

## **Citizens' Assembly on Gender Equality**

### **Personal experience panel – January 2021**

#### **Aisling Glynn**

Children with disabilities, adults with disabilities and older people are the three groups of (potential) care recipients. Many of us will be required to provide care or will require care at some point in our lives, whether through illness, injury or the process of ageing. According to the most recent census, 1 in 7 people in Ireland have a disability. It is estimated that over half a million people in Ireland provide regular unpaid care. These statistics apply to men and women. They apply to all of us. As a society we need to care more about care. I am contributing as a disabled woman who is in receipt of formal and informal care. I have a physical disability and use an electric wheelchair.

Women and girls have been more involved in caring than men and boys. Much of the care I have received and continue to receive is from my family. Personal care is only one aspect of care. I have received equally important care and support from male family members. As a child, both my parents worked outside the home and both were responsible for caring for my siblings and I. When I was diagnosed with a physical disability and as my needs increased, my parents, together, continued to support and care for me. This continued throughout my time at school, at University when I lived away from home, and when I returned home to live with my parents having secured a job in my home town. During my time at University, I had a personal assistant who assisted me in my student accommodation and I learned the importance of a personal assistant in allowing me to lead an independent life. During this time, one of the most significant providers of care was Tony. Tony was a father and grandfather at home. At work, Tony's role was to provide transport to students with disabilities, to and from lectures and around campus, but in reality, the care and support he provided was much more than that. He drove me to many medical appointments. He knew which books were too heavy for me to carry and which doors were too heavy for me to open. He was a carer in the true sense of the word.

Having qualified as a solicitor I returned home to live with my parents. The support, care and encouragement I have received from my family has allowed me to realise my goals in terms of education and securing a job. I continue to rely on my family every day, to get to work, to prepare meals for me, to drive me to appointments, to meet my friends at restaurants.

Although I see myself as independent, the reality is that I am dependent on my mother, father and sisters and on the informal support that I receive from friends and colleagues. There are disabled people in Ireland like me in their twenties and thirties living in nursing homes. I am acutely aware that without the support and care I receive from my family, that could be my story. We need to support people to live at home and in the community. We must acknowledge the immense contribution of those who provide regular informal and often unpaid care, but more importantly we must support those providing care by increasing care and support services within the home.

Covid-19 has shown how essential those who provide care are to the well-functioning of society. We have shown our appreciation for those providing care and perhaps we now recognise the value of care work somewhat more. We need to continue to raise awareness and to promote the value of those providing care, including informal care/care within the family. Awareness is the first step in bringing about change. We need to include the voices of those who provide care and those who receive care and to promote their inclusion in all decisions and policies relating to care. I recommend the development of a refreshed National Carers' Strategy.

COVID-19 has changed how many of us work, with more employers embracing flexible and remote working. Remote working has presented many opportunities for people with disabilities who may have encountered barriers to work including lack of transport and inaccessible workplaces. Now is the prime opportunity to introduce flexible working policies that support all men and women and that allow them to balance their home and work lives.

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. Ireland has a duty to promote the rights of persons with disabilities and their caregivers, in line with the UNCRPD. The UNCRPD requires change, from viewing people with disabilities as receivers of charity to viewing people with disabilities as people with rights who are capable and who are active members of society. The UNCRPD identifies 26 important rights that impact the lives of persons with disabilities and it should inform the development of all policies, services and supports relating to care. Article 23 on respect for home and family has particular relevance. Key articles include: equality and non-discrimination, awareness raising, accessibility, independent and adequate standard of living and social protection, education, employment and health. The UNCRPD promotes equality and independent living within the community. It promotes person

centred supports, independent living and community living as opposed to institutional care.

We need to reflect on our own attitudes and to challenge negative perceptions. We need to avoid using terms such as 'burden' and recognise the abilities of all people. My experience is that negative perceptions and attitudes still exist towards people with disabilities in Ireland. People with disabilities are still often seen as incapable, or certainly as less capable. We need to embrace the social model of disability. This model says that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets, or they can be caused by people's attitudes to difference, for example by assuming disabled people can't do certain things. Terminology and language should be carefully chosen to reflect the values of equality.

Although I have a significant physical disability and require ongoing support or care, I have learned to focus on my abilities. As I see it, I require support with day-to-day activities I can't physically do myself. This support or care is provided by my family and I also receive a personal assistance service. I have a disability that requires 24 hour support. Like many others, much of that care is provided by my family. There are 24 hours in a day. According to recent figures 44.41 per cent of those in receipt of personal assistance hours receive an average of 42 minutes a day of personal assistance. Think about the reality of those 42 minutes. We need to acknowledge the immense contribution of those who provide regular informal and often unpaid care. We need to increase personal assistance hours and care and support services within the home.

Home help is a term that is widely used and understood. We need to understand and define models of care, and in particular personal assistance and person centred supports. A personal assistance service is about providing disabled people with the necessary supports, both inside and outside of the home. Personal assistants allow disabled persons to fully participate in an inclusive society as equals. Choice and control in relation to housing, transport, education and employment. For me as a disabled person, independent living can be best achieved by the provision of a personal assistance service. I recommend that we invest in, define, promote and legislate for the right to personal assistants for persons with disabilities. This is also necessary to alleviate the strain on families, for example where there are ageing parents or to allow family members to balance their own careers with their caring obligations.

## Summary of Recommendations

- Development of a refreshed National Carers' Strategy that includes actions to deliver increased care and support services within the home. Resources must be directed to ensure that people with disabilities can participate in society as equals.
- Introduction of flexible working policies that support all men and women and that allow them to balance their home and work lives. Flexible working benefits those who provide care and also persons with disabilities.
- Increased personal assistance hours and care and support services, including legislating for the right to personal assistants for persons with disabilities.
- The UNCRPD and social model of disability should inform all policy discussions and decisions. All decisions in relation to disabled people's lives must be made in direct consultation with disabled people. Terminology and language should be carefully chosen to reflect the values of equality.
- Caring is not exclusive to women, yet in line with enduring stereotypes women are seen as the default carers. My experience has shown that women and men being co-responsible for care leads to better outcomes for all within the family.