



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

JAN ŠIŠKA, JULIE BEADLE-BROWN ET AL.

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**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 imagery.

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 Psychology¹ 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.

1 <https://apastyle.apa.org/6th-edition-resources/nonhandicapping-language>.

This model situates the disability in the individual, as a result of the impairment that the person has either been born with or acquired during their life as a result of injury or illness. The focus of services and intervention is often on treatment and rehabilitation or at least ways of helping to minimise the impact of the disability in some way e.g. using prosthetics, communication devices, or teaching the person skills or behaviours to facilitate their participation in wider society.

Changes in how disability was viewed began to emerge in the 1960s with sociological theories such as that of Goffman (1961). Goffman introduced the concept of the “deviancy cycle”, which proposed that devalued people, which disabled people tend to be, themselves tend to behave in accordance with the “deviant label” assigned to them by society. Rather later, there was a transference away from the “problem” being one of a person’s impairment, to being the result of the person’s physical environment. In the early 1980s, Mike Oliver presented both the individual model and the social model of disability (Oliver 1983). The social model suggested that it was not the person’s “impairment” which disabled them but the barriers and attitudes in society which resulted in the person being “disabled”. This model became widely used (as well as criticised) and has been the model that strengthened the disabled people’s movement and provided the structural scrutiny of disabled people’s social exclusion. It is also the model that underpins the UN Convention on the Rights of Persons with a Disability.

Finkelstein (2001) wrote that he and others, as disabled people, were confronted with a simple choice: “you see disability fundamentally as a personal tragedy or you see it as a form of social oppression”. He further explained: “It is society that disables us and disabled people are an oppressed social group.”

The opinion that society disables people with impairments, and that it is this challenging societal response that constructs disability became the catalyst for a new movement based on the principle that disabled people’s political campaign should be directed toward changing society and captivating control over their own lives. For Finkelstein it was a question of an emancipatory strategy rather than a “compensatory” one. Later, discrimination against persons with disabilities became illegal in most countries and the UN Convention imposes the moral responsibility on society to dismantle barriers which have been enforced, and to empower disabled people to contribute.

Shakespeare saw the social model similarly as a driver for change: “the social model is easily explained and understood, and it generates a clear agenda for social change. The social model offers a straightforward way of distinguishing allies from enemies” (Shakespeare 2006, 199). The model became the key framework for identifying and eliminating the disability barriers in the media, public transportation, and public buildings. However, Shakespeare also suggests that the social model may work better for some individuals than others – e.g. for individuals with mobility impairments which are not linked

with medical complications. In this case, it might be possible to regard disability as exclusively socially produced. However, for those who have degenerative conditions which involve pain and discomfort, it is harder to overlook the destructive features of impairment (Shakespeare 2006).

In 2013, Oliver revisited his original paper and responded to some of the ways the social model had been used and the criticisms that had been levelled at the model. He highlighted that his aim back in 2013 had been to alert professionals to a different way of thinking, suggesting that until that point those working with disabled people had operated largely within a framework based on the individual model and arguing that “in order to make their practice more relevant to the needs of disabled people they needed to re-orient their work to a framework based upon the social model” (Oliver 2013, 2024). Oliver highlights that he did not suggest that the individual model should be completely abandoned nor that the social model “was an all-encompassing framework within which everything that happens to disabled people could be understood or explained” but rather he accepts many of the criticisms and asserts that the model was intended only as a tool to improve the lives of people with disabilities, asserting that focusing on impairment was less helpful as for many people this cannot be changed, whereas making society more accessible and friendly is something we can do to improve the experiences of those with disabilities.

In summary, the social model is only one of the available options for theorizing disability. As both Oliver (1990) and Shakespeare (2006) argued, more sophisticated and complex approaches are needed, recognising that disability is a complex phenomenon, requiring different levels of analysis and intervention, ranging from the medical to the socio-political.

This book aims to bring together some of the different ways that different countries have tried to improve the lives of disabled people, through different systems, approaches and methods of support. In doing this it is essential to start with what we already know about how things have changed for people with disabilities in recent years and what the current situation is, in particular with regard to living situation and systems of support. This is the focus of section 1 of this book.

QUALITY

The second theme for this book relates to Quality - its definition, measurement and improvement. Research has shown that having an ordinary home dispersed in the community is a necessary but not sufficient condition for better outcomes, in particular if we define outcomes in terms of quality of life (Mansell 2006). Rather attention has to be also be paid to the “quality” of the services provided, with a particular focus on the nature of the support provid-

ed. Quality has been, and continues to be, conceptualised in many different ways in different countries and in different parts of the service system.

