

Preface

Indigenous peoples across the world have other stories to tell (Smith L.T., 1999)

Indigenous people are just as much a part of the complex modern world as any of us; they may be different, they may be unique, but they must be nurtured, respected, and allowed to emerge. This is particularly pertinent in regard to children with disabilities, in light of the fact that worldwide, minorities are overrepresented in populations of people with disabilities. In some areas of the world, the disability rate among indigenous peoples is more than double the rate in the non-indigenous population (see Chap. 2 for specific data). Indigenous populations collaborating with the parents of children with disabilities are a prerequisite for treatment to prove effective; hence, the subject of this book is of paramount importance.

There are seven chapters in the book, some informative and some practicable. Chapters 1–4 provide the background, bringing the reader up to date on the relevant professional literature and terminology, and review the current state of several indigenous communities worldwide. Chapters 5–7 take an in-depth look, through the case studies presented, at the Bedouin community in the Negev desert in Israel, and examine the collaboration between professionals and parents of children with disabilities in this community. The following is a detailed description of the chapters in the book.

Chapter 1

The first chapter, which opens the book, is the backdrop for the entire book; in this chapter, I present the common characteristics unique to indigenous communities and to children with disabilities in these communities. It opens with a definition of indigenous peoples, and presents the world's indigenous population numbering about 257–350 million people. Later in the chapter, I survey the attempt to explain the source of the difficulties and challenges common to all indigenous communities

around the world; these include high frequency of health risks, elevated school dropout rates, child labor, the need for more extensive support services, a lack of financial resources and the resulting condition of perpetual poverty, and subjection to acts of dispossession and spirit-breaking.

The second part of the chapter, titled *Indigenous Communities and Children with Disabilities in the World*, examines the concept of *disability* and the problematic nature of the definition, and then focuses on children with disabilities in indigenous communities, more specifically, the issue of precisely documenting their numbers, the fact that it is nevertheless known that the rates of children with disabilities in the indigenous communities are extraordinarily high. Some explanatory factors are suggested and the topic of support services is broached.

The work of preparing the first chapter was like assembling a mosaic: gathering information from all over the world, in an attempt to produce a representative image. Unfortunately, the image presented here is still only partial. This is due to the absence of data and the incomplete nature of the data available in the existing literature and research reports. Furthermore, there is also a certain bias in the data. Remote locations and language barriers have made it logistically difficult to include indigenous areas in major surveys; and even when indigenous peoples are included in surveys, the resulting disaggregated data are rarely used to reflect their particular conditions.

We know least about the regions with the largest estimated indigenous populations: for example, there is a dearth of accurate demographic and health data from Africa, China, South Asia, and the Former Soviet Union. Despite these gaps of information, there is much evidence about the situation of indigenous peoples in Canada, the USA, Australia, and New Zealand, and to a lesser extent, Latin America. Even in this nation, most studies show an alarming situation.

In order to deal with the lack of data or the partial data, I chose to structure the review as a mosaic, namely, by providing concrete examples so as to illustrate the topics I discuss, each time presenting a different country/countries, with the available existing data. In addition, the purpose of the dichotomous presentation of the subtopics in this first chapter was to provide as wide an overview as possible of indigenous communities around the world and the difficult reality with which they must contend, a reality in which it is often impossible to discern the various characteristics of the indigenous group, as they are so intricately related. Thus, for example, there is an indifferntiable connection between poverty, health conditions, and lack of education.

Given that the study of indigenous populations is conducted both globally and locally, I had to read a wide variety of materials from a wide variety of countries. This is one of the book's advantages, yet it is also a disadvantage. Due to the fact that most of the existing material is in English, there is a disproportionate representation of materials written about indigenous communities in English-speaking countries. However, since English-language texts are an important means of communication among those who study and represent indigenous issues in different countries, this literature is likely to play an important role in the understanding of indigenous psychologies.

Chapter 2

This chapter presents concepts that are crucial to understanding how indigenous parents view disability. Understanding the concept of “culture,” for instance, enables us to understand how indigenous communities differ in their conceptualization of disability, and the perspective, understanding, and expectations with which parents of children with disabilities approach collaboration with professionals in school. The concepts that will be discussed in this chapter are *culture*, *lands and territories*, *indigenous knowledge*, and *indigenous psychology*.

