



Reflections on the Implementation of an Ongoing Inclusive Research Project

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Abstract: This reflective piece is co-authored by four members of an inclusive research team, who have been working on a project that aims to create an online resource with a video curriculum vitae of individuals with intellectual disability to showcase their achievements and skills. Taking the view that conducting research inclusively is a dynamic and ongoing process, we discuss our experiences in implementing the project and the steps we took to ensure that the process was as inclusive as possible. We first present an overview of the aims of the project and what we have achieved so far. We then provide our individual perspectives on the experience of being involved in the project so far and how inclusive it has been. Together, we then reflect on the main outcomes of the project so far, on the factors that affected how we implemented it, and on how we plan to work towards the last phase of the project.

Keywords: inclusive research; employment; COVID-19; intellectual disability



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1. About Our Project

We are a team of individuals with and without intellectual disability. We are working on a project called *ĊaVetta għall-Futur: Creating video curriculum vitae with persons with intellectual disability*. The first part of the title means “key to the future” in Maltese. The idea for this project was developed from another inclusive research project on overprotection that was carried out by Isabel and Anne-Marie (Callus et al. 2019). From this research, we could see that, although there are many people with intellectual disability in Malta who are overprotected, there are also many individuals who have the support they need to develop and use their abilities. Therefore, the aim of this project is to show what many people with intellectual disability are capable of achieving when the people around them believe in them and support them.

The focus of the project is on employment. The main reason for this, as explained by Anne-Marie, was to help us obtain funding for the project. However, focusing on employment meant that we could not present the lives of people with intellectual disability who do not work and are not looking for work. On the other hand, employment is an important aspect of adult life and, therefore, very important for people with intellectual disability too (Autism Society 2018; Garrels and Sigstad 2021).

By creating these video CVs, we could show how people with intellectual disability succeed thanks to the support of parents and other family members and those who work with various service-providers, employers and colleagues. People with intellectual disability also succeed thanks to their own efforts and abilities, as shown in the videos. Creating CVs through a video also means that we used a medium that is accessible for people with intellectual disability and which can be viewed many times (Goodwin et al. 2015). The videos are available for free viewing on YouTube.

Following ethical approval from the University of Malta, we issued a call for applications and held interviews with those who applied. After lengthy discussions, we chose the ten individuals who we agreed would represent the widest variety of experiences of people with intellectual disability in the employment sector.

So far, we have produced ten video CVs of people with intellectual disability who work or are looking for work. Those who work do so in different places, including a local council, a hotel, a factory, in residential aged care and in a disability organisation. These video CVs also show other abilities of the ten individuals with intellectual disability, especially in sport, handicrafts and the performing arts. We have included some stills from four of the videos.

In the second part of the project, we created a video that provides disability equality training (DET) ([Carr et al. 2012](#)) for employers regarding people with intellectual disabilities. As persons with intellectual disability, Isabel and Cristina also provided their reflections as experts by experience ([Care Quality Commission 2021](#)). We also created instructions on how to create a video CV. In the final part, we plan to produce more video CVs to show a wider range of abilities and achievements of people with intellectual disability in Malta. After the end of the project, we plan to analyse the content of the video CVs in an in-depth manner and discuss this content together, along with the possible impacts of the project.

These videos show the capabilities and achievements of people with intellectual disability and how much they can succeed in an environment in which they are provided with the support that they need. The implementation of the project itself is also a testimony to this dynamic and ongoing process, since the four members of the team contributed with different skills and areas of expertise. We also supported each other where needed. We made sure that all members of the research team were actively involved in each phase of the project and that any written material was produced in an easy-to-read format. We pooled our ideas about how to develop the project idea, obtain funding and implement the project, and, as [García Iriarte et al. \(2021\)](#) describe, we provided each other with different “forms of material, social and emotional support” (p. 16).

In the next sections, each of us reflects on our experience in implementing this project.

2. Isabel

I work as an office support worker at the Commission for the Rights of Persons with Disabilities (CRPD).

