

miss this point. It may be true that "as society becomes more productive distribution rather than production is the key economic issue" (p.39), but the problems of distribution, jobs and poverty do need to be linked to the problems of investment and trade, otherwise the two debates will continue in isolation from each other and the narrowest version of economic policy is a likely winner. The outcome of that will be a divided dual

society of the kind implied by Scenario 2.

If all Australian children are to escape the misery of poverty and unemployment, we do need to open up a radically different set of options about the future of work and the purposes of economic policy. "*Children and the Future of Work*" is a most helpful contribution to this task.

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Love, Sweat and Tears by Barbara Szwarc

The Victorian Children's Aid Society, 1990. 135pp. \$12.50

Hope, fear, despair, joy and above all, great love – all these are present in Barbara Szwarc's book. *Love, Sweat and Tears* is the personal story of Barbara and her family during a turbulent six years of their lives. The family's hitherto quiet existence was thrown into disarray following the birth, first of Daniel and two years later, of little Joshua. Both these boys were born with a rare and incurable genetic condition called Canavin's Disease, which caused physical and intellectual degeneration, ultimately leading to the death of both children within a few short years.

The book tells of the family's great courage and strength as they struggle to provide the best care possible for Daniel and Joshua while at the same time, maintain some semblance of an ordinary life. It follows events from the heartbreaking revelations that all was not well, through the gradual acceptance by the family and adjustment to a different way of living.

The author simply and frankly reveals the vast array of emotions she, her husband Martin and eldest son Simon, all experienced. She relates how two very special children brought joy and agony into their lives, teaching them all lessons which under usual circumstances may never be learned in a lifetime.

The demands placed on families who care for children with disabilities is

clearly portrayed. Life is a constant round of meeting physical, medical and emotional needs without outside assistance all day and every day, every week of each year. There is no time out, no let up from the physical tasks and emotional demands.

The Szwarc's life is dotted with contrasting episodes ranging from pleasure to sheer exhaustion. The children were delightful, with charming personalities and senses of humour. They were loved by all who knew them and shared with them their fight to find their place in life. The author's struggles to find the best resources for the boys, led her into contact with some marvellous and caring people and organisations who somehow appeared to provide both respite for the family and residential care of foster care just when most needed.

However, Szwarc also recounts times when she had to advocate or plead for much needed assistance. Although the services she used provided excellent and caring help, there were few available and access to them was limited. The family had little choice and were sometimes forced by circumstances to 'grab what they could.' Although not the central message, the book highlights how crucial the availability of appropriate and high quality services are, for children like Daniel and Joshua and those who care for them. Their right to such services is indisputable. However, so often in our

community these rights are reduced to mere rhetoric, leaving the primary caring role to the families concerned with little or no assistance. We just expect them to cope.

One of the most important sources of comfort which the family found came through the friendship of another family who also had two children with Canavin's disease. The importance of families being linked to others in similar circumstances cannot be underestimated for the sharing of experiences, support and help they can offer each other.

Love, Sweat and Tears, although demonstrating the difficulties confronting families with disabled children, also brings with it a message of hope and encouragement to families in similar circumstances. For those working with children with disabilities and their families, it offers a rare insight into the lives of service users. For all of us, it is a tribute to the human spirit and a reminder of our responsibility as a society to provide for all our members in all their difference.

In the prelude, Szwarc dreams of a place for her boys where they can be participants not just observers. Surely our society can be such a place, if only we can 'get it right'.

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