BOOK REVIEW

QUALITY OF LIFE AND INTELLECTUAL DISABILITY: KNOWLEDGE APPLICATION TO OTHER SOCIAL AND EDUCATIONAL CHALLENGES (2014)

Roy I. Brown and Rhonda M. Faragher, Editors

Reviewed by James Cairns

James Cairns, M.A., is a researcher and counsellor who is committed to providing opportunities for marginalized voices to share their experiences. E-mail: jcairns@uvic.ca

In Quality of Life and Intellectual Disability: Knowledge Application to Other Social and Educational Challenges, editors Roy I. Brown and Rhonda M. Faragher (2014), focus on what they characterize as the emerging field of Quality of Life (QOL) research that has been developing within studies focusing on intellectual and developmental disabilities (I&DD). Brown and Faragher show that the research enhances our understanding of QOL and family quality of life (FQOL), and helps us to see that we can utilize this information in the development of policies and practices that align with the principles of QOL to enhance the lives of not only those individuals with a disability, but of people in general. They hope to provide both a reorientation of the ways in which we approach life’s challenging problems and demands, and a framework for dealing with these, with a particular focus on families with members who have disabilities, their helpers, and their service providers.
This engrossing volume contains over 300 pages and consists of five sections and 17 chapters (not including a final section of acknowledgements) on the broad topic of QOL and intellectual disability. Section One provides theoretical perspectives on QOL. Section Two offers an overview of how to apply this body of theory within educational settings. Section Three focuses on the topic of families and QOL. Section Four invites the reader to discover other social contexts in which to apply knowledge about QOL. Section Five ends the text with two chapters focusing on conclusions drawn from the assembled new knowledge.

The theoretical overview provided in Section One of the book provides the reader with an important introduction both to the history of QOL and FQOL, and to their relationship to the field of I&DD. This section helps to acknowledge how much the field of disability care has changed throughout the years. We have come a long way from the old practice of institutionalizing individuals with a disability, to more modern approaches that aim to create accessible opportunities for such individuals within mainstream environments. In this section, the writers do an excellent job of recognizing the positive steps that have been taken; however, they also show that much change is still needed. An important point discussed here is that the life expectancy of persons with I&DD has lengthened considerably (probably due to improvements in care) and that recognizing the improved survival rate of persons with disabilities is vital. The extension of life brings with it numerous impacts for the individuals, their families, and the supports that they require. As the writers in this section point out, a QOL focus can have its greatest impact when adopted by the human services organizations that interact with individuals with a disability and their families. A QOL focus leads to the organizations working with the families within a supportive framework that does not exclude the family from the treatment process. By way of introduction, many subsequent chapters provide a recap of some of the information about QOL and its history that is presented in this first section.

Since much of my own research and work experience falls within the field of education, I was most interested in reading Section Two and its focus on the applications of QOL in education. The beginning of this section provides a historical overview of QOL in the field of education, showing that, unfortunately, not much research on QOL has been conducted in this field due to the relative newness of these ideas. It also shows that access to schools for individuals with an intellectual disability has been uneven at best. With the introduction of the UN’s Convention on the Rights of Persons with Disabilities, however, schools are beginning to make some of the many needed changes. Given the relative lack of access to education for persons with disabilities, a strong focus in this section is on the empowering of individuals with a disability to face the challenges that they encounter on a daily basis. The authors call on both parents and teaching staff to view the support of educational opportunities for persons with disabilities not as an additional duty, but as a core part of their responsibilities.

Section Three enters deeply into the discussion of FQOL. This section is a significant reminder to families that their QOL matters: a good FQOL is necessary for building an effective plan of support for their disabled family member. The contributors to this section also show that recognizing the importance of FQOL is relevant to human services organizations that need to understand the substantial value that FQOL has for the
effectiveness of their work with individuals with a disability. While the authors in this section of the book recognize that many organizations are beginning to increase the involvement of the whole family in the treatment of disabled family members, evaluations of these inclusive and holistic family-based approaches are unfortunately not provided. As a researcher, and youth and family worker, I found this section to be highly informative both with respect to the work that needs to be done in the education realm and the knowledge that already exists in the disability field. This section highlights the complex conditions and demands that families face, the interventions that are presently being utilized, and the much-needed work that remains to be done.

By far the longest part of this book is Section Four, which covers in its seven chapters a wide range of applications for QOL and FQOL within different social contexts. Depending on the reader’s circumstances, one may find some chapters more applicable to one’s own situation than others. Taken as a whole, this section serves as an excellent reminder of the many barriers faced by individuals with a disability, and as a good source of information about what is being done to find multiple ways to overcome these barriers. I will focus here on just two of the chapters, Chapter 9: **Enhancing the Quality of Life of Marginalized Populations through Employment**, and Chapter 14: **Quality of Life and Older-Aged Adults**, that spoke most directly to my own knowledge and experience.

As noted earlier, individuals with an I&DD are experiencing greater life expectancy, and with longer life comes a need to participate more fully in the social world. Many of these people are underemployed or unemployed. Chapter 9 focuses on this important topic, but also provides techniques for creating inclusive work environments. This chapter also serves as a reminder that employment can lead to a better life and that we all have common ground in this regard. Chapter 14 builds on the topic of longer life expectancy, focusing on older adults. This chapter, like the one on employment, does not focus exclusively on individuals with a disability, but affirms the universality of the aging process, that our cognitive abilities will certainly change and may well recede. With that in mind, the chapter underlines the importance of continuing to strive to maintain QOL in the face of these challenges.

In the Conclusion, we are again reminded that there is still much work to be done. The two chapters in this section present areas that need to be further recognized within the framework of QOL. These chapters focus on the importance of the individual, of families, and of service organizations, but also examine the significance of their intersections with society, and especially with its laws and policies. Also reviewed are the barriers to social and community inclusion that may result from philosophical, economic, and political forces. Placing a discussion of these difficulties in the conclusion may seem like a negative way to end a text, but balance is provided with a positive discussion of inspiring ways to promote social and community inclusion. It is important that we recognize that there is still much work to be done, especially with regard to social policy, law, and governance, and the ways in which these can play a part in creating change.

As the editors themselves acknowledge, no book can offer an overview of each and every intervention that exists to enhance both individual and family QOL. However, this text does succeed in providing us with an overview of a number of different...
interventions that can be applied to individuals with an I&DD, their families, and beyond. I would have preferred that the book include personal stories from individuals with an I&DD. The work that we do with these individuals is intimate, and while this text, with its heavier focus on quantitative data and opinions of professionals, is informative, it does leave out the personal touch.

That said, I believe strongly that Roy I. Brown and Rhonda M. Faragher are to be commended for their efforts to offer an encompassing text on the emerging topic of QOL and its relationship to individuals with a disability, their families, and the professionals that support them. This book can help contribute towards creating positive changes in today’s society. It is not enough for any of us to focus on meeting only our own needs; we do better collectively when we focus on everyone’s overall quality of life. On that subject, this text is full of important questions, answers, perspectives, interventions, research, and innovations. It is equally suited to readers who jump into a particular chapter of interest and those who read from start to finish. I offer my sincere appreciation not only to the editors, but also to the many contributing authors for their time and efforts in researching this important topic and presenting their findings in a readable fashion. Now that we have the text, it is up to all of us to use it as we work together to create changes in each of our environments of influence.

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