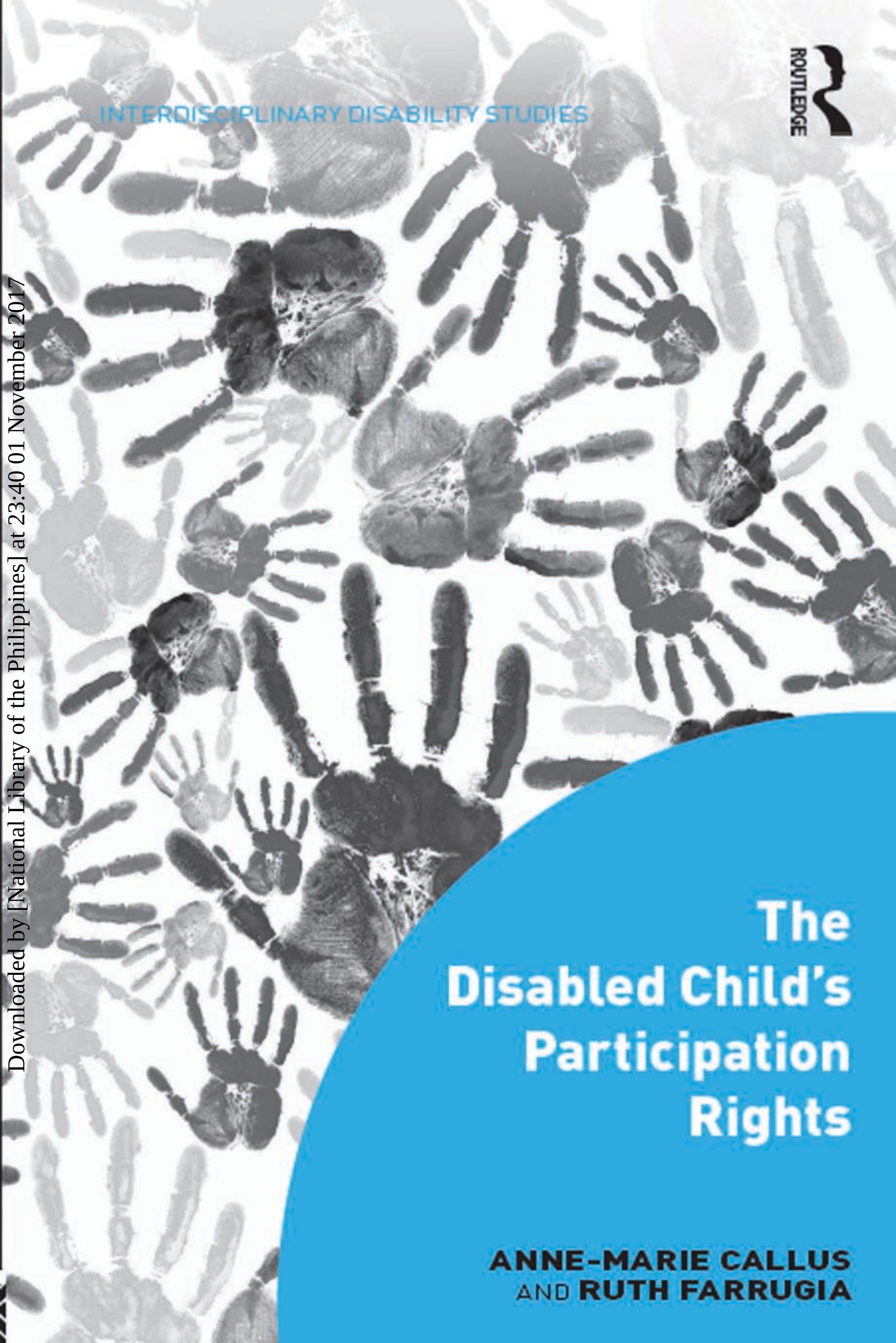

INTERDISCIPLINARY DISABILITY STUDIES

The Disabled Child's Participation Rights

ANNE-MARIE CALLUS
AND RUTH FARRUGIA

THE DISABLED CHILD'S PARTICIPATION RIGHTS

The United Nations Convention on the Rights of Persons with Disabilities is the only UN treaty to date in which the people who are its target, that is disabled people, were actively involved in its drafting and the only one which requires the active participation of disabled people in its implementation. This does not, of course, automatically guarantee the direct participation of all disabled people. This is especially so for children with disabilities, whose status as legal minors may inhibit them from participating in decisions affecting their lives.

This book focuses on the participation rights of the disabled child with regard to health, education, home life and relationships, highlighting ways in which these rights are safeguarded and promoted throughout the EU, as well as exploring the factors that put these rights at risk. Finally, this groundbreaking text analyses whether disabled children's needs for assistance in order to realise their participation rights results in fewer opportunities to participate or in an increase in support in order for them to be able to do so.

Anne-Marie Callus is Lecturer in the Faculty of Laws at the University of Malta, Malta. She is also Executive Director of the National Commission for Persons with Disability in Malta.

Ruth Farrugia is Senior Lecturer in the Faculty of Laws at the University of Malta, Malta. She is a legal consultant to Malta's Commissioner for Children and was was commissioned by the Maltese government to draft both the gender Equality Act and the Children's.

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The Disabled Child's Participation Rights

ANNE-MARIE CALLUS and RUTH FARRUGIA

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Preface

This book is about the right of the disabled child to participate in decision-making processes that affect their lives. Participation can take place at different levels, from asking the disabled child for their views about specific aspects of their lives to their being actively involved in making major decisions. The right of the disabled child to participate in these processes is enshrined in the United Nations Convention on the Rights of Child (CRC) and upheld in the Convention on the Rights of Persons with Disabilities (CRPD). This book uses the requirements of these two Conventions as its basis. In line with the latter Convention, it considers disability to be the outcome of the interaction between people with impairments and the societal barriers that they encounter. In considering different aspects of disabled children's lives, namely health, education, home life and relationships, the book reviews their rights as they are stated in the CRC and CRPD and then focuses specifically on their right to participate in decisions related to these areas. The book brings together the study of Law and Disability Studies as well as Childhood Studies. Disabled children are thus seen as holders of rights and as human beings in their own right, rather than incomplete human beings or, as Qvorturp (1994, cited in Tisdall and Punch 2012) puts it, 'human becomings'.

This book has a largely European focus, concentrating mostly (but not exclusively) on the member states of the European Union. It draws from international human rights treaties, case law of the European Court of Human Rights, official reports and other documents as well as the relevant research literature, especially that literature which includes disabled children's voices. After a detailed description of the background to the development of disabled people's rights in the first chapter, it examines the scope for participation in decision-making that disabled children enjoy in their everyday lives, identifying the factors that promote or hinder participation in the different aspects of life analysed in the next four chapters. The final chapter brings together the main points elicited from these analyses and puts forward recommendations to ensure that the realisation of the participation rights of the disabled child does not happen sporadically but in a systematic fashion. For this to happen, the exercise of participation rights by disabled children, whatever shape or form it may take, should not be contingent on the presence of adults who happen to believe in its importance and have the skills to make it happen. Adults need to fully understand what is meant when one speaks of the disabled child's participation rights, and learn how to make these rights a reality.

This book is aimed at a wide-ranging audience. Scholars and students in Law, Disability Studies and Childhood Studies will find it relevant, as will those who come into contact with disabled children in their work, whether directly or indirectly. It is also relevant for the parents and other primary caregivers of disabled children. In their daily work of bringing up their disabled children it is important that they are aware not only of their children's right to community living, inclusive education, adequate social protection, leisure activities among other rights, but also of the right of those children to have a say in what goes on in their lives. It is our hope that this book will make a contribution towards improving the wellbeing of disabled children by promoting the understanding of their participation rights.

Anne-Marie Callus and Ruth Farrugia

Chapter 1

Introduction

The rights of the disabled child are enshrined in several international treaties, most notably the 1948 Universal Declaration of Human Rights, the 1989 Convention on the Rights of the Child, and the 2006 Convention on the Rights of Persons with Disabilities. These treaties, along with other international and national legislative instruments, protect the rights of the disabled child by virtue of their being human, and also safeguard their rights as a child and as a person with disabilities. The rights which are thus protected cover different aspects of life, starting from the right to life itself, the right to health, habilitation and rehabilitation services and adequate social protection, education, family life, leisure, sport and culture among others. The disabled child thus has the right to enjoy life and participate in their community on an equal basis with other children.

Together with all these rights, the disabled child also has a right to have their views heard and to have those views taken into account when decisions are taken which affect their lives. The right for the disabled child to exercise these participation rights, which is the subject matter of this book, are found in both the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). The latter places a great deal of emphasis on the importance of *all* disabled persons exercising their participation rights not only in matters affecting them directly but at all levels, including in the implementation and monitoring of the CRPD itself. This introductory chapter contextualises this Convention within the development of the disabled people's movement, one of whose main struggles has always been the realisation and exercise of disabled people's participation rights. The chapter then considers the place of disabled children in the disability rights movement, before focusing on their participation rights in general. Underlying all rights is the right to life itself. Given the fundamental nature of this right, without which there cannot be access to any other right, the right to life is considered in the present chapter. The next four chapters then consider the disabled child's participation rights in health, education, home life and relationships, highlighting ways in which these rights are safeguarded and promoted, as well as exploring the factors that put these rights at risk. The final chapter draws together the various issues and themes that were analysed in the previous four chapters and proposes ways of accomplishing the exercise of the disabled child's participation rights in a comprehensive manner.

The theme of this book is universal. Participation rights belong to disabled children everywhere, regardless of where they happen to live. The chapters mainly draw on European documents and research literature, in particular that from the member states of the European Union and the European Free Trade Area. This focus is especially useful in the light of the ratification of the CRPD by the European Union as a bloc. It also reflects the fact that the book was written within a European context. References to literature from other countries are made where it is especially relevant to the realisation of the participation rights of the child with disability. The themes explored, issues raised and recommendations made are applicable to all disabled children everywhere.

The terms 'disabled child/children' and 'child/children with disability' are used interchangeably. We are aware that some prefer to use 'disabled people/person(s)' (or in this case 'child(ren)') in order to emphasise that disability is a condition imposed on those who have a significant and long-term impairment, while others prefer 'people first language' and opt for 'person(s)/child(ren) with disability/disabilities'. There is validity in both arguments and therefore both options are used on the understanding that 'disabled'/'disability' refers to the socially constructed barriers not to the impairment itself. This distinction is set out in more detail below.

Furthermore, child rights activists frequently prefer to refer to 'the child' rather than 'children'. The use of the latter term seems to allude to a universal indeterminate group, while 'the child' emphasises that each child is an individual with distinct rights and needs. Consequently, as much as possible 'the child' is used throughout the book, with the use of the plural pronoun 'they' to use gender-neutral language.

The United Nations Convention on the Rights of Persons with Disabilities

The adoption of the CRPD and its Optional Protocol by the United Nations on 13 December 2006 marked both a point of arrival and a point of departure for persons with disability and the protection of their rights. It is a point of arrival because it marks the acceptance by governments of United Nations Member States, the majority of which have now ratified the Convention, of what many disabled people had been arguing for many decades – that the difficulties faced by disabled people in participating in the ordinary life of any given society arise not so much from their impairments as from the disabling barriers created by that society. This point was made by Ban Ki-moon, the Secretary-General of the United Nations, when he referred to the Convention as a milestone as well as 'a new dawn' on the day that the Convention and Protocol came into force on 12 May 2008 (Ban 2008).

The deleterious effects that disabling barriers have on people who have impairments is explicitly recognised in the CRPD itself. The Preamble to the Convention recognises that

> […] disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. (United Nations 2006: 2)

The CRPD is the first international legislative instrument to describe disability not only in terms of impairment but also in terms of the interaction between that impairment and the environment in which the disabled person is living. It is also significant that disability is not defined as a stable condition in this Convention but rather as an evolving concept. There is thus an important shift from a focus on impairment to recognition of the multifarious barriers created by society which impose difficulties on disabled people's lives.

The CRPD scores a number of other firsts. Apart from being the first human rights treaty of the third millennium, it is the longest such treaty, and the one that took the least time for United Nations member states to reach agreement upon. The CRPD is also a point of departure because, as with all international conventions, its coming into force and its ratification by the majority of United Nations member states does not automatically guarantee that disabled people's rights will henceforth be respected and all discrimination against them eliminated. However, like other recent international human rights conventions, the CRPD is not simply a catalogue of rights but includes an in-built mechanism for its implementation. In this regard, another unique characteristic of the CRPD, compared to previous conventions, is the inclusion of an independent mechanism to monitor the implementation of the Convention and effectively strive to ensure the protection of disabled people's rights.

More importantly, it is the only treaty to date in which the people who are its target, that is disabled people, were actively involved in its drafting and the only one which requires the active participation of disabled people in its implementation. It also marks a significant point of arrival for the disabled people's movements and the battle cry of 'nothing about us without us' that has characterised this movement from its inception.

The aim of the CRPD is for disabled people to enjoy 'full and effective participation in society on an equal basis with others' (United Nations 2006: 1). The CRPD, then, is not about the creation of separate rights for disabled people, but about their ability to share the same life experiences as their non-disabled counterparts and within the same communities. It is noteworthy that the phrase 'on an equal basis with others' is used no less than 35 times in the CRPD. The phrase has dual implications that, on the one hand, disabled people are not demanding special privileges and that, on the other hand, they cannot yet take for granted the enjoyment of the same opportunities as non-disabled people living in the same communities. As Yee and Golden (2002: 449) put it:

> People with disabilities are not asking for anything extraordinary when they want to shop for groceries, watch their children play with their peers, move into a neighborhood, or go to college.

Articles 9 to 30 of the CRPD deal with the barriers that hinder disabled people from being in the mainstream of society. As the disabled people's movement has consistently argued, such barriers must be removed in order for equal rights to become a reality. These articles require States Parties to the Convention to identify and remove obstacles which limit access to the built environment, transport, information and communication, and services and facilities that are open to the public. In these articles, the CRPD also asserts disabled people's right to life, and their rights to equal recognition before the law and to access to justice. These articles deal with everyday aspects of life such as living independently and being included in the community. Other articles are about participation in culture, leisure and sport, participation in political life, and entering into relationships and forming a family. Furthermore, these articles assert disabled people's rights to access to health and rehabilitation services, inclusive education and employment. They also deal with access to information and freedom of expression, and an adequate standard of living and social protection.

As can be seen, the subject matter of these articles pertains to an ordinary life within society and the enjoyment of the same opportunities and rights as other people living within the same society. It is of interest to note that articles 10 to 30 are informed by underlying principles which are set out in the Preamble of the CRPD together with articles 1 to 4. First and foremost, the CRPD refers to all human beings' 'equal and inalienable rights', placing disabled people firmly within the ambit of these rights, especially as they are expressed in the United Nations Declaration of Human Rights and other international and regional human rights covenants. Importantly, the CRPD affirms that discrimination against disabled people is a violation of these rights and that the barriers to participate in society that disabled people face constitute discrimination.

In these first sections, the CRPD also recognises the contribution that persons with disability can themselves give to their communities and to human diversity in general. Enabling disabled people to give a contribution entails providing them with reasonable accommodation, practising universal design, ensuring accessibility in all areas of community life, addressing the poverty many disabled people live in, and providing the necessary support to disabled people and their families. This work, the CRPD states, should be done while also promoting the autonomy and independence of disabled people and their ability to make their own choices and be involved in decisions affecting them, including decisions made at the highest levels. The CRPD obliges States Parties to take these decisions in order to provide the necessary legislation, policies, programmes and other measures that are needed to implement the CRPD itself.

The CRPD therefore can be considered to be a point of arrival since it brings together the many different issues that the disabled people's movement has been campaigning about, especially in the latter half of the twentieth century. It is to the development of this movement that our attention now turns.

The Disabled People's Movement

The disabled people's movement is the collectivity of disabled individuals and organisations led by disabled people that have fought for their rights. Driedger (1989) describes it as the 'last civil rights movement' in that it emerged as an organised movement after the feminist, gay rights and black civil rights movements. While this movement gathered pace in many Western countries in the 1960s and 1970s (Barnes, Oliver and Barton 2002), its inception can be traced to earlier dates. Campbell and Oliver (1996) refer to a campaign, themed 'Rights Not Charity' by blind people in the United Kingdom in 1926. Similarly, Driedger (1989) refers to blind and deaf people in the Scandinavian countries beginning to organise themselves in groups, albeit separately, from the late nineteenth century. Disabled people gradually became more organised and more vocal in their demands for their rights and for equal opportunities as fellow citizens. In Denmark, disability organisations started to unite in their struggle for disabled people's rights in the 1930s (Langvad 2011), in Sweden a decade later (Swedish Disability Federation 2013).

After the end of the Second World War, disabled people's struggle took on a new momentum. The closure of long-term large-scale institutions in Scandinavian countries started slowly after the Second World War within the context of an increased awareness of the importance of safeguarding human rights, even while eugenics was still being practised especially in terms of the forced sterilisation of disabled persons. Deinstitutionalisation reached a peak in the 1970s. As Mansell and Eriksson (1995) state, it was a process which affected mainly disabled children and adults with a mild intellectual disability who had been placed in these institutions but it gradually grew into the creation of community-based services for disabled people with different impairments. It also spread to other countries, most notably the United States and the United Kingdom. In parallel to this process, people with physical disabilities, especially those with acquired impairments, began to form their own organisations. As Oliver (1990) says, the self-mobilisation of disabled people had three main aims: redefining disability in social (rather than purely medical) terms, becoming an organised political movement and creating services that suited disabled people's needs.

The disabled people's movement and all work related to the promotion of disabled people's rights have been inspired by one fundamental idea – that disability is not purely caused by biological impairment but rather it is the failure of society to adapt itself to the needs of those who do have an impairment. There is thus a radical shift of focus from the individual to the social model of disability (Oliver 1996). This shift has been used in all efforts to ensure that disabled people can enjoy the same rights as non-disabled people. Significantly, the disabled people's movement has not limited its fight for disabled people's rights to the narrow goal of simply participating in the life of the community around them. They have also fought for their right to participate in decisions affecting their lives, thus striving to ensure that it is disabled people themselves who ascertain what their own needs are.

In this context, when talking about disability organisations, a distinction has historically been made between organisations *of* and *for* disabled people (Oliver 1984). The former are organisations in which disabled people are in control, while the latter are those organisations which are run by non-disabled people. There is a debate about the usefulness of such a clear-cut distinction (Shakespeare 2006, Oliver and Barnes 2012) between these two types of organisations. However, the issue of control by disabled people remains an important issue in the disability sector since the setting up of organisations by disabled people themselves formed a crucial part of the disabled people's movement. Driedger's (1989) book discusses the formation of Disabled People's International. It was set up after disabled people attending the 1981 conference of Rehabilitation International which took place in Winnipeg in Canada. They took issue with the dominance of the non-disabled health professionals in the conference and the lack of voice of disabled persons themselves, especially when they were not ensured disabled people's direct representation in the International Year of Disabled People which was organised by the United Nations that year. As a result, disabled people walked out of the conference. They established Disabled People's International later on that year in Singapore – an organisation which exists to this day (Disabled People's International 2015).

The stand that disabled people took in the Rehabilitation International conference was part of their struggle to gain control over their own lives by changing the power relations between them and members of the medical professions. In his history of disability, especially in France, Stiker (1999) describes how the aftermath of the First World War brought with it a focus on rehabilitating injured soldiers with the aim of re-integrating them into society. Rehabilitation gradually grew into a 'collection of medical, therapeutic, social, and professional actions directed at those who are grouped under the generic term of disabled' (Stiker 1999: 122). This development meant that disabled people's lives increasingly came under the control of doctors and rehabilitation professionals. It was they who decided what disabled people needed, with the emphasis being on making them whole so that they could integrate into society. Medical intervention is obviously important and can bring about positive and lasting changes in attenuating impairment effects (Thomas 1999), as seen in Chapter 2. But an exclusive emphasis on cure and rehabilitation means that decisions about disabled people's lives are made by relevant professionals with little or no account being taken of what disabled people want for themselves. The dramatic walk-out from the 1981 Rehabilitation International Conference and the subsequent setting up of Disabled People's International, referred to above, were thus a reaction by disabled people against the hold that these professionals had over their lives and the fact that disabled people's lack of control over their own lives was not even perceived to be problematic.

The creation of Disabled People's International and other disabled people's organisations by disabled people themselves also changed the power relations between disabled and non-disabled people within the non-governmental sector. Both Barnes (1997) and Stiker (1999) place the rise of the concept of carrying out acts of charity with disabled people within the period of early Christianity. Stiker refers to Zotikos, who lived in Byzantium (later Constantinople and today Istanbul) at the time of the Emperor Constantine, that is, in the fourth century AD. Zotikos's work with lepers, Stiker says, marks the start of organised charity work being carried out initially with those who were ill but eventually also with those who were permanently disabled. This work was inspired by a worldview in which disabled people were no longer seen as a product of sin or evil, but as people whom Christians had a duty to love and be charitable towards. As Stiker (1999: 77) states, 'this new view would for centuries result in nothing more than alms, either individually given or in the form of institutionalized works of charity'.

The view of disabled people as objects of charity has lasted for almost two millennia and in the early twentieth century was complemented by the view of disabled people as subjects of the medical and rehabilitation professions. Both Stiker (1999) and Barnes (1997) argue that the shift towards the charity model of disability was an improvement on ostracising disabled people because they were seen as being the product of sin and evil. After St Zotikos started working with lepers,[1] many charitable organisations set up by non-disabled benefactors followed suit, bringing positive changes in the lives of many disabled individuals. This critique of traditional disability organisations that operate on the charity or medical models of disability is not meant to detract from the benefits that many disabled people have reaped through the work carried out by charitable and medical organisations and by non-disabled philanthropists. Rather, it is meant to highlight the importance that the disabled people's movement has given to disabled people being in control of their own lives and of decisions affecting them and to bringing about lasting social change, thus addressing also the root causes of disability rather than only treating impairment effects.

The Disabled Child's Rights

The disabled people's movement can be said to have been very much an adults' movement, with disabled children's experiences and concerns being mostly represented vicariously through their parents or through the recollection of disabled adults of their childhood. For example, in their seminal history of the disabled people's movement in the United Kingdom, Campbell and Oliver (1996) based their book on interviews with adults with disability, a number of whom recall their childhoods focusing especially on their experiences in mainstream and segregated schools. An almost-exclusive focus on disabled adults is also found in Driedger's (1989) account of the establishment of Disabled People's International, which has also been referred to above.