I think that this project is very important because, by making these video CVs, we showed that people with intellectual disabilities can work with different people: those with a disability and those without. This project also means a lot to me because the people with intellectual disability who took part do many different things. Many of them do not mention work only, they also mention drama, music, pottery, dance, sport, handicrafts and going out with their friends. With these videos, we met a lot of people with intellectual disability who were not overprotected and had a job. But when we carried out research on overprotection, as mentioned above, we met people who were overprotected and did not work. I think that this shows that when a person is not overprotected, they can do a lot of things.

When Anne-Marie and I wanted to do this project, we had to find funding. We tried to get funding from private companies but it was difficult. Then, with COVID-19, it became even more difficult to do so. I suggested to Anne-Marie to apply for funds from a programme called PEKTUR, which is run by the CRPD where I work. This was a very good idea because we got funds for ten video CVs in 2020 and then, in 2021, we had some more funds to do the DET video. I am happy that I made this suggestion because it meant that we could work on our project.

The fact that we worked in a team of four researchers was very helpful. We had different ideas that we could use and there were more people to do the work. I had already worked with Anne-Marie on the overprotection project and we both felt that, since this new project involved much more work, it would be better to have a bigger team. We therefore

invited Cristina to join us so that there were two co-researchers on the team. This way we could share our experiences together. Once we obtained funding from CRPD, Sandra also joined us and we had someone who specialises in media on the team as well.

There were some parts of the project that I enjoyed and others that I didn't. After we received the applications from those who were interested in taking part, we held interviews with them. I really enjoyed holding these interviews with the applicants. There were the four of us doing these interviews. We did many of them online because of the pandemic, but I still enjoyed them and also our meetings. We held some of our meetings in person—for example to choose the ten participants—and other meetings online, for example, to discuss with the ten chosen participants about what to include in their video CVs.

What I didn't like was the fact that Cristina and I could not go to most of the filming sessions. This was because of the COVID-19 restrictions, especially because most of the filming had to be done at the place of work of the participants. The employers could only accept a few people to attend; those doing the filming and Sandra or Anne-Marie to supervise. There was an opportunity for Cristina and I to attend a long filming session in which different persons were being recorded speaking. I really enjoyed this. If we could have done this more often, the project would have been more inclusive.

It was very interesting to take part in the DET video. During the filming, I met new people. I was filmed at the office where I work. It was great to have support; for example, the script I had written was printed in a large format so that I could read it during filming. It was also a great experience for me and Cristina to speak in this video because, in this way, we were able to help the people who watch the video learn from our experiences and we were able to share our thoughts about the importance of employment for people with intellectual disability. I hope that we manage to do more interesting video CVs and maybe even make one for myself.

3. Sandra

As the Communications Manager for the Commission for the Rights of Persons with Disability (CRPD), my role on the *Cavetta għall-Futur* team was to share my technical skills on how to produce videos, as well as to represent the Commission, which part-funded the project. On a personal level, I am also the mother of a young child with Down Syndrome, so the project was doubly meaningful to me because any strides made in the world of intellectual disability, employment and representation have direct and personal implications for my daughter's future.

The project set out to be as inclusive as possible by sending out an open call to all people with intellectual disability on the Commission's database, inviting them to apply. We received 20 applications and interviewed all the applicants. At this point, the pandemic was already presenting challenges, as people living in institutions were not allowed to leave their communities; interviews with these applicants were therefore carried out online.

The four members of the team discussed the applications and we selected ten which seemed to be the most representative across as broad a range as possible, factoring in age, gender, residence, disability, ethnicity, employment status, and skill level.

Already at this point, it became clear to me that the project, in its conception, was nothing short of extraordinary. We had embarked to create video CVs for persons whom society would have no trouble writing off in a few moments, especially in an employment context, where value is generally determined by a narrow definition of productivity. We therefore re-interviewed the ten selected applicants with the aim of uncovering layers of skills and aptitudes of each one. In this way, we came up with a script for each person that included all the brushstrokes; not just traditional employment skills, but also soft skills such as being a team player, creativity, dedication, punctuality, kind-heartedness, discipline and perseverance in reaching a goal.

