LIFT EACH OTHER UP

Embracing research by everyone, for everyone
Margaret Turley and Paula Camino

There may be some difficult words in this blog. We have underlined them and included a definition at the end of the blog.

Looking back on Disability Pride Month, there are many issues we could talk about. We want to focus on one: The right to participate through inclusive research*.

The Convention on the Rights of Persons with Disabilities and meaningful participation

The 2006 Convention on the Rights of Persons with Disabilities (CRPD) is an important agreement for disability inclusion. It has a key message: **'Nothing about us without us'**.

This means that anything that affects people with disabilities should include their ideas. That way, we can make sure what we do is actually useful. We call this **meaningful participation**.

Meaningful participation is part of the Convention's principles (the big ideas that guide it) and obligations (what countries have to do). It can look like many things:

- Listening carefully to what organizations say before making a law.
- Including people with disabilities on your team when you are doing research to make decisions. We call this inclusive research*.

Inclusive research

Inclusive research is a really powerful way to create participation. It means that when you are studying something that affects a specific group of people *(for example, people with disabilities)*, people from that group *(people with disabilities)* need to be on the research team.

This makes our research more complete, because it has better information and is accessible to more people.

But inclusive research isn't easy! In fact, research has always left out many people.

It doesn't include people with disabilities or people from different backgrounds.

This means that their needs and experiences are not seen. That's not fair, and it stops us from building more inclusive societies.
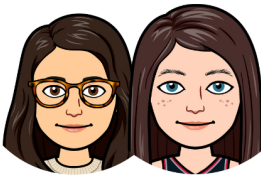
In this fellowship, Margaret and Paula are working together on an inclusive research project about education. Based on our experience, we want to share three important ideas for researchers who want to start their own inclusive research:

1. Consider your positionality

Positionality is an important concept in inclusive research. It means accepting that researchers, like the people we study, bring our own assumptions to the table.

So, we need to understand our own background (like our race, gender, beliefs, and more) and know how it affects our work.
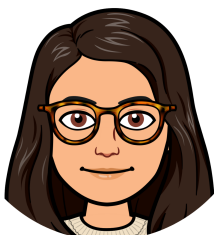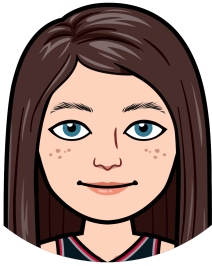
Let's look at **Paula** as an example.

Paula is a Peruvian woman who does not have any learning differences. She had a good education and resources that helped her become a successful researcher.

Paula's positionality means she may not fully understand what it's like for people who don't have the same advantages.

Now, let's look at **Margaret**.

Margaret is an Irish woman and has an intellectual disability. She had access to an inclusive school (but she did not enjoy it), and then went on to Trinity College.

Margaret's positionality means that she can relate very well to the experiences of people who fight for inclusive education in Europe.

But it also means that she might have a harder time relating to someone from Latin America, where education looks really different.

By understanding our own positionality, we can create more inclusive research that reflects the experiences of everyone involved. For example, Paula and Margaret can...

- Work together so they can combine Margaret's experience of inclusive education and Paula's experience of Latin America. This will help them understand the full picture.

- Read about experiences of inclusive education around the world to help them understand different backgrounds.

## 2. Meaningfully involve people with disabilities in the research

Sometimes, people with disabilities are included in research just for show. This is called tokenism.

This is not inclusive research.

Inclusive research means meaningfully involving people with disabilities in all parts of the research process.

When people with disabilities are involved meaningfully, they have important roles in designing the research, working with data, and writing the report.
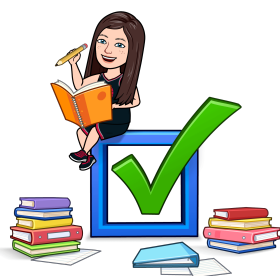
Let's look at Margaret as an example. She learned how to do research with Inclusion Ireland. After her training, Margaret worked with Inclusion Ireland, Special Olympics International, and the Samuel Center.

The researchers made sure that she and other researchers with disabilities were really involved in the research. They wanted them to do their best work.

They did this in different ways, like:

- **Adapting to different ways of working.** The researchers made sure to adjust how they work to fit everyone's needs. Margaret feels more comfortable talking instead of writing. So, when she was getting ready for a talk, the lead researchers helped her practice by writing down her speech in her own words.

- **Respecting Margaret's independence.** They let Margaret take the lead in the research process and only helped when she asked.

3. Prioritize easy read above all

Inclusive research is about more than just including people from different backgrounds. It's also about making sure that the information we communicate is accessible to everyone.

This is because research documents can sometimes be difficult to read, especially for people with disabilities or those who have different educational backgrounds.
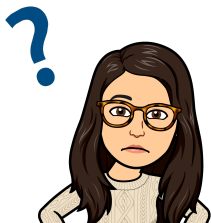
Margaret and Paula have both experienced the challenges of complicated research documents. They have needed help from their mentors to fill out ethics forms.

These forms are essential for research, but are written in very complicated language and are very long. This shows that research documents can be inaccessible to many people, even those who are trained to read them.

Margaret and Paula's mentors could explain the forms to them. But not everyone has a mentor that can help. We should build research tools that are easy for everyone to access and understand.

One way is by using easy-read text. It uses short sentences, simple words, and clear images. This helps people with disabilities and different educational backgrounds understand information.

When we include everyone and make research accessible, we can learn so much more. We can challenge the way things are and make important changes that include everyone. Reflecting on Disability Pride Month, we want to remind you that research is for everyone, not just a few!

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What do the difficult words mean?
- **Tokenism:** When an organization does something to support a group, but it's only for show. It won't really make a difference. (Adapted from Cambridge English Dictionary)
- **Inclusive research:** When everyone is involved in doing research, including the people whom the research is about. For example, research about people with intellectual disabilities is done by and with people with intellectual disabilities.
- **Advocacy:** "Advocacy is when someone helps you and speaks up for you to:
    - say what you want to say
    - and make things happen" (Easy Read Definition Dictionary)
- **Participation:** "Participation means taking part and being involved in decisions" (Easy Read Definition Dictionary)

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