This is not to say that the rights of the child with disability have been ignored. The struggle to make not just education but *inclusive* education a right for all disabled children, the move towards the deinstitutionalisation of disabled children's out-of-home care and the establishment of a wide variety of inclusive and specialist services for disabled children are among the many advancements that attest to the importance given to these children's rights. What is missing very often, rather, are the voices of disabled children themselves. As Davis and Watson (2000) remark, most of the research that focuses on disabled children's concerns is *about* them rather than *with* them. The same can be said of official documents such as state reports and policies which focus on what services are provided for disabled children while giving little or no account to their perspectives.[2]

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[1] Leprosy in now called Hanson's disease.

[2] There is a growing body of research that focuses on the perspectives of the disabled child (see for example Curran and Runswick-Cole (2013) and Slater (2015)).

The assertion of the disabled child's participation rights mirrors the struggles of disabled adults to participate in decisions regarding services that are designed for them. It is a struggle that is still being fought by many disabled people, who still run the risk of being perceived as passive recipients of charity and of various types of services. The risk for disabled children is even greater, especially because legally they are considered to be minors and therefore under the care and responsibility of their parents or of those acting *in loco parentis*. In fact, being a child and being a legal minor are synonymous as childhood refers to the years of a human being's life prior to attaining the state of majority (see Article 1 of the CRC, United Nations 1989). In addition, there is the connection between the disabled child and charity which can be seen clearly in the historic use of images of disabled children by non-governmental disability organisations to raise funds. J. Shapiro describes this connection very well in his book about the disability rights movement in the United States:

> The poster child is a surefire tug at our hearts. The children picked to represent charity fund-raising drives are brave, determined, and inspirational, the most innocent victims of the cruelest whims of life and health. Yet they smile through their "unlucky" fates—a condition that weakens muscles or cuts life expectancy to a brutish handful of years, a birth "defect" or childhood trauma. No other symbol of disability is more beloved by Americans than the cute and courageous poster child—or more loathed by people with disabilities themselves. (J. Shapiro 1994: 12)

Shapiro describes the experiences of Cyndi Jones who has post-polio syndrome and who, in 1956, at the age of five, was chosen as the poster girl for the March of Dimes in her city.[3] He recounts how upset she was when she saw her photograph in a poster depicting two young children happily skipping in a field captioned 'THIS' juxtaposed against an image of herself in her braces which was captioned 'NOT THIS'. Traditionally, and controversially, sentimental and pitiable depictions of disabled children have also been used in fund-raising telethons by charities (Borg and Camilleri 2009).

Such depictions reinforce the combined status of children with disabilities as legal minors and as disabled people in need of care and welfare which in turn places them in a highly disadvantageous position compared to the rights

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It should be noted however that neither of these books focus on the ways in which laws influence the rights of the disabled child.

[3] The March of Dimes was established by President Franklin Delano Roosevelt as a campaign to end polio. Its focus has now shifted to avoiding premature birth and birth defects (Fleishcer and Zames 2011).

exercised by both non-disabled children and disabled adults. Disabled children are therefore worthy of attention as a group in their own right, although of course they are not homogenous or completely different from other children and from disabled adults. There is clearly a high degree of heterogeneity among disabled children because of their family, socioeconomic and cultural backgrounds, the nature of their impairments and the impact of that on their functional abilities, the opportunities and support they enjoy, and not least because of their differences as individual human beings in their own right. However, as will become amply clear in the following chapters, there are sufficient commonalities in the experiences and concerns of disabled children for them to be considered a specific group.

As seen above, the disabled people's movement's rallying cry of 'nothing about us without us' is a reaction against the lack of control of disabled people over their own lives. Establishing this control has particular implications for the disabled child. Without the presence of disabled adults asserting their own participation rights, there is a danger of not seeing these rights as being applicable to disabled children at all. If the disabled child is merely seen as being destined to grow up into a dependent adult it would also be seen as futile to foster their participation rights. After all, the ability to exercise participation rights is seen as evolving in children in both the CRC and the CRPD and is a way of preparing them to become autonomous adults once they reach the age of majority. Therefore, a perceived lack of autonomy in disabled adults has deleterious effects on their ability to have their views heard and participate in decision-making processes when they are still children.

People with mental or intellectual disabilities are at a particular risk of not being heard. While Article 12 of the CRPD recognises that all disabled people have legal capacity and the right to receive support to exercise that capacity if they require it, the response in the vast majority of countries is the enforcement of substitute decision-making legislation such as through guardianship (Shogren and Wehmeyer 2015). The appointment of a guardian, especially one who has plenary powers over a disabled person's rights, effectively amounts to perpetuating the status of that disabled person as a legal minor and therefore as an eternal child.

Supported decision-making legislation for adults is still very much the exception rather than the rule and for most states, it is still unthinkable to automatically accord many persons with diminished mental capacity the right to self-determination on the understanding that such a step is beyond them. The notion of assisted decision-making for these disabled persons therefore remains challenged by many, even in circles where it has been accepted for persons whose impairments are entirely of a physical nature. For the latter, the state is expected to supplement the assistance required to enable decisions which they have freely made. The provision of support is in fact an underlying principle of the CRPD. However, it has yet to be accepted as being applicable for *all* disabled people.[4] As will be seen throughout this book, children with intellectual disability are particularly affected since they are especially vulnerable to not having their participation rights respected.

Therefore, it cannot be overemphasised that disabled children's rights, as they are set out in the CRC and the CRPD, are the rights of *all* disabled children. The presence of a specific article on children with disabilities (Article 23) in the former addresses the specific needs of children who happen to be disabled. Likewise, the specific references to children with disabilities in the CRPD reinforce the rights of disabled people who happen to be children. This can be seen from the repeated assertion in the CRPD that children with disabilities should enjoy their rights 'on an equal basis with other children'.

The disabled child's rights include among others the right to inclusive education, to living in the community, to participating in decision-making processes and the right to life itself. One cannot argue that inclusive education is a right for the disabled child, except if the child poses significant challenges to current educational systems; or that community living is the right of the disabled child, except if they have severe challenging behaviour or complex dependency needs. Likewise, the right to life is there for all disabled children, even those who will be born with significant and lifelong impairments. And, of course, participation rights also belong to all disabled children, including those who have communication difficulties or cognitive impairments.

The disabled child has a right to participate in mainstream education, in community-based services and in society in general and a right to have a say about their participation in different services and activities. There can therefore be said to be two aspects to participation, but very often people focus on the first and ignore the second. Some issues overlap. The lack of physical accessibility can hinder the participation of a child with mobility impairments in a mainstream school or a leisure activity. It can also hinder the child's participation in a consultation meeting with children. Likewise, lack of information in child-friendly and accessible formats can result in a disabled child with print disabilities losing out on taking part in an activity and it can also result in that disabled child not having the information they need to be able to form an opinion or even take a decision. Information about the rights accorded to disabled children both through the CRC and the CRPD should also be accessible for disabled children. These two aspects of participation are complementary. The disabled child cannot be truly considered to be participating in the mainstream if they always do so on terms set down

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[4] See the 'General Comment on Article 12 of the Convention – Equal Recognition before the Law' (Committee on the Rights of Persons with Disabilities 2014).

by others. And by enabling the disabled child's participation in decision-making, adults can become more aware as to what the child wants in their lives and therefore be more motivated to bring about their participation in the mainstream.

The Disabled Child's Participation in Decision-Making

Both the CRPD and the CRC assert, either directly or indirectly, the disabled child's right to participate in decisions that affect their lives. In the case of the CRPD, the Preamble states that 'children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children' (United Nations 2006: 2–3). Furthermore, Article 3(h) (General Principles) refers to disabled children's evolving capacities and their right to preserve their identity. Children with disabilities are also specifically referred to in the General Obligations set out in Article 4(3). States Parties' obligation to consult closely and actively with persons with disabilities which is found in this sub-article specifically refers to active and close consultation with children with disabilities. The subject of Article 7, then, is exclusively the rights of disabled children with the focus being on giving primary consideration to the best interests of the child and ensuring that disabled children can:

> express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize their right. (p. 8)

The ability of disabled children to make decisions, which evolves as they grow older, is also recognised. However, it can only evolve if disabled children are given the opportunity to participate actively in decision-making processes. This principle applies equally to all children and is expressly referred to in the CRC which makes reference to criteria such as maturity and understanding.

Like most aspects of child development – from walking to talking – the disabled child's capability of making choices and taking decisions does not grow spontaneously but needs to be nurtured through the agency of those directly involved in their lives. The CRPD itself provides guidance in how to develop this capability. First of all, there are different levels of decision-making, as can be seen in Article 4 (General Obligations) and Article 7 (Children with Disabilities) of the CRPD. The former includes governments' obligations to consult with disabled people in the implementation of the CRPD, including consultations with disabled children. Then, Article 7 focuses on all types of decisions on matters that affect them, including of course everyday decisions. Secondly, as Article 7 states, disabled children should be able to express their views freely and on an equal basis with other (non-disabled) children, with their age and level of maturity being taken into consideration.

The disabled child's right to participation in decision-making is therefore not an all-or-nothing affair. Although the child does have a right to express their views in *all* matters that affect their lives, it does not mean that if they cannot participate in all decisions then they cannot participate in any at all. Furthermore, it should be assumed that the disabled child has the capacity to participate in decision-making. Article 12 of the CRPD (Equal Recognition Before the Law) asserts that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life' (United Nations 2006: 10). If therefore it is felt that a disabled child does not have the capacity to express their views or participate in decision-making meaningfully, it is not the child who has to prove they have capacity but others (presumably adults) who must prove the contrary. Such a shift in onus is crucial if all children are to be automatically accorded participation rights as a matter of course, rather than being subject to an extra hurdle set to gauge their capacity. This issue is of particular interest to the child with cognitive impairments who may be at a greater risk of being perceived as lacking capacity than the child whose impairment does not affect their intellectual abilities.

Moreover, a lack of capacity in one area of decision-making does not translate into a lack of capacity in all decisions. For example, some disabled children with complex dependency needs may only ever be able to participate in small everyday decisions, such as for example whether to play a game or not, or whether to drink a glass of milk or a glass of water. But having complex dependency needs should not be used as a reason to exclude them completely from any decision-making processes. Most children with disability will develop their decision-making capabilities, albeit at different rates and to different extents in different areas of life. Participation in decision-making can therefore be seen as a continuum, with disabled children being on various parts of the continuum and progressing at a different pace along it as they grow older, from small and mundane decisions to bigger and more long-term ones.

Thirdly, it is important for the disabled child to be provided with the assistance needed to assert their participation rights and to participate meaningfully in decision-making opportunities. The right to assistance in decision-making is in fact also included in Article 7. The type of assistance needed depends on the impairment-related requirements. For the disabled child to assert their participation rights, therefore, measures need to be actively put in place and the responsibility for these measures lies squarely with the

State. These include providing information in accessible formats especially for children with print disabilities (for example those who have visual, perceptual or cognitive impairments), providing access to communication (for example through sign language interpretation or alternative and augmentative communication aids), and ensuring physical access to venues where activities are held aimed at providing a forum for children to express their views.

Neither the CRC nor the CRPD place the onus of actually taking decisions on the disabled child. What they provide is the child's right to be heard in the decision-making process and to express their views freely and without any coercion. Therefore, the ultimate decision of whether or not to engage with the process should remain with the child. Article 12 of the CRC states that:

> States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (United Nations 1989: 4)

Furthermore, both Conventions use the concept of 'best interest', a concept which in the CRPD is used only in relation to children. Article 7(2) states that '[i]n all actions concerning children with disabilities, the best interests of the child shall be a primary consideration' (United Nations 2006: 8), reflecting the requirements of Article 3 of the CRC. It is significant that in these articles, while the best interest of the (disabled) child is presented as a primary consideration, it is only *a* not *the* primary consideration. It is only in articles that deal with situations where children have to be removed from the family home for a variety of reasons that the best interest of the child become *the* primary consideration (see articles 18, 20, 21, 37 and 40 of the CRC and Article 23 (Respect for the Home and Family Life) of the CRPD). Issues regarding the participation rights of disabled children in such situations are taken up in Chapter 4 which focuses on home life.

Even if the best interest of the disabled child were to be made of paramount importance in all circumstances, the fact that the onus of decision-making remains with adults means that ultimately it is adults who decide what is in a child's best interests. According participation rights to the disabled child means that the decision is mediated by the child's own perspective. But that decision-making is contingent on participation taking place in an effective manner and, while the capacity of the disabled child to participate in some way in a decision should be assumed, the judgement almost always ends up being made by adults who deem whether or not the disabled child is capable of forming their own views and who decide what weight to give to those views. Consequently, while the disabled child's participation rights are entrenched in the CRPD and CRC, to assert the child's participation rights, these rights need to be translated into reality through the actions and decisions taken mostly by the adults around them.

The disabled child's participation in the decision-making process is not just a question of asking them a few questions every now and again. It must be, as Franklin and Sloper (2009) argue, an embedded practice in the way services are developed and provided and policies made. Franklin and Sloper are among the researchers who have done a great deal of research with disabled children themselves and their research, which is discussed in the next chapters, provides several examples of participation by disabled children in decision-making. However, as they note, disabled children are less likely to be involved in participation than non-disabled children, and disabled children with severe communication difficulties even less so. The lack of involvement is partly because of a lack of adaptation of consultation methods and processes to suit the needs of different disabled children and the lack of use of different methods for communication. These researchers also note the need for coordination and partnership between those adults who are involved in disabled children's rights and the importance for these adults to have a shared understanding of what participation means. The issue of participation rights is dealt with in Chapter 6.

There is also a State responsibility to ensure that the disabled child's participation rights are truly respected and enforced at all levels. In their reports to the United Nations' Committee on the Rights of Persons with Disabilities, several European Union member states refer to initiatives and policies that are aimed at promoting these rights. In its State Report, Belgium refers to the importance of making information and complaints mechanisms accessible for disabled children (Belgium 2011). Croatia (2011: 232) states that the Office of the Ombudsman for Children (OOC) 'specially promotes the principle of children's participation in making decisions that affect them. *Insisting on the application of this principle in relation with children with developmental difficulties is a permanent task of the OOC*' (authors' emphasis). Likewise, the Cypriot Ombudsman for the Protection of the Rights of the Child has put action schemes in place which include, among other aims, 'the empowerment and participation of children' (Cyprus 2013: 34). Slovakia (2012) reports on a 2011 initiative whereby the Committee of Children and Young People took part in policy-related decision-making and evaluation processes and included the participation of children and young people with disabilities. In the case of Spain, the Constitution recognises children's rights, including the rights to information, freedom of thought and freedom of expression, and the right to be heard (Spain 2010). The final example comes from Wales where 'the "Disabled Children Matter Wales" campaign aims to enable disabled children to express their views directly to Ministers in Wales' (United Kingdom 2011: 163).

These and similar initiatives are laudable in their aims but the questions remains as to the extent to which they are being effective in ensuring that the disabled child can exercise their participation rights. While they may be beneficial, there has been no research that has systematically and specifically assessed the overall effectiveness of each and every one of these measures. The research literature cited in this book offers some answers as to ways in which the disabled child has the opportunity to make their voice heard in decision-making processes. The overall conclusion that can be reached when considering the body of research that focuses specifically on the disabled child's participation in decision-making and in making their views heard is that opportunities do exist especially at the local level but that they are far from reaching a critical mass that signals a paradigm shift towards a comprehensive realisation of the disabled child's participation rights.

The Right to Life

As stated above, the disabled child cannot enjoy any of their rights without first having the right to life. Disabled children's right to life is secured in Article 3 of the Universal Declaration of Human Rights, Article 6 of the CRC and Article 10 (Right to Life) of the CRPD, with the latter stating that 'States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others' (United Nations 2006: 11).

In practice, this right is not always guaranteed since there are countries, Austria and Denmark being just two of them, in which abortion is permissible beyond the normal legal limits and up to the end of the pregnancy if the foetus is diagnosed as having a serious health condition or severe disorder (Austria 2010, Denmark 2011). As the Austrian CRPD State Report states, such abortions are vehemently opposed by disabled activists. The Committee on the Rights of Persons with Disabilities (2013: 3) also '**recommends that the State party abolish any distinction, allowed by law, in the period within which a pregnancy can be terminated based solely on disability**' (bold in the original). The motivation for opposing these laws comes from the fact that they are based on an extremely negative view of the value of a disabled person's life. In fact, such views are so negative that they negate life itself to those who will be born with a lifelong impairment. These laws and the practices that they allow are also in complete contradiction to all the policies, services and measures that are set in place in order to safeguard disabled children's rights and provide them with their entitlements.

In 2011, a Danish newspaper is reported to have carried an article headlined 'Plans to make Denmark a Down syndrome-free perfect society', the aim being not to have any people with Down syndrome by the year 2030 (Phatmass 2011, Somerville 2011). Ware (2011) quotes Niels Uldbjerg, a gynaecologist-obstetrician at Aarhus University and researcher in medical ethics, as describing it as a 'fantastic achievement'. But the abortion of babies with Down syndrome or other permanent and severe impairments is based on an exclusive focus on the impairment of the child which is yet to be born. It is also based on a view of their only having a prospect of suffering in life and of being a burden on their carers and society, without in any way taking into account how many people with Down syndrome and other lifelong conditions can and do enjoy life and are valued members of their families and their communities.

European Court of Human Rights cases that are relevant to this subject focus on the right for the parents-to-be to be informed about any abnormalities in the development of the foetus so that they can take a decision about whether or not to terminate. Two such cases are R.R. vs Poland (European Court of Human Rights 2011, decided on 26 May 2011) and Draon vs France and Maurice vs France (European Court of Human Rights 2005, decided on 6 October 2005, Grand Chamber). In R.R. vs Poland, the case is about lack of access to prenatal genetic tests, specifically a woman who was pregnant with her third child who was thought to have a severe genetic abnormality. She alleged that the doctors did not give her the results of genetic testing and of an ultrasound scan that indicated that the foetus might have developmental abnormalities because they opposed abortion. Additionally, when she was given the amniocentesis test result, it was too late for her to be able to take an informed decision or for her to have an abortion, since the legal time limit had expired. Subsequently, she gave birth to a baby girl who had chromosomal abnormalities. The mother brought the case to court on the grounds that bringing up her seriously ill child had had damaging effects on herself, her two other children and on her relationship with her husband, who had left her.

Significantly, the court found a violation of Article 8 (Right to Respect for Private and Family Life) of the European Convention on Human Rights (Council of Europe 1950) on the grounds that Polish law did not provide for mechanisms to be in place to ensure that the applicant had access to the necessary diagnostic services and information for her to be able to take a decision regarding whether or not to have an abortion. The court stated further that, since Polish law allows abortion on the ground of foetal malformation, the authorities were obliged to make sure that these services and information were available for the woman while she was pregnant with her third baby. Furthermore, the court rejected the Polish government's submission that the doctors had a right to act on their conscience because in this case providing access to the diagnostic services and information amounted to providing access to abortion. The court stated that patients were not prevented from exercising their right to information and to the services they were entitled to. It therefore also found a violation of Article 3 of the Convention (Prohibition of Inhuman and Degrading Treatment), arguing that the applicant had been humiliated and made vulnerable, and that the doctors had failed to provide her with access to timely and clear information and counselling.

The second case, Draon vs France and Maurice vs France, also concerns information about the foetus' congenital malformations not being made available to the prospective parents, although the details of the case are different. The case concerns the parents of children whose severe congenital impairments were not identified during prenatal medical check-ups because of errors committed by the medical staff. During the course of the parents bringing proceedings against the hospital, a new law was introduced in France that gave awards for non-pecuniary damage, although not for the actual incurred as a result of the child's disability. The court found a violation of Article 1 of the European Convention (Protection of Property) which the new law had abolished. The court decided therefore that the parents were not eligible for part of the damages that they should have been able to claim as compensation.

These and similar cases of wrongful birth are about the parents' rights and do not in any way take into account the baby's right to life. Other interventions do not result in the termination of the life of a disabled unborn child but seek to prevent the development of impairments in the foetus during pregnancy. Some of these interventions address the health of the mother-to-be since it directly affects the health of her baby. They can either involve the mother not engaging in certain behaviours, most notably not smoking, not drinking alcohol and avoiding certain medications, or the mother taking precautionary measures such as increasing the intake of folic acid during pregnancy to avoid the risk of spina bifida for her baby and taking the German measles vaccination before becoming pregnant as contracting this disease during pregnancy often results in sensory impairments in the child. Other interventions go further than simply regulating the mother's behaviour and target the embryo itself. Preimplantation genetic diagnosis and screening in the case of in-vitro fertilisation treatment are two such interventions. Apart from the issues raised by such interventions regarding the value of disabled children's lives, selecting for certain characteristics in embryos has an impact on the choices that the child will be born with. The German philosopher Jürgen Habermas states that the "'liberty of the prospective offspring" ought to constrain parental freedom' (cited in Prusak 2005: 34). Their participation is thus compromised even before they are born.

Allowing disabled children to be born does not mean not intervening to improve their health or attenuate the effect of their impairments to the maximum extent possible. But it does mean ensuring that interventions are also respectful of children's wishes and their views.

The Next Chapters

This book will explore and analyse the disabled child's participation rights in decisions affecting various aspects of life, how they are safeguarded in law and in policy as well as how these rights are implemented in practice through various programmes, initiatives and measures. The areas dealt with will mainly be health, education, home life, and relationships. The book will explore whether the disabled child's need for assistance to realise their participation rights is responded to by their being given fewer opportunities to participate or whether the response is to increase support in order for them to be able to do so. The focus of each chapter is summarised below.

Chapter 2: 'Health'

Health issues range from decisions regarding minor medical treatment to end of life decisions. These issues are particularly relevant for many disabled people, especially those living with conditions which are debilitating, progressive or terminal. The conditions themselves may reduce a person's capacity to participate in the decision-making process unsupported. In the case of the disabled child, the situation is compounded by the fact that it is their parents, or legal guardians, who are very often considered the persons legally entitled to take such decisions, especially when it comes to young children. The chapter will first consider what the CRPD and CRC state about the health-related rights of the disabled child. This is followed by an overview of health-related issues for disabled children especially in European countries. The disabled child's participation rights within healthcare systems are then considered, with the role of the parents of disabled children in decision-making also being taken into account. The chapter then considers participation rights issues related to health that are relevant for two different age groups: infants and young children on the one hand, and older children on the other, especially in terms of issues related to sexual health. Participation rights for disabled children in the mental healthcare system are also considered, followed by a focus on end of life issues and the right to die.