In section 2 of the book, we will explore some of the ways quality has been conceptualised and what good services and good support looks like. We will explore models such as Donabedian's Structure-Process-Outcomes model of service quality and concepts such as quality of life and active citizenship. Quality of life is frequently conceptualised as the desired outcome of services (Schalock et al. 2002) and is conceptualised as comprising basic needs being met (e.g. shelter, food, drink, personal care needs, control, dignity) in conjunction with opportunities and support to achieve what Schalock refers to as "life enrichers" (e.g. social relationships, choice, self-esteem and fulfilment, social inclusion).

Interest in the concept of quality of life emerged in social services particularly in connection with their transformation, especially in the USA, Great Britain, Australia and the Netherlands. In addition, politicians and administrators became interested in financial assessment of the costs associated with deinstitutionalization (eg Knapp 1998, 2011), and in the impact of deinstitutionalization on the quality of life of service users. Positive changes in quality of life have been used to judge the success of deinstitutionalisation.

The concept of quality of life gradually replaced the concept of normalization as the "ideal direction" for the transformation of social services. The worldwide politics of disability rights has propelled a category of social descriptions of disability. For example, in many countries, the idea of normalisation and social role valorisation introduced in 1970s by Wolfensberger was inspirational, particularly amongst those working with people with intellectual disabilities (Wolfensberger 1972). Normalisation ideas drew on a mixture of human rights and deviancy theories. In the Scandinavian model, the emphasis was on rights: "The normalisation principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society." (Nirje 1980, 33) In the North American manifestation of normalisation (renamed "social role valorisation" by Wolfensberger c.1983) (Wolfensberger and Tullman 1989), the emphasis was on social devaluation and reversing its consequences, i.e. it had more in common with Goffman's deviancy theory: "Normalisation implies, as much as possible, the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people (Wolfensberger and Tullman 1989, 131).

One of the most important elements of quality of life in this book is that of social inclusion. Social inclusion is used as a concept related to the process of improving the terms of participation in society, particularly for people who are disadvantaged, through enhancing opportunities, access to resources, voice and respect for rights (United Nations 2016). Related to quality of life is the concept of (active) citizenship, another key concept of the book. We analyse

how public policies and practices have influenced the lived experiences of persons with disabilities and discuss potential improvements. In the book, we use the definition of active citizenship set out in the FP 7 project exploring active citizenship of persons with disabilities (DISCIT). “Being an active citizen involves exercising social rights and duties, enjoying choice and autonomy and participating in political decision-making processes that are important for one’s life and society as a whole” (Halvorsen et al. 2018, 3).

For full and meaningful inclusion in the local community and in society more generally one needs not to be only present in that community, but to feel part of that community and contributing to that community (O’Brien 1981 cited in O’Brien 1992; Miller and Katz 2002; Mansell and Beadle-Brown 2012). The UN Convention (UN-CRPD) enshrines the right for people with disabilities to a life in the community and sets out that living situation, participation in all aspects of community life, having choice and autonomy, is not just to be made available but to be turned into reality on an equal basis with others with the necessary support.

MAKING SYSTEM CHANGE

The third theme explored in the book relates to what is needed to ensure system wide change and high-quality services. In section 3, we present some of the theories and lessons from previous attempts related to making change at organisational and system levels. In our overview chapter, we draw on the recommendations of a large study on Deinstitutionalisation and Community Living in Europe (Mansell et al. 2007) and explore how the recommendations might still apply and how further change might be achieved. In addition, Section 3 responds to the issues that are highlighted in the chapters in Section 1 in terms of the living situation of people with disabilities. Chapters from our colleagues explore some examples of how some of these recommendations have and can be implemented, for example through better local planning systems, data monitoring and quality assurance systems. Other chapters draw on the lessons from one country with relevance to particular barriers to change, such as understanding and supporting decision making, autonomy and the legal safeguards required.

