Journeys out of Isolation - Eleanor’s Story

Eleanor, our daughter, has profound and multiple learning disabilities and has mobility problems that restrict her independent movement. Eleanor can’t talk although she can communicate. But these things are not Eleanor, just things that Eleanor can’t do. Eleanor is the person described above, a nine year old girl, just as complex a human being as any other and with a love of life that shines from her. Eleanor began singing at an early age and stored tunes in her head like a human i-pod repeating them at what she perceived as the appropriate venue or interlude. Thus a visit to a church might elicit a hymn whilst the sight of snow always calls for a rendition of Frosty the Snowman. Likewise the sight of a candle guarantees a high volume recital of Happy Birthday.

Before Eleanor joined Hartlepool Youth Choir Junior Section she had never before been accepted into a group because of something she could do alongside people without her disabilities – that is to say – accepted on merit. The function of the choir is to sing and Eleanor is not excused the hard practice and required attendance at rehearsal and concert. Chris Simmons who then headed the choir had a simple philosophy regarding Eleanor’s joining the choir - that every child deserves a chance. By giving Eleanor this chance to participate in a community activity and a discipline that asks much of the participant Eleanor is offered a route that leads away from isolation. People who would never have met Eleanor know her as a friend. Sitting in the choir, wearing her uniform, and singing, it’s hard to see Eleanor as special. She looks like a team member doing her job, a small but equally vital cog in the larger machine. It’s very difficult to explain just how important that is for Eleanor or how significant it is for us as parents.

Eleanor grows in confidence. She has been given responsibilities through her participation in the choir but also the opportunity to show that her disability is not the most significant thing about her. She clearly enjoys her time with the choir even if sometimes she finds it exhausting. And being in the choir allows her to grow up. She is nine years old and is treated like a nine year old, not a very large three year old.

When we exclude children from activities on the grounds of disability we begin a process that repeats itself over and over again, each refusal further isolating the child confirming them as outsiders, condemned forever to gaze upon a world that pursues its business avidly and asks of them no question but rather bids their silent acquiescence. Unwittingly we begin to build the invisible walls that imprison the spirit and frustrate the will, remove the possibility of friendship and the bonds of shared experience. And the sentence is life, with no remission or possibility of parole.

Children with a disability have enough to struggle with and often have to show remarkable spirit and determination to achieve that which the majority can take for granted. That which we can discard as a prize too lightly won. But by giving everyone a chance what do we ultimately achieve? In Eleanor’s case that simple philosophy has enabled her to gain her dignity and respect. That is something we cannot lightly measure.

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