Chapter 3: 'Education'

Education is a very important aspect of childhood. It is what most children spend many of their waking hours doing. Inclusive education is recognised as a right by the CRPD and the chapter will first set out the disabled child's education rights as they are found in the CRPD as well as in the CRC. An investigation into how inclusive education is developing especially within the European Union follows. The disabled child's participation rights are then considered first in terms of an analysis of who has the right to take education-related decisions, whether it is educational authorities, parents or the children themselves. The scope for the disabled child to air views about their education is then considered. Inclusive education is achieved through a process of drawing up and implementing an Individual Education Programme for each disabled child. Opportunities for the child to take part in this process are considered. For some disabled children therapy forms part of their programme and can be considered as part of their education. Participation rights issues related to this subject are considered in this chapter. The chapter then ends with arguments on the crucial nature of the disabled child's participation rights in education.

Chapter 4: 'Home Life'

The CRPD recognises the disabled child's right to family life and, as far as possible, to be known by and brought up by their parents. The need for this right to be included in the CRPD stems from the higher risk for the child to be taken away from the family home because of their impairment-related needs. These needs may require adjustments within the home or the provision of additional services to the family, which are above what is usually considered as the basic standards of minimum care for non-disabled children. This chapter will start with what the CRPD and CRC say about the subject, followed by a discussion of the main issues for the disabled child when it comes to family life, or to residential care if they have been taken out of the family home. The participation rights of the disabled child in both settings are then considered separately. Finally, the chapter analyses the role of advocacy and self-advocacy in the everyday life of the disabled child, and the implications for the child's ability to exercise their participation rights in the home where they live.

Chapter 5: 'Relationships'

The final aspect of life that will be considered in this book is that of relationships – including socialisation and friendships as well as sexual relationships for older children. Of the four areas investigated, this is the area which is least regulated by legislation, with the exception of the establishment of the age when a person can lawfully engage in sexual relationships. It is also the area where it is most difficult to impose rules in, since socialisation and the formation of friendships and relationships grow out of people's informal dealings with each other. It is nonetheless an important topic to consider since the degree of social inclusion enjoyed by disabled people is an indication of the success of legislation, policies and measures in other areas, including those investigated in the previous three chapters. The chapter will start by considering the CRPD and CRC articles that are related to this topic and that have not been considered in the previous chapters. The next section outlines the way disabled children build relationships as they come into contact with adults and with other children in different settings. The scope for the child with disability to exercise their participation rights within these settings is then analysed. As children grow older, they develop stronger relationships with their peers. Accordingly, the participation rights of older disabled children in relationships are considered separately. The chapter then switches focus to the role that adults play in the development of disabled children's relationships, discussing how adults can provide the impetus and structures that enable disabled children's relationships to thrive and for these children to exercise their agency in the development of these relationships.

Chapter 6: 'Realising Disabled Children's Participation Rights'

This is the final chapter and it will bring together the main findings in the previous four chapters and then propose ways of building on what has already been achieved in the exercise of the disabled child's participation rights so that these rights are realised in a comprehensive manner for all disabled children. The chapter first focuses on the role that the disabled child plays as causal agent in their own life. Examples of good practice in terms of disabled children having their views heard and participating in decision-making in each of the four areas explored will then be highlighted. Most of these examples relate to disabled children taking part in decisions affecting them only. The chapter then proposes how the disabled child can also exercise their participation rights at higher levels through involvement in research and policy-making processes. The need for adults to be trained in how to foster the disabled child's participation rights is then investigated with recommendations being made about the nature of the training that is needed. Finally, the realisation of the disabled child's right to participate in decisions can only happen if there is a shared understanding of what these rights are. This chapter therefore ends with a proposed detailed definition of the disabled child's participation rights. The ultimate aim of the realisation of these rights is to ensure that the disabled child enjoys opportunities to participate in society on their own terms as children and also as they prepare for adulthood and seek their rightful place in their community alongside non-disabled people.

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Chapter 2
Health

Introduction

The subject of health presents an intersection between the medical and social models of disability, which were discussed in the previous chapter. At one extreme, a lack of access to adequate healthcare can lead to life threatening situations. But, even when lives are not threatened so directly, this lack can also lead to the acquisition of new impairments or the exacerbation of existing ones. To take just one example, control over the polio virus, which mainly attacks in childhood, means a drop in the amount of children, and eventually adults, who have mobility impairments. From a health perspective, therefore, prevention and rehabilitation services are as important as measures to remove socially-created disabling barriers. All these efforts contribute towards ensuring the wellbeing of the disabled child.

This chapter first looks at the rights of the disabled child in healthcare, as found in the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). It then provides an overview of issues related to access to healthcare for disabled children, when compared to non-disabled children especially in European countries. The focus of the chapter is then placed on the disabled child's participation rights within healthcare and the extent to which they are involved in decisions related to their own health and wellbeing. The role of the parents of disabled children in decision-making is also considered. The chapter then considers participation rights issues related to health that are relevant for infants and young children, followed by issues related to sexual health, especially for older children, and to mental health. End of life issues and the right to die are also considered.

The Disabled Child's Rights to Healthcare

The importance of accessibility to healthcare and health services as a factor in enabling children with disabilities to enjoy their fundamental rights is recognised in the Preamble of the CRPD ((v), United Nations 2006: 3). Article 25 (ibid.: 18) focuses specifically on health, with a reference to access to healthcare for disabled people which is free and affordable on the same level as non-disabled people. The healthcare services mentioned in Article 25 include those related to sexual and reproductive health, and services that are gender sensitive. Furthermore, the article makes mention of the provision 'in a fair and reasonable manner' of life and health insurance. Very importantly, this article refers to the prevention of discrimination in the denial of healthcare, including the provision of 'food and fluids on the basis of disability'.

Article 25 also includes, among other things, early identification and intervention in order to minimise the effect of impairments and to prevent the acquisition of additional impairments. Related to this is rehabilitation, which is then dealt with in more detail in Article 26, Habilitation and Rehabilitation (CRPD), and which is linked to disabled persons achieving independence and developing their abilities to the maximum extent possible. As in Article 25, importance is given to early intervention. Both articles refer to the importance of the availability of health and rehabilitation services in the communities in which disabled people live, including those who live in rural areas. Another aspect that is key to ensuring that the requirements of these articles are adhered to is training. In fact, both articles refer to the importance of ensuring that healthcare professionals receive the necessary training to respond in a timely and appropriate manner, as well as training in rights and ethical issues

One of the key tools to effective participation in decision-making is having access to information, which is addressed in both Article 25 and Article 26 of the CRPD. Very importantly, and very pertinently within the scope of this book, Article 25 refers to 'free and informed consent' to be given by disabled persons while Article 26 refers to the *voluntary* participation in services and knowledge about assistive devices. Another aspect of information is access to information by the disabled person. The right to protecting the privacy of, among others, health and rehabilitation information is addressed in Article 22, Respect for Privacy in the CRPD (United Nations 2006: 15).

While these CRPD articles refer to all disabled persons, regardless of age, they are of course also applicable to disabled children. Indeed, the disabled child's rights with regard to health are also asserted in the CRC, specifically in Article 3 and 24 (CRC) which refer to health and Article 23 (CPRD) which focuses on children with disabilities. Among others, Article 24 refers to the provision of health-related information and education to children.

Being healthy is of course more than simply a lack of physical illness. The World Health Organisation (WHO) states that '[h]ealth is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (World Health Organisation 1948). Consequently, the articles in the CRC and the CRPD that deal with the right to freedom from violence, injury, exploitation, abuse and maltreatment are relevant too. This right is dealt with in Article 19 and 39 of the CRC and Article 15 and 16 of the CRPD which also respectively give children and disabled people the right to services that enable them to recover from any traumatic experiences, and assert the need for related service-provision to take place in a manner that fosters, among others, the health of the child. Related to this is Article 32 of the CRC which asserts the right of the child to protection from carrying out work that compromises the child's health.

It is telling that, in the case of Article 16 of the CRPD, there is repeated reference to age-appropriate (as well as gender-appropriate) treatment and assistance. The article also obliges States Parties to enact 'women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted' (United Nations 2006: 12). The specific focus on children is important as they are at greater risk of adverse treatment when compared both to other children and to disabled adults. As Curran (2013) states, disabled children are not only at higher risk of abuse but there is also a higher risk of such abuse being under-reported. Within this context, the exercise of participation rights by the disabled child takes on a very important dimension as their being able to speak out about maltreatment, abuse or other forms of adverse treatment should these occur is an important aspect of their healthcare needs.

Two articles which may not be obviously related to health are Article 37 of the CRC and Article 14 of the CRPD. Both articles deal with the person's right to liberty and security. However, both articles also allow for situations where the child or the disabled person may be deprived of their liberty. These situations include instances where it is deemed necessary for the person to be confined to a hospital or other institution for treatment related to their mental health needs as well as instances where disabled persons may be seeking asylum in a state which practices detention. Both articles put a number of obligations on States Parties to ensure that any deprivation of liberty (for any reason) is carried out in line with international human rights legislation and takes into account the needs of the child or the disabled person. Such situations, however, have profound implications for the disabled child's participation rights. These are considered later in this chapter.

Access to Healthcare for the Disabled Child

The CRPD and CRC articles outlined above deal with the various rights related to the health of the disabled child. A primary issue for persons to be able to enjoy these rights is of course that of access to healthcare and health and rehabilitation services in the first place, which it why it is pertinent to establish whether there is any inequality of access between disabled and non-disabled children. Adequate access to healthcare and health services can have a direct impact on any child's quality of life. But it has a particular relevance for the disabled child since, as argued above, inadequate healthcare can itself lead to the acquisition of impairments or the exacerbation of existing ones. The distinction between impairment and disability, made in the previous chapter, is particularly pertinent here. As stated, this book is based on the tenets of the social model of disability and its main focus is on removing the disabling barriers that exist in society that prevent disabled children from enjoying equal rights as other children, especially participation rights.

Books, papers and other disability-research texts that are based on the social model tend to focus on aspects of life such as education, employment and community-based independent living. When health-related topics are dealt with within disability studies, the focus tends to be on the contrasts between the medical and the social model. This is not surprising given that, as seen in the previous chapter, the social model was developed by disabled people as a reaction to the models of disability propounded principally by healthcare professionals. Even medical sociology views disability differently than literature that is placed within the disability studies approach (Thomas 2007), mainly because the focus is still on the individual rather than on society. When it comes to a discussion of health issues, a focus on impairments is inevitable and may be seen as being incompatible with a primary focus on the social model. However, it need not be the case. Society, and in this case especially the State, also has a duty to attenuate the deleterious effects of impairments, which can help reduce the effect of socially created disabling barriers in a child's life and the disabled child has as much a right to participate in decision-making processes related to health as those related to other aspects of life.

Furthermore, health conditions, especially when they are chronic, can themselves lead to the creation of disability. The link between chronic health conditions and disability has been confirmed in a ruling by the European Court of Justice (ECJ) in the case of two Danish women with chronic health conditions (chronic back pain and whiplash injuries respectively) who took their employers to court on the basis of disability discrimination. The Danish court referred a number of issues related to these cases to the ECJ, among them whether chronic health conditions constituted a disability. In its ruling (decided on 11 April 2013), the ECJ said thus:

> It must therefore be concluded that if a curable or incurable illness entails a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers, and the limitation is a long-term one, such an illness

> can be covered by the concept of "disability" within the meaning of Directive 2000/78. (European Court of Justice 2013: 9)

Although the ruling here focuses on workers and discrimination in employment, the link between illness and disability can of course be extrapolated to other aspects of life, and to children as well as adults.

A focus on health-related issues does not in any way obviate the need to also remove disabling barriers, especially for those disabled children (and adults) whose impairments cannot be reduced through medical intervention. But, to the extent that medical conditions can be treated and the effects of impairment attenuated, possible interventions and treatments should be carried out in order to avoid giving rise to physical or mental impairments that could have been avoided and a concomitant rise in the number and seriousness of disabling barriers encountered. To this end, both the CRPD and the CRC establish access to early intervention and prevention services as a right for the disabled child. Early intervention services started to be provided in the 1960s and grew as a result of lobbying by parents of disabled children and the professionals working with them (Carpenter 2005). These services are aimed both at children who have impairments and those who are at risk of developing impairments either from biological or environmental causes. As Majnemer (1998) says, early intervention does not necessarily remove the impairment but it can minimise its effects.

Apart from having access to those services which disabled children need by dint of having a disability, such as early intervention, it is also important for them to have equal access to the healthcare and health services that are available to other children living in the same country. Equal access to healthcare and health services for disabled children is not simply a question of access to exactly the same type and quality of care and services as other children. The principle of equality does not arise from sameness. One can argue that if children were all the same we would not need to talk about and strive for equality. The need for international conventions and the assertion of the disabled child's rights comes from a lack of inequality that arises from the circumstances they live in or characteristics they possess. Indeed, the extension of human rights to disabled people came after the recognition that the difficulties they face originate from social and structural inequalities and are not an inevitable outcome of living with an impairment (Yee 2002: 132). It follows therefore that lack of inequality cannot be treated through identical services but through ones which differentiate between various needs.

According to Save the Children (2009), for many disabled children living in developing countries, equality of access to healthcare has not yet become a reality, with the result of a high mortality rate among them. Information about access to healthcare in European Union member states, the geopolitical focus of this book, can be gleaned from the State Reports submitted to the CRPD Committee. To give just a few examples, Austria (2010) provides extra health-related support for disabled children; Belgium (2011) ensures free access for healthcare for disabled persons; Croatia (2011) launched an early childhood intervention initiative in 2010; Cyprus (2013) provides physiotherapy and other services needed by children attending segregated schools; the Danish Health Act (Denmark 2011) ensures that interdisciplinary groups follow disabled children; and Germany (2011) screens newborns for specific conditions. The implementation of these and similar measures does not mean that discrimination does not occur. There can be a gap between what is available *de jure* and de facto, as the Save the Children Fund (2009) reports about Romania where the need to pay for additional treatment means that disabled children whose parents cannot afford to pay remain without. Impairments also bring with them additional costs which compound inequality. The 2011 WHO 'World Report on Disability' reports that failures and problems in Europe's health systems particularly affect disabled people negatively:

> [they] may find it difficult to arrive early, or wait all day, or […] cannot navigate complex systems. While discrimination is not intended, the system indirectly excludes persons with disabilities by not taking their needs into account. (World Health Organisation 2011: 6)

Access to Participation Rights in Healthcare for the Disabled Child

Beyond the rights to access healthcare on an equal basis with other children, the CRC and the CRPD also provided the disabled child with the right to participate in decisions related to their healthcare, rights which are set out in the previous chapter. The CRC of course gives this right to all children, regardless of whether or not they have a long-term disability or health condition. The child also has the right to access information about medical treatment. Trends have started to shift towards permitting a child to request treatment, based on criteria of maturity and understanding rather than age. (Refusal of treatment is another issue altogether, which is dealt with later on in this chapter.) Ever since the Gillick case which established a benchmark for competence (actually referred to as Gillick competence[1]) courts throughout many parts of the world, particularly the English-speaking world, have acknowledged children as capable of making decisions regarding their own

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[1] Although the case was about access to contraception and was not specifically related to disability, its ruling is relevant nonetheless.

medical treatment, provided they can show themselves to understand the consequences and display a degree of maturity acceptable to the authority engaged (House of Lords 1986). However, being heard does not equate with making a concluding decision, although all contested court cases both parties have the right to be heard but know that the court's decision may not necessarily please either party (Elliston 2007). The Council of Europe also has a widely ratified treaty referring to this issue: the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (known as the Oviedo Convention, Council of Europe 1997). Article 6(2) makes specific reference to the protection of persons not able to consent:

> Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.

Apart from the Oviedo Convention, other affirmations allocating responsibility to elicit consent as a means of participation are found in the CRC and CRPD. It can be argued that participation rights in healthcare are particularly pertinent for the disabled child since, as Shilling et al. (2012) state, they are more frequently admitted to hospital. They are also more likely to access therapy services over a long period of time, especially in a bid to offset the deleterious effects of certain impairments.

Participation rights in healthcare comprise the right to consent to medical treatment. Such participation can be a contentious issue not only because of the child's legal status as minors but also because certain health conditions can themselves impair a child's ability to signal their preferences. Examples include children who are in a persistent vegetative state and those whose complex dependency needs are such that render discussions with them of their health conditions extremely difficult if not impossible. It is significant to note that among the few reservations and interpretations made by European countries upon signing or ratifying the CRPD, most of them deal with health issues (United Nations 2015). Within a European context, of particular interest there are the declarations submitted by France, the Netherlands and Norway. Both France and the Netherlands refer to instances where the disabled person cannot give informed consent. In these instances, such persons are regarded as being in need of special protection with consent being by given another person or by a body as provided for by legislation. The declarations made by Norway and by the Netherlands also deal with two opposing aspects of consent – compulsory treatment in mental healthcare in the case of Norway and the right to refuse treatment in the case of the Netherlands. Both of these issues are dealt with in this chapter.

In providing opportunities for disabled children to express their views concerning their own healthcare, consideration must be given, according to both the CRC and the CRPD, to their age and maturity. Both conventions also state that the child's views are to be given 'due weight'. Consequently, the exercise of participation rights by the disabled child depends on assessments made by the adults concerned (who are usually parents and medical staff) about the child's ability to express their views. When these assessments are made without following a formal assessment procedure, there is bound to be a great deal of subjectivity in the decisions made on the part of the adults. More formal and structured assessment procedures would introduce at least a degree of objectivity in the judgement. Furthermore, introducing a degree of formality to the assessment process could enable the adults concerned to become actively conscious of the factors that are impinging on the judgements that they make, especially in terms of the disabled child's maturity and the weight to be given to their views. As things stand, the assessments do not encourage the adults concerned to think reflectively about the judgements they are making and to be aware of subjective elements in that process. As a result, the conclusions reached can end up being more reflective of their attitudes towards participation rights than the child's actual ability to exercise their participation rights.

To begin with, the assessment of a child's ability is based on a multiplicity of factors, many of which cannot be easily measured. Of these, age might seem to be the factor that is easiest to establish. However, even in regard to age, the situation is a complex one. Alderson (2009: 162) argues that

> [t]he answer to the question, "At what age are children able to have the understanding and discretion to make wise decisions about consenting to their health care?" is that there is no single age. Too much depends on each complicated child and their context.

Alderson's own research attests to this complexity. She asked the 300 respondents who participated in her research when they think that a child can start making these decisions. The replies she received varied from eight years or younger. The reason for such a wide variation in the replies reported may be reflective not only of adults' views of children's abilities but also of what they understand by concepts such as participation and decision-making. Some might see participation as being restricted to taking major decisions about healthcare, such as whether or not to proceed with a specific surgical procedure. Others may include everyday decisions such as processes in which children can make their voice heard.

The level of participation afforded to the disabled child within a healthcare setting can also vary. Citing Alderson and Montgomery (1996), Franklin and Sloper (2005: 15) discuss four levels of participation:

1. being informed
2. expressing a view
3. influencing a decision
4. being the main decider

As Franklin and Sloper (2005) state, the first three levels are catered for by the CRC. These authors present two views of these levels of participation. In one view, the levels are seen as being incremental. Thus, obtaining the necessary information is a means of exercising one's participation rights and also a *sine qua non* for moving to higher levels of participation. These first three levels are also seen as essential steps to the other end of this decision-making hierarchy, that is, being the person to mainly take the decision. Another view of the different levels of participation does not place them in a hierarchy. Rather, different levels can be seen as applicable according to the level of seriousness of the decision, the context in which the decision needs to be taken and the characteristics of the children to be included in the decision.

The setting in which the decisions are contextualised varies greatly and includes disabled children who are inpatients, outpatients or receive medical care at home. Shilling et al. (2012) conducted a structured review of eight qualitative studies carried out in the United Kingdom, Ireland and Canada that report the views of children, parents and professionals about the experience of disabled children as inpatients. A number of themes were identified in their synthesis, including the emotions experienced during periods of hospitalisation, the effect that the ward environment has on the children, and the confidence that is expressed in the staff. However, the dominant theme identified by these authors is that of communication. Not surprisingly, the studies reviewed all concluded that when disabled children were given the opportunity to communicate their views, their stay as inpatients was a more positive one. What is significant is that the effectiveness of communication with the children affected the other aspects of their inpatient experience – that is whether or not the children focused on positive or negative aspects of the overall experience, and their opinions of the ward environment and the hospital staff. The positive effects of communication between adults and disabled children in a healthcare setting have further ramifications. For instance, Franklin and Sloper (2005) refer to better health outcomes that are experienced by disabled children whose views are taken into account. Similarly, Cavet and Sloper (2004) report that effective communication with disabled children can lead to increased adherence to treatment regimes.

Moreover, some of the studies reviewed by Shilling et al. (2012) identified the active role that disabled children can play in communication while they are inpatients. Children, therefore, do not necessarily passively wait for their views to be heard but can actively recognise the valid part that they can play in the decision-making process. To this end, as some of the studies report, disabled children may be proactive in ensuring that communication takes place by seeking information themselves. Having the necessary information is an essential part of participating in decisions and ensures that the views expressed by disabled children are formed after consideration of the facts at hand and that these views are based on current and appropriate information pitched to the abilities of the child accessing it. The right to seek and to receive information are recognised in both the CRC and the CRPD (in Article 13 and 21 respectively). Significantly, both articles directly link these rights to the right of freedom of expression. One should not be expected to give an opinion on a matter on which one is not well-informed. In the case of the disabled child, being well-informed also means receiving information and communication in a manner that is accessible and takes into account the child's impairment-related requirements, as provided for by the CRPD. However, some professionals may find it difficult to deal with a well-informed disabled child; one of the studies reviewed by Shilling et al. (2012) suggests that nurses reported difficulty in including children who were very knowledgeable about their condition.

Shilling et al. (2012) also highlight other important issues regarding the participation of disabled children in healthcare-related decisions while they are inpatients. One such issue is the fact that there is variation not only in the capacity to participate in a decision but also in the desire to do so. Parents, on their part, may be concerned that involving children in decision-making can result in burdening their children with a responsibility they are not yet ready to shoulder. Diduck (1999) identifies this concern in according rights to children, which she calls the 'adultification' of the child. The author suggests that any rights discourse and emphasis on the duty to participate may be distorting the social conceptualisation of childhood, requiring an 'unchildlike sense of autonomy' (p. 128). Muncie (2006) has also suggested that shifting responsibility onto children may paradoxically end up leading to increased control over them and greater intolerance towards them. These concerns need to be addressed when assessing capacity for participation, especially because there are no formal methods for carrying out this assessment. As a result, healthcare staff base their judgement of children's communication and decision-making abilities on their own perceptions.