INTRODUCTION TO SECTION 1: THE CURRENT SITUATION FOR PEOPLE WITH DISABILITIES

In the book we examine various pathways towards community-based services. These pathways differ from country to country following specific traditions, history, culture and values. The development of community-based processes

cannot be attributed to one single factor but rather a combination of factors. Although there are some common factors that appear to have been important in some countries, these do not necessarily feature strongly if at all in other countries. For example, in some countries the relative cost of community based and institutional services was important part of the process. In others, this was not the case. In some, new ways of funding through social care rather than health care was key. In some countries, the revelation of scandals and poor practice in institutions was a key driver, but not in other countries. Relatively important in all countries though appears to have been the availability of alternative models – ie. it had been shown that it was possible for even people with the most severe disabilities to live in the community.

Consistently important has been the role ideology and a rights-based agenda has played, although again the ideologies and rights have changed over time and have been conceptualised in different ways in different countries: from the early influence of normalisation and its various offshoots as described above, to the role of civil and human rights. The social model of disability also played a role here to some extent, particularly influencing the development of the UN Convention on the Rights of Persons with Disabilities (UN-CRPD, 2006), considered by many as the most significant disability human rights document.

The UN-CRPD highlights the importance of both presence in the community and active participation. In particular, Article 19 gives people with disabilities the right to not only have a home in the community like everyone else with choice over where and with whom they live but also states that they should have support for full inclusion and participation in the community. In addition, Article 29, spells out the right to participation in political and public life, Article 30 highlights the right to participation in cultural life, recreation, leisure and sports and Article 27 set out the right to employment

Underlying all the articles in the Convention, is the concept of rights “on an equal basis with others”, thus emphasising the importance of equality (as opposed to equity). For example, Article 19 uses “with choices equal to others”, “opportunity to choose their place of residence and where and with whom they live on an equal basis with others” and “Community services and facilities for the general population are available on an equal basis to persons with disabilities ...”

Also fundamental for all the articles is the concept of choice. According to article 12, State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. The Committee stresses that legal capacity comprises both the capacity to hold rights (legal standing) and the capacity to be an actor under the law (legal agency). The Committee further explains that while legal standing “entitles a person to full protection of his or her rights by the legal system”, legal agency licenses a person to “engage in transactions and create,

modify or end legal relationships”. We can elaborate from the statement that by making informed treatment/service choices one exercises legal agency. This means that the right to make one’s own decisions about social services is a critical element of legal capacity. The second paragraph of article 12 accordingly obliges states parties to recognise that persons with disabilities have the right to make their own decisions.

Finally, and very importantly, the convention makes it very clear that people should have support to do all of these things – people do not need to be able to do things independently in order to avail of these rights. This is particularly important if we are thinking about supporting people with more severe disabilities. For example, article 19 states: “Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”; Article 12 says “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

Throughout this book, we will be paying attention to how well the UN Convention is being implemented currently and considering what is needed for future improvement in the situation of people with disabilities.

WHAT DO WE KNOW IN TERMS OF THE CURRENT SITUATION OF PEOPLE WITH DISABILITIES AND THE IMPLEMENTATION OF THE UN CONVENTION?

In this section we draw, in particular, on two recent studies conducted in Europe. The EU Framework 7 project Making Persons with Disabilities Full Citizens (DISCIT²) and a report on the transition from institutional to community care in 27 EU states (Šiška and Beadle-Brown 2020). The DISCIT study focused on active citizenship more widely although a key focus was on active citizenship through community living (Šiška et al. 2017). This study highlighted that although there had been some positive change in terms of policy and living situation for some groups, overall, the number of people living in large residential services/institutions had not decreased since the UN-CRPD had been published. In addition, there was a lack of research (or official statistics) on many areas of the UN Convention and so it was not possible to judge whether people were really having more choice over living situation and over the support they receive, whether people were actively participating in the community, accessing leisure, education, cultural activities, etc. However, interviews with people with disabilities in each of the nine countries and with expert

² <https://blogg.hioa.no/discit/>.

informants identified that, although some of those we interviewed were employed, experienced political participation and had chosen their living situation, there were still many barriers to active citizenship for all. We will come back to looking at these in Section 3. In particular, people with intellectual disabilities were particularly likely to still be in large, segregated settings and less likely to be experiencing active citizenship.

Šiška and Beadle-Brown (2020) focused specifically on reviewing the current situation in terms of the transition from institutional to community living for a number of different groups, including children and adults with disabilities, in 27 EU Member states. Although limited by the lack and completeness of data, Šiška and Beadle-Brown reported that there were at least 1,438,696 children and adults still living in institutions. The number of people in institutions was almost the same as the figure estimated by Mansell et al., (2007). At least some residential care was still provided for all groups, even for children without disabilities. Only in Sweden was all residential provision for adults small scale and community-based. In most countries, such small residential services were a minority form of services. This study also identified that those who had seen the least change were those with intellectual disability and those with mental health needs.