The prism through which I chose to address the concepts in this chapter is educational (rather than judicial, anthropological, medical, sociological, or based on any other discipline that deals with this domain). Hence, these concepts, which were selected out of a wide range of concepts that could be examined when dealing with indigenous communities, are those which enable the (lay) reader, as well as the professional, to understand the concept of disability from the perspective of indigenous peoples, and to take into account the beliefs, perceptions, values, context, and history that parents of children with disabilities bring with them into a collaboration with professionals at the school. The argument enfolded into this chapter (and book) is that there is something universal in the phenomenon of indigenous peoples as a group, and specifically on the topic of children with disabilities and parents of children with disabilities in indigenous communities.

In addition, it is important to note that there are many difficulties regarding the issue of conceptualization: almost every key concept introduced in this book, such as *indigenous*, and *culture*, has many possible definitions, and some of the concepts, such as the concept of *indigenous psychology*, are subject to disagreement in the professional literature.

Chapter 3

This chapter, titled *School Professionals and Parents of Children with Disabilities*, first introduces the importance of the school and the benefits of a multidisciplinary team, and includes a detailed description of a research study that aimed to locate indigenous (Bedouin) children with disabilities living in tents. Then the chapter takes a close look at the parents of children with disabilities and the act of parenting and considers psychological models of parents’ reactions to a child’s disability, and finally contemplates the roles of the professionals and parents in special educational schools.

This chapter (like the entire book) focuses on parents of children and adolescents of ages 3–21, in the context of educational systems in the State of Israel, which, like in other Western countries, provide support services and give care to children of these ages, in special education kindergarten and schools. The book does not deal with adults, that is, people with disabilities older than 21; dealing with adults with

disabilities of these age requires focusing on different issues altogether, such as employment, quality of life, independence, integration in the community and society, and so on. This required another book.

Chapter 4

The first part of the chapter discusses collaboration between parents of children with disabilities and professionals in schools, which encompasses the following issues: definition of the term *collaboration*, characteristics of collaboration with culturally and linguistically diverse (CLD) parents of children with disabilities at school, effective collaboration between professionals and parents of children with disabilities at special education schools, and collaboration between professionals and parents in indigenous communities. The second part of the chapter presents a study that reveals the dimensions of collaboration between professionals and parents in a special education school in a Western country.

Chapter 5

This chapter is divided into two parts: the first part focuses on the background of the Bedouin community in the Negev desert, that is, the characteristics unique to the Bedouin community, while the second part examines the characteristics, the challenges, and the difficulties that the Bedouin community shares with other indigenous communities. This last part is based on the first chapter of this book, which considered the characteristics that indigenous communities around the world have in common.

Chapter 6

This chapter presents a situation report on children with disabilities in the Bedouin community and a review of the conditions and functioning of the special education framework available to the Bedouin community in southern Israeli's Negev region.

Chapter 7

In this chapter I have sought to give voice to the Bedouin professionals working with children with disabilities, as well as to Bedouin parents of children with disabilities, whose voices are not heard in the existing research, and to try to

understand their perceptions and the ways in which they comprehend and define parenting and the concept and the practice of collaboration in the school.

This chapter concludes with a section in which I suggest principles of indigenously inclined collaboration derived from the chapters of the book and the case study discussed in the previous part of this chapter. These principles can be used as a springboard for discussion. At the same time, they provide a backdrop from which to formulate new questions in a way that increases our understanding and our capacity to provide the best possible bridge to collaboration. Each of the principles is presented in an identical manner, referring to three elements: the subject that the principle addresses, the goal of the principle, and the assumptions behind it.

Chapters 6 and 7 are based on studies that I conducted during my postdoctoral work. The study was funded by two different sources: the Shalem Foundation and the Arno Center for the Study of the Bedouin community.

I hope that the readers of this book come away with a better understanding of this complex subject, the collaboration between professionals and parents of children with disabilities in indigenous communities, and find in it a resource for developing and promoting this type of collaboration.

My greatest wish is that this book will in some small way contribute to the work of a variety of people involved with the population of children with disabilities and their parents in indigenous communities worldwide, namely, students, researchers, and/or professionals of various disciplines—education, special education, psychology, medicine, social work, health, welfare, anthropology—as well to policy makers and those who implement the intervention, by inspiring them to introduce future improvements in the education and services intended for and children with disabilities and their parents in indigenous communities.

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Providing Services for Children with Disabilities

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