

Follow your instincts

Parent insights on having a child with a disability

Edited by Robyn Cummins and Joan Bratel



CEREBRAL PALSY | INSTITUTE

Acknowledgements

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someone I love

Someone I love relies on me in ways you will never understand

Someone I love endures pain and challenges that break my heart and renew my spirit at the same time

Someone I love is unable to advocate for themselves for things that most of us take for granted

Someone I love will never have the opportunities that every child should have

Someone I love will need unconditional love and support after I am gone - this frightens me to the core

Someone I love encounters pity, stereotyping responses, and prejudice at every turn, because they look, act, and/or learn differently than others

Someone I love has needs that require me to allow “outsiders” to have power and input in areas that should be mine alone to meet

Someone I love will continue to look to me for everything in life long after other children are able to assume a place as part of the world

Someone I love has needs that require more time and energy than I have to give

Someone I love has needs that mean I am not able to meet basic needs of my own

Someone I love has needs that have become the driving force behind major decisions my family makes

Someone I love has changed me in ways I will never be able to describe

Someone I love has taught me about love and about the really important things in life...

And still others don't understand what it is to be me.. they aren't living in my skin.

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Please Note. The children featured in photographs in this book are not those of parents interviewed for the project.

Introduction

Parents of a child with a disability have often said that talking to other parents, sharing experiences, information and practical ideas gave them the encouragement and strength to pursue what was needed for their child's wellbeing and future opportunities. This book has sought to collect a range of experiences, comments and practical ideas from parents and family members about their own search for a diagnosis for their child. Also included are comments regarding finding and dealing with professionals and services, and managing the impact that disability had on them individually, on their relationship, on their child and family. Most of the children whose parents were interviewed have cerebral palsy, but these experiences and observations are common to many parents of children with a disability.

Those participating in the interviews were asked to reflect on the early period prior to their child's commencement at school. Care was taken to ensure that a wide cross section of opinions and comments were gathered from both men and women, in rural and metropolitan areas, and from people from different ethnic backgrounds and beliefs.

For some parents, memories of the supports that they received from medical and community service groups were positive. For others the memories were more painful. While each person's experience was unique, one of the strongest messages given by the participating parents to other parents was to have confidence in your instincts about what is right for your child and not be afraid to seek full information and the most appropriate services available. It is an important message for those of us in service provision, and in the medical community, to hear and respect.

Our thanks to all those who participated in this venture, for your time, patience and compassion.