In terms of the wider context, most of the research related to living situation and the transition from institution to community living in Asia has focused on children and the impact deinstitutionalisation has. Although the majority of people with disabilities in Australia live in their own home or with their family (Wiesel et al. 2015), those with intellectual disabilities, in particular those with more severe disabilities, primarily live in residential care settings. Most of these tend to be relatively small (6 or fewer people) although some are larger in size. Recent statistics about living situation were not identified but in 2012 it was reported that there were 11,000 people aged 64 or less who were living in what was referred to as cared accommodation – defined as hospitals, nursing homes, hostels and other homes with six or more people. The issue of young adults with severe disabilities living in aged care settings has also been raised as an issue, with almost 8000 people with disabilities under 65 identified as living in aged care services (Community Affairs References Committee, 2015³).

In the US, the situation varies from State to State – with some states only providing community-based settings (e.g. Vermont) but with others still providing residential institutions for a substantial number of people with intellectual disabilities (e.g. Texas). In 2015 it was reported that over 21,000 people with intellectual disabilities across 37 states still lived in congregate accommodation including state institutions (Lulinski, Tanis and Nelis 2018). This equated to around 18% of people with intellectual disability, with the remain-

3 https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care/Report.

ing 82% of those who lived outside the family home, living with six or fewer people. At this stage, 13 States had no institutions (Lulinski, Tanis and Nelis 2018).

OUTLINE OF THIS SECTION

The first chapter in this section is potentially a little unusual. It comprises two interviews – past and present. The first interview was conducted in 2011 with the late Professor Jim Mansell, one of the pioneers of community-based services and support for people with intellectual disability in the UK. This interview tells the story of closing institutions in England, some of the challenges in doing so and what was needed for success in the future. The second interview is with Milan Šveřepa and looks at how far we have come in the past 10 years in transforming social care services as well as at what is still needed to continue the transformation. The chapter serves to remind us that we all have a part to play in this transformation and that perseverance and optimism is needed.

The other chapters in this section draw on examples from six countries to explore the current situation for people with disabilities, with some analysis of key factors that have driven the process of change in many countries. In Chapter 1.3, Jan Tøssebro outlines both the drivers that were important in the transformation process and the current state of community living for people with intellectual disability in Norway, 25 years after deinstitutionalisation. In Chapter 1.4, Johanna Gustafsson focuses specifically on how people with disabilities in Sweden are supported to have more independent lives through personal assistance and considers the legal, financial and service systems that need to be in place. Christine Linehan (Chapter 1.5) traces changes in policy, and in the regulation, delivery and quality monitoring of services for people with intellectual, physical and sensory disabilities in Ireland, finishing with an analysis of the current implementation of policy and practice. Chapter 1.6 takes us to Austria and an analysis by Gertraud Kreamsner of both the process of change so far and the challenges in implementing Article 19 of the UN-CRPD for people with intellectual disabilities. In Chapter 1.7, Flavia Santos, Luciana Fonseca and Eder Silva introduce us to the current situation in terms of the inclusion of people with disabilities in Brazil, both in terms of living situation and but also with respect to wider community inclusion – e.g. in education and in the workforce. The role of policy and self-advocacy are explored as drivers in the process of change. Last, but by no means least, Čáslava and Šiška (Chapter 1.8) lead us into Section 2 with a chapter tracing the process of deinstitutionalisation and the development of community living in the Czech Republic.

Across these chapters there are some common themes that emerge as potentially important when considering how to start, expand or maintain efforts

to improve the inclusion of people with disabilities in society and the implementation of the UN-CRPD.