Regardless of the extent to which disabled children are involved in the decision-making process, these decisions are often taken by adults. But there is certainly scope for more and better involvement of the children, as Shilling et al. (2012) conclude in their review article. It is worth noting that while these authors' review focused on qualitative research about disabled children as inpatients, other quantitative and outpatient-focused studies also point towards a situation where opportunities for participation of these children are not maximised. Perhaps this is not surprising, given the many variables that must be factored into the decision of providing scope for this participation. Ultimately, it seems, one of the most important factors that enables the disabled child to exercise their participation rights is the predisposition of parents and healthcare staff to acknowledge their ability to participate. Participation therefore seems to be considered as being tantamount to a gift to be bestowed out of the goodwill of others rather than a right to be accessed by the child, and therefore an obligation for adults to make it possible for the child to do so. Mechanisms for participation to take place effectively should also be put in place – Lightfoot and Sloper (2003) conclude from their study that when a staff member is made specifically responsible for participation, it is more likely to take place. It is therefore important for these adults, and especially staff, to be more aware of children's participation rights, the obstacles to the realisation of these rights, and ways of enabling the effective participation of disabled children. As Cavet and Sloper (2004) point out, this entails bringing about attitudinal changes among healthcare staff and the provision of training that enables them to develop the necessary skills.

The research literature cited in this section provides rich material that shows how the disabled child can and does participate effectively in decisions related to their healthcare. Many of the practices presented here can be used as examples of good practice. However, there is no indication that such practices are widespread. Health service providers who are proactive in involving disabled children in decision-making are more likely to participate in research on this subject. And those children for whom such participation was successful are also more likely to consent to involvement in research – a point made by Carroll (2002) in her small-scale study of the views of children involved in play therapy.

As with any other areas of research, children's consent to participate in health research usually does not come directly from the children themselves, but from adults acting as gatekeepers (parents and staff in healthcare settings among others). If those adults are not inclined to include disabled children in decision-making processes related to the treatments they need to undergo and other health-related issues, it is unlikely that they would see any validity in these children participating in research about participation. It may therefore be difficult to gauge how widespread these practices are, which in itself suggests that Franklin and Sloper's (2005: 19) judgement that the involvement of disabled children in health decisions is 'patchy' still stands. Health services for disabled children focus on ensuring access to these services on an equal basis with other children. Equal access is vital of course and in line with the rights accorded by both the CRPD and the CRC. The importance placed on equality of access is also reflected in State Reports submitted to the UN in connection with the implementation of these two Conventions. On the other hand, the dearth of references to the involvement of disabled children in health-related decisions further indicates that this is not a right that is being given a great deal of importance in a systematic and formal manner as yet.

Research in the area is itself patchy and comprehensive quantitative and qualitative studies are needed to gauge how widespread and how effective participatory practices are. For such studies to be meaningful, there needs to be a common understanding of the key concepts, especially of what participation rights are and what exercising them effectively means. Having such a common understanding cannot overcome fully the issue of personal interpretation but it can provide a model which is used as consistently as possible in different countries, different cultures and sub-cultures, and different healthcare settings. In Chapter 6, we propose a description of disabled children's participation rights which can be the basis of a common understanding.

Thus, the participation of disabled children in healthcare-related decisions does not simply depend on their capacity to do so. It also depends on the attitudes, perceptions and skills of the adults who can open up the decision-making process to the participation of disabled children. Since all children have the right to participate, the criterion should not be whether the disabled child has the capacity to make their views heard and to participate in decisions but whether the adults involved in the decision have the capacity to enable the child to do so. This approach removes the burden of proof from the child to prove their capacity and places the onus of providing effective means with the adults responsible for the inclusion of the child in the decision-making process. The shift of responsibility is also important because, as Alderson (2009) points out, competence to make, or at least participate in, health-related decisions is not fixed.

> Competence is assessed not by tests of general ability but by discovering how much, with help, the child is able to understand and share in making the decision, and how skilful, supportive and competent the adults can be. (Alderson 2009: 162)

In relation to people with intellectual disability, Gill (2015) suggests that particularly for people with intellectual disabilities, competence is 'situational' – it can change from time to time, from place to place, and from one context to another. It can also grow with each opportunity for the disabled child to take part in decisions. Given that, as pointed out above, disabled children tend to visit the hospital and access health services frequently, there is scope for a relationship to be fostered in which parents, children and healthcare staff become increasingly better skilled and more confident in sharing the decision-making process.

Moreover, parents and staff also need to keep in mind that different methods need to be applied according to the type of decision that is being discussed and according to which methods best suit the particular disabled child. This is one of the conclusions that Lightfoot and Sloper (2003) arrive at in their research with 23 young people with a disability or chronic illness. These researchers also point out that the level of formality of the process of consulting the disabled child need always be directly correlated with the seriousness of the decision to be taken. That is to say, while there may be a formal request to consult with the disabled child about health-related decisions, the views of the child about major decisions can be obtained in a non-formal, conversational manner as this is more likely to elicit active participation than a formal interviewing style.

As Franklin and Sloper (2005: 15) state, 'meaningful participation must also be seen as a process not simply an isolated activity or event'. Garth, Murphy and Reddihough (2009) make a similar point in their research about the relationship between disabled children, their parents and paediatricians and how this relationship often evolves from a dyadic one between parent and doctor to a triadic one involving the child in which decisions are taken collectively. It is important for parents and healthcare professionals to be aware of all these issues and to take conscious steps towards increasing the participation of disabled children in healthcare decisions and towards identifying and removing existing barriers which prohibit disabled children from participation because, as Lightfoot and Sloper (2003: 277) put it: 'parents are not reliable proxies for disabled children's views'. However, parents do take decisions about the healthcare of their disabled children. The parents' participation rights are considered in the next section.

The Participation Rights of the Parents of the Disabled Child

At the outset of their lives, disabled children, just like any other children, are completely dependent on adults, most usually their parents. Parents' actions, therefore, can have profound effects on their disabled children's lives, for it is they who provide them with access to healthcare services which are available and who enable them to enjoy their health-related rights. Crucially, it is parents who, in the early years of the disabled child's life, are ultimately responsible for taking decisions regarding their children's health.

On an everyday level, it is parents, or adults acting *in loco parentis*, who organise appointments with doctors, therapists and other healthcare professionals who can provide the necessary therapies and services. Indeed, parents can themselves take on at least some of the responsibilities of therapy provision. As Colyvas, Sawyer and Campbell (2010) write, in many early intervention approaches healthcare professionals involve parents in the intervention by showing them how to apply the necessary interventions and therapies themselves within the home. Very often, parents go beyond that and act as advocates for their disabled children, lobbying for services and treatments that may not be easily forthcoming, at the cost of being seen as troublemakers by health service providers (Care Quality Commission 2012). Derbyshire (2013), the British mother of a disabled child, refers to her 'fights' with health services (p. 30) that she and many other parents of disabled children experience because of the low expectations from professionals that they encounter. Sometimes, parents set out to defy what doctors and other healthcare professionals have told them. Freyja Haraldsdóttir (2013) from Iceland, who has osteogenesis imperfecta, recounts how her parents 'tried to push away the constant reminder from health professionals that [… her] life wouldn't be very long' (p. 13) and focused on giving her the same life experiences as other children because they decided on her 'being raised as a child and not as a physical impairment' (p. 16).

Parents' advocacy for their disabled child sometimes gets involved in battles with hospitals treating their child to provide the necessary medical interventions. Cases occur from time to time where these interventions are not provided on the basis that the child has a disability. Such cases are not restricted to Europe – they are a global phenomenon. For instance, Maverick Higgs, a New York-born boy with Coffin-Siris syndrome, was taken by his parents to a hospital in Boston after he was refused a heart transplant in his State, where he was given life-saving treatment which did not require a transplant (*Daily Mail* 2013). While life and death scenarios such as Maverick's are exceptional, they do serve to highlight the crucial role that parents play in the lives of disabled children, especially in the first years of their lives. When he was refused treatment by his own hospital, Maverick was less than a year old – certainly not an age when he could participate in any decision. It was his parents who could take decisions on his behalf.

Parents may decide to advocate for medical procedures in order to promote the life of a sibling as in the case of a bone marrow transplant or organ donation. Similarly they may agree to therapeutic research where assent is usually required but may be difficult to obtain from a child with severe communication disabilities. P. Lewis (2002) makes the point that, although such procedures may not be harmful to the health of the individual, they may be painful and uncomfortable, while Friedman Ross (2002) observes that, in organ donation, all efforts must be made to include the child in the decision if negative repercussions and feelings are to be avoided. These decisions can be contentious since it is not always clear whether they are of benefit or not for the child. In the case of the disabled child these issues can be even more challenging.

Other decisions may have obviously deleterious effects to the extent that they impact negatively on the child's health, and may also result in the development of an impairment, especially during pregnancy. For instance, as seen in Chapter 1, a lack of folic acid in the mother-to-be can result in the baby being born with spina bifida, the contraction of German measles during pregnancy can result in sensory impairment and preimplantation genetic diagnosis can enable parents to select for specific characteristics in their baby. The thalidomide cases of the 1960s are another case in point, as is foetal alcoholic syndrome today. Abuse of drugs and alcohol can have a direct impact on the health of the child and may cause impairments. In such cases it is interesting to question whether the parent would be liable in law by acting in such a way as to knowingly cause the birth of a child with disability. Similar cases could be called under examination where parents knowingly withhold knowledge of genetic conditions leading to lifelong impairments and go on to have children with these conditions.

But, for some parents, having children with a specific condition may actually be desirable. Some parents who have a profound hearing impairment and use sign language as their first language, for instance, desire to have children who also have a hearing impairment. Sign language users very often consider themselves to be part of a linguistic and cultural minority. The right of deaf people to develop their own linguistic and cultural identity is recognised by the CRPD. McKie and Hinsliff (2008) report on a case where a deaf couple who already have a deaf child and who may need IVF to conceive their second child, wanted to use the fertilisation process to select *for* deafness since they consider being deaf an important part of their own and their family's cultural identity. In a different case, Tucker (1998) discusses the perspectives of some deaf people who argue against cochlear implants for hearing impaired babies as this denies them the option of being raised as deaf.

These are often controversial issues and merit extensive discussions in their own right. The point we want to make here is that the disabled child finds themselves growing up in situations which are determined by decisions made by their parents and by other adults, sometimes even before they are born. Whether these decisions are for the child's benefit or to their detriment depends on one's point of view as well as the actual outcomes for that child.

But, whether for better or for worse, they invariably determine what options are available for the disabled child as they grow up and develop. Whichever way the disabled child is affected by such decisions and whatever options are available to them, it is only right for that child to be accorded their participation rights so that they can have a say in the changes that are needed to improve their situation.

After birth, there may also be scenarios where parents' decisions and actions have negative effects, whether wittingly or unwittingly, on the health or long-term outcomes of the disabled child, and therefore also on the options that will be available to them throughout their lives. Failure by parents to respond to seemingly simple medical conditions may result in a permanent disability for the child. Child protection cases centre on numerous examples of such behaviour where neglect or abuse leads to such results. In extreme cases, Munchausen Syndrome by Proxy can lead to a parent committing bodily harm on a child that exacerbates existing medical conditions. But permanent harm can also be created in less dramatic ways. An untreated ear infection may lead to loss of hearing; neglected eye conditions may lead to loss of sight; deliberate failure without justification to take the child for vaccinations may result in contraction of serious and sometimes seriously debilitating illnesses.

Social workers are often the persons who make the decision to intervene and remove the child from a potentially or already threatening situation which causes harm or potential harm to the child. At one level this action may prevent the onset of disability but it may also serve to ensure that a child with disability receives the care and attention necessary to wellbeing. The CRC and most national legislation in the European Union provides for State intervention to ensure 'special' care for the child whose parents are unable or unwilling to provide it. In the case of the child with disability, the urgency of such intervention may be more pressing and more particular, given the particular needs of each individual child and given the benefits of early intervention, as seen above. Intervention is also necessary in light of the increased risk for disabled children of being removed from their family home, an issue that is dealt with in Chapter 4.

Even if parents are the ones who take most health-related decisions about their disabled child, sometimes these decisions are taken even out of *their* hands by medical or other professionals. Studies such as those carried out by Fiks et al. (2012) in the United States and the Care Quality Commission (2012) in England shows that the involvement of parents in health-related decisions cannot be assumed to happen de facto. Parents frequently accede to professional advice in the hope of better serving their child's interests. The healthcare professional thus carries considerable responsibility to identify appropriate treatment and intervention for the child with disability, in the knowledge that parents will most often look to their considered opinion, often overriding their gut instinct when acting in their child's best interests. The child who is informed and enabled to participate actively may not be so easily swayed by the professional in determining treatment options, particularly when innovative methods are vaunted or painful procedures are advised. The corollary to the right to information is the right to confidentiality. Medical practitioners have a duty of confidentiality towards the disabled child and the parents where they are acting on behalf of the child. Competent adults and minors are assured confidentiality and it must follow that the disabled child and the persons representing the child should be afforded that same duty of confidence. Jackson (2006) goes as far as to conclude that the duty of confidentiality is not restricted to adults and competent minors but also to children who lack competence unless there is an overriding justification for not doing so.

Decision-Making in Infancy and Early Childhood

Given the various channels and agents through which health-related decisions regarding young disabled children are mediated, it is easy to assume that participation rights are not directly relevant for them in their infancy and early years. Even the etymology of the word 'infant' as found in the *Oxford English Dictionary* indicates this irrelevance, since it comes from the Latin for 'not speaking'. However, the argument put forward by Alderson, Hawthorne and Killen (2005) in their discussion of the participation rights of premature babies shows otherwise. These authors refer to studies that show how even babies act as agents in their interactions with the adults caring for them:

> Babies contribute to the parent–infant dyad and to their own development. They seek comforting stimuli, and avoid and shut out unwanted stimuli […] Babies vary greatly in how far they have a robust capacity to learn to handle multiple stimuli, to organise themselves, to interact with the complex environment, and to control their states so that they can avoid becoming overwhelmed and disorganised. (Alderson, Hawthorne and Killen 2005: 34)

As a result, these authors argue, those interacting with premature babies should be aware of the baby's varying levels of awareness and the cue s/he provides in order to optimise their interaction with the baby.

In their argument in favour of considering premature babies as holders of participation rights, Alderson, Hawthorne and Killen contrast the positions adopted by Peter Singer on the one hand and John Wyatt on the other. They say that while Singer does not regard babies as being holders of human rights (let alone participation rights), Wyatt focuses on parents who relate to their premature baby as an individual in their own right, 'not a thing but a person to be treated with gentleness and respect, irreplaceable, a loving child' (Alderson, Hawthorne and Killen 2005: 38).

Yet again, therefore, it can be seen how the level of interaction afforded to disabled infants and young children depends not so much on their own ability to be agents in their own lives but on the readiness of the adults caring for them to treat them as such. The development of the disabled child's participation rights is therefore often contingent on the perceptions of these adults. Consequently, when the CRPD states in Article 7 (Children with Disabilities) that the views of disabled children should be 'given due weight in accordance with their age and maturity', it is important to keep in mind that the assessment of what is 'due weight' and what is the level of maturity reached by the child is made by the same adults on whom the effective participation of the disabled child depends. The dependence on the judgement of adults has important ramifications for the participation rights of all disabled children, irrespective of age, but even more so of those children who have developmental and communication difficulties.

Sexual Health and the Child with Disability

The CRC and CRPD both acknowledge the 'evolving capacities of the child'. In fact, it is not just the ability of the disabled child to participate in decision-making that changes as they grow up. The nature of their health-related concerns changes too. For adolescents, sexual health issues come more to the forefront. It is pertinent to highlight a practical distinction between disabled young girls and disabled young boys. The disadvantages faced by women, children and disabled people can create many obstacles to the participation rights of disabled young girls. In his address to the Commission on the Status of Women, Khattab (2006) refers to the provisions of the CRC as well as those of the Convention on the Elimination of Discrimination Against Women which together highlight the problems faced by the girl child. As Khattab says, when compared to boys, girls are at greater risk of poverty, illiteracy and violence (including sexual violence). Disabled young girls can also face situations where decisions are taken which directly affect their bodies. As the World Health Organisation (2011: 78) report states:

> Despite legal prohibitions, there are many cases of involuntary sterilization being used to restrict the fertility of some people with a disability, particularly those with an intellectual disability, almost always women. Sterilization may also be used as a technique for menstrual management.

These issues can be faced by disabled people regardless of their gender, sexuality, race, age and impairment. However, the various social obstacles that impinge negatively on the lives of certain social groups means that young disabled girls with intellectual disability are among the most likely to have decisions taken for them that directly affect their body and without their being consulted.

The area of the sexuality of disabled people has been extensively researched.[2] Stereotypical ideas about disabled people tend to cast them as asexual beings, with their impairments rather than their gender being considered to be the dominant aspect of their identity. Consequently, as the disabled child grows up, the physical and emotional changes brought about by puberty may not be accorded the importance they are given for other children since concerns about impairment-related issues remain at the forefront for parents and professionals. As a result, young disabled people tend to be ill-informed about sexual matters and about the possibility of their being gender non-conforming or lesbian, gay or trans. People who have intellectual disability and who are not heteronormative tend to encounter even more difficulties (Servais 2006).

For girls with intellectual disability, menstruation and the risk of pregnancy places them at greater risk of drastic actions such as hysterectomies. In Gauer and Others vs France, the European Court of Human Rights (2011a) considered the admissibility of a case regarding the forced sterilisation for the purposes of contraception of five young women with intellectual disabilities who were employed at a local work-based support centre (Centre d'aide pour le travail – CAT). The girls alleged a violation of their right to respect for their private life and their right to found a family based on the discrimination they had suffered as a result of their disability. However the court found that the application had been lodged out of time and therefore declared it inadmissible pursuant to Article 35 of the European Convention on Human Rights (Council of Europe 1950). Similar cases are reported in the research literature such as one the contributors to Traustadóttir and Johnson's (2000) book on the lives of women with intellectual disability who was informed that she was having an appendectomy and years later discovered that it was actually a hysterectomy.

In exceptional cases, medical intervention may even include growth attenuation and breast bud attenuation as well as a hysterectomy, as was the

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[2] *Sexuality and Disability* is a journal dedicated entirely to the intersection between the two subjects. Of relevance is also the work by Tom Shakespeare (see for example Shakespeare, Gillespie-Sells and Davies (1996) and Shakespeare (2000), McRuer and Mollow's (2012) edited book on the subject, as well as other work such as that of Deepark (2002), Esmail et al. (2010) and Frohmander and Ortoleva (2013)).

case with Ashley X, an American girl with profound developmental delay and whose parents decided to opt for surgery to prevent her from growing and also from developing her sexual characteristics, as these interventions would make it easier for them to continue taking care of her (Gunther and Diekema 2006). Ashley X was six at the time that she underwent this surgery. Not surprisingly, the decision by the ethics committee of the Seattle Children's Hospital to accede to the parents' request and to give the go-ahead to the doctors to perform the surgery created a great deal of controversy especially among disability rights advocates who saw it as an infringement of Ashley's rights and as a dangerous precedent for other disabled people (Gibbs and Lee-St John 2007, Kafer 2013).

Fortunately, many disabled children are not subjected to such drastic invasive medical treatment but Ashley's case throws light on various issues related to the participation rights of the disabled child in the area of sexuality and sexual health which they face in a less dramatic but nonetheless disenfranchising manner. The first issue is of course the fact that Ashley did not have a say at any stage of the decision-making process. More to the point Ashley could not have a say because the severity of her developmental delay meant that at the age of six her brain had not developed beyond the equivalent of a six-month old baby's. Her parents and doctors would argue that it is precisely this lack of development which necessitated the surgery. Therefore, for disabled children who have profound and multiple disabilities, the complexity of their impairments can place them in the doubly disadvantageous situation of not being able to participate in major decisions about medical interventions that will affect not only their lives but even their bodies and at the same time as being in need of those interventions because of the very same impairments.

It is safe to say that such interventions on non-disabled girls would be seen as scandalous in many countries. The campaign against female genital mutilation is perhaps testimony to that. That they happen to disabled children and young people indicates that these are not always seen as being equal to their non-disabled peers and that Article 23.1(c) of the CRPD (Respect for Home and the Family) that obliges States Parties to ensure that '[p]ersons with disabilities, including children, retain their fertility on an equal basis with others' is not always respected (United Nations 2006: 15).

Ashley X's case also highlights the issue of mental capacity. There are certainly children with profound and multiple disabilities whose mental capacity is restricted to participating in decisions about small everyday decisions – when to get up, what food to eat, what television show to watch, whether to stay in or go out and so on. For such children, participation is usually achieved through vocalisations and bodily gestures that their caregivers learn to interpret as communication. But for most disabled children, including those who have an intellectual disability, their capacity to decide is much wider in scope. Very often, what they lack is the opportunity for them to do so. In the area of sexuality and sexual health, opportunities may be especially lacking because impairment-related concerns are seen as more salient.

Related to this issue is the right of the disabled child to preserve their own identity, a right which is upheld by the CRPD. Disabled children need to develop their identities as children, making their own choices about their gender identity if appropriate, and identify as persons with disability among other aspects of their identity. How and to what extent these various aspects are developed should be left in their hands. Medical interventions, especially those which interfere with sexual development or the establishment of gender, can severely disrupt the development of one's identity. Consequently, when they are applied to a child without any discussion it is not just the child's participation rights that are infringed. But, attending to those rights can be an effective way of ensuring that such practices are stopped. This is because respecting a disabled child's participation rights goes beyond simply asking them for their opinion and making sure that they have the necessary information to form that opinion. It is also about respecting the child for what they are and seeing them first and foremost as a child in their own right and not as a manifestation of a particular impairment or medical condition.

Mental Health and the Child with Disability

Although, as pointed out earlier in this chapter, health refers to both physical and mental health, the word is almost always taken to be synonymous with the former, and literature about health most often deals with *physical* health, with mental health issues being considered as a different area altogether. The rights of children with mental health issues are covered both by the CRC and by the CRPD, which includes mental impairments in its description of disability in Article 1. Given the separation between mental and physical health, it is important to also consider the disabled child's participation rights in the sphere of mental health.

Participation rights are particularly significant in mental health for two reasons. A primary concern is that this is an area where disabled children (as well as adults) may be legally subjected to involuntary treatment. As pointed out earlier in this chapter, the CRC and CRPD articles that deal with the liberty and security of the person allow for such situations. It is significant to note that Norway's declaration regarding the ratification of the CRPD asserts

> its understanding that the Convention allows for compulsory care or treatment of persons, including measures to treat mental illnesses, when circumstances

> render treatment of this kind necessary as a last resort, and the treatment is subject to legal safeguards. (United Nations 2015: n.p.)

