

On being a Parent

An article written by Faith Bowers - a member of Bloomsbury Central Baptist Church since 1961 and a cofounder of Build, the Baptist group helping churches in their ministry to people with learning disabilities and their families. Faith has also served on the LBA and BUGB Councils. This article was written for the Baptist Ministers' Journal – October 2014



Richard Bowers sharing God's word at the Baptist Assembly 2012

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by Faith Bowers

As I write, the media is full of the story of a couple who wanted a family so much they paid a surrogate mother. When one twin was born with Down's Syndrome they only took his sister, leaving the boy with the woman whose poverty, presumably, had led her to lease out her womb. She is willing to give the baby love, and publicity has now ensured funds for medical care.

Forty-five years ago Brian and I learned that our newborn had Down's Syndrome. We were devastated, but it did not occur to us to reject the baby. If his hold on life had been tenuous in those early days, we would not have wanted him kept alive, but, unlike many with Down's, Richard had a sound heart and fed enthusiastically. It seemed that God intended him to survive and that made it easier for us to accept the challenge. It is tough to come to terms with having a child disabled from birth: you have all the grief for the lost child of your dreams and also a future changed for ever. At least we were spared the prenatal testing and decisions that later parents have had to face.

The paediatrician painted the gloomiest prognosis. In retrospect, we assume he had only seen Down's children who had received physical care but no mental stimulation. Today most are capable of much more. That was 1969, when few Down's children had the benefit of schooling: the 1970 Education Act opened doors for children like Richard. Nevertheless, throughout the early years we found medical 'experts' were continually depressing. We shall never forget being roundly told off by one who was assessing Richard for school because we had taught him to read about 30 words on flash cards. 'You middle-class parents, thinking that reading matters! He may recognise words parrot-fashion but he will never understand them!' We had begun when we saw him sort post by Daddy (Dr) and Mummy (Mrs/Mr) letters.

In the face of repeated discouragement it was natural for us, from the first, to turn to our church as our natural support group; and the church did not fail us. There—and for a long time almost only there—he was never, as elsewhere, stereotyped as 'one of those children' but always 'Richard'. God's people valued his individuality and, in so doing, conveying God's love for him just as he was. The church was great—years of hearing an inclusive gospel preached undoubtedly helped. The lady who ran the creche had raised a daughter with learning disabilities, who in turn was gifted in relating to small children and took the youngest Sunday school class: both took Richard to heart.

Nonetheless, we felt uncomfortable about imposing our child's disability on the church. We were conscious that the church had an added incentive to welcome him, since his father was the church treasurer. Would it have been as welcoming if we were on the fringe? I hope—I believe—that Bloomsbury would have responded well anyway, but that has not been the experience of all parents in all churches.

We have learned, through the work of BUild, that many Christian parents wrestle with theological questions forced on them by disability. Most would not otherwise normally tackle weighty theology. There is something challenging about what appears to be creation 'going wrong'—particularly when the disability dates from conception, as with genetic aberrations like Down's.

A God of love?

For me, it raised questions about the omnipotence of a God of love. We were young parents, not in a high-risk category. We had prayed for this baby even before he was conceived, yet it seemed that from the first he never 'had a chance'. I was not helped by Christian books sent by well-meaning friends. The mothers in them seemed to have devoted themselves to the Down's child to the exclusion of husband and other children. I had no wish to emulate them! But one letter was salutary: a woman who was barren wrote, 'I know you must be angry with God'— and I realised that we had not blamed God, but rather those forces of evil that distort God's good world. Gradually I came to see God's omnipotence in the power to bring good out of apparently bad situations.

Being Baptists did not help. Infant baptism might have been reassuring, embracing the baby within the church rather than wondering whether he would ever be capable of personal faith. Later I discovered that some who baptise infants have declined this for a Down's baby, saying there is no point since God loves the child anyway. Rejection by the church does not convey God's love to the parents!

Meanwhile, we had to accept the child we had and do our best by him. We struggled not to see the baby as 'subhuman', and the demanding process of raising him ultimately futile, as doctors implied. Parents do not want 'holy innocents', 'angels unawares'—and actually delight in signs of deliberate naughtiness as a mark of normal humanity. We prayed that somehow God would make Richard's life—and our efforts—useful. I found most comfort in the words of an old hymn, *How firm a foundation, especially God's promise to 'sanctify to you your deepest distress'*.

