

Journeys out of Isolation - Eleanor's Story



This is how it sometimes happens. You are a bright happy sociable person. You are confident and outgoing. You try to make the best of every situation. You have sat on a hill with the wind blowing

your hair behind you in a golden cloud and laughed for the sheer joy of being alive. You have held hands with people at moments of extreme sadness and understood their needs and distress intuitively. You love singing. In fact you need to sing, because by singing you make some sense of the world.

What life offers you is a trip to a special school every weekday morning on a special bus with other special people. Life offers you a programme of special learning that is designed for special people to learn. Not being able to walk creates other difficulties. You can't walk out into the street and play with the children next door. You can't follow them when their games move away from you and you are left sitting alone. Not being able to talk compounds this. You can smile, you can shout hello but you can't discuss last night's television. But life has an answer. You can go to special social activities with other special people. You have special needs and these can be catered for in a special environment. The innocent label, so casually granted at birth, gains weight, as you carry it through life. Each road offered may be strewn with inducements, the boughs of the trees along the wayside hung with golden apples. But you know as you grow what the problem is. These routes lead away from inclusion, away from the community you were born into. Away from the children who live and play around you and the adults who, if they knew you, would not be frightened of a nine year old girl. And when you try to join groups that cater for everyone, not just special people, you find out a significant fact. Being special means you cannot and, in fact, are not. Being special means that doors are closed to you. Your label becomes a millstone to be dragged behind you as you negotiate the obstacles you face. And through this time of testing you sing, your small voice defiant, sometimes resonating with sadness and at other times vibrant with joy. You sing and as you sing you tell your story. Your story – in the way that you choose.

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 being 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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