In their editorial to the *Children and Society* journal special issue on 'Psychiatrised Children and Their Rights', LeFrançois and Pocock (2014) are highly critical of the psychiatric system and its lack of respect to children's participation rights. They state that

> children's participation rights are ignored or are applied in tokenistic fashion […] to varying degrees within different countries in the Global North. Emphasis on the "best interest principle" within children's services has become an institutional tool to control children and limit their direct involvement in decision-making regarding their treatment and care. (LeFrançois and Pocock 2014: 165)

As these authors and the other contributors to the journal's special edition show in their research, psychiatric treatments for children often sanction the invasion of their privacy, solitary confinement, restrictive schedules, drugs and electro-shock therapy under the guise of medical treatment. The authors refer to Goffman's (1961) concept of total institutions, that is, long-term residential places where all aspects of a person's life are determined by the system leaving very little scope for the person to exercise any agency in their life.

Disabled children whose impairments are of a mental nature are thus among those whose participation rights are least likely to be respected. LeFrançois and Pocock (2014: 165) state that they use the term 'psychiatrised' rather than 'mentally ill' children because the term 'denotes that something has been done to the children rather than seeing their distress as natural and internal to the children themselves'. By not respecting their participation rights, what is done to these disabled children is often carried out without any discussion with them, let alone their being involved in the decisions. For that involvement to happen, these children must be perceived as having the capacity to engage in discussions, receive and process information regarding their treatment and put forward their own views. In the same way that, as LeFrançois and Pocock say, the distress experienced by children with mental health issues can arise from the treatment itself, so their inability to exercise their participation rights arises from the misconceptions of those delivering that treatment. In her article about listening to the voices of adolescents who are mental health service users, Claveirole (2004) argues that very often it is those providing these services who decide what is best for the adolescent, although there are instances where the adolescents' views are given their due weight. The research points to the need for systemic changes to ensure that the views of young mental health services users become as important a factor in the decision-making process as the biomedical aspects of their conditions.

There is another reason why participation rights are particularly significant in mental healthcare. Aside from drugs, electro-shock therapy and similar treatments, another approach to mental healthcare is through the so called 'talk therapies'. These therapies involve mental health professionals (be they psychiatrists, psychologists, counsellors or others) talking to their patients as part of the treatment of their mental health issues. Given that talking to patients, in this case young patients, is also essential in ensuring that they can participate in the decision-making process concerning their care, talk therapies can be a particularly appropriate way of combining treatment with the exercise of participation rights. A shift in the power relationship between therapist and young patient is thus needed. LeFrançois (2007) remarks that in inpatient mental healthcare, children tend to be able to put their views forward in environments which are controlled by the adults since the professional–patient conversation is enacted purely in therapeutic terms. Bringing in the element of participation rights entails the professional not determining completely the conditions within which the conversation takes place, including where it occurs, what time and what is discussed.

Giving participation rights their due importance and also means valuing the views and opinions of young mental health patients on their own terms, rather than evaluating them on the basis of criteria that are pre-determined on the basis of their diagnosis. The latter stance can easily see the disabled child's views being pathologised and therefore being dismissed as being irrelevant at best. Carroll (2002), a play therapist, provides an excellent example of how it should be done. In her research, Carroll sought the opinions of the children who attended her play therapy sessions. She gives an account of the methods she used to gain their opinions and how the process helped to improve her practice with them. She concludes by saying:

> hearing children talk about the vital, and vibrant, relationships they develop with their therapists has been humbling; trying to understand their views of therapeutic processes and thinking about my own responses in the playroom personally challenging. Children have much to teach us, if we can find ways to listen. (Carroll 2002: 186)

The focus that has been placed here on the barriers to the exercise of participation rights of the disabled child's within the mental health system risks presenting these children as passive and helpless recipients of treatment and care. This is not a realistic picture. The disabled child or young person can and does find ways of exercising agency even within mental health institutions. Polvere (2014) carried out interviews with young people who had been in such institutions and who describe the strategies they used to put up resistance where they deemed it to be necessary, while Brady (2014) describes how children with ADHD manage their lives and take responsibility for their own wellbeing, despite the constraints placed upon them. But the disabled child, regardless of whether they have physical or mental health issues, should not have to exercise agency despite the healthcare system or to deal with its shortcomings. The exercise of their agency should be an integral part of that system.

End of Life Issues

Unfortunately, some children's illnesses are terminal and they and their parents have to deal with end of life issues. In other cases, children may be suffering from illnesses which, while not being terminal, are incurable and bring about severe physical and/or mental limitations as well as severe chronic pain. These are situations which can bring about discussions about voluntary euthanasia or the right to die. On a different but related level is the right to refuse treatment which is referred to later in this section. Unlike the right to life, and other rights considered in this book, the right to die is not inscribed in international law. While suicide has been decriminalised in most countries in the world, taking one's own life without any assistance is not necessarily an option for those whose physical condition does not permit them to carry out the act without physical assistance from others, and this is where legislation regarding the right to die comes in. There are a few countries in the world where some form of voluntary euthanasia has been made legal: Belgium, Germany, Luxembourg, the Netherlands, Switzerland and five American States (Montana, New Mexico, Oregon, Vermont and Washington). Of these countries, three permit euthanasia – Belgium, Luxembourg and the Netherlands. In some other places, such as the United Kingdom, Italy and some other states in the US, there are cases of individual people who apply for permission from the court to die.

Among the countries and states that permit voluntary euthanasia, there are different limitations on what is allowed by law. One variation regards the means that are considered legal for a person to willingly end their life – with some countries accepting assisted suicide (for example a family member procuring a lethal pill for the patient), active assisted suicide (for example the family member holding the patient's hand to swallow the lethal pill) and physician-assisted suicide. Another variation concerns the health conditions which are considered to make a person an eligible candidate for voluntary euthanasia – whether it has to be a terminal illness which will inevitably result in death in a specific number of weeks or months, or whether long-term painful or distressing conditions which are not terminal are also considered. Yet another variation, and the one which is most relevant for the theme of this book, is the lower age limit for eligibility. While in most countries the limit is set at 16, there are two notable exceptions: Belgium and the Netherlands. In the latter, children between the ages of 12 and 16 can request voluntary euthanasia, which request must be accompanied by the consent of their parents. In the former, the lower age limit has been removed completely which means that, as long as there is parental consent, a child with certain physical conditions can request voluntary euthanasia at any age.

Inevitably, the passing of this law in Belgium caused a great deal of controversy (France 24: 2014). The controversy can be placed within the wider debate of euthanasia, a subject which is hotly contested within disability activist circles, with Not Dead Yet being a disability rights group that focuses specifically on opposing 'legalization of assisted suicide and euthanasia as deadly forms of discrimination' (Not Dead Yet 2015: n.p.). Barnes and Mercer (2010) provide an in-depth analysis of the reasons for this opposition. As they conclude, decisions about the right to end one's life are taken

> within an economic and cultural environment in which prejudice and ignorance about impairment and disability still predominate [… and] serve only to reinforce the traditional personal tragedy view of impairment and disability and, in so doing, undermine disabled people's calls for effective political and social change with which to bring about a more equitable and just society. (Barnes and Mercer 2010: 237–8)

These arguments are reinforced by cases such as that of the Dutch twins who were granted the permission to die after being diagnosed with a condition that would leave them deafblind and who felt that they would thus not have anything to live for (Cendrowitz 2014).

This brings into the equation voluntary euthanasia not only for those who are going to die anyway but also for disabled people whose life expectancy itself is not threatened but who live, or will have to live, with conditions that bring about severe physical or mental limitations. The arguments in favour of the applicability of euthanasia laws in such cases are based on the assumption that living with these limitations takes away the possibility of a person living in dignity and of having a decent quality of life, an assumption that is vehemently opposed by many disability rights activists. Ultimately, one's understanding of dignity and quality of life is highly subjective. One cannot doubt that the Dutch twins' belief that they would not have any quality of life without their sight and their hearing was genuinely held. But the implications for those who are deafblind can be terrible, especially if it is other people's perceptions of their quality of life, and not their own, which are given weight.

It is quite ironic that in an age when medical and surgical interventions are giving babies with complex health conditions much better survival rates and longer life expectancy, and in an age when such interventions on children with Down syndrome are no longer seen by doctors as being inadvisable (Bridgeman 2005), voluntary euthanasia for disabled adults and children is increasingly being seen as acceptable.

Granting the disabled child the right to choose when to die if they have a terminal illness or the right to die if they have to live with severe impairments can be considered as the ultimate participation right. The pun is coincidental but significant. It is the ultimate right because it signifies the extension of participation rights to the maximum extent possible; and it is ultimate because, once the right to die is granted, there is no comeback for the child, all other options are gone. These are very complex issues for which no conclusive answers may ever be found. Advocating for the disabled child's participation rights should *prima facie* also include the acceptance of disabled children's right to die. But this logic only operates at an individual level. While the child with disability should not be seen as a helpless victim who is totally dependent on others, it is also the case that, as Bridgeman (2005) argues in her article about the care of children with severe disabilities, it would be wrong to think of disabled children as completely autonomous individuals. Like everyone else, they are bound in relations to others. Rights that are granted to them (even if with the consent of their parents as in the case of the right to die in Belgium and the Netherlands) affect other disabled children themselves and the perceptions of their quality of life. As Barnes and Mercer (2010) argue, in an age where economic and financial considerations are factored into health-related policy making, the financial costs of providing long-term care can be weighed against the possibility of ending a person's life (regardless of whether the decision to do so is taken by the person themselves, family members on their behalf or the courts). This is not a far-fetched scenario, given that such reasoning is already being applied in certain countries which sanction abortion on the basis of the unborn baby's impairment, as seen in the previous chapter.

Unlike other participation rights, the right to die is not an affirmative right. It is a right that ends all other rights and is especially perilous when applied to those whose impairments, however severe they may be, do not require long-term *medical* care and are not life-threatening in themselves. When it comes to disabled children, and adults, who have terminal illnesses, the issues are more fraught especially since, in addition to euthanasia, there is also the possibility to withdraw treatment. This means that, rather than actively ending a life through a deliberate action, lifesaving medication or other treatments are not applied and the disease is allowed to take its course with the patient being kept as comfortable and as pain-free as possible. MacKenzie and Watts (2014) deal with the subject of withdrawal of treatment in relation to children and state that '[m]inors attempting to refuse treatment, particularly when it is potentially life-saving, have experienced difficulties having their refusal accepted, and are usually found to be incompetent to do so by the courts' (MacKenzie and Watts 2014: 98). As seen earlier, coercive treatment is used particularly in mental health services where the child (or adult) is not deemed to have the mental capacity to assess what is in their best interest precisely because of the mental health condition that is to be treated. The right not to receive treatment is a participation right in itself but its application is also fraught with controversy and can be a harder one to attain than other participation rights.

Of course best interests may be applied for the opposite reasons where court mandated euthanasia may override the wishes of the parents of a disabled child. In re C (a minor) the Family Division of the English High Court rejected the parents' wishes where they questioned medical advice and wished their 16-month-old child to continue to receive treatment for spinal muscular atrophy (cited in Mason, McCall Smith and Laurie 1999). The court ruled that as the child had no chance of survival, it was in the best interests of that child that treatment should be terminated. At times, medical and parental opinions may also be at odds with one another.

In Glass vs United Kingdom, the European Court of Human Rights (European Court of Human Rights 2004, decided 9 March 2004) decided on a case relating to the administration of drugs to a severely disabled child notwithstanding his mother's opposition. The doctors had concluded that the child was terminally ill and administered diamorphine to alleviate the pain against the mother's wishes. They also placed a notice against resuscitation in the child's file without consulting the mother. The child survived and was discharged home so the case was based on disregard for the child's physical and moral integrity. The court found a breach of Article 8 (right to respect for private and family life) of the European Convention on Human Rights. Although the hospital had acted legitimately it had interfered with the right to respect for private life and in particular his right to physical integrity. The doctors should have consulted with the mother instead of imposing their decisions on her and the child.

Conclusion

This chapter has considered the participation rights of the disabled child with regards to health-related issues. It has shown how the disabled child does not only have equal rights to healthcare as the non-disabled child but they should also have participation rights within the healthcare system, regardless of whether it tends to their physical or mental health needs, and regardless of the age or impairment of the child. Disabled children's participation rights in healthcare however are not exercised in a consistent manner across all aspects of healthcare. While there are plenty of healthcare professionals as well as parents who seek to consult with the disabled child regarding their treatment, the degree and nature of participation in decision-making processes on the part of the disabled child depends on the willingness and ability of the adults around them to facilitate that participation. This situation obtains in other aspects of life as well, including education, which is considered in the next chapter.

Chapter 3
Education

Introduction

A school is one of the places where the vast majority of children spend their childhood, and it has an enormous influence on children's development in their crucial formative years. Granting the disabled child the opportunity to make choices and to take decisions in education is therefore an essential aspect of ensuring that their participation rights are respected. For the disabled child, it is not just a question of receiving an education but an *inclusive* education, as this is the means for them to enjoy their right to education on an equal basis with others. Education of course does not only take place within the precincts of the school. It also happens at home and in places which children frequent outside school hours. These places are usually associated with structured or unstructured leisure and sport activities and can provide the disabled child with rich ground for developing friendships and relationships with their non-disabled and disabled peers. Consequently, the disabled child's participation rights in these settings are considered in Chapter 5.

The focus of this chapter is mainly on the disabled child's participation rights within inclusive compulsory formal education. The chapter begins by discussing disabled child's rights in education as set out in the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), and then focuses on the extent to which disabled children in Europe have access to inclusive education. This is followed by an analysis of participants in education-related decisions, and whether it is educational authorities, parents or the children themselves. The scope for the disabled child to air views about their education is considered. The chapter then focuses on the Individual Education Programme (IEP) as the single most important tool in inclusive education, and a tool which lends itself totally to the inclusion of the disabled child in the decision-making process. When properly drawn up, IEPs not only include the academic aspect of education, but take into account all of the developmental needs of the disabled child. Therapy in its various forms can therefore be a part of a disabled child's education and the issues on the subject are considered in this chapter. The chapter then ends with a presentation of arguments why the disabled child's participation rights in education are crucial.

The Disabled Child's Educational Rights

All children have the right to education under the CRC with the State identified as responsible to provide this right as a positive obligation (Rabin 2008). Indeed, education can be considered as one of the most vital functions of the State (Janis, Kay and Bradley 2008). As far back as the 1924 Geneva Declaration of the Rights of the Child the issue of state commitment to education is highlighted in Principle 7 in terms of ensuring that 'the child that is backward should be helped' and that 'the child must be put in a position to earn a livelihood' (League of Nations 1924: n.p.). This was followed by the Universal Declaration of Human Rights in 1948 where Article 26 declares the rights of education to belong to everyone (United Nations 1948) and then the 1959 Declaration of the Rights of the Child which states that each child should be seen as an individual having individual rights and education and should be accorded on the basis of 'equal opportunity' (United Nations 1959: 1).

Building on this, in 1960 the Convention Against Discrimination in Education was concluded making specific reference in Article 1(2) to the requirement that education refers to 'all types and levels of education, and includes access to education, the standard and quality of education, and the conditions under which it is given' (UNESCO 1960: 1). Since then the International Covenants, the CRC, the European Convention of Human Rights, the Charter of Fundamental Rights of the European Union together with a number of influential fora and statements have continued to develop the concept of accessibility in education and confirm the right to education as a right belonging to each and every individual. This right to education also includes the right to choose a school as set out in a United States landmark judgment often cited worldwide as a basic tenet to underpin participation rights in education (Brown vs Board of Education of Topeka (1954) 347 US 483) (Patterson 2001). This case was about discrimination on the basis of race, but as seen below the right to choose a school is also very relevant for disabled child and their parents.

Article 28 of the CRC recognises the child's rights to education and includes provisions which also bolster the disabled child's rights within this area, especially the provision of free primary education 'to all', and making different forms of secondary and other education 'available and accessible to every child' (United Nations 1989: 8). The disabled child's right to education are also recognised in Article 23. However, it should be noted that the disabled child's rights in this area are to be provided 'in a manner conducive to *the child's achieving the fullest possible social integration and individual development*, including his or her cultural and spiritual development' (United Nations 1989: 7, authors' emphasis). In the italicised phrase, there is an implicit recognition of the disabled child's individual potential and therefore the need to work with each child on an individual basis rather than judging a disabled child's potential on the basis of their impairment. However, this article speaks of 'the fullest possible social integration', thereby acknowledging that not all disabled children can achieve full social integration. This acknowledgement compromises the disabled child's rights to education on an equal basis with other children since it leads to an approach whereby judgements regarding the educational provisions to be made available to a disabled child are based on an assessment of that child's potential, rather than on ways of making educational provisions available to other children accessible to that disabled child as well. This therefore can seriously undermine the disabled child's equal rights in education.

Thankfully, this anomaly is rectified in Article 24 of the CRPD which requires the provision of an inclusive education system 'on the basis of equal opportunity' (United Nations 2006: 16). While like the CRC, the CRPD recognises the importance of enabling disabled children to develop their full potential, unlike the CRC it specifically requires that this development takes place in an inclusive setting 'on an equal basis with others in the communities in which they live' (United Nations 2006: 17). Article 24, which is among the longest in the CRPD, also states that reasonable accommodation and individualised support within the general education system are to be provided according to the individual needs of the disabled child. This is a crucial requirement since it places the onus on education providers to make the education system accessible for all, rather than accepting disabled children only insofar as they can adapt to existing systems. Furthermore, the CRPD refers to specific measures which are to be provided for disabled children, including Braille, sign language, and augmentative and alternative means and formats of communication.

The Disabled Child's Access to Inclusive Education

The insertion of the term 'inclusive education' in the CRPD is crucial as it gives the disabled child not just the right to be educated but also to be educated alongside their non-disabled peers. Inclusive education is not only for disabled children. It is about children being educated together on an equal basis with each other regardless of their 'sex, ethnic origin, language, religion, nationality, social origin, economic condition, ability, etc.' (UNESCO 2015: n.p.). In the case of disabled children, it seeks to overturn a long tradition of educating them in segregated settings. Historically, the education of disabled children has developed in parallel to that of non-disabled children. The development of compulsory education in Luxembourg is a case in point.

According to the information available on the website of the Academic Network of European Disability Experts (ANED 2015b), the Compulsory Education Act in 1912 gave children the right to education with the exception of children with disabilities, with only a convent foster care centre providing some schooling for these children. It was in 1966 that the first segregated classes were set up and the emergence of special schools took hold after the Special Education Act in 1973 which extended compulsory education to disabled children. Increased participation in mainstream schooling in Luxembourg became possible after the reformulation of this Act in 1994/95 and the number of disabled children in special schools has been steadily decreasing. According to the WHO World Report on Disability, half of Luxembourg's disabled children attended special schools and half were in inclusive settings (World Health Organisation 2011).

Education in segregated settings is a reality especially for children whose disabilities lead to their experiencing difficulties in learning through conventional methods. It is one thing to ensure that a school is physically accessible, that information is available in different formats include those which are accessible to students with print disabilities, that communication is accessible for students with hearing difficulties, and that staff in a school are aware of particular children's health needs. It is another to cater for different levels of achievement in the same classroom and for the teacher to differentiate not only the teaching methods used with different children but also the level of difficulty at which the topic is pegged for each child. To take a practical example, a 14-year-old boy with intellectual disability attending a mainstream school may still be learning how to do simple arithmetic using the calculator while his classmates are doing algebra and trigonometry. The boy may have a learning support assistant to focus on his individual educational targets in mathematics but his presence in the classroom can easily be questioned when there is such a great distance between his attainment level and that of his classmates. Danforth and Ressa (2013) argue that the education system of children who have difficulties in learning in the United States was predicated on segregation from its very inception. This can be applied to most, if not all, countries in the world and it can be applied to children with other disabilities as well, but is particularly salient for those children whose disabilities directly affect the educational levels that they can attain in each subject and the means by which they attain these levels. The IEP is the main tool which has been developed to facilitate the inclusion of these children in mainstream schools and is considered later on in this chapter.

The assumption that disabled children naturally belong in segregated educational settings is based on a deficit model of disability, since it focuses on disabled children's inabilities to adapt to the regular education system (Barton 1997, Slee 2008). Inclusive education, on the other hand, is based on the social model of disability as it seeks ways in which to adapt the education system to cater for the individual educational needs of disabled children within it. Ferguson (2013) provides a critique of the logic of segregation: debating whether a particular disabled child should be educated in a mainstream or a special school implies the acceptance and the acceptability of two parallel education systems. 'We may end up with a discussion where the specific choices of placement may be challenged, but the underlying logic of the options remains hidden' (Ferguson 2013: 152). Vehkakoski's (2008) analysis of the discourse of professionals discussing educational options for hearing impaired children with cochlear implants in Finland is a good illustration of how this logic is applied. Vehkakoski's analysis shows that the discussions were based on

> whether a child is good enough for school […] which shows that despite a general striving towards inclusion, general education settings are not necessarily considered to fit students classified as too challenging or disturbing from the viewpoint of teachers. (Vehkakoski 2008: 509)

It is important to note that Vehkakoski's research took place more than 20 years after the signing of the Salamanca Statement (UNESCO 1994). Despite the impetus towards inclusion provided in that statement, children still tend to be expected to adapt to the education system rather than the other way round. The ratification of the CRPD by the vast majority of European Union/European Economic Area countries has not yet brought about a paradigm shift in education even if, with the exception of the United Kingdom, these countries have accepted Article 24 without any reservation.[1] The practice of placing 'children and pupils in special schools in cases where integrated

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[1] Upon ratification of the CRPD, the United Kingdom made the following reservation and declaration:

> Reservation: Education – Convention Article 24 Clause 2 (a) and 2 (b):
>
> The United Kingdom reserves the right for disabled children to be educated outside their local community where more appropriate education provision is available elsewhere. Nevertheless, parents of disabled children have the same opportunity as other parents to state a preference for the school at which they wish their child to be educated.
>
> Declaration: Education – Convention Article 24 Clause 2 (a) and (b):
>
> The United Kingdom Government is committed to continuing to develop an inclusive system where parents of disabled children have increasing access to mainstream schools and staff, which have the capacity to meet the needs of disabled children. The General Education System in the United Kingdom includes mainstream, and special schools, which the UK Government understands is allowed under the Convention. (United Nations 2015)

education is not possible or beneficial', as is documented in Slovakia's initial report on the CRPD (Slovakia 2012: 14), is still prevalent. This is not a situation that is deemed satisfactory by the Committee on the Rights of Persons with Disabilities which, in connection with the report submitted by Hungary '**reiterates that denial of reasonable accommodation constitutes discrimination**' (Hungary 2010: 6; bold in the original).

