A Commentary from Disability Activism in Israel

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I participated in this research because I am a mother of four children and grandmother to twelve grandchildren. My youngest daughter, Nitzan, is a young woman with Down syndrome. I was 36 years old when I became pregnant with Nitzan and so because of my age was not offered any NIPT/NIPS testing. At that time only women over the age of 37 were tested in Israel. Hence, we were completely unprepared physically and emotionally for the arrival into our lives of a baby with Down syndrome.

The name we chose for our daughter, Nitzan, means a flower bud and now 40 years later I can see how appropriate this was for her. Nitzan has been married for almost twenty years to her husband Sagi, who also has Down syndrome. They live together on a kibbutz in a warden assisted hostel with 13 other young people. They go to work every day and enjoy a full range of social and creative activities. Nitzan and Sagi are a loving couple. They care for each other, support each other and they are great together. I often say to people how we all learn from observing their relationship.

As well as being a parent, I am also the head of an organisation in Israel called *Atid,* which means *Future* in Hebrew. In our organisation we encourage preventative medical practice and support the view in Israeli society to test for abnormalities during pregnancy. With today's medical improvements we should be, and in Israel we are, using such methods as widely as possible, including NIPT/NIPS. Testing allows parents to consider their options regarding a pregnancy termination but also provides an invaluable opportunity to be informed and prepared for outcomes should they choose to proceed. I too encourage and support this approach. If a baby is born with Down syndrome (there are approximately 120 each year in Israel), *Atid* strives to do everything to support the whole family and provide the best options for a decent quality of life. This can include home visits, telephone and group support, helping with government agencies, and so much more.

Down syndrome can occur in any pregnancy. The consequences are enormous for the immediate family and their extended network. The impact on parents, siblings and their wider circle is huge. For some parents, the situation is overwhelming and they decide to leave their baby in the care of others; the hospital, foster care and/or adoption. Not everyone can cope with the immense strain of having a child with Down syndrome and families can disintegrate at different stages, causing further ongoing issues. The whole family needs support and encouragement from those around them. I am fortunate enough to have this, but many do not.

Becoming a mother means accepting that your priorities will be different from those you had before. Caring for a Down syndrome child, such as my daughter, requires a huge amount of time and commitment. It took me a few years before I eventually realised that we only have one life and while I would try and do everything to help Nitzan, I also needed to live my own life. I was a working mother and a student. I wanted to encourage Nitzan to be as independent as possible. I wanted her to be responsible so she could live a fulfilled, functioning life as she grew older. Finding the balance between her needs and mine was a constant juggling act, and remains so even today. As a result of publishing two books, plus my long-standing involvement with *Atid* and my active role in the management of Nitzan's and Sagi's hostel life and activities, I am now a recognised name in the field of Down syndrome in Israel. Consequently, over the years I have been approached many times for advice and guidance by couples and families dealing with the issues surrounding a diagnosis or life with a child with Down syndrome.

I am often asked whether if I had known I was carrying a baby with Down syndrome I would have considered terminating the pregnancy. In principle I do support termination of such a pregnancy, but this is not a fair question and I cannot give an objective answer. My daughter is an integral part of our lives, not an abstract, hypothetical situation. To those that ask whether they should terminate their Down syndrome pregnancy, my advice is straightforward. Always consider your opinions and values. If you have support, patience and strength, and you can rise to the challenge, then your life will be certainly interesting, with many successes but also difficult moments and failures. Ultimately each person needs to make their own decision on how to proceed.

Further to this, parents and the wider family not only need to come to terms with their situation but they also need to prepare themselves for the struggles that await them in the wider world. Family, society and many institutions, including education, will all be challenges. They require a strong and well-prepared nuclear family with a “thick skin” to act as a protective wall around them and their child. Even today people and agencies can be ignorant and ill-informed. For the whole family it is a lifelong commitment to ensure that a child with Down syndrome can be supported in the most appropriate and stimulating way. Ideally the state should fund this care, but parents cannot rely on this and need to prepare for when they may no longer be able to be the primary carer for their child.

When I look back on all that we as a family have achieved and gained in our journey with my daughter, I know with all my heart that she and those living with her in her hostel have brought a huge contribution to wider society. What could have been achieved if she and her group had not been affected by Down syndrome is something we will never know. As a society with NIPT/NIPS options and other medical testing we have an opportunity to minimise disability, but just as importantly, we also have a duty to support and care for those who require lifelong help.