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THE DEVELOPMENT, CONCEPTUALISATION AND IMPLEMENTATION OF QUALITY IN DISABILITY SUPPORT SERVICES

JAN ŠIŠKA, JULIE BEADLE-BROWN ET AL.

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TABLE OF CONTENTS

SECTION 1: THE DEVELOPMENT OF COMMUNITY LIVING: TRAJECTORIES AND TURNING POINTS

/1.1/

Introduction to the book and to the development of community living

Jan Šiška and Julie Beadle-Brown

OVERVIEW OF THE BOOK AND ITS AIMS

Since 2006, stakeholders at international, European and national level have been working on promoting social inclusion, combating poverty and discrimination, and making community-based disability support services a widespread reality for a variety of target groups. This has generally been considered as the second wave of deinstitutionalisation, with the first wave happening particularly in Scandinavia, the UK and the US but also in Australia and Italy (Ericsson and Mansell 1996; de Leonardis et al. 1986; Rosen 2006) and Italy for mental health services. The research evidence over many decades suggests that community-based alternatives can provide better outcomes (Kozma et al. 2009; McCarron et al. 2019). In addition, costly improvements in the physical conditions of existing institutions or the division/redesign of existing institutions into smaller units fail to change the institutional culture and make it more difficult to close these institutions in the long term (Ericsson and Mansell 1996; Mansell 2006).

In 2004 The European Commission invited tenders for a project focused on the Outcomes and Costs of Deinstitutionalisation and Community Living. The findings from this study were reported in 2007 (Mansell et al. 2007) and provided three important contributions towards the second wave of deinstitutionalisation. Firstly, the report provided an account of the situation across Europe in terms of the availability of data and the number of people still living in institutions at the point of the publication of the UN Convention on the Rights of Persons with Disabilities (2006). Secondly, it provided an analysis of the learning from countries who had already made progress towards community living. Thirdly, it gave a framework to think about what was needed to make community living a reality for many more people with disabilities and a set of recommendations to guide the process.

Since this project, we have continued to be passionate about improving the lives of children and adults with disabilities and their families, conducting research and development work in many parts of the world. Some of the recent projects we have been involved in have highlighted that, although some things have changed and many more people with disabilities are benefitting from support in the community, this is not yet extended to all people with disabilities and in particular to people with intellectual disabilities. Recent research has estimated that roughly the same number of people still live in large residential services and institutions as between 2005 and 2006 and in addition, just because people live in an ordinary house in the community, this is not necessarily enough on its own to bring about a change in the inclusion of people with disabilities.

The aim of this book is to bring together current research and experience related to the process of ensuring that people with disabilities can realise their rights, in particular, to live in the community, with choice over where and with whom they live and with support to experience full participation in society on an equal basis with others. We acknowledge that there are many factors involved in transition process and that the situation varies from country to country. This process has taken different directions in different countries often connected to individual history, political climate and factors deriving activism of national civil society same as international community. Our intention was not necessarily to deliver a completely comprehensive overview of all the potential factors influencing the process of transition and the quality of community-based services but to explore some of the more recently identified facilitators, barriers, and potential solutions, revisiting and building on the recommendations of the Mansell et al. (2007) study but taking it further to think about the quality of services not just the nature of them. Many of the chapters will focus primarily on people with intellectual disability as this is the group of people who tend to still be experiencing exclusion and institutional care, by and large. Whilst the book will be grounded in the research evidence base it will also draw on learning from practice.

The book will explore three core themes related to achieving positive outcomes for people with disabilities through community living. The first theme focuses on the varying trajectories towards community living in different countries, including an analysis of the factors or turning points that have been important in different countries. As part of this, the book describes the current situation of people with disabilities in terms of living situation, support and quality of life. The second theme is centred around defining, measuring and delivering high quality community-based services to ensure that people live better lives in the community than they did in institutions. Quality is viewed through different lenses and is explored through the prism of Donabedian's Structure-Process-Outcomes model. The third and final theme focuses on some of the mechanisms, systems and structures that have been and are likely to continue to be important in determining not only whether people move from institutions to live in the community but also whether services are of a high quality. Each theme is explored in a section of the book, although inevitably there is overlap between the three themes too. Each section of the book begins with an overview chapter that will set the scene and introduce the chapters in each section.

In this first overview chapter, we will start with an introduction into disability terminology and models for approaching disability and then will provide a slightly more expanded introduction to each theme and introduce the seven chapters in Section 1.

A NOTE ON TERMINOLOGY

One of the challenges in compiling a book related to disability is which terminology to use. Numerous opinions have been expressed regarding the need to adopt appropriate terminology when referring to people with disabilities. Yet, there are no clear and consistent findings demonstrating the relationship between inappropriate language and attitudes towards people with disabilities. It is even more difficult when history shows that 1) preferred terminology changes over time, 2) views vary within the group of people to whom the terminology refers and 3) almost any term can become used as a label that conjures up negative imaginary.

The use of labels particularly for people with intellectual disabilities has in the past served as a way of segregating this group from society at large. Carlyn Mueller (2019) noted "that disability as a marker of difference has its own stigma attached which does not have any particular initial source or point of origin; it is part of the air that we breathe and the culture that we live in, by nature of the way we interact with one another around difference" (Mueller 2019, 366). For Goffman (1968), stigma is "the situation of the individual who is disqualified from full social acceptance" including on the grounds of "abominations of the body" or "blemishes of individual character" (p. 9). Stigma attached to disability is present at every level of interaction between persons with disabilities and their peers, teachers, and family members, care-givers and other professionals. Stereotypes about disability are at the core of these negative attitudes (Yuker 1988).

In 1992, the American Psychological Association Committee on Disability Issues in Psychology[1] suggested that terminology should (I) Put people first, not their disability (e.g. a person with a disability) and avoid implying that "a person as a whole is disabled (e.g., disabled person)"; (II) Not label people by their disability/Avoid equating "persons with their condition (e.g., epileptics)"; (III) Not overextend the severity of a disability/Avoid expressions that extend the scope of the disability (e.g., the disabled); (IV) Use emotionally neutral expressions/Avoid suggestion of helplessness (e.g., stroke victim, suffer from a stroke, confined to a wheelchair); (V) Avoid offensive expressions (e.g., cripple).

The UN Convention on the Rights of Persons with a Disability generally follows this guidance, as we will do in this book. However, we acknowledge that not everyone who might be considered under the UN Convention prefers person-first language – for example, research and advocacy by those who are diagnosed as being on the autism spectrum, indicates that many of this group prefer what is referred to as "identify" first language – ie. they wish to be referred to as an "autistic person". This can make it difficult to have one consistent approach to terminology.

Finally, with regards to terminology, many of the chapters in the book will relate specifically to people with an intellectual disability. Although this term also has its critics, it is generally accepted within the academic world as the term that is recognised internationally with a consistent definition. It replaced the terms "mental retardation" and "mental deficiency" in academic circles in the late 1990s and had finally replaced mental retardation in clinical and policy contexts in the USA by 2010, The term "intellectual disability" is synonymous with the term "learning disability" as used in UK policy and service contexts.

DOCUMENTING TRAJECTORIES AND TURNING POINTS TOWARDS COMMUNITY LIVING

Often interacting with the issue of terminology has been how disability itself has been conceptualised. Overtime, there has been substantial change in the models used to explain and contextualise disability and consider the effects of labelling. Historically, the most prevalent model of disability has been the individual model (sometimes referred to as the medical model) of disability.

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[1] https://apastyle.apa.org/6th-edition-resources/nonhandicapping-language.