



CENTRE FOR AUTISM
MIDDLETOWN

Interview conducted by Mr Gary Cooper OBE, Middletown Centre for Autism, with Professor Mary McAleese, former President of Ireland.

- 1. Enable Ireland’s “Helping Hands” programme and Middletown Centre for Autism’s, “Autism, The Facts and How to Help” are examples of effective voluntary and statutory sector support for parents of children just recently diagnosed with autism. In your opinion, how can these sectors work better together to support and meet the acute needs of families of children with autism in Ireland?**

Avoid sectoral silos. Ensure communication between the sectors is fluent and effective and that the support for parents and children is non-bureaucratic, easily accessible, based on best-practice and makes them feel supported. The parents of a child recently diagnosed with autism have already been through a nightmarish web of worry from the moment when they first began to be concerned that all was not well with their child. The diagnosis may have brought to a conclusion that grinding uncertainty but it also opens up a welter of new worries about the child’s future, about their own coping skills, about how much real help and guidance is available.

- 2. What do you see as the issues of critical importance for parents and professionals working and living with children and young people with autism in Ireland, today?**

The need for tangible reassurance about the present and the future is enormous for so are the fears. Enable Ireland and Middletown Centre for Autism are part of a growing infrastructure of professional assistance designed to share the burden of care, to inform and sustain parents over the lifetime of their child, to create the educational and social models which promote the development and dignity of autistic children, to promote public awareness of autism, to scour the world for best practice and to advance research into this complex and difficult condition.

- 3. How can we ensure the empowerment of children and young people with autism to maximise their potential and also enable their parents, families and teachers to support this objective effectively?**

The creation of a culture which is comfortable with children and young people who communicate in ways that may differ from the norm is essential. The voices and views of young people with autism who communicate whether verbally or non-verbally need to be heard, seen, mainstreamed.

4. As a former President of Ireland and advocate of inclusion how do you feel society can contribute to the greater inclusion of children and young people with autism?

There are so many levels of support needed from local to national level: beginning with the neighbour, family and friends who surround the family with loving care and on-going reliable practical support, who regularly offer to babysit and let parents have a night out or go shopping; the employer who gives a job to a young adult with autism and ensures that the workplace is a comfortable and encouraging place for him or her; the community group that fundraises for facilities and research or organises local child-care, youth groups or respite; the volunteers who help families adjust their homes to the need of the child; the young adults who make working with autism their vocation whether as teachers, counsellors, health professionals, researchers, advocates and the local and national government which funds support services and responds to persistent and informed advocacy. Above all as a society we need to listen carefully and often to those living and working with autism, so that we are fully aware of how we need to respond to cherish these children of our nation equally.

5. Meaningful employment is such a strong component of adult life. Have you any advice on how to work more closely with employers and / or further and higher education providers to ensure that they appreciate the skill set of the young people with autism with whom we work?

The best advert and advocate for employing young people with autism or admitting them to higher education is to showcase the success stories of which there are many. Fear, prejudice, complacency can often get in the way but more often than not what holds back the opening of the door is the door-keeper's concern that he or she will not have the skill or support to successfully integrate a person with autism into the workplace or classroom. That reassurance is essential. The support in whatever form is required needs to be in place, whether by way of training, advice, help-line, mentoring, on-going supervision, special resources etc.

6. Autism need not be a barrier to success in life: how can we develop further a platform where Ireland's successful and innovative young people with autism can be heard and their ability appreciated?

The Special Olympics created a tremendous platform which revealed the talent, enthusiasm, courage, determination and sheer exuberant love of life of the participants. It also unveiled a legion of spirited communicators whose sporting ability is now appreciated in ways that it was not previously. Replicating that in other spheres of life where young people and adults with autism have quietly excelled is crying out for notice. There is a role for regular national showcases of the excellence achieved by our citizens with autism that goes on daily under the radar. Initiatives like recognition and awards ceremonies, (Gaisce (President's Award) is a good case in point where the work is already being done). The positive power of that witness is waiting to be harnessed.

7. Who, from the field of autism, has inspired you when you have heard them speak? What was your key “take home” message?

It was at an art exhibition in Dublin where the artwork of youngsters with autism was on show. Based on a successful Spanish exhibition called Desde el silencio, it too was designed to break the silence through art. I met a couple whose son’s stunning painting was on view. It showed a family including a baby in a pram. Through that painting, the parents had become aware for the very first time of their son’s profound feelings for his new-born sibling. Until then they had no idea how he viewed this change in family life. It was a precious gift to them and the message I took from their conversation was how vital it is that we do not settle for silence or presumption but pursue with every tool available ways of giving a meaningful voice to those for whom speech is difficult or impossible.

8. As a unique organisation, designed to work over the 32 counties of Ireland, across two political and legislative jurisdictions, how do you see the Centre’s future?

The original idea for the Centre focused on the needs of children and their families. Those needs are the same in all parts of the island and it was inspirational to create a cross-border facility, underlining the commonality of concerns and proving the power of partnership. The reasons why the Centre was created are as valid as ever and the needs as great and urgent as ever. From the outset, it has always challenged and transcended silo mentalities to ensure the fullest free flow of all the resources needed to provide the best outcomes for children with autism and their families. Brexit notwithstanding, Middletown Centre for Autism is one place where the soft border shows its unique and irreplaceable worth.