Inclusive Research – a stepping stone on the road to empowerment
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1) A little about us

Isabel

I am Isabel and I have dopa-responsive dystonia.

When I was young, I didn’t use to walk and I had a lot of volunteers who helped me in therapy.

Now I take a pill and today I have made a lot of progress.

I attended MCAST for three years. MCAST is a post-secondary college. First I did a two-year course called Pathway and then a one-year Level 1 ICT course. As part of the Pathway course, I did a work placement with the National Commission Persons with Disability (KNPD) in Malta. Now I work there as a part-time office support-worker.

When I started working there it was my birthday and I had an interview on the newspaper. I am very happy because when the work is difficult, someone explains it to me and then I understand and do my work well.

I take part in drama and at the moment I am doing a course.
Anne-Marie

I am Anne-Marie and I am a lecturer in Disability Studies at the University of Malta.

I do not have a disability. I have been working with disabled persons for twenty years.

I work mostly with people with intellectual disability.

I have done a lot of research in which persons with intellectual disability took part.

Now I am also working with persons with intellectual disability as researchers.

One of them is Isabel.

2) What we’ve done so far

Isabel

At KNPD we have a Committee of Persons with Intellectual Disability. This Committe is split into two – the Full Committee and the Core Group. I am a member of the Core Group. There are two non-disabled persons who support us. Every year we do a barbecue at the Dar tal-Providenza which is a residence for persons with disability. Then we give them a donation to help them.

The Core Group meets every month and write the minutes and the questions for the Full Committee meetings.

We have done a lot of Committee meetings. We have talked about education, work, the rights and responsibilities of persons with disability, and where we would like to live and with whom. Many of us would like to live in flats where there are support workers 24 hours a day.
About school, we said how important it is that disabled students do not stay at home when their learning support assistant is unwell. They have the same right to learn as other students.

Then we do reports on what we talk about and we present these in seminars. There is also Disabled Persons’ Week in December. A lot of activities and meetings are held and I take part in as many of them as possible.

We have been holding Committee meetings since 2007 when we were twelve persons with intellectual disability. At first, Anne-Marie used to lead the meetings. But little by little we started leading the meetings ourselves. Then in 2009 we invited our friends to become members. Now we have thirty committee members. We created the Core Group to lead the meetings, with the support of Anne-Marie and Lorraine, who works at KNPD.

We also do live-ins to discuss and take part in meetings. The last live-in was held in Gozo. We learnt and had fun together. I took part in the meetings. Anne-Marie helped me do my make-up and Nicolette had to help me choose what clothes to wear because I couldn’t choose from the clothes I had packed!

Apart from these meetings, my friends and I also take part in lectures. These are held at University and other places. I find these lectures very interesting because they are about our lives, our work, support workers, friends, school, and other subjects.

I and my Committee friends also have opportunities to take part in radio and television programmes in Malta. We talk about our lives and about the rights of persons with intellectual disability.

Through this work we have started to learn more about research, why it is important and how it is done. Then we did research ourselves. This was about relationships and sexuality. We chose the subject ourselves and then Anne-Marie and Claire helped us do the research and a seminar to present the research to our parents and those who work with us. This is called inclusive research because it is done by people with intellectual disability with non-disabled persons.

My sister also has an intellectual disability. My sister and I wrote an article with Anne-Marie about our experiences in school. This article is in a book about inclusive education in Malta -
Roots to Inclusive Education: a question of wellbeing. In this article we talked about a lot of things, including bullying because many disabled people experience bullying.

Some of my friends wrote an article called How We Like To Live When We Have The Chance. This article was published in the British Journal of Learning Disabilities.

This is the first time that I am doing a presentation abroad. And I am the first person with intellectual disability to do so.

Little by little we are doing new things together through inclusive research.

Anne-Marie

I had started to work on increasing opportunities for self-advocacy for person with intellectual disability in Malta around ten years ago at KNPD.

Helen Attard and I had done research with persons with intellectual disability who attend day centres.

And we did a course for persons with intellectual disability to learn how to make their voice heard. This course was called Speak Out!

Little by little, opportunities for self-advocacy increased. And persons with intellectual disability became more and more able to make their voice heard. They also learnt more about their rights and responsibilities.

The Committee that Isabel mentioned was set up at the time that I was starting my Ph.D. research. So I used the work I did with the Committee as part of the research. I did interviews with each Committee member. At first they did not know why I was doing these interviews. During the interview, one of the members told me: ‘So why are we doing this, Anne-Marie?’

There were also opportunities for persons with intellectual disabilities to take part in the activities that Isabel mentioned. But it was almost always the case that persons with intellectual
disability took part in activities that were planned by non-disabled persons, including me. The research about relationships and sexuality is the only one so far which was the idea of persons with intellectual disability from the start.

3) What we’ve learnt so far

_Isabel_

I have learnt a lot from what we’ve done so far.

I have learnt about disabled persons’ rights.

At first I did not want to go. But then there was a friend who wanted me to go. Nowadays, I always go and I thank this friend for helping me.

When I started going to these meetings I learnt how to do an agenda and write minutes, and what these words mean. We have ground rules for the meetings. I also learnt to give other people a chance. For example sometimes I write the minutes and sometimes someone else does.

I learnt that we should not give up. If something appears difficult, you should continue trying and if you need help, you ask for it.

I also learnt how important it is to do research so that people know more about disabled persons.

And now I am learning how to do research myself. Anne-Marie helps me in this.
I have learnt how to give persons with intellectual disability the chance to have their say. There were times when I did not give them this chance because I spoke too much. But then I realised my mistake and next time I gave them the chance.

I also learnt how much persons with intellectual disability are capable of if they have good opportunities and if they have the support that they would like to have.

I learnt how to do interviews and meetings with persons with intellectual disability so that they can participate in full.

I learnt how to support persons with intellectual disability to write articles and reports.

And now I am learning how to do research with persons with intellectual disability as co-researchers.

To do inclusive research, one needs a lot of time as you need to do many meetings for persons with intellectual disability to learn about research and to discuss the research they are doing. You also need a lot of resources, especially transport for those who do not use the bus on their own.

In inclusive research, non-disabled persons should be careful to support persons with intellectual disability without controlling them. You have to give everyone the chance to have their say and to work in the way they want to. At the same time, you have to give advice where you think that things can be done better or more easily. It is not always easy to keep a balance between these two. Hanna (1978) describes this role as a ‘balance beam’. It is easy to make a wrong step and fall. But when this happens, you can pick yourself up and try again and not make the same mistake.
What we would like for the future

Anne-Marie

I would like very much to continue doing research with people with intellectual disability. I would like to help them do the research they want to do.

I would also like that Maltese society understands better how capable persons with intellectual disability are in speaking for themselves. And I wish that these persons have more opportunities to speak for themselves, in public and in private.

And I wish that I myself learn how to listen better to persons with intellectual disability, and understand them better while I learn more about how to give them better support to say what they would really like to say.

Isabel

I would like to do more research about persons with intellectual disability. For example, research about work, because this is a very important subject for us. Another important subject is friends, because many persons with intellectual disability do not have many friends. And research about challenging behaviour.

I would like to do more lectures at University and other places because these are interesting and it is important that non-disabled people learn more about persons with intellectual disability and hear us speak.

I would like to take part in other conferences in Malta and abroad.

I would like to do more research about disability with Anne-Marie and other people so that disabled people have more equal opportunities.
References


