

Book Review

Real Lives: Personal and photographic perspectives on albinism

Archie W.N. Roy and Robin Mackenzie Spinks

Glasgow: Albinism Fellowship, 2005

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This very appealing and highly enjoyable book explores the *real issues* that affect the lives of twelve people living with albinism in Scotland, England and Northern Ireland. The written style and content would appeal to a variety of audiences including GPs, ophthalmologists, other eye specialists, educationalists as well as parents of children of albinism and people with albinism. The authors are able to use the book to dispel some of the ‘myths’ that surround albinism, making interesting reading for the public and use a positive lens to highlight some of the issues that have affected lives of people with albinism in the past (e.g. negative experiences at school, mixed family attitudes and creating social relationships) as well as areas that affect their lives today e.g. establishing personal relationships, parenting children with or without albinism or combating public stigma. There is a strong message of ‘positivism’ that is carried through the book culminating with some final pieces of advice aimed at people with albinism to dissemble the old ways of being and ‘get a positive and genuine way of being’ (p.140). This book makes an important contribution to a group of people who have remained almost invisible as a result of little interest in academic and media circles.

The two authors take the reader through a number of phases starting with an introduction to albinism, followed immediately by a ‘Chapter for Parents’. This is a well constructed summary of the main issues that affect parents of children with albinism, guiding them through important childcare including ‘sun and skin protection’ and ‘support in school’. Chapter three offers a succinct review of the literature drawing on international biographical and autobiographical accounts and recommended websites. A separate index for the websites discussed would have been useful for quick reference at the end of the book.

The creation of the book is seen as a project that has helped a small group of people to talk about their lives and experience moments of photographic prominence through the

professional eye of Rick Guidotti. The photography increases the visibility of people with albinism making it vibrant and joyful. The photographs are supported through the telling of stories of some of the captured people. The scattering of images without captions unexpectedly throughout the text gives the book a sense of strong identity and ownership for those who participated in the project. It also increase the level of interest among ‘this golden circle of opportunity’ (p.137) and portrays the beauty of the images which capture the striking differences of people from around the Earth.

The focus of the book, after these introductory chapters, is on listening to the voices of twelve volunteers with albinism (aged between 18 and 81). The authors/researchers choose a set of questions that help the interviewees to examine their lives in the past, present and future. All had been successful in terms of career with half of them university graduates. One of the authors, who has albinism, was able to create a sense of empathy with the interviewees by briefly referring to his similar difficulties or frustrations he experienced. This encourages a dialogue that enriches the data set with real issues that have negatively affected their lives in the past and impacted on their self-perception. As the chapters progress, the more we find out about the personal, professional and in a few testimonies, their ambitions for the future. What is most powerful about this book, is the prominence of each voice and the excellent writing of chapters to allow for a maximum amount of dialogue and little commentary. The voices of these twelve people speak so clearly and are able to draw the reader into their ‘invisible’ lives. Chapter 16 ‘Conversations’ is an informal meeting of five of the voices with the second author, Robin, to discuss some of the respondents’ views in more depth and compare his experiences and reflections with them. This chapter takes a retrospective look at some of the issues that concerned the five interviewees and the ways they coped with or built strategies to deal with them.

There are some nice touches of humour scattered throughout this chapter helping with the flow of the book. The book contains a useful references section of recent publications as well as subject, author and portrait indices for consultation.

By the end of the book the reader has a better understanding of albinism, the life of a person with albinism and their perspective. It highlights the personal challenges of having to live in a society that has done very little to understand their individual needs,

preferences and ambitions. There is a general sense of frustration at times but this despondency is reduced by the strong advocacy messages that emerge from their personal stories. The final chapter takes an active role in trying to cast off the negative experiences by providing advice to young people by 'disassembling the old ways of being' and adopting 'some new models for self-categorisation' which encourages an 'unconditional acceptance of self' (p.141). The final message to all readers is to begin seeing albinism in a 'holistic way'. It would be hard not to do this after reading this inspirational book. It successfully raises the profile of a highly 'visual people' who until now have not had the opportunity to speak about their lives and portray themselves in positive ways.

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