The final result is, I think, moving and extremely eye-opening at once. Not only do most of the people in these videos have jobs they love and are good at, but they are also loved and valued by their colleagues for who they are and what they bring.

In retrospect, the main challenges to the process were brought about by the pandemic. For instance, filming had to be restricted to the presence of one team member. Team meetings also had to be moved online, with the corresponding loss in physical participation and teamwork.

There were other challenges intrinsic to the nature of the project too. The project includes participants who are non-verbal, so we had to be creative with their scripts, making sure that their skills and qualities were still articulated by their colleagues and tutors. Rather than having a centred narrative articulated by a protagonist, their stories were related mainly by the voices of those around them, which turned out to be equally moving and effective.

Taken together, however, the videos are a set of voices of people with intellectual disability and those who support them, which not only show the richness of the qualities and skill sets these persons bring but are also profoundly human. They are a reminder that, even at the workplace, where dealings are often done solely in terms of productivity, given the right setting and support, people with an intellectual disability truly have a lot to offer, not just in the work they do but also in the qualities they bring, which can change the dynamic of a workplace to one that is ultimately far more inclusive for all concerned.

4. Anne-Marie

I am a lecturer in disability studies and my main research interest is the empowerment of people with intellectual disability, including through inclusive research. This project is different from other research projects that I have been involved in so far. In these projects, my focus and that of various co-researchers has mostly been on the difficulties encountered by people with intellectual disability. With this project, we could focus only on the positive stories of different people with intellectual disability. It is important to show positive aspects of the lives of persons with intellectual disability. Another positive experience came from working in a team of four, with each of us having different types of expertise and different perspectives.

Getting funding was not easy. We originally wanted to have a series of short videos of the life stories of different persons with intellectual disability in Malta. However, it was difficult to find funding for this idea. We were advised that a focus on employment would be easier to fund. The idea of producing video CVs made the project more attractive to funders, even if we did not manage to get all the money we hoped to get all at once. We could only choose participants who were in employment or were looking for work. This meant not being able to choose people who were very young, as well as older people with intellectual disability, and those who—for different reasons—were not involved in employment. We did not leave them out because they do not have valuable lives. We are aware that focusing only on individuals with intellectual disability who have noteworthy achievements can feed into the ableist narrative that disabled people's lives are only worth living when they have achieved success (Campbell 2008). However, the project did become an excellent opportunity to show the employment experiences of the individuals whose video CVs were created. Many of them also have other skills, which we included in the videos because they are important as well.

Working inclusively was not easy because of the COVID-19 pandemic. One challenge was to do interviews and meetings online as much as possible. Online meetings between us four were not a problem because we all have access to the internet and learnt how to use online meeting platforms. However, some of the persons with intellectual disability who applied to take part did not have internet access or they did not have anyone who could help them use the internet. Therefore, we held some interviews in person.

Another challenge came with the filming of the video CVs. There was a lockdown in Malta and work on this part of the project was put on hold. Once people were getting vaccinated, we could start again. However, there were a lot of restrictions and we could not all attend the filming sessions, especially when we went to the participants' workplaces.

Fortunately, we had one long filming session at the University of Malta where all the research team could attend.

The delay in starting the filming also meant that we had a very short time in which to finish the first phase of the project. If we had delayed any further, we would have lost the funding. As [Embregts et al. \(2018\)](#) state, doing research inclusively needs a lot of time and we had to take some shortcuts. Most of the editing was done by Sandra and myself. However, we all watched the final version together to make sure that everyone was happy with the video CVs. For the DET video and the information on how to make a video CV, we had more time to work inclusively. In line with the principles of inclusive research set out by [Johnson and Walmsley \(2003\)](#), we developed the content of the DET video and the information on how to make a video CV together. With regard to the former, we agreed together on the speakers to be included in the video. Additionally, Isabel and Cristina participated in the video itself. As for the latter, we built the information together and made sure that it was easy-to-read.

We now have funds for the last part of the project and we need to make sure that we work more inclusively. I think it will also be useful to keep a diary in which the four of us reflect on how we are feeling about the way we are working on the project. That way, we will be able to reflect further on the inclusive research process once the project is ready, and use these reflections in the article that we plan to write together, once the project is ready.

