to the use of 'people with cognitive impairment' since few in the IRN heard of this term and did not know what it meant.
	IRN members were not keen on any of the choices. Since we need to have a way to tell people who we are, in the end IRN members said 'yes' to 'people with learning disabilities'. We are so much more than what this label says about us.
	We are brothers and sisters, aunts and uncles, sons and daughters, researchers, colleagues, workers, authors, film makers, Irish Citizens, Olympic athletes, lobbyists, friends.
	We will keep talking about this. One day we hope that we can stop using these labels.

Why we wrote this report

	When research teams are made up of members who are self-advocates with learning disabilities, their supporters from services and academic supporters it is called Inclusive Research.
	More people around the world are doing research this way
	In the past people with learning disabilities were left out of research teams and were only seen as people who could take part in a project.
	But there are things about inclusive research that raise questions about the strength and quality of studies done this way. For example, some people wonder if teams that claim be inclusive are not really treating people with learning disabilities as equal partners.
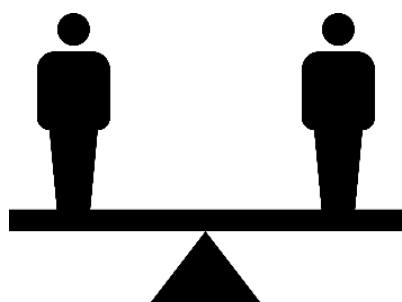
	Others are not sure that people with learning disabilities can really be research leaders.
	The IRN wanted to reply to these key issues as we think about how we work together.

Work of the IRN since 2008

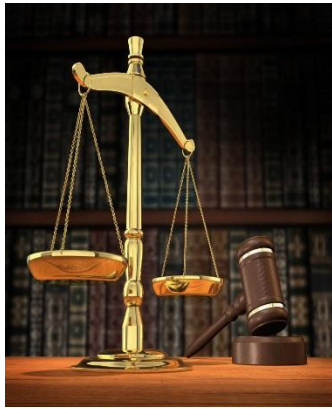|	
	The Inclusive Research Network in Ireland started back in 2008. We have completed 5 big research projects, given talks about our work in local services, at Irish meetings and in many places across Europe.
	To get easy read reports of all our projects you can click on this link: http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html

	We have also worked hard to change laws in Ireland that were not fair to people with disabilities. For example, we wrote letters and did talks about the Sexual Offences Act and the Assisted Decision Making (Legal Capacity) Act.
	The IRN has a steering group of self-advocates who sets the agenda and they lead monthly meetings at sites around Ireland.
	Now that our works spans more than a decade, we agreed that it was time to take a close look at how we work together. We wanted to note what we do well and where we can get better at working together.
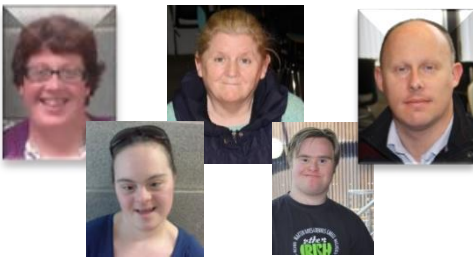
How we did this project

	To do this we gathered up many papers. These included our 5 easy read reports, looked at slides from 11 research workshops, went over 5 research handbooks, over 40 meeting agendas and meeting notes, and one formal letter to government.

