

Marthese Deguara: an appreciation

From The Sunday Times of Malta, 28 June 2020, p. 50.

On the 10th June, Marthese Deguara passed away. For many working in the disability sector in Malta and for her family and friends, her passing is a huge loss. I got to know Marthese in 2003 when I was working at the National Commission Persons with Disability (KNPD) and we had launched a plan to promote the self-advocacy of persons with intellectual disability for the European Year of Disabled Persons. At first it was a top-down approach – a group of non-disabled people deciding that persons with intellectual disability should speak for themselves. Marthese was among the first persons with intellectual disability to participate. Her valid contribution to KNPD's work on self-advocacy helped me and all those involved realise just how much persons with intellectual disability can achieve if they find themselves in nurturing environments, and how important it is to let them lead the way while providing them with the support that they need.

Marthese challenged all the mistaken stereotypes of people with intellectual disability not being aware of what is going on around them and being helplessly dependent on others. She could reflect on her life and identify her wishes and aspirations, and was very much aware of what was working in her life and what could be improved. Through her involvement in various self-advocacy activities, she also proved herself to be a very capable and articulate speaker. Like everyone else, the more she was involved in different events, the more she honed her skills as a public speaker. She spoke in many events organised by KNPD, including the Disabled People's Parliament and various seminars and conferences. She was also a member of KNPD's Consultative Committee of Persons with Intellectual Disability. Additionally, Marthese delivered talks about self-advocacy and disabled people's rights to students at the University of Malta and in disability equality training sessions. She was also the secretary of the self-advocacy group *Grupp Flimkien Naslu*.

Whoever had the good fortune of knowing Marthese will always remember her for her joyful character, her genial smile, her mischievous chuckle and her charm. She was also a very caring person: always ready to help disabled people who had higher dependency needs than hers, always asking after people she knew, especially when they were unwell. She loved going out, socializing with her friends and making new ones – something she had to give up on lately because of the lockdown.

Marthese touched the lives of her family, service-users and staff at Mtarfa Day Centre, *Dar il-Kaptan*; of staff at the Commission for the Rights of Persons with Disability and former KNPD staff; of members of *Grupp Flimkien Naslu* and other disability organisations she was involved in; of members of the prayer groups she frequented; of the staff and residents at the Mtarfa Home for the Elderly; and of the many friends she made along the way. We all have our anecdotes about Marthese which we will cherish as we remember the joy she brought into each of our lives.

We will always miss Marthese. Our lives are emptier without her presence, but her legacy continues and is an inspiration for other self-advocates, those of us who support their work, and all those fighting the good fight for disabled people's rights. And we know that she is in a better place now and that Heaven has won itself a most charming soul.

Anne-Marie Callus