Acceptance was important for our faith and for Richard's development. Later we knew a girl with a different learning disability and no self-confidence. She too was loved by Christian parents, but her mother prayed daily for healing, looking for a change that never happened. Every day her daughter was a disappointment. The leader of the group both attended saw the mothers' attitudes reflected in the young adults.

We embarked on the slow process of teaching Richard, helped by his brother, only 3½ years older, but determined to teach through their play: 'Can you find two red cars, Richard? Good, now is there a yellow one?'. Although slow to absorb anything new, Richard had a good memory and retained things once learnt. When he went to a special school, the teachers were 'on our side', always trying to move him forward rather than telling us that it was hopeless.

At church he blossomed, often showing new skills there first, probably because he had a certain freedom—with everyone looking out for him, we could be less protective. We still felt that we were imposing him on the Sunday school, especially as he lagged further behind others of the same age. Those nearest in age were girls so it was easy for him to join the mixed group a little younger, but it still cannot have been easy for the teachers. They never complained to us, bless them, and always tried to include him—even on weekends away. On one occasion he got separated from the group in the middle of York, to the alarm of the minister in charge. Richard, however, told some policemen that Barbara and the others had disappeared while he retied a shoelace and he was regaled with lemonade and buns at the police station until they tracked down his party. His speech, not very clear in those days, had proved adequate.

Baptism

When he was 16, Richard told Barbara he wanted her to take him in the water. 'Why?' She asked. 'Because I love Jesus!'. We were grateful that she decided he was ready for baptism and that the church supported her. Some churches refer to the parents and that is really not fair. They are probably the least able to determine the reality of faith, torn between wanting to see the best in their child and their reluctance to impose on their church. His brother laughed at our doubts—sharing a room he was privy to Richard's nightly prayer conversations.

Baptismal studies, carefully adjusted to his understanding, were a great delight—not least to be given homework for the first time. We had not realised he was conscious of missing out on something his brother and cousins did. In the first baptismal class Barbara was surprised to find he could look up Bible references for himself—he must have watched us. He learns best visually. He had just about mastered reading by the time he left school but would soon have lost the skill without practice—the motivation to maintain it lay in those Bible studies with

Barbara. We began to appreciate the Bible as a primer—most stories are contained in a few verses, perfect for someone who can read but not sustain the necessary concentration for long. Thus his reading skills became well established. Barbara and then her successors have continued to give him occasional special teaching which he greatly appreciates.

The church celebrated Richard's baptism with cards and gifts, and he marks the anniversary each year. Becoming a church member was precious to him and, with the church's patient encouragement, he has found ways to serve. Nearly 30 years on he is on rotas for stewarding and catering, ready to move furniture or tidy up, contribute to open prayer times, and always one of the first to greet people.

It was difficult when the teenager began to recognise the features of others with Down's. It was painful to hear him ask God to change his face. Happily he grew beyond this, helped by joining in the work of BUild and grasping that through his disability he could help others. Once, at a Baptist Assembly, Richard Kidd told me that he hardly knew what to say to friends whose grandchild had just been born with Down's. My adult Richard volunteered, 'Tell them it's not the end of the world. I don't mind having Down's Syndrome. It's not the end of the world.' No, indeed—it just feels like that in the early days!

Richard still lives with us and it is a moot point who is carer and cared for as we get older. I love the way he ensures that I, with my skirt and stick, am safely in the car before he closes the door—after all those years when I was checking him! He has proved able to do far more than those early doctors predicted—as have many of his friends. He is a 'people person' and we have learned from him much about friendly interaction. He has a friendly word with anyone he meets, leaving all smiling.

So we have a success story, but it has not always been easy. We were blessed with a strong marriage and a supportive church. Often, fathers cannot cope with a disabled child and its toll on the mother's energy. Churches are not always a great support.

A success story: but my life was changed. We learned that parents of a disabled child are effectively disabled (and often treated as unintelligent too). I would probably have picked up a career when the children were at school, but possibilities were restricted by his short school day, plus the way every cold turned to bronchitis. The council provided a car to take him to and fro but I had to be at home for it (no other Mum for back-up cover at the school gate). As he got older, I developed a satisfying alternative voluntary career—possible on my husband's income, as long as we did not envy the more luxurious homes and holidays our friends could afford.

We had it relatively easy. It is harder for single mothers, or when children have more severe and multiple disabilities. It is important that pastors and friends get beyond a certain easy admiration for those who try to smile as they struggle to cope.

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