The tendency for disabled children to continue to be placed in segregated settings in these member states comes out clearly in the WHO World Report on Disability (WHO 2011). According to this report, in Belgium, Denmark, Germany, Greece, Latvia, Sweden and Switzerland, all or almost all disabled children attend school in a segregated setting. At the other end of the spectrum lie countries where very few disabled children are not in inclusive settings. These are Cyprus, Iceland, Ireland, Lithuania, Malta, Norway, Portugal, Scotland and Spain. That leaves 13 countries within the region where 40 to 80 per cent of disabled children attend either special schools or special classes in integrated settings.

While the latter settings move a step away from complete segregation in separate schools and present a higher degree of integration for disabled children, they cannot be considered to be inclusive. The placement of disabled children in separate classes in mainstream schools does not impose any obligation on these schools and on the wider education system to adapt to the needs of these children. The same lack of adaptation also occurs when the disabled child is placed in mainstream classes because they can fit into the system with minimal or no adjustments. These types of settings provide integration rather than inclusion (Harman 2014). Although there are obvious and very significant differences between placing a disabled child in a special school, in a segregated class within a mainstream, or within a mainstream class without any changes being made, these three options are all based on the same logic – the logic that it is the disabled child who needs to adapt to the education system rather than the other way round. They are also all based on the deficit model of disability – an assessment is made as to whether the disabled child's difficulties will affect the quality of their education in a mainstream setting. The onus of adaptation is therefore placed squarely on the shoulders of the child. Inclusive education does not take this logic as a given since it starts with the premise that *all* children should be educated in mainstream settings and seeks ways in which to adapt those settings to suit children's different needs. Crucially, it is *individual* educational needs that mainstream schools are required to respond to within inclusive education settings.

There is evidence that education settings which are presented as inclusive do not always adhere completely to the principles of inclusion and still expect the disabled child to adapt to the education setting. This is evident from the state reports to the Committee on the Rights of Persons with Disabilities as well as the research literature. Kelly et al. (2014) also explored the reasons why disabled students in Ireland seek to move from mainstream to segregated schools after the end of their primary education. These authors note that 'Ireland's inclusive educational experience is akin to those of countries still struggling with introducing inclusion practices amid socioeconomic and educational resource restraints' (Kelly et al. 2014: 78). Furthermore, in their review of the placements of children with cerebral palsy in nine different European regions, Sentenac et al. (2012) conclude that the decision of whether to place these children in special or mainstream settings is not based only on their impairment but on external factors as well, such that 'two children with the same impairment (in terms of motor impairment, IQ, seizures or communication) but from two different regions did not have the same chance of being in a mainstream school' (Sentenac et al. 2012: 592).

Interestingly, the practice of segregation is echoed in the very particular response to Roma children who are systematically assumed to have some form of cognitive impairments and are placed in special schooling with no reference to participation rights for either parents or child. A series of cases brought before the European Court of Human Rights have highlighted the inherent discrimination against Roma children in allocating them to special schools on the basis of their ethnicity. The basis of the discrimination is directly linked to discrimination on the basis of disability as it is based on the assumption that children who experience disabilities that lead to learning difficulties should be placed in segregated educational settings. One such case is D.H. and Others vs the Czech Republic (European Court of Human Rights (2007), decided on 13 November 2007 (Grand Chamber)) the court gave judgment on a case regarding 18 Roma children, all Czech nationals, who had been sent to special schools during the period from 1996 to 1999. The premise of the claim was based on the state's presumption that Roma children should be subjected to a segregated system whereby they received an education through a modified curriculum. This was grounded in the practice that entry to school was reliant on a psychological screening test which did not take into consideration the situation of this particular ethnic group. The court observed that, during the period under review, the majority of children in special schools in the Czech Republic were of Roma origin and concluded that the law at that time had a disproportionately prejudicial effect on Roma children, in violation of Article 14 (Prohibition of Discrimination) of the European Convention on Human Rights (Council of Europe 1950) taken in conjunction with Article 2 (Right to Education) of Protocol No. 1 to this Convention.

In Oršuš and Others vs Croatia (European Court of Human Rights (2010), decided on 16 March 2010 (Grand Chamber)), the court considered a case that concerned 15 Croatian nationals of Roma origin who alleged that the state had placed them in Roma-only classes and that they had consequently suffered educational, psychological and emotional damage. These grounds were different to those cited in D.H. and Others vs the Czech Republic, where the tests determining their placement in such classes did not focus specifically on language skills, and the educational programme provided did not target language problems and the children's progress was not clearly monitored. The court found that the placement of the applicants in special classes had therefore been unjustified, in violation of Article 14 (Prohibition of Discrimination) of the European Convention on Human Rights taken in conjunction with Article 2 (Right to Education) of Protocol No. 1 to this Convention.[2]

In the more recent case of Horváth and Kiss vs Hungary (European Court of Human Rights (2013b), decided on 29 January 2013) two young Roma men had been diagnosed as having mild mental disabilities while they were children and were therefore placed in special 'remedial' schooling. However the education they received was such that it did not prepare them for access to employment and effectively segregated them from the rest of the population. Their claim was based on the premise that the education provided was linked to ethnic discrimination which violated their right to education (Article 2 Protocol 1 in conjunction with Article 14 ECHR). The court applied a similar approach to the judgments cited in DH and others vs Croatia and Oršuš vs Croatia by affirming the way Roma children are overrepresented in remedial schools in Hungary, establishing this to be a prima facie case of discrimination which places the onus on the State to disprove. Furthermore, the court identified the requirement for the state to cite 'to what extent special safeguards were applied […] In view of the high risk of discriminatory misdiagnosis and misplacement' (par. 121) to which the state admitted no such safeguards had been put into place, leading the court to conclude that:

> [a]s a consequence, [the applicants] received an education which did not offer the necessary guarantees stemming from the positive obligations of the State to undo a history of racial segregation in special schools. The education provided might have compounded their difficulties and compromised their subsequent personal development instead of helping them to integrate into the ordinary schools and develop the skills that would facilitate life among the majority population. (European Court of Human Rights 2013b: par. 127)

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[2] Similar judgments have been given in the cases of Sampanis and Others vs Greece, judgment of 5 June 2008; Horvàth and Vadàzi vs Hungary, decision on the admissibility of 9 November 2010; Sampani and Others vs Greece, judgment of 11 December 2012; Horváth and Kiss c. Hongrie, judgment of 29 January 2013; Lavida and Others vs Greece, judgment of 28 May 2013.

The importance of this judgment in the field of access to education and the right to participate in its choice cannot be underestimated and its ramifications are valid for disabled children as well, especially in light of the fact that the CRPD enshrines the right of *inclusive* education. The court noted that a general policy or measure that produced a disproportionate effect to prejudice a particularly vulnerable group was unacceptable whether or not it only affected a particular minority because of a pertaining situation such as the circumstances of the Roma (par. 110) This is significant because it reiterates the court's refusal to accept such attempts to justify the violation of access to a right and for the first times affirms 'the positive obligations of the State to undo a history of racial segregation in special schools' (par. 127). '[I]n light of the recognised bias in past placement procedures', the court says, 'that the State has specific positive obligations to avoid the perpetuation of past discrimination or discriminative practices disguised in allegedly neutral tests' (par. 116). In the Oršuš case, for example, the court had spoken of the obligation to put in place 'safeguards that would ensure that […] the State had sufficient regard to [Roma children's] special needs as members of a disadvantaged group' (European Court of Human Rights 2010: par. 183). In the Horváth and Kiss vs Hungary, the court goes a step further by insisting on a substantive positive obligation, namely to 'undo a history of racial segregation in special schools' (European Court of Human Rights 2013b). These judgments highlight how obstacles to participation rights in education and more specifically when linked to other inequalities may and do lead to compounding the impact of disability in a way that is unnecessary, harmful and ultimately illegal.

The realization of a fully inclusive education system also needs to undo the segregation of children with disabilities. Obstacles to realizing these goals can also be encountered at a policy level. In her analysis of Cypriot educational policies, Liasidou (2008) points to the contradictions inherent in these policies which allow for special schools to co-exist alongside inclusive mainstream schools, with the result of assessments still being made about whether to send a disabled child to a special or a mainstream school. These assessments are couched in terms of which type of school is best suited for the child when in reality what is being decided is where the child best fits without needing to bring about too much change in the education system. A similar situation is reported by D'Alessio (2012) who notes the presence of disabled children in segregated units placed within schools that are renowned for their inclusive practices. In his review of research about the effectiveness of inclusive education in the United Kingdom, Lindsay (2007) argues that rather than evaluating inclusive education practices and comparing them with education practices in segregated settings, we should consider the inclusion of the disabled child in mainstream schools as a given and focus on seeking the best ways to implement the principles of inclusive education in practice, by making it possible for disabled children to be educated in the mainstream. Without this possibility, any attempts to promote disabled children's participation rights in education-related decisions lose much of their meaning. If the disabled child is afforded the opportunity to participate in decisions within structures that have been completely pre-determined by others, that participation is significantly reduced in value. Therefore, if the decision is taken to place a disabled child in a segregated setting on the grounds that the local mainstream school is not equipped to meet the child's needs, then enabling that child to participate in any decision, whether big or small, loses much of its purpose. This is especially the case where participation in decision-making contributes towards redressing the power imbalance between the disabled child and the adults around them. Exercising one's participation rights in such contexts does nothing to change the structures that discriminate against and exclude disabled children as it cannot have any effect beyond the immediate scope of the decision itself.

This situation will continue to obtain as long as segregated schooling is an option, and even more so as long as it is considered to be the *default* option for disabled children, especially those with intellectual disability or with complex dependency needs which may be seen as imposing too heavy a burden on mainstream schools that have not historically developed in such a way as to cater for different individual educational needs. Crucially, decisions about school placements are taken at the earliest stage of a disabled child's education. It is a fundamental decision that affects the trajectory that that child's education will follow. It is also a decision taken by adults – whether it is the parents (including those acting *in loco parentis*), professionals in the education sector or other adults representing educational authorities. Of these three, it is the parents who are closest to the disabled child. The next section investigates the scope that parents have for taking decisions about their disabled children's education.

The Rights of the Disabled Child and Parents in Education-Related Decisions

It is pertinent to question what avenues of recourse are available to the disabled child and the parents of that child should the state fail to comply with the requirement of an education suited to the needs of the child, in a manner which is also inclusive. A series of cases before the European Court of Human Rights have failed to apportion responsibility to the state mainly because states are invariably allocated a wide discretion when deciding on the 'allocation of children with special education needs to mainstream schools or to suitable special schools' (Harris, O'Boyle and Warbrick 2009: 701). These authors conclude that it would be up to the court to 'adopt a more demanding interpretation by regarding the failure to provide the requisite quality of education in a particular case (for example, special needs schooling) as a denial of the right to effective education' (ibid.: 709).

The reports on education for disabled children in individual European Union member states found in the ANED database show that in 12 of these 28 countries, parents have varying degrees of rights over the type of school that their disabled children attend (ANED 2015a). In some, for example Estonia, Malta and Finland, they have a right to choose the school themselves. In others, among them Cyprus and Portugal, parents have a right to appeal the decision taken by the education authorities. In those countries where parents do not have such rights, they may be consulted by the authorities or professionals who then take the final decision. Furthermore, in some countries where parents' rights to choose inclusive or segregated schooling for their disabled children are enshrined in law, it may not be that easy for them to exercise these rights. The Polish report, for example, notes that parents are often placed under pressure to choose a special school for their children. In Slovenia, parents can only effectively exercise their right to place their disabled child in a mainstream school if it can cater for that child's needs.

Reports submitted by European Union Member States who have ratified the CRPD are also indicative of a situation where decisions regarding the education of disabled children are mostly taken by professionals working within or on behalf of educational authorities. These reports provide a comprehensive description of the types of support that are available for disabled children in mainstream or special schools. The rights of these children in the educational sphere are also set out in these reports. The overall picture seems to be one where a significant amount of each country's resources are used to provide disabled children with the support that they are judged to need in their education, whether it is human support in terms of specialised teachers, learning assistants and other professionals, or support in terms of assistive technology and educational material. Most of these resources are provided in segregated settings, and these settings, as argued above, are inherently problematic.

What is also problematic is that decisions about segregated placements and the support to be provided are also mostly made by professionals and therefore taken away from those who are at the centre of education, that is, disabled children, and those who are closest to them, that is, their parents. While there are countries, or regions within countries that have a federal system, where parents do have a degree of power over decisions regarding their disabled children's education, it must be borne in mind that 'exercise of power by parents of children with disabilities is not the same thing as effective exercise of power by people with disabilities' (Weber 2013: 208). In the reports submitted to the CRPD Committee as well as the reports by the Academic Network of European Disability Experts (ANED), no mention is made of the rights that the children themselves have over decisions about their own education. Significantly, the Portuguese ANED report does comment on the fact that in Portuguese legislation there is no reference 'to the ability of children or youth to contest decisions made in relation to their own education' (ANED 2015c). On the other hand, there are structures within a few European countries that facilitate the participation of disabled children in decisions related to their education. In Croatia, Cyprus, the Czech Republic and Spain, the right of disabled children to be heard in matters that concern them is safeguarded in legislation and through the work of the Ombudsman for Children or similar structures (Croatia 2011, Cyprus 2013, Czech Republic 2011, Spain 2010). However, these seem to be the exceptions rather than the rule. An evaluation of the legal implementation of disabled children's right to be heard is found in the European Parliament's (2013) report on 'Member States' Policies for Children with Disabilities'. According to this report, there is full legal implementation of disabled children's right to be heard, including in education-related decisions, in Estonia, France and Poland and partial implementation in all the other member states.

The extent to which this legislation translates into disabled children actually participating in education-related decisions is not evaluated in the CRPD reports but the European Parliament report does state that progress needs to be made in effectively implementing children's rights to be heard in practice. While there is much focus on the rights of the child to education, and the support available to them in educational settings, it is educators and other professionals who decide how the disabled child's rights are best safeguarded. The comment in the Swedish CRPD report on the fact that municipalities decide on pre-school activities 'on the basis of local conditions, the needs of the child and the wishes of the parents' (Sweden 2011: 32) can be applied to all levels of schooling in the vast majority of member states. Decision-making is very much in the hands of the respective educational authorities. Disabled children are twice removed from the decision-making process. While the wishes of their parents may be taken into account, theirs are not since the focus is on their needs, and the assessment and evaluation of those needs and their abilities/disabilities. In her reflections on her own childhood in England, Jo Skitteral (2013: 25–6), a disabled woman, comments that

> [f]or disabled children there are many more "transitions" characterised by meetings to make decisions about where the disabled child will go – who and where will accept them. This is one the many differences disabled children face. Decisions are made that have ramifications for their future.

It is interesting to note that, despite the passive role that the disabled child all too often play in these decisions, the active voice is used in the many descriptions of the rights of disabled children in education. To take just one example, in the Croatian report it is disabled children 'who [obtain] decisions on appropriate forms of education' and it is they who 'may continue their secondary education in regular secondary school education programmes with individualised approach' (Croatia 2011: 32–3). But the children themselves do not participate in decisions about what the appropriate forms of education are or whether or not to move on to a regular secondary school after finishing their primary education.

In his paper about the powers of decision-making that the Individuals with Disabilities Education Act of 1990 gives to parents of disabled children in the United States, Weber (2013) argues that it is not enough for these parents to act as proxies for their children and that disabled children should be able to represent their views directly. They do play a very important mediating role between educators and disabled children, for example by providing information (De Schauwer et al. 2009). But, as Weber argues, parents' views of what is best for their children are not always aligned with the children's own perspectives. The lack of involvement of disabled children in decisions about their own education is particularly problematic in inclusive education settings. Given that in such settings it is the environment that needs to adapt to disabled children's individual needs, it is particularly unsatisfactory that their views are not taken into account. '[T]he individual who has a disability should be treated as an agent, not an object' (Weber 2013: 209). This is also the view of the Committee on the Rights of Persons with Disabilities (2013: 6–7) who, in their comments on the Austrian report, state that:

> **it particularly recommends that the State party ensure that persons with disabilities, including children with disabilities and their representative organizations, are involved in the day-to-day implementation of the inclusive education models introduced in various Länder.** (Bold in the original)

This country-specific recommendation can certainly be applied to many, and even most, other countries. Potentially, one of the barriers to implementing it is a lack of belief in the ability of the disabled child to take part in these decisions or even a belief that this would be detrimental to them. In their international review of assessment procedures in the area of special educational needs (SEN), Desforges and Lindsay (2010) cite the English SEN Code of Practice as stating that

> [t]here is a fine balance between giving the child a voice and encouraging them to make informed decisions, and overburdening them with decision-making procedures where they have insufficient experience and knowledge to make

> appropriate judgements without additional support. (Cited in Desforges and Lindsay 2010: 41)

The question of course remains of who is going to judge whether the disabled child has sufficient experience and knowledge to make judgements and who will evaluate whether the judgement made is appropriate or not. Given that children's capacities for decision-making differ widely, do not develop at the same rate, are contingent on various factors such as the nature of the disability, socioeconomic and cultural background and age, and may be more easily exercised in certain areas than in others, making such a judgement is a very complex matter.

Indeed, it is doubtful whether such a judgement should be made at all, a priori to providing the disabled child with the opportunity to have their views heard. The Committee on the Rights of the Child (2012: 9) provides guidance in this regard when it states that State parties

> should **presume that a child has the capacity to form her or his own views** and recognise that she or he has the right to express them; it is not up to the child to first prove her or his capacity. (Bold in the original)

One way in which disabled children are provided with the opportunity to air their views about their education is through research that involves them as participants. The main outcomes of this type of research are considered in the next section.

Disabled Children's Views about their Education

Research that explores and analyses the perspectives and experiences of disabled children in mainstream schools points to a mixed bag of responses. Not surprisingly, much of this research centres on the relationships between the disabled children and the people they encounter on a daily basis at school – peers, educators and other professionals. What these children have to say about their experiences in inclusive education indicates strongly that schools are a long way from being able to state with any degree of certainty that they are truly inclusive of all children. The research provides plenty of examples of positive experiences by disabled children and of good practice in inclusion. For example, in their research in the Flemish speaking community in Belgium, De Schauwer et al. (2009) report how the disabled children they interviewed appreciated efforts by teachers to be flexible in their teaching methods in order to cater for these children's individual educational needs. Periera et al. (2010) report similar findings in Portugal in relation to adaptations to physical education lessons. At the same time, some of the disabled children whom these researchers interviewed expressed feelings of loneliness and of being outsiders to the school even if nominally they are a part of it. The sense of being included is dependent on adaptations being made to activities within the school so that disabled children can take part on an equal basis. Periera et al. (2010) distinguish between different types of participation with disabled children either participating fully in everyday or special activities, being onlookers to others' participation, or being excluded from activities.

Adaptations to the curriculum and to school-based activities often entail the presence of other adults, in addition to the teacher, whose role is specifically to provide support to children who have individual educational needs. Many of the disabled children interviewed expressed a preference for assistants who were younger and the same sex as them, as they felt they could relate more easily with them. For these children, building a personal relationship with their assistants is important but difficult. One of the problems is the lack of mutual exchange of information. As one of the Swedish children interviewed by Skär and Tam (2001: 922) observed, 'They (the assistant) know everything about me, but I hardly know a thing about them. They barge right into my life'. This is reflected in the account by Isabel Bonello of her experiences as a student with intellectual disability in a mainstream school in Malta.

> The first day she [the assistant] was with her, Isabel asked her the name of her son. She told her "That's a personal matter". That is not right. It is important that one is not cold and proud with disabled children. You should be friendly and joke with them. We want to be friends with our assistants. (Bonello, Bonello and Callus 2012: 32)

Disabled children can end up feeling completely alienated from the education system. This is the experience recounted by Hugo Horiot, who has autism, in relation to his education in France. He describes his years at school as 'dark and lonely […] The teachers had no other attitude towards me except for a cold distance that they kept on the basis of their rank and the mediocrity of my results' (authors' translation; Horiot 2011: 44–5).[3] When he personally changed his name from Julien to Hugo, as a way of distancing himself from his unhappy childhood, he was still called Julien by his teachers: 'This is how I passed all my schooling: under the name of a dead person while waiting to live anew' (authors' translation; Horiot 2011:

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[3] 'noires et solitaires […] Les professeurs n'avaient d'autre attitude envers mois qu'une distance froide due á leur rang et á la médiocrité de mes résultats'.

45).[4] Horiot's experience provides a stark example of why it is important for educators to take into account the views of disabled children about their education. Even if educators work in terms of what they perceive as being the best interests of each child, they can never really know what these best interests are without giving weight to the perspectives of that child. And, as seen from these three examples, that perspective can be very different from that of the adults around them.

As the relevant research shows, disabled children spend most of their time with adults while at school. While the adults are there to provide support, their presence can also be a hindrance to the very inclusion they aim to achieve. This happens especially at a social level when it comes to disabled children interacting with their peers. Some of the children interviewed by De Schauwer et al. (2009) pointed out that they do not appreciate being assisted by adults all the time.

> Disabled children spend a large amount of their time in the company of adults and in social spaces where adults are actively present […] If the help of the support person implies they have to miss things that are fun, children do not like help either. (De Schauwer et al. 2009: 108)

Similar findings are reported by Skär and Tam (2001) in Sweden. These researchers also argue that assistants play varying roles in their work with disabled children in inclusive education settings. They can act variously as parent substitutes, professional assistants and friends. These assistants therefore need to be aware of how the children they are supporting look at this support and 'consult them about the kinds of support they need' (Lightfoot, Wright and Sloper 1999: 281). Even when disabled children do build relationships with their peers, these relationships are not always given the same value by adults as friendships between non-disabled children. This is noted by De Schauwer et al. (2009) who comment on the fact that relationships with disabled children in mainstream school, even when it comes to relationships with the other children, are very much based on care. This theme is discussed extensively in Chapter 5.