1. The situation of people with disabilities more generally has improved over time. However, this is not true for all people and more limited for people with intellectual and developmental disabilities, who are more likely to be living in segregated or congregated settings and less likely to be experiencing real inclusion.
2. The UN-Convention on the Rights of Persons with disabilities has been influential in some ways, in particular in influencing policy. Policy that supports the change process is important, although is not enough on its own and implementation is limited.
3. Monitoring how well the CPRD is being implemented is also important (and a requirement under the UN-CRPD Article 31) but rarely done well. There is a lack of data on the outcomes of the change process and on the lived experiences of people and how included they really are in the community.
4. How people with disabilities are viewed in society and the models and values that are in place continue to play an important role, especially in countries where the process is less advanced. In some countries an individual or medical model of disability still prevails, which makes it very difficult to persuade people of the need to change the system.
5. The importance of self-advocacy, self-determination and supporting people with disabilities to demand their rights is highlighted, whether at an individual level with regards to their own or at a local or national lobbying. People with intellectual disability are particularly affected by a lack of choice and control.
6. Taking a life span and holistic approach appears to be key in ensuring that all people with disabilities are included. Lack of inclusion in education has a negative effect on the options available for people when they are older – people appear to experience completely segregated life trajectories. Lack of planning around support as people with disabilities age means that they can often experience even further exclusion as they grow into older age.
7. The availability of personal assistance appears to be a key driver for participation and inclusion but this is not available everywhere or for some groups of people. Even in countries where community living is well-established recent, the number of those living in less independent settings such as group homes, which themselves have been growing in size, rather than having personal assistance, has been rising.
8. The importance of people with disabilities being present and accepted as part of the “social landscape” (Tøssebro, chapter 2) in some countries is highlighted, although at the same time recognised as not being the same as social inclusion or integration.

We will go on to explore many of these issues in Sections 2 and 3 of this book.

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Deinstitutionalisation and community living: The past, the present and the future

Julie Beadle-Brown, Milan Šveřepa, Jan Šiška
(with contributions from the late Jim Mansell)

This chapter comprises two interviews. The first one was conducted with the late Professor Jim Mansell at his Festschrift in September 2011 by Dr. Nick Gore. Jim was the founder of the Tizard Centre and a pioneer in the development of community-based services in the UK and dedicated most of his career to ensuring that people with intellectual disabilities and their families experienced good lives through good services. As an 18 year old student at Cardiff University he fought for the closure of a local institution, including starting a student charity to support 5 people to move from the institution into the community, living with them and providing the support they needed. Each time he and others demonstrated that people with intellectual disability could live in the community, someone would say “but of course *those people* can live in the community but *these people* (those with more severe disabilities, those who show challenging behaviour, those who are older, autistic ... etc) can’t possibly live in the community”.

So Jim and his colleagues kept going until they had demonstrated that even those who had been incarcerated in high security institutions could be supported safely in the community. In the 1980s he was appointed to the Uni-

versity of Kent to support the closure of institutions in the South East of England. In 1993, the Centre he established was renamed as the Tizard Centre and he directed the work of the Centre for many years, continuing to advise UK governments and doing research into deinstitutionalisation and the development of high quality services focused on improving the lives of people with intellectual disability and their families until his death in March 2012.

In the extract reproduced below, Jim reflects on the early stages of closing institutions for people with intellectual disabilities in the UK and what he felt was needed to keep making progress in realising inclusion for all.

The second interview was conducted in May 2020 with Milan Šveřepa, director of Inclusion Europe. From 2018 to 2020, Milan was co-chair of the EEG, European expert group on transition from institutional to community-based care. Before becoming director of Inclusion Europe, Milan worked on replacing segregated “care” institutions for people with disabilities with community-based support in the Czech Republic and other countries in Central and Eastern Europe and has authored many publications related to how social services and social care system should be organised, as well as about the media and public relations for social sector.

In the interview below, Milan considers what he thinks has changed and what has not changed in the past ten years, 15 years after the publication of the UN-CRPD. He provides an extremely insightful and thought provoking overview of what is needed now to ensure that the reality of community living is achieved for everyone, including those with more severe and complex needs.

INTERVIEW WITH JIM MANSELL

How did you first start to work in the field of intellectual disability?

Well, like so many people working in this field, of course, it was accidental! I had worked at school, as part of a school civics programme, visiting families with...adults that had learning disabilities. ... so when the zoology lab demonstrator said that he took what he called disadvantaged children out to the cinema, to the matinée performance on a Saturday, and he was short of someone to help that weekend, would someone help, ... I readily agreed to go with him. I didn't know how disadvantaged those children were, because they were the children on the children's ward at Ely, and it sounds strange I know, but it was like a concentration camp. Their heads were shaved, because lice were endemic, they all wore gabardine raincoats, white down the front with dried spittle, because they couldn't be laundered, in those days everything was sent to the hospital laundry was boiled. I had never seen anything like this, nothing at all, and so it seemed to me that you had to do something about it, so I started to do something about it! So it wasn't in the sense interest in the field in a