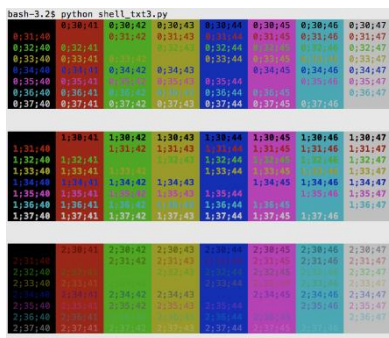|	
	Even though most of these files were in easy read text, there were so many of them that we needed help to get them all sorted.
	Gemma Diaz Garolera, a PhD student from Spain, was visiting the IRN in autumn 2017. She agreed to work with Edurne Garcia Iriarte to organise all the papers into one big table. They used excel software to manage all the details about the IRN for the past 10 years.
	Edurne and Gemma could see many ways to arrange all these IRN papers. Since we are a research group, they created a table that had a place for details about each stage of research: setting research question, choosing how to answer the question, getting ethics approval, collecting data, finding answers, writing up reports, and sharing our projects with others.
	Edurne, Gemma and Nancy – all academic supporters—read through the big excel table and talked about what each of them saw as key points to bring to the IRN members.
	At a monthly meeting 12 IRN members chose to be part of the working group to write this easy read report.
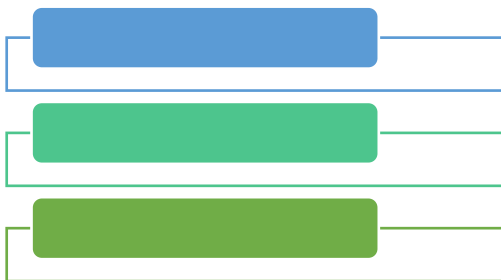
	Edurne met with the IRN working group for this report. She told them what other researchers say about working in an inclusive way.
Christine Melanie	The group talked about the work of Christine Bigby in 2014 and Melanie Nind in 2016. The papers by Christine, Melanie and their co-authors are cited at the end of this report.
	The working group had a long talk about what kind of team the Inclusive Research Network is. The IRN members said that we are a group where self-advocates make all the key choices about how we work.
	Smaller groups worked between IRN meetings in person or over skype to agree the wording in the report. They also agreed on pictures to help explain the words.

Our Key Points

	After a long talk the IRN working group agreed on key points. Please read on to see some of the big things that took place over the past 10 years with the IRN.

	In the early years the IRN was led by nondisabled researchers. Over time the self-advocates took part in more and more decisions about how the IRN worked and the kind of projects we do.
	This was shown clearly when the first IRN Steering Group was elected in 2012 where all the leaders were self-advocates.
	The working group found that the IRN now works with people with learning disabilities and supporters as full partners. The academic supporters provide information and guidance but IRN members make the final choices about our work.
  Nancy Edurne	Academic supporters like Nancy Salmon and Edurne Garcia Iriarte, do a lot of the background work and explain what is already known about topics we are working on. They do this by reading many research papers and then telling us about them.
	In our current project, Doctors and Us, a student from University of Limerick did a review of all research on this topic. She will present this work to the IRN so we can use it in our easy read report when our project is finished.

	We decide together what our research topic will be and how we will do the project. Over the years we have learned to do surveys, interviews and focus groups. Once we sort out exactly how we will do the project the academic supporters then work with us so that we feel ready to go out and talk to people either on-one-one or in focus groups.
	IRN members then go and talk to people to hear their stories. IRN members said, "fieldwork is about other people with disabilities, so we should be the ones doing it."
	Most IRN members have a supporter who is there to help out when they are hearing the stories of people taking part in a study. The supporter helps with anything the IRN member needs like reading project details out loud, making copies of consent forms, taking notes, asking follow up questions and helping with sending the research files back to the IRN secretary.
	IRN members, their supporters and academic supporters look for what is shared and unique about the stories of people we talk to in each project.

	When we write up our easy read reports, like this one, all of our names are included as co-authors. Getting credit as authors is very important to IRN members.
	We all bring something to the research team, but it is still hard to get the balance right between the voices of IRN members and supporters. This is something we need to keep working on.
	For example, in our meetings sometimes the supporters talk more than IRN members. When we are learning something new this is ok, but we want to be sure that IRN members always have a chance to speak up.
	We are also coming up with ways to record how inclusive we are at each stage in the research process. For example, starting in November 2018, at the end of each IRN meeting the Chair will ask 3 key questions: 1. Did you get a chance to speak up today? 2. What went well in our meeting? 3. What could we do better next time to be sure everyone feels part of the team?

The IRN has changed a lot over ten years. Our work has moved from being led by academics to IRN members being full partners in projects.

Some projects, like this one, are still led by our academic supporters, but it is only with the agreement of the IRN Steering Group. Thus, the IRN members control what we do as a research team.

This report shows that people with learning disabilities can be full research partners and can also say how to improve how we do inclusive research.

This easy read report will be written up as a full research article in 2019 with Edurne Garcia Iriarte leading the writing team.

Research Papers We Talk About in this Report

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *27*(1), 3-12.

Nind, M., Chapman, R., Seale, J., & Tilley, L. (2016). The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 542-551.