



ANDREW ON WEDNESDAY

We need to start from the disabled person's aspirations

I have always been passionate about the disability sector. It goes back to some thirty or so years ago when I used to hitchhike two or three times a week from the Siggiewi Pjazza to go to Dar tal-Providenza, first as part of a community work programme I was involved in and later because I had developed some beautiful friendships that I treasure till this day. After that, I studied, researched, worked, published in the field of disability, always recognising that as an ally I have a role to accompany disabled people who are left at the margins of society.

caught up with Dr Anne Marie Callus, Senior Lecturer, Head of the UM ACCESS Disability Support Unit and Acting Head of the Department of Disability Studies within the Faculty for Social Wellbeing.

With Dr Callus, I spoke on whether there is more acceptance of disabled people now than half a century ago. She said that there is more realization that the difficulties faced by disabled people do not arise solely from their impairments and that society plays a part in creating obstacles. She also spoke about the fact that there is more recognition of disabled people's rights. Quoting her, '...in principle there is greater acceptance and more awareness. However, there is still a general lack of understanding of what all this means in reality and how it can be applied in practice, in the fine detail of everyday life'. She goes on to say that, '...one area where there is still a lack of understanding is the importance of disabled people living their own lives on their own terms, and what needs to be done for this to happen.'

Society in a way has evolved in this sector.

She also pointed out that the fact that disabled people's rights are now enshrined in Maltese laws, the fact that there are various measures and services that promote independent and community-based living, the fact that we have inclusive education and support for employment, and so on, means that disabled people have access to better quality of life than they would have had 50 years ago. Dr Callus goes on to say that '...however, making adjustments for disabled people to be included in various aspects of community life is still very often seen as something extra that needs to be done, a burden even. And sometimes these adjustments are seen as being optional extras despite being made obligatory through legislation.' One would almost expect a sense of gratefulness when such actions take place.

An issue that has always fascinated me is whether disabled people still lie at the margins of society. Dr Callus said, '...disabled people are physically more present in society than they ever used to be and opportunities for disabled people have been steadily increasing over the past few decades. But disabled people are still at the margins. Without accessible road infrastructure, a truly accessible and reliable public transport service, a wider availability of personal assistance services, access to information and communication, and so on, it is difficult for disabled people to



Dr Anne Marie Callus

be included in society, to be able to assume that they can engage in community-based activities that so many of us take for granted.'

Another matter that keeps coming to mind is whether society interprets disabled persons as an opportunity or otherwise. Dr Callus states that it very much depends. She says, '...whilst there is greater awareness of the contribution that disabled people give to society, that they can learn and work alongside non-disabled people and that a significant number of people who have made a success of their lives have a disability. The argument that disabled people should be valued because they too make a contribution is also used'. She goes on to say that, '...this argument is dangerous for those disabled people who, because of the complexity and severity of their disabilities (especially if they also have a profound intellectual disability), cannot be expected to give a tangible contribution to society. Their lives need to be valued alongside those of others. Disabled people should be valued, and not seen as a liability. People should not simply be measured simply because they can give an economic contribution but primarily because they are human beings in their own right.'

When we think about disabled persons we also think about 'service provision'. I discussed this matter with Dr Callus.

Dr Callus states that, '...there are areas where there is a lack of services, especially when it comes to supporting disabled people to live independently'. She claims that this is the case both in terms of support within their homes and assistance to go out and about. She expands on this issue and says that, '...it is not simply a question of how many services are provided, but how they are

provided. We need more personalized services. We need to start from what the disabled person's wishes and aspirations are, supporting the person to identify and articulate them if necessary, and provide services that cater for the support needs that they have in order to realise those wishes and aspirations.'

Another issue that I discussed with Dr Callus was that disabled people are often depicted as 'objects' of pity and charity. She says, '...disabled people are still seen by many as objects of pity and charity. For many people, words like 'msieken' and 'jahasra' seem to trip off the tongue when they are talking about disabled people. Such an attitude stops a person from providing the adjustments needed for disabled people to be able to enjoy their rights. Worse still, it can dehumanize them.' Callus goes on to argue that an extension of the pity and charity perspective is in viewing disabled people as living happily and succeeding in life 'despite their disability'. There is almost an assumption that living with a disability is tragic and inevitably leads to unhappiness and failure.

This issue is further perpetuated during telethons and in the 'use' of disabled people to collect money. This is her take on the matter, 'I understand that non-governmental organisations that provide services for disabled people need to raise funds to keep their services running. I appreciate that they provide vital services that complement those provided by the State. So it is a question of how disabled people are portrayed in these fundraising events. If it is shown how funding can help empower disabled people and what is needed to remove disabling barriers, then it would not be problematic. However, sometimes attempts to do this are not wholly successful because of the way that the general public still tend to perceive disabled people through the lens of pity and charity.' She goes on to explain that, '...let's say for instance that an organization is raising funds to provide vocational training for persons with intellectual disability. The fundraising includes an interview with a person with intellectual disability who is in employment. But then the reactions to that interview include comments like 'how sweet' or 'it's amazing that s/he can work even if they are disabled'.

In terms of research the Department of Disability Studies focuses on a mix of areas, namely inclusive education, employment, sexuality, gender issues, assistive technology, the empowerment of

people with intellectual disability, and cultural representations of disabled people. Their courses help to address the gap that still seems to exist in Maltese society about the complex nature of disability, about the perspectives of disabled people which all too often goes unheeded, about the role that society itself plays in creating disabled barriers, and about what can and needs to be done to address the problems that so many disabled people in Malta are still facing in their everyday lives.

Dr Callus says, '...we also have postgraduate students who are working or have worked on a wide variety of topics in addition to the above, including mental health issues, sibling relationships, play for disabled children and leisure for disabled adults, sport, disabled youth, among others. There are also post-graduate dissertations that explore the life stories of different disabled persons and of their families.' The Department of Disability Studies is currently offering a Higher Diploma in Community Access to Disabled People (it is pegged at the level of the first year of an undergraduate degree) and is primarily aimed at disabled people and people who live or work with disabled people to have a better understanding of disability issues, societal factors that create disabling barriers, and ways and means of removing these barriers. The Department also offers a Masters in Disability Studies, a part-time evening course spread over three years. Anyone who has a first degree in any subject can apply for this Masters.

Dr Callus explained that, 'Disability Studies is in itself interdisciplinary and having students who have graduated and are working in different areas is great as it is a means of bringing together different perspectives. To date, most of our students have been disabled people, parents of disabled people, allied health professionals, educators and persons who work in organisations that provide services for disabled people. Most of our students therefore already have some knowledge or experience of disability but when they start the Masters they realise how much more there is to know, especially in terms of how society itself creates disability, often unwittingly. What they learn, they apply to their work, to do it more effectively, or to move on to a different career'. The Department also offers MPhil/PhD programs.

The course overview can be obtained from this link: www.um.edu.mt/courses/overview/P/MADBSPET2-2018-9-0.

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