The main point that emerges from these and similar studies is the importance of listening to the voices of disabled children and of providing them with the opportunity to express their opinions about their education. In their research with Swedish children with disabilities and learning difficulties in mainstream schools, Nilholm and Alm (2010) used a variety of techniques to elicit the opinions of the children, including asking them to write poems

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[4] 'C'est ainsi que j'ai passé toute ma scolarité: sous le nom d'un mort en attendant de vivre á nouveau'.

about their experience. This excerpt from a poem by Anna, one of the children involved in this research, encapsulates the importance of disabled children's voices:

> Everyone is different really which I think is good.
> Otherwise it would be boring.
> You must be allowed to be who you are.
> I am never alone, never feel that way,
> even though the others seem to think so.
> They don't really know what I feel.
> (Nilholm and Alm 2010: 248)

The issues and themes addressed in research are sometimes at least as interesting as that which is not addressed. This research focuses on the experiences and concerns of disabled children in mainstream schools. There does not seem to be any research that canvasses the opinion of children who attend segregated schools. The lack of opportunities for disabled children attending special schools to make their voice heard in research may be due to a number of factors. Among them is the fact that children who are placed in segregated schools tend to be the ones who have the more complex and severe disabilities which often entail communication difficulties. However, it should be noted that some of the research referred to in this section has been carried out with children who have communication difficulties, using methods that enable them to participate meaningfully in research. Another reason may be that, given that by its very nature inclusive education is based on taking into account *individual* educational needs, it may lend itself more easily to research that takes individual children's views into account. Inclusive education is also a more recent and growing phenomenon than special education and the commitment in various countries towards achieving inclusion for disabled children in education may also spur researchers to focus on the views of disabled children in mainstream schools rather than on the views of disabled children in segregated schooling.

Another characteristic of this research literature is that it is about academic researchers carrying out studies with disabled children to elicit their perspectives of inclusive education. This research does not address the extent to which the perspectives of disabled children are elicited by the educators and other professionals working within their inclusive education setting. It is very important for research about inclusive education to include the views of disabled children because, as Nilholm and Alm (2010: 249) state, 'classrooms should by no means be labelled "inclusive" if we do not have firm data regarding how children experience the classroom'. But the inclusion of disabled children's voices in research is not enough in order to ensure that they can exercise their participation rights in education. Those rights also need to be exercised in the course of daily life at school and decision-making processes about their education. This is the subject of the next section.

Individual Education Programmes

The CRPD's commitment to inclusive education is set out in detail in Article 24. Among the strategies identified in this article as being a necessary part of an inclusive education system, Sub-Article 2 states that State Parties shall ensure that:

> (*c*) Reasonable accommodation of the individual's requirements is provided;
>
> […]
>
> (*e*) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion. (United Nations 2006: 18)

These obligations follow logically from the principle of inclusive education that expects education systems to adapt to the different needs of individual children. This is exemplified in the definition of Universal Design for Learning as:

> a set of principles for curriculum development that give all individuals equal opportunities to learn.
>
> UDL provides a blueprint for creating instructional goals, methods, materials, and assessments that work for everyone – not a single, one-size-fits-all solution but rather flexible approaches that can be customized and adjusted for individual needs. (National Centre on Universal Design for Learning 2015: n.p.)

At an initial glance, it may seem paradoxical that a set of principles that focus on being universal and comprehensive place so much emphasis on individual differences. However, the reality of children's educational needs are such that one would be very hard-pressed to find a single classroom where all students have the same needs and are able to learn in the same way. The universal approach to inclusive education then must perforce also be an approach that zooms down to the individual educational needs of different children, especially those who experience difficulties in learning.

These needs are usually addressed through the development of implementation of an Individual Education Programme (or Plan) (IEP):[5]

> An Individual Education Plan (IEP) is "a written document prepared for a named student which specifies the learning goals that are to be achieved by the student over a set period of time and the teaching strategies, resources and supports necessary to achieve those goals" (NCSE 2006b, xii). (Cited in Prunty 2011: 25)

The National Center for Learning Disabilities in the United States sets out the stages for the development and implementation of the IEP:

- Child is identified as possibly needing special education and related services.
- Child is evaluated.
- Eligibility is decided.
- Child is found eligible for services.
- IEP meeting is scheduled.
- IEP meeting is held and the IEP is written.
- Services are provided.
- Progress is measured and reported to parents.
- IEP is reviewed.
- Child is reevaluated. (Stanberry 2014: n.p.)

In this approach therefore, the focus is on each individual child since educational planning must be suited for each disabled child. The IEP process described in the list above is very much in the hands of adults. It is usually educators or parents who identify children as having individual educational needs. Assessment for eligibility may be carried out by a variety of professionals and once eligibility is confirmed, decision-making is mostly in the hands of educators. The research literature on IEPs points to the importance of collaboration among people who play different roles in a child's education. Implementing inclusive education, therefore, involves some complex reconfigurations of relationships between the different stakeholders involved in education. Among these stakeholders are disabled children and their parents. Prunty (2011) identifies both of these as having a critical role in the successful drawing up and implementation of IEPs. After all, it should follow logically that an education system that places so much emphasis on the *individual* educational needs of disabled children also provides ample scope for those

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[5] Slightly different terms are used in different contexts to refer to the IEP. In the United States, for example, IEP stands for Individualized Education Program.

children to make their voice heard. Indeed, in inclusive education settings, the participation of disabled children in decision-making is both more necessary and more possible to obtain than it is in a system based on a continuum between total segregation and mere integration. If the education system is being adapted according to the different needs of individual children, listening to what the children have to say takes on an added significance in order to ensure that their needs are actually being catered for. And the process of listening to them does not remain an academic exercise but can be transformed into one which achieves concrete changes in that child's education.

Furthermore, the research literature strongly indicates that when children are involved in the planning stages of the IEP process, its implementation is more likely to be effective (see for instance Curtin and Clarke 2005, Goepel 2009, Pawley and Tennant 2008). Goepel's (2009) research was carried out with four British junior school students with a statement of individual educational needs. Her analysis of the four case studies brings out clearly how the least effective partnership was where the child's input was not taken into account during the process of drawing up the IEP. She reports that the child disengaged from the targets set for him while the other three children were willing to take on learning targets that they had not set themselves because they had been actively involved and listened to in the process. 'A child who is unaware of the targets on their IEP and whose perceived needs are being overlooked is in danger of becoming disengaged and isolated both from the curriculum and possibly socially' (Goepel 2009: 131).

However, despite the clear advantages of disabled children's participation in drawing up the IEP and setting learning targets, research indicates that the practice is not widespread. In his international review of how IEPs are drawn up, McCausland (2005) shows that in the countries surveyed the official policy is to involve disabled children in their IEPs if this is considered to be appropriate. This assessment is inevitably done by adults who may decide *a priori* that some children (especially those who are very young and those who have cognitive or communication difficulties) would not be able to participate meaningfully in the IEP process and that requiring them to participate may cause them to be 'overburdened', to cite the English Code of Practice quoted above. Pawley and Tennant's (2008) research in three British secondary schools shows the varying degrees of involvement of disabled children in their IEPs, with many not even being able to identify the targets set or even show a clear understanding of what is an IEP. Significantly, these researchers report that 'students with the strongest awareness attended one particular school: these students did not stand out in the student sample in terms of communication, recall or cognitive ability' (Pawley and Tennant 2008: 185).

As can be seen from the steps listed by Stanberry (2015) above, review and re-evaluation are an essential part of the IEP development and implementation process. This brings one back to the second step of the list set out by the National Center for Learning Disabilities, quoted earlier. This makes the process a circular one, with a new or revised IEP then being implemented and subsequently revised and so on. The revision and re-evaluation process is essential to ensure that the milestones set for each disabled child's educational journey are in line with that child's developmental trajectory and that the educational targets, measures and support needs identified are effectively addressing the child's individual educational needs.

Furthermore, the participation of the disabled child in this process is crucial. The assessment of an IEP's effectiveness must ensure that the evaluation process itself is effective by taking on board various points of view, especially those of the educators, parents and, very importantly, that of the disabled child. This evaluation includes decisions about the choice of options within the curriculum especially for older children, decisions on whether or not to drop or take on certain subjects, on the level of difficulty at which the disabled child can engage with different subjects if s/he has learning difficulties, on the strategies that best work for the child, and the reasonable accommodation and support to be provided. Educators and parents will be able to put forward their opinions about these different aspects and disabled children should be able to do so as well. Crucially, and over and above all this, for disabled children's education to fulfil the CRPD's obligation of 'full development of human potential and sense of dignity and self-worth' (as set out in Article 24.1(a) (United Nations 2006: 16)), they must have the opportunity to identify and discuss their own aspirations and support needs and the strengths and weaknesses of their own education. If the disabled child identifies goals or issues that do not tally with those set by the educators and/or the parents, these need to be taken fully into account in the decisions made. For education to be holistic and to be truly directed towards the wellbeing of the disabled child, that child's perspective is as valid as that of the adults who are in control of their education.

One effective strategy of making sure that this happens is by placing the child's perspective at the heart of educational planning. This can happen through the use of person-centred planning tools 'which take the responsibility off one person and puts planning in the hands of a team comprised of school personnel, family and the children themselves' (Forest and Pearpoint 2001: n.p.). One such tool is Making Action Plan (MAP) which provides a specific way for conducting planning meetings. As explained in detail by Forest and Pearpoint (2001), a MAP meeting is managed by a facilitator and attended by the disabled child, their family members and close friends, educators and any professionals directly involved in the child's life. There is a set of questions to be asked and discussed regarding the child's story and their strengths and weaknesses; aspirations and concerns about the future; long and short-term goals; and support needs to achieve those goals. Crucially, the questions are first asked to the child. In the hands of a skilled facilitator, this has the symbolic value of presenting the child's input as the most important input and the practical effect of making this input the reference point for all subsequent discussions.

As Forest and Pearpoint (2001) point out, a MAP meeting is not a substitute for an IEP meeting (which needs to go into much more detail at the micro-level of educational planning), but the report from the MAP meeting can feed into the IEP. It can in fact be held as an initial session prior to the drawing up of the IEP. This means that if the MAP session is conducted in a way that is true to the principle of putting planning not just in the hands of educators but also of the disabled child and their family, what goes into the IEP draws from these persons' various perspectives. Furthermore, facilitating the active involvement of the disabled child in the MAP meeting will give the child the confidence to participate in their own planning meetings and the skills to do so effectively. But it is not only the disabled child who needs to develop the necessary confidence and skills. Family members, educators and other professionals too need to have the disposition and the skills to involve the disabled child meaningfully in planning meetings. When done in the right manner, this sets the tone for all future planning meetings, be they MAP meetings, IEP meetings, evaluation meetings, or other gatherings that are aimed at planning out the disabled child's educational process. As the child grows older and as all parties involved grow in confidence and skills in realising disabled children's participation rights in education, that participation can increase and gain in importance. After all, it is not only the disabled child's decision-making abilities that evolve. An evolution is also necessary, and possible, in adults' ability and willingness to make participation in decisions by disabled children to happen.

The ability of the disabled child to participate in the decision-making processes that are an integral part of the development and implementation of the IEP is therefore dependent not so much on their own capacity to participate but on whether educators deem them capable to do so and are themselves capable of facilitating children's participation. Ability then translates into opportunity, and disabled children may well find themselves in a situation where their lack of ability to participate meaningfully in their IEP meetings comes from a lack of opportunity to develop the necessary skills for this to happen. And the development of those skills necessarily entails the opportunity to take part in meetings. As Pawley and Tennant (2008) and Goepel (2009) point out, educators themselves must develop skills to involve the disabled children under their charge in IEP meetings. Training is important in this regard. If this involvement is not carried out appropriately, there is a high risk of having disabled children participating in a tokenistic manner, and their educators taking this as a sign that participation is not opportune. The ramifications of disabled children's participation in education-related decisions go beyond taking part in IEP meetings. The importance of participation is analysed further in the last section of this chapter after a consideration of the role of therapy in a disabled child's education.

Participation Rights in Therapy as Part of the Inclusive Education Process

The areas covered in the IEP include academic development within the cognitive domain as well as other aspects of the disabled child's development, including the physical and psychosocial domains. This ensures a holistic view of the child's education with full consideration being given to impairment-related requirements and to ensuring that the child develops independence skills to the maximum extent possible. The IEP therefore may include reference to therapy and activities which would not readily fall within the scope of a narrow understanding of education. Consequently, while interventions by professionals such as physiotherapists, occupational therapists and speech and language therapists among others are usually associated with health, inclusive education also includes them within its remit.

In their United Kingdom research with children receiving speech and language therapy at school, Owen, Hayett and Roulstone (2004) observed that the children accepted the therapy as part of their schooling and did not feel stigmatised by it, seeing the activities carried out as fun and the sessions with the therapists as opportunities for learning. As one of the children aptly put it: 'It just helps my brain, that's what school's about […] you go to school to learn stuff' (Owen, Hayett and Roulstone 2004: 63). The authors argue that their research confirms that it is better to base therapy in the school rather than in a hospital or clinic. One advantage of this policy is that there is minimal disruption to the disabled child's school day. In practical terms, a child who gets pulled out of certain lessons to attend a speech and language therapy session within the school precincts will obviously waste less time toing and froing than the child who has to leave the school premises to attend sessions in a hospital or clinic and then travel back to school.

Disabled children tend to have different views about the various forms of therapy. De Schauwer et al. (2009) conducted research in the Flemish community in Belgium about disabled children's views of inclusive education. In their paper, they observe how the children did not like physiotherapy but enjoyed occupational therapy and speech therapy. Similar views are recorded by Connors and Stalker (2003) in the United Kingdom. De Schauwer et al.

(2009) also note the disabled children's concern that attending therapy sessions puts extra pressure on their day since they then have to catch up with the homework. Juggling the demands of a mainstream education and the need for therapy can therefore create difficulties in the lives of disabled children. For other disabled children, the small or even negligible improvement obtained from various types of therapy do not justify the effort expended on the exercises set by the therapist, especially since when they take previous time away from education or from more fruitful activities. French and Swain (2008) cite quotations from a number of disabled adults who reflect on the negative effects of the therapy they had received in their childhood. The quotation from the late Mairian Scott-Hill (formerly Mairian Corker), who was a prominent deaf activist, is representative of these views:

> I hated learning speech – hated it – I felt so stupid having to repeat the s,s,s. […] Every time I got it wrong. I had to do it all over again, and I was asking myself, "Why do I have to keep going over and over? I don't understand what it all means!" […] It was just so stupid, a waste of time when I could have been learning more important things. (Corker 1996, cited in French and Swain 2008: 85)

Disabled children should have the right to have a reduction in the intensity of the therapy they are receiving or refuse it outright if they have good reasons for this. One must especially question the wisdom of taking disabled children away from their lessons or their leisure activities if the therapy they are undergoing cannot bring about substantial improvement to their impairment. This may seem contradictory to the argument put forward earlier that therapy can be a part of disabled children's education. In reality, both positions are right – it is just a question of knowing for which disabled child to adopt one position and for which to adopt the other. The question then arises of how educators and health professionals can know when to use one strategy and when to use the other. The answer of course lies with the disabled child and canvassing their opinion is vital in order to find out what the answer is. The effectiveness of therapy cannot be assessed only from a medical and an educational perspective. There is also the disabled child's overall sense of wellbeing to be taken into account and it is the disabled child who is best placed to express an opinion about that.

Connors and Stalker (2003) report that the disabled children they interviewed appreciated those therapists and educators who were willing to communicate with them and listen to their concerns. In this way, major or minor adjustments can be made to the way therapy is provided – especially its timing, location and intensity as well as in the nature of exercises set. Discussing therapy with disabled children can also make them more willing to engage in it, in the same way that discussions help with the compliance in medical treatment regimens and the implementation of the IEP, as reported in the previous chapter and earlier on in this chapter respectively. But, as was also argued earlier, this is not the main reason why the disabled child should be able to exercise their participation rights in decisions about their therapy. The main reason is that it is the child's right to do so.

The Case for the Disabled Child's Participation Rights in Education

Given the vital role that education in general and schools in particular play in the formative years of any child's development, it is essential for the disabled child to be able to exercise their participation rights in decisions related to their own education. And given that the ability and capacity to participate in decision-making processes can evolve and develop when the right conditions obtain, the exercise of participation rights by disabled children should also be seen as an integral part of their education. Lincoln's (1995) article about the importance of hearing students' voices in education is applicable for disabled as much as for non-disabled children. She writes:

> teachers must be willing to hear and honor those voices. […] teachers must know *how* to elicit student voices […] the old-fashioned Socratic method […] may be helpful in working with students who have learned silence. (Lincoln 1995: 89)

Among children who learn silence are those who have a disability, and even more so those whose impairments affect their ability to communicate easily. It is all too easy to assume that they cannot meaningfully participate in decisions and in meetings about their IEPs and other aspects of their education. Such assumptions are based on a focus on the disabled child's deficits rather than their potential and while their impairments do need to be taken into account, this should be done for the purpose of identifying their support needs not only for them to access the curriculum but also to play an active part in discussions and decisions about how to bring that access about.

As seen above, disabled students' lives tend to be dominated by adults. While the input of those adults is important for disabled students to be able to access the curriculum, it may be detrimental to these students' education in the wider sense, if it inhibits their ability to achieve self-determination. One of the main purposes of the CRPD is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities' (United Nations 2006: 5). Within the European context in which this book is based, the enjoyment of these rights and freedoms are linked with the right to freedom of thought, information and expression as set down in the Charter of Fundamental Rights of the European Union (European Union 2000). This Charter also recognises the right of disabled people to be a part of the democratic society set out in the Charter itself. For this to happen, they must be allowed the opportunity to develop the skills necessary for them to participate in decision-making processes from when they are children. Indeed, one can say that it is particularly important for disabled adults and children to do so. This is because, in the same way that inclusive schools must provide reasonable accommodation for the individual educational needs of disabled children, so must societies accommodate the needs of disabled people if they are to be truly inclusive. And, in line with the precepts of the disabled people's movement outlined in Chapter 1, it is disabled people themselves who can best identify what those needs are.

Barton (1997) argues that teachers should consider the question of the role that education plays in forming societies and therefore the role played by inclusive education in forming inclusive societies. 'When we talk about an inclusive society, we are concerned with the question of citizenship and the politics of difference' (Barton 1997: 234). This argument is also reflected in Biesta's (2010) paper on the role of education in the emancipation of children. Biesta, who bases his argument on the work about democracy and equality by Jacques Rancière, points out that education should not be about the knowledgeable teacher transmitting his or her expertise to the ignorant schoolchild. Teachers, rather, should see their role as that of emancipators and of enablers of children's empowerment.

Realising disabled child's participation rights in education is therefore of particular importance as it has significant ramifications for their ability to participate as equal citizens in their adulthood. This is because in the same way that opportunities for disabled children to exercise their participation rights are dependent on a positive attitude on the part of adults who play a significant role in their lives, so opportunities for inclusion and participation for disabled adults depends on their finding an accepting and inclusive society. Inclusive education can have a positive impact not just on disabled people but also on non-disabled people whose daily interactions with disabled children within mainstream settings can help them shift the focus from these children's deficits (perceived or actual) to their abilities. This counts for everyone at all levels – the policy makers, the school's senior management team, educators, the parents of all children (disabled and non-disabled), the administration staff, the mini bus driver, the cleaner and anyone else who comes into direct contact with disabled children.

When disabled children's participation rights are promoted and the right environment created for them to be exercised, attitudinal changes can happen more quickly and to a greater extent. An articulate disabled child who can express informed views about their education and their lives can provide a very powerful way of dispelling myths about disabled children's inabilities and of allaying parents' concerns that the presence of a disabled child in their son's or daughter's class will slow the pace of learning for all children.

Conclusion

This chapter has shown the vital importance that the exercise of participation rights by the disabled child plays in their education. It can help indirectly in enabling educators, therapists and other professionals to communicate with the children about the need for them to pursue certain goals which are essential to their personal as well as their educational development. It also contributes to the disabled child's education and the evolving of their capacities, and to dispel myths about disabled people's inabilities. But, most importantly, it was seen how the disabled child's participation rights in education have their own inherent value and are a matter for enforcement at law, particularly in cases where the positive obligation of the state has not been honoured. It is therefore of crucial importance for adults, in this case especially educators, to be aware of the disabled child's participation rights and of ways to make them a reality. This needs to happen through specific training, an issue dealt with in Chapter 6. The next chapter deals with the disabled child's participation rights in the family home or other place of residence.

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Chapter 4
Home Life

While the focus of this book is on the individual child with disability, this chapter on home life and the dwelling place of the child inevitably brings with it issues that affect the whole family. As Goodley and Runswick-Cole (2010b) argue, disability has an impact on the whole family. In fact, many authors (including Whiting (2014)) speak of the disabled *family*. Furthermore, more than any of the other themes discussed in this book, the theme of this chapter touches on issues which are located within the private sphere of family life. The exception of course is those disabled children who have been removed from the family home and placed in residential services. And disabled children are at a greater risk of experiencing this fate than children who do not have a disability. Indeed, while in other chapters the distinction between parents and those acting *in loco parentis* has not been made; in this particular chapter the distinction is very pertinent. While disabled children are at the heart of decisions taken to remove them from the family home, for any number of reasons, they themselves are most often far removed from a decision-making process that has such a profound effect on their lives.

As with previous chapters, this chapter will start by looking at the relevant rights afforded to the disabled child by the CRPD and the CRC. It will then discuss the main issues related to family life and residential care, with a distinction being kept between the two throughout the chapter. This discussion is followed by a consideration of the disabled child's participation rights in both settings. The chapter concludes with a consideration of the roles played by advocacy and self-advocacy in the disabled child's daily life and the implications for their ability to exercise their participation rights in the home where they live.

Family Life and the Rights of the Disabled Child

Article 23 of the CRPD deals with rights related to the home and the family. It states that '[i]n no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents' (Article 23.4, United Nations 2006: 6). The article does acknowledge that there are circumstances which warrant the separation of the disabled child from their parents. It is important to note that the alternatives provided for by this article in such circumstances do not include the placement of disabled children in large-scale institutions. This is an interesting development from the CRC which, in Article 20, contemplates 'placement in suitable institutions for the care of children' (United Nations 1989: 7). Rather, Article 23.5 of the CRPD refers first to the provision of support for the child within the wider family network of the child, and secondly in community-based family settings. Moreover, the CRPD contemplates these scenarios very much as a last resort, since it obliges States Parties first of all to take preventive measures by providing early intervention and support for the family to be able to raise and take care of the disabled child themselves. This obligation is in line with the CRC which in the Preamble states that the child 'should grow up in a family environment, in an atmosphere of happiness, love and understanding' (United Nations 1989: 3). The Preamble to the CRPD reinforces this principle:

> (*x*) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities. (United Nations 2006: 3; italics in the original)

Such assistance is over and above the 'special care and assistance' that all children are entitled to, as stated in the Universal Declaration of Human Rights (United Nations 1948), and referred to also in the Preamble to the CRC (United Nations 1989). The CRC itself refers to the need of supporting families through financial benefits, material assistance and other forms of support in Article 26 and 27, and acknowledges the additional support needed by families of disabled children in Article 23.

