



Pirkko Karvonen

HOME-BASED TREATMENT

in the life stories
of Finnish young people

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Translation is based on the original in Finnish: *Rajojen rikkojat - kotikuntoutus nuorten elämäntarinoissa* (Karvonen, 2015)

Cover picture by Tiia Keskiaho

Publisher: Books on Demand GmbH, Helsinki, Suomi;

Manufacturer: Books on Demand GmbH, Norderstedt, Saksa.

ISBN: 978-952-330-384-3

A little girl was severely disabled. She refused to go out and play so that nobody would see her.

- I can't stand people staring at me, she said to her parents.

- Those people who stare have been infected with a staring sickness, her mother told.

- Only people like you can cure them.

- How come? asked the girl

- Look them in the eye and say: I am doing fine - how about you?

- When you see them turning red, you know that they have been cured from the staring sickness, with your help.

It is amazing how many persons the little girl has been able to cure.

(Positiivari-magazine, 1996)

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To the reader

This book describes the life stories of young adults who have participated in the Kerland/Brainwave home-based treatment program. Rehabilitation conducted at home requires strength, patience and money from the family. Without external assistants this kind of rehabilitation would not be possible.

The life stories were collected from accounts of nearly 30 years' time. Most of these young adults were born premature. The moment of birth was extremely critical and *the thread of life was very thin*, as one mother said. Almost all of these young adults have cerebral palsy and some of them also other disturbances in development. The life stories describe the lives of these young adults during the years.

The Finnish health care experts didn't give much future prospects for the children, so their parents had a strong feeling that hope for their child's development was taken from them in Finland. The knowledge of different, foreign rehabilitation methods, where the parents were active in their child's rehabilitation, tempted the parents to give them a try.

This book tells about the Kerland Centre, which came into the awareness of Finnish families at the beginning of the 1990's, and the families participating in the program. The Kerland Centre answered the parents' need to participate in their child's rehabilitation in larger amount than it was possible in Finland at that time. The name of the Centre changed into Brainwave Centre with the new owners. In this book I use the name Kerland/Brainwave due to the fact that most of the Finnish families participated in the program already before the name was changed. First the families traveled to England but later on the Centre opened a receptioncentre in Kankaanpää, Finland also.

The Finnish health care experts criticized the foreign rehabilitation method, sometimes with quite strong wordings. They saw that the theory base of the rehabilitation didn't base enough on scientific research and that the parents cannot act as the rehabilitator of their own child. Despite all this, the parents had the courage to question the traditional Finnish concepts of parents' participation in supporting their own child's development.

The life stories of the children are based on the memories of the children and of their parents, but the most important parts are the current affairs. Some of the young adults were able to write themselves and I edited those texts to fit into this book. Other life stories are based on what the parents have told. Also some young adults have their siblings describing their memories.

I started the interviews in the summer of 2013 and added some information during the following years. The interviews took place in the homes of the families all around Finland. The families were selected on the basis of them I was able to reach after such a long time since the start of the rehabilitation.

The life stories start with description of childhood and problems with birth. Then, how home-based treatment was realized and its benefits are described. The book also describes school years of the children and their life today, what are they doing now, where they live and what kind of choices they have made in life.

The functioning principles of the Kerland/Brainwave Centre are described in this book and also the background history and how the Centre was brought to Finland. Some of the young adults tell the story of their travel to England with their parents.

The idea to write this book has been influenced by my possibility to follow the life of one of the young adults in this book, Juha, and his rehabilitation by the home-based treatment program from the first years onwards. I visited the Kerland/Brainwave Centre with Juha's family a couple of times and I wrote a book of Juha's rehabilitation years called *Juhan askeleet* (Karvonen, 1999). Many years afterwards I had the pleasure of attending Juha's wedding. And there I had the idea

This book tells the life stories of nine physically handicapped young adults in Finland. Each of these young adults received the Engilsh Kerland/Brainwave home based treatment when they were young. The rehabilitation was given three hours a day by the parents of the children and volunteers who came to assist in the process.

These were the first children in Finland who participated in the home based treatment program in the early 1990's. The health care professionals had given them little hope for the future due to complications in birth. But their brave parents wanted to do more for their children than the traditional Finnish rehabilitation had to offer.

These children developed remarkably well and some of them showed signs of improvement already from the start of the home based treatment program. Many of them learned to walk during the years. All this encouraged the parents to continue to do their utmost for their children. These life stories give hope to all families of physically handicapped children who have the opportunity to rehabilitate their child at home. This book is about perseverance, willpower and hope, and how parents can actively take part in rehabilitating their children.