5. Cristina

I work in the Head's office in a school. I help the secretaries of the primary and the secondary schools. Before COVID-19, I worked in the reception, sorted out books in the library and did office work like shredding, photocopying and laminating. Now I work in the office only and am doing new work as well, such as sorting students' records in alphabetical order and also doing work on the computer.

When Anne-Marie and Isabel asked me to join them to work on this project, I did not have any experience in research. I learnt a lot from the project. I learnt that doing research is a lot of work but it is worth it. I learnt a lot about the lives of other people with intellectual disability and I learnt how to interact with different types of people. I also learnt how, by doing research, we can increase awareness of the rights of individuals with intellectual disability.

After we chose the participants, filming had to be done. We could not all go to the filming because of COVID-19 restrictions. However, Isabel and I attended a filming session where different participants came to talk about their life and the people who knew them talked about them. We really enjoyed watching the filming being done.

Isabel and I did not apply to have a video CV for ourselves because we are part of the research team and coordinating the project. We wanted to give other persons with intellectual disability the chance to have their video CV made. However, when we saw the filming being done, we really wanted to have our own video CV. It was very interesting and I would like to have my video CV made. I would like to show other people what I am good at and to show them how capable persons with disabilities are. That way, we can educate other people.

When the videos were ready, we met to see them. We really enjoyed watching the video CVs. We could see that people with intellectual disability are capable of doing different types of work. There are those who work in factories or in offices, those who do cleaning work, kitchen helpers and also other types of work. There are also many people with intellectual disability who have other skills. There are people who are actors, dancers, play a musical instrument or handicraft. These activities help them to continue developing their abilities. I spoke about these things in a video we did to provide training for employers, so that they know that they can employ people with intellectual disability.

There is now more funding to do more video CVs and I will be able to apply to have my own CV made. I hope I get chosen. It will be very exciting! I hope that with the new video CVs, we will be able to show even more abilities of individuals with intellectual disabilities, because we are all capable of doing different things. For example, I paint

pictures and had an exhibition in my hometown with my paintings. There are other things I used to do before COVID-19. The same thing happened to other people with intellectual disability: they had to stop some activities because of COVID-19. I hope that with the new video CVs we can still show the different types of work and activities that we are capable of doing.

6. Conclusions

These videos can be used by scholars and students conducting research about individuals with intellectual disability. They can also be used for teaching and training purposes for employers and colleagues of people with intellectual disability, as well as professionals who work with the latter. The videos can also be a useful tool to make parents and other caregivers aware of what many individuals with intellectual disability can achieve when they are given the right opportunities, and support and can also be a source of empowerment for people with intellectual disability.

Reflecting on the way we carried out the first two parts of the project has been very helpful for us to identify the strengths of our team and the aspects of our work on the project that need improving. These reflections can also be helpful for other inclusive research teams and the main conclusions are presented below.

The importance of having the right opportunities and support was something that we experienced directly as an inclusive research team. Through working together, we could see how valuable it is to appreciate the experiences and perspectives of different people. We also saw how providing each other with support made our team stronger. The fact that we get on well with each other and enjoy working with each other was also a very positive factor.

The changes that we had to make show how conducting inclusive research has to adapt to the realities of the world we live in. The most significant changes were the decision to focus on employment related activities so as to obtain funding, and the adaptations to how we carried out the project due to the COVID-19 pandemic. Being flexible in carrying out inclusive research is important, but it is vital not to make too many compromises, otherwise it is easy to lose sight of the original intentions of the project, or to end up not working inclusively at all.

We are really looking forward to the next part of our research. We plan to keep a record of our work and what we think about how we are doing the work. That way, we can find ways of being more inclusive. Moreover, once the project is finished, we can reflect more in-depth on the inclusive research process. We also want to work on making sure that these video CVs are watched by as many people as possible, so that the project achieves its aims.

See [CaVetta għall-Futur \(2020\)](#) for the link to the videos from this project.

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of the University of Malta (5904) on 29 July 2020.

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