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LIFE PLANNING FOR PEOPLE WITH NEURODEVELOPMENTAL AND INTELLECTUAL DISABILITY: EFFECTIVE SUPPORT, QUALITY OF LIFE, AND COMMUNITY ENGAGEMENT

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Preface

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It is an honour and a pleasure to be asked to introduce this monograph. The contents of the articles it contains represent recent thinking and research in the field of neurodevelopmental and intellectual disabilities (NDID) that are important to share and apply. It also affords me an opportunity to review the major trends in the field of NDID today, and to stress the importance of its principal applications.

Over the past three decades, two philosophical concepts have dominated our thinking and guided our research and practice: social inclusion and quality of life. Social inclusion represents a major shift in our thinking – away from seeing disability as "difference" and something that is devalued and unwanted in our societies, and toward seeing human diversity of all kinds (including disability) as contributing to a richer and healthier society. The central view here is that all citizens have a right to fully access the life that is common to us all but, more than that, we are all better individuals, better communities, and better societies when we adopt practices that include and involve everyone. Quality of life represents the end goal we are striving for when we put social inclusion into practice. Its core sub-concepts – life satisfaction, availability of opportunities, and freedom of choice in important areas of life across the lifespan – act as ways for us to enhance quality of life within the broader context of social inclusion.

Both social inclusion and quality of life are socially-constructed concepts. That is, they do not have concrete meaning, but rather have a meaning that we ascribe to them. But all socially-constructed concepts evolve over time in response to changing thinking, values, and conditions, and it is for this reason that they need to be re-examined and tweaked from time to time so that they are relevant to the present times and conditions. This is precisely what several of the authors in this monograph have endeavoured to do, with the article by Bertelli, Francescutti, and Brown an explicit example.

Philosophical concepts such as social inclusion and quality of life guide our thinking and sometimes our actions, but two things that are highlighted in this monograph are essential to put them into practice effectively. First, international, country-specific, and disability organization policies that set out rights, entitlements, and systems of support for people with disabilities create the environment for a better life. The United Nations' 2006 *Convention on the Rights of Persons with Disabilities* (CRPD) [1] is one of the most important international documents that has ever emerged in this regard. Its 50 Articles combine to act as the standard against which all other national and organizational policy is judged. But rights are ideals and are not always acted on. Our challenge is to ensure that they are acted on to best effect for all, and, perhaps even more important, that they are acted on in person-centred ways that respond to the characteristics and needs of individuals.

Second, for rights to be acted on effectively there needs to be commitment from governments, social service organizations, the education sector, and even the business sector. Applied rights need new models of organizing services, providing care, and allocating funds that respond to individual conditions and to changing social and economic conditions, and these need to be constantly generated and assessed. Genuine attempts to explore new models are represented by the contributions of Cappa *et al.*, Varrucciu *et al.* and of Camoni and Venerosi, and are accentuated by the interesting alternative in social agriculture described by Borgi *et al.* Two areas of social functioning that are particularly important to applying rights, and the philosophical concepts that underlie them, are those that almost every citizen participates in to some degree: school and work. The article by Laghi stresses the importance of both, and it sets out some practical ways to apply rights and principles in a useful and inclusive way.

It is individuals with NDID who experience both social inclusion and quality of life in a personal way, and the focus of our field needs to be kept on ensuring that they are able to do so. As such, the ultimate measures of success for all our efforts and endeavours are the an-

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swers to the questions: "Do they feel truly included?" and "Are they leading lives that they consider to be of high quality?". But people's lives do not unfold in isolation, and the degree to which these questions are answered in a positive way often relies on the immediate context of their lives – the family for children and the family or other close others for adults. As exemplified by the Ferraro *et al*., and the Leoni *et al*. articles, the field of NDID has recognized the importance of family and caregiver quality of life since 2000 as the immediate environment within which inclusion and quality of life can flourish (or languish) for people with NDID. The personal and professional lives of family members and close others are highly affected by the very presence of disability and the support they provide, and, in turn, they are in the best position to understand the unique aspects of individual and family life that contribute to both inclusion and quality (see Bertelli *et al*.). The Alzani and Cavagnola article highlights the importance of understanding that the process of providing care and a nurturing environment needs to evolve over the lifespan of individuals with NDID and those who share their closest personal relationships, because life-stage needs and the circumstances within which they unfold change over time.

The field of NDID is not without future challenges. Three of these, in particular, come to light implicitly or explicitly in the articles of this monograph. First, family life is critically important, but it is not always ideal. What Robert Cummins [2] calls the "golden triangle of happiness" eludes some families: they struggle financially or receive financial support that is not individualized enough to meet their needs, they experience severed personal relationships, or they struggle to identify a positive meaning to disability and to their family life. In addition, not all family members are willing or able to provide positive care and a quality living environment that promotes social inclusion. How to support families and caregivers in the best way requires ongoing focus, experimentation, and assessment. Second, although inclusive education is becoming the usual practice, at least in the more developed countries, the quality of the educational experience has only begun to be examined in both theoretical and practical ways [3]. For children, particularly, the school environment is without doubt the most important environment outside the family for fostering social inclusion and quality of life. We need to learn the multiple ways that we can foster both in creative and productive ways, thereby applying aspects of the CRPD that address the right to education. Third, how to find meaningful roles for people with NDID as they live their adult and senior years has often eluded us to date. Large numbers of people with disability are not employed in our market-driven economies, despite sustained efforts by disability organizations to find jobs and willing employers. Other ways that adults with NDID can contribute to the betterment of their immediate environments to their larger societies is often not a strong focus of our research or our applied work. The ultimate question here is how people with NDID attribute positive purpose and meaning to their lives, how they experience a feeling of being worthwhile and valued, and how they understand that their life makes a contribution to the human condition.

The explosion of knowledge and practice in recent years in the areas of human anatomy, disease prevention, and especially genetics are having a strong influence on the ways we think about disability. The human genome – the approximately 25 000 genes contained in the nucleus of most cells of our bodies – has been mapped, and we now understand the causes and contributing factors of more than 300 neurodevelopmental disorders [4]. We can already identify a great many of these prenatally, and some genetic interventions can be carried out at this early stage of development. Gene therapies and stem-cell therapies are gaining in both acceptance and effectiveness. Genetic manipulation is a common practice in vegetable, fruit, and animal production, and thus in the foods that we eat. It seems highly likely, although illegal in most countries at this point in time, that it will be scientifically possible before long to carry out at least some genetic manipulation of our species itself. In other words, the means to prevent or amend some disabilities by identifying their causes and intervening in their development appears to be a future reality [5]. Thus, as we focus on the social inclusion and quality of life of people with disabilities and that of their family members and closest associates, we need also to be mindful of the fact that there is a strong wave of "progress" that appears to be working against valuing disability and even against the presence of disability within our cultures.

Speaking out for the positive experience of disability to out broader culture and the positive contribution it makes to the lives of individuals, as occurs throughout this monograph, is an important way to ensure that disability is not devalued. Disability is a reality in our current cultures, and it will continue to be as far as we can see into the future. Our focus must remain on finding valued ways for disability to contribute to the way we currently live, and on finding ways for people with disabilities themselves to experience the full enjoyment of human life.

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