

Why We Need Parity for Disability

By Paul Roper

Father to Mark

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All parents know the joys and very significant responsibilities that come with bringing a child into the world and trying to guide them towards independence and adulthood. For a family with a youngster who is profoundly disabled, these challenges can seem insurmountable. My eldest son, Mark, was profoundly disabled and we loved him dearly. However, raising him involved not only the usual challenges of parenthood but also what felt like a never-ending battle to gain support, recognition and information. Having met a number of parents in a similar situation, it seems our experience was typical.

When a family first discovers that their child has a disability, they must quickly come to terms with what they are facing. There are, of course many emotions that must be worked through but there are also endless practical challenges. We realised very quickly that we were ill-equipped to move forward because we simply did not know what we did not know. We had to get to grips with medical terms and come to our own conclusions about what the implications of Mark's disabilities would be for us as a family. We became aware that there would be regular visits to hospitals and consultants and had to find ways to balance these with work and other family commitments. When we began looking into education for Mark, it became clear that we would need to arm ourselves with knowledge about the school system so that we would be able to battle through it on his behalf. We also had to learn about social services and local councils so that we could access financial help and adapt our home to a basic useable standard for our disabled child. It really did feel like a constant fight. We soon began to feel that our whole family had become disabled and we often felt like we were just dealing with one obstacle after another. In addition to the practical challenges one must overcome are the profound effects this exhausting battle can have on a family. Siblings feel overlooked and sometimes resentful and relationships are placed under enormous pressure.

The challenges by no means diminish as the child grows up. Society appears to believe that a disabled child grows into an able-bodied adult. As young people leave school, families find all the services previously delivered are withdrawn. There is no physiotherapy, no speech therapy and the ongoing further education to which their non-disabled peers have access is largely non-existent for people with multiple disabilities.

On the whole, people with disabilities and in particular those who are profoundly disabled are on the margins of society. This is reflected in the lack of provision for young adults with multiple disabilities.

Parity for Disability has evolved to address this enormous shortfall and our services have been developed to enable each individual to achieve their potential and ensure that their equality, dignity and rights are safeguarded.