The importance of support for the family also comes through in Article 18 of the CRC and Article 28 of the CRPD 'Adequate social protection and standard of living'. The latter caters for the provision of services, equipment and other forms of support for disability-related needs, as well as training, counselling, financial assistance and respite care for the family. Support and assistance are of course also to be provided to those disabled children who do not live in the family home. While, as the CRPD itself states, children should not be removed from their family solely on the basis of their disability, such situations might happen because of abuse or neglect which, unfortunately, some children experience (regardless of whether they have a disability or not). The disabled child's rights are safeguarded through Article 16 of the CRPD 'Freedom from exploitation, violence and abuse'.

These rights enable the disabled child to grow up in a family environment which as stated in the CRC Preamble provides 'the natural environment for the growth and well-being of all its members and particularly children' (United Nations 1989: 3). This environment in turn helps to ensure that the disabled child grows into an autonomous and independent adult who is able to make their own choices. The importance of the development of the child's autonomy is recognised in paragraph (*n*) of the CRPD Preamble. The following sections look at the relevant research in order to assess the extent to which disabled children do in fact grow in such an environment whether within the family home or in alternative placements. Given the fundamental importance given to the family environment by both the CRPD and the CRC and the clear distinction made between this environment and placements outside of the family home, the experiences of disabled children in these different settings will be considered in separate sections.

Disabled Children's Experiences within the Family Home

In their research about the views of children and young people with autism spectrum disorders about their experience of daily life and social care support, Preece and Jordan (2010) highlight the lack of research involving the direct voice of children with ASD, with most research using family members and other adults as 'proxy informants' (p. 11). This insight can be extended to most research about the experiences of disabled children in residential services and even more so in their family homes. While there is a paucity of research of the experiences of young disabled children in their family homes, there is some research about the experiences of older children and young adults with disability. In their study about the transition to adulthood of young men with Duchenne Muscular Dystrophy in the United Kingdom, Abbott and Carpenter (2010) observe how parents act as advocates for their sons and fight for them to attend mainstream schools, to find employment once they leave school and to secure for them the services they are entitled to. Some parents also struggle to overcome prejudice in other people. One mother is quoted as saying, 'Everybody perceived him as a sick and dying boy and I keep saying to people, "No he's a burger and chips boy and he's doing a GCSE in Art"' (Abbott and Carpenter 2010: 9).

On their part, some of the young men interviewed speak of their ambitions to continue studying, find employment and gain more independence. The latter is particularly difficult because they remain dependent on their parents for their daily needs within the home, as well as for transport for the various activities they want to engage in. As they enter the phase of the transition to adulthood, young people with disability feel particularly disadvantaged, when compared to their non-disabled friends and siblings, in terms of their prospects for achieving autonomy as adults. Julia

Boivin and Marie-Sophie Chaumont (2011), two young French girls with cerebral palsy, comment on their own struggle to become autonomous adults. Chaumont speaks of being overprotected not only by her parents, but also by her older brother, while Boivin comments on how she is treated differently from her two sisters.

The same pattern is found among people with intellectual disability who have a greater risk than other disabled people to remain being seen as children well into their adulthood and for whom, as Mill, Mayes and McConnell (2010: 195) state, the attainment of 'adult status […] remains illusory'. From the six young people interviewed by these researchers, only one person reported that she wanted more independence. The other five were either happy with the level of independence they enjoyed or were working with the family to gain more independence. Other research also indicates a mixture of experiences with some people with intellectual disability expressing frustration at the lack of independence granted to them by their family members and others citing family members as champions for their independence (Mitchell 1998, Goodley 2000, Sutcliffe and Simons 1993). As Callus (2013: 222) notes, many people with intellectual disability find themselves in 'a rather paradoxical relationship with their families, with their dependence on them, especially their mothers and sisters, being counterbalanced by a wish to be independent from them'.

The participants in the studies cited above are not all adolescents or young people. Many would have been well into their adulthood when they were interviewed. The fact that, even at that stage in their life, they were still yearning for independence indicates that while some disabled children grow up in family environments which nurture their independence and autonomy and enable them to achieve self-determination and 'to enhance skills, abilities, and attitudes which enable them to become causal agents in their own lives' (Wehmeyer, Wehmeyer and Bolding 2001: 372), not all disabled children enjoy this experience. Presumably, the younger the child is and the more severe their disability, the less they are given the opportunity to exercise their participation rights. Both Article 5 of the CRC and Article 3 of the CRPD refer to the *evolving* capacities of the child. And, as autonomy, independence and decision-making are associated with adulthood, it is more likely for older disabled children, rather than younger ones, to be afforded opportunities to practise them. The fact that there is so little research with young disabled children about their family life is indicative of the different opportunities available to different children. The research, such as that cited here, certainly shows that the achievement of autonomy is more problematic for children with intellectual impairments than those whose impairments are physical.

Needless to say, the issue of autonomy and lack of participation in decision-making becomes more pronounced among disabled children who have complex dependency needs. As the report by Inclusion Europe (2007) states, disabled children's high level of dependence on others and the fact that they are virtually always placed under plenary guardianship do not encourage practices that foster their autonomy. While the complex and profound nature of these children's impairments may be a major obstacle to their developing a high enough level of awareness of themselves and their surroundings to be able to participate in decisions that affect their lives, their views can be taken into account on minor decisions, such as activities to be engaged in at specific moments in time. After all, as was argued in Chapter 2 with reference to participation in health-related decisions, participation can be considered to be valid at all levels.

Being surrounded by adults who are willing to 'listen' to what a disabled child with complex dependency needs is articulating through vocalisations, gestures and other non-verbal means of communication can enable that child to have a say in their own life and may at an extreme also be essential to safeguard that life. There are of course difficulties attendant with this approach, which arise from the fact that the child's communication in such situations will always be subject to interpretations by others which cannot be checked back with the person. A very good illustration of the problems that can arise from conflicting interpretations is an incident recounted by Porter et al. (2001). They describe how Peter, a disabled boy with complex dependency needs, tapped a balloon while he was in the classroom surrounded by school staff and family members. They report how some of the adults interpreted Peter's action as an indication that he wanted to play, while others took it as a rejection of the invitation to play with the balloon. What this example shows is the importance of adults consulting and collaborating with each other is such situations in order to maximise these children's ability to exercise their participation rights.

The Disabled Child's Care Away from the Family Home

The focus in the previous section is on disabled children who, like Peter, live with their families. But there are also disabled children who, for various reasons, do not live with their family. These may be reasons related to negative experiences that are sometimes unfortunately experienced by children within the family home, such as parents' drug or alcohol abuse, domestic violence or child sexual abuse (Ghaffar, Manby and Race 2012). In such cases and in other cases where parents do not have the capacity or the disposition to care for and protect their children, the state is considered to have a higher responsibility than the family. This additional responsibility is noted by Svevo-Cianci et al. (2011) in their analysis of policies and measures taken by States Parties with reference to Article 19 of the CRC, which gives children the right to protection from violence, abuse and other forms of ill treatment. In fact, Article 20 of the CRC also places on the state the obligation to safeguard children who are not under their family's protection.

As seen above, for the disabled child, an additional factor that leads to their being taken away from the family home and ending up in the care system can be the disability itself. While Article 23 of the CRPD prohibits this, it is still a reality for many disabled children in Europe and around the world for them to be not only taken from their family home but also placed in institutions because they have a disability. A press release by Inclusion Europe (2014) refers to the '[h]undreds of thousands of children, young people, people with disabilities and mental health problems, older or homeless people [who] still live segregated in closed institutions across the European Union, suffering from the life-long impact of institutionalisation'. Children with severe disabilities and those with complex dependency needs are at particular risk because their families may not be able to cater for their impairment-related requirements (Anonymous 2008). It is a right for disabled children not to be placed in segregated institutions (as it is of course for other persons who end up being institutionalised).

This right was invoked by Nils Muižnieks, the European Human Rights Commissioner, who issued a report in July 2014 calling for the Romanian government to end the segregation of disabled people in institutions, apart from calling for the abolishing of guardianship and segregated schooling for disabled children (Mental Disability Advocacy Centre 2014a). Later on in the same year, the Czech Supreme Administrative Court affirmed that 'children with disabilities have an enforceable right to receive social services to ensure that they can continue living in the community, with their families' (Mental Disability Advocacy Centre 2014b). The judgment followed a case brought forward by the parents of three boys with autism who also have intellectual disability and behavioural issues. As the boys grew older, their parents were finding it increasingly difficult to provide them with the support they needed. Because of the lack of community-based support services, the only solution seemed to be institutionalisation. The Czech court found that, with the ratification of the CRPD, the local authorities were duty-bound to provide social services for these boys, and other disabled children in similar situations, to remain living in the community.

There are many reasons why the disabled child should not be institutionalised. One of them is that institutions are places that engender abuse (Inclusion Europe 2014). Conroy (2010), writing in the context of disabled children living in residential institutions in Ireland, highlights the fact that children with communication difficulties are particularly at risk in such situations as they cannot easily report the abuse they are suffering. Some cases of neglect and abuse in residential institutions have been taken to the

European Court of Human Rights and are considered later in this chapter. Even where there are no instances of deliberate abuse, when removal from the family home results in institutionalisation, especially for very young children, there are risks of these children experiencing developmental delays as well as attachment disorders which have long-term consequences; Browne (2005) reports on a survey of out-of-home care for children aged three and under in European countries. Another risk associated with institutionalisation is that of abuse. In addition, within the context of the United Kingdom, Winter (2006) also reports that disabled children who have been removed from the family home have decreased access to healthcare, while Cousins (2009) notes how long-term institutionalisation can lead to disabled children losing their sense of family life and being isolated from their community. In their paper on the needs of disabled children in residential care in Spain, Sainero et al. (2013) also note that institutionalisation can itself give rise to mental health issues. Consequently, given that, as Cousins (2009) notes, children who have a disability are at increased risk of being taken away from their families, especially in Central and Eastern Europe, the deleterious effects of institutionalisation can only serve to compound already existing impairments. Browne's (2005) paper also reports on great variations in the ways different countries respond to the care needs of these children, with a third of the countries surveyed having more children under the age of three in institutions than in foster care, and the tendency for placements in institutions to be more prevalent in countries with a lower level of economic development.

In more developed countries, foster care is the preferred option. As Strunk (2010) points out, foster care is a way for families to keep on caring for disabled children. This approach is in line with the requirements of Article 23.5 of the CRPD which, as discussed earlier, only considers family-based settings in the community as acceptable solutions for disabled children who cannot remain in their own family home. The focus of the paper by Strunk (2010) is mostly on respite care (in Australia, the United Kingdom and the United States). Respite care is one way of providing the support services that families of disabled children are entitled to in order to be able to continue caring for them in their own family home. Anonymous (2008) refers to the system used in the Netherlands which entails careful matching of foster carers and disabled children by ensuring that there is attachment between them. However, even foster care services for disabled children do not always work out as they should. As Cousins (2009) notes, disabled children are least likely to find foster families and to be found permanent placements in families. Baker (2007), whose research was based in England, notes that, from among children in foster care, disabled children were the least likely to be permanently adopted or to return to their own family home. Similar findings emerge from the research conducted by McConkey, Kelly and

Craig (2014) in their research on out-of-home placements of children with intellectual disability in Ireland over a 10-year period. The authors note a drop in residential placements for all children over the decade. However, when compared to their non-disabled peers, children with intellectual disability were more likely to be taken from their family home and less likely to return there or to move from residential to foster care.

The research cited in this and the previous section points to the many obstacles to the assertion of participation rights by disabled children in the setting within which they live, whether that is the family home, a foster care home or a large- or small-scale residential setting. While there are many different types of family set-ups and out-of-home care services, with some arrangements (such as out-of-home respite care) straddling the two, a clear distinction can be made between them. For disabled children who live with their own family, the exercise of participation rights happens within the privacy of the family home, whereas when the state has intervened in some way to provide alternative residential care, there are obligations which lend themselves more easily to regulation, and which also make regulation important. It is within this context that the next two sections consider first the disabled child's participation rights within the family home and then these rights in out-of-home care.

The Disabled Child's Participation Rights in Family Life

The development of self-determination and the acquisition of skills that help nurture autonomy for the disabled child within the family home do not depend on the parents alone. Parents themselves are living in societies which not only do not necessarily prize the achievement of autonomy by disabled people as a primary aim, and may not even value disabled people positively in the first place. Consequently, when parents are presented with a diagnosis of disability for their child, their response almost inevitably draws from the association of disability with inability and deficit and the concomitant perception of disabled people as being permanently dependent on others. Parents' reaction to the news that their child has a permanent disability has been likened to the grieving process. As Poslawsky et al. (2014) argue, parents who find themselves in this situation have to adjust their expectations for the child's future, including an acceptance that the child is unlikely to reach some or many developmental milestones in the same manner as their typically developing peers and an acceptance of the likelihood that the child will continue to need support well into their adulthood. Parents of disabled children thus have to juggle the provision of additional support for their disabled children with enabling them to develop their autonomy and independence.

Gardou (2011) discusses how having a disability very often equates with privation of liberty. He identifies the lack of social acceptance of disabled people as a cause of this privation, arguing that disabled people 'are not outside society but at its mercy' (p. 11, authors' translation).[1] Gardou argues further that since disabled people do not conform to social norms, society seeks to contain them. Such responses can hardly aid the fostering of a culture where the disabled child is given the opportunities to participate in decisions affecting them in order to nurture their independence and autonomy. This culture then leads to a situation in which it is non-disabled others who take decisions on behalf of disabled people. Discussing French disabled people's life experiences, Nuss (2011: 125) states that '[t]he worst enemy is the tendency for helpers to want to put themselves in our place. Think for us, act for us, suffer for us' (authors' translation).

While Nuss is speaking within the context of French culture, there are strong indications that the situation is similar in other European countries. In their research about young men with muscular dystrophy cited earlier, Abbott and Carpenter (2010) comment about how the young men interviewed often felt that they were marginalised in decisions taken by parents and professionals about their transition from child to adult services. More widely, it can be observed that the state reports on the implementation of both the CRC and the CRPD do not give much importance to the scope for disabled children to take decisions in their everyday lives or at least participate in decision-making processes. The reports tend to focus on the quality of life of disabled children and their families and the quality of support that they receive, and on the support needs of the whole family rather than the direct needs of the disabled child within the family. There is no doubt of course that the families of disabled children do need support. Research findings by the British charity Contact a Family reported that out of the 2000 parents of disabled children surveyed, more than half reported experiencing relationship difficulties (A. Shapiro 2003). This comes from the energy that they need to invest in supporting their disabled child and in obtaining support, financial and otherwise, from the state and from service-providers. Similar situations are reported by Benjak (2011) regarding parents of children with autism spectrum disorders in Croatia, and Čagran, Schmidt and Brown (2011) regarding parents of children with intellectual and developmental disabilities in Slovenia. As Brown et al. (2011) report:

> Since the development of inclusion and integration, parents have increasingly become the major, and sometimes the only, carers of their children with disabilities. Many families speak of stress and frustration with service and

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[1] 'ne sont pas en dehors de la collectivité mais à sa merci.'

> community support, and some have turned to residential and specialised day care services to overcome challenges. (p. 904)

There are therefore strong indications that despite the widespread availability of social protection measures, there is still not enough support for the families of disabled children.

Significantly, the support that does exist is not oriented towards increasing the disabled child's participation rights within the family home, as can be seen from the State Reports of various European countries that have already been submitted to the United Nation's Committee on the Rights of Persons with Disabilities. To take just a few examples, in the Austrian report (Austria 2010), it is stated that additional benefits are given to families of disabled children to help cover the costs associated with long-term care for children and young people with severe disabilities. Likewise, in Belgium supplementary allowances are given to families of disabled children and young people to cover impairment-related costs including assistive equipment and medical expenses (Belgium 2011). In Denmark, financial benefits are oriented towards covering lost wages while taking care of a disabled child (Denmark 2011) while in Croatia the focus is on avoiding institutionalisation (Croatia 2011). There is no doubt that social protection measures and support services are invaluable for the families of disabled children.

The European Court of Human Rights (has not been very sympathetic to such claims as yet. In La Parola and Others vs Italy (European Court of Human Rights 2010, decided on the 30 November 2000) the court declared as inadmissible the allegation by the unemployed parents of a disabled child that the Italian State was violating their child's right to life and health in particular by refusing to provide effective medical and financial assistance. The court declared the application inadmissible (manifestly ill-founded), pursuant to Article 35 (admissibility criteria) of the European Convention on Human Rights (Council of Europe 1950) and noted that Italy was observing its positive obligations under Article 8. It observed that the applicants were already in receipt of benefit on a permanent basis to assist them to cope with their son's disabilities. The scale of that benefit showed that Italy was already discharging its positive obligations under Article 8 (Right to Respect for Private and Family Life) of this Convention. The question therefore remains as to the extent to which these measures and services directly enable the disabled child to exercise their participation rights. The exercise of these rights is essential for children to 'be fully prepared to live an individual life in society' (United Nations 1989: 3). In the CRC, these rights are also recognised in Article 5:

> States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community

> as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention. (Ibid.: 4)

These rights of course belong to all children, disabled or not. But, as has been seen above, disabled children are particularly vulnerable to not having these rights respected given that even disabled adults encounter problems in this regard.

Gaining the views of the disabled child about their family life also presents difficulties. In discussing his own experience of doing research with disabled children, Abbott (2013) talks about the importance of establishing a relationship with the whole family and about how parents effectively act as gatekeepers, not only by deciding whether or not their children should participate in a study, but also by sitting on and even participating in the interview if they choose to do so. And, as Abbott goes on to argue, if the researcher is interviewing children in their family home, s/he must respect the parents' preferences. One must also respect the fact that the parents' perspectives about their disabled children's lives and about their support needs are invaluable since in most cases they are the people who have seen these children develop from the day they were born. They are therefore most often the people who know the intimate details of the disabled child's development, the milestones reached, and the child's support needs. Parents are also the people most likely to know their disabled children's preferences and while they cannot know them or express them as well as the children themselves, they can lay claim to having a perspective that their children do not yet have.

Therefore, the importance of parents' perspectives and opinions and the importance of providing support services and measures for the whole family are not at issue here. What is being questioned rather is the tendency for these perspectives and opinions not to be complemented by those of the disabled children themselves. In 'Speaking on behalf of others', Alcoff (1991: 8) discusses the question of 'whether all instances of speaking for others should be condemned and, if not, where the line of demarcation should be drawn'. Alcoff's focus is on adults speaking on behalf of other adults. As she says, the tendency is for those in positions of power to speak on behalf of less powerful ones. Alcoff acknowledges that such situations are inevitable and sometimes even desirable. But she argues that it is very important that when one is representing others one is aware of 'all attendant problems with speaking for others. One is still interpreting the other's situation and wishes [...] and so one is still creating for them a self in the presence of others' (ibid.: 10).

This is particularly relevant for disabled children since when they grow up they will not necessarily be in a position to directly represent themselves without their opinions and views being mediated through their parents or significant others, for various reasons. One such reason is that the disabled child's cognitive and physical impairments may be so profound and complex and permanent that they never become capable of developing even the most basic communication skills necessary to verbally express an opinion. Such communication difficulties may last throughout a lifetime. McKie (2006: 115) makes this point about her daughter Heather who, she states, 'has no explicit way of telling her own life-story'. She therefore proceeds to tell her daughter's story, focusing on the strategies that are used to elicit Heather's wishes, needs and intentions. A significant detail about McKie's story is that Heather is 46. Because of her profound and multiple disabilities, Heather did not evolve the capacity to express herself directly and with ease the way that most children do. Consequently, in the case of Heather and other disabled people in similar positions it is necessary to explore the ways in which communication of preferences may be possible for them.

Another reason for disabled children's lack of opportunity to represent themselves is that, even if they are capable of doing so, culturally it is often considered appropriate for parents to speak and even act on behalf of their disabled child. McKie presents her paper as Heather's story. Linda Ware, writing in the same issue of the journal *Equity and Excellence in Education*, argues that McKie's account can never be Heather's story, but her mother's representation of that story. Ware (2006) refers to Alcoff's paper, cited above, to discuss the issue of the representations of disabled people's lives by their parents, especially their mothers. Ware's disabled son, Justin, was 30 at the time. Justin has a physical disability, is articulate and lives in supported accommodation in New Mexico thousands of miles away from his parents who live in New York. Ware refers to the overlaps between the lives of disabled children and their parents and how the two lives remain inextricably intertwined even if they live far away from each other. She also talks of the complexity of her own relationship with Justin, and describes her dual role as 'mother-advocate' and 'mother-intruder'. As she herself says, the first is a role that she herself has identified, the second a name that Justin sometimes uses for her.

Ware also talks of Justin's insistence on 'his right to be in the world on his own terms' (Ware 2006: 125). She remarks on the difficulties inherent in this enterprise that do not necessarily arise from Justin's impairments, or even from parental intrusions, but from a culture that keeps holding his parents responsible for him even long after he has grown up. Ware (2006: 124) recounts how '[e]ven among family, some wonder why I would "allow" him to live "alone"'. The implication is that even if he is an articulate adult living in a supported setting, with staff available around the clock, he is still considered to be his parents' responsibility. The fact that Ware is writing about her and her son's life in the United States gives her account and reflections an added poignancy. It seems that even in a country which has a constitution based on, among other things, the rights of 'liberty and the pursuit of happiness', disabled adults are not necessarily seen as being capable of enjoying these rights on their own terms and are seen as remaining dependent on their families.

Participation is also dependent on effective access to justice for disabled children and their families. This is a challenging issue for any child and has started to be addressed in the Council of Europe Guidelines in Child Friendly Justice (Council of Europe 2010) which has been taken on board by the European Commission. For the child with a disability access to justice is a series of hurdles which must be overcome through a number of components from different sources, such as family, the judicial system, the care system and whichever support structures promote and validate participation rights in the spirit of the CRC and CRPD. A case in point was decided by the European Court of Human Rights in A.M.M. vs Romania (European Court of Human Rights 2012a, decided on 14 February 2012). This case concerned proceedings to establish paternity of a minor with numerous disabilities who was born in 2001 outside marriage. He had been registered in his birth certificate as having a father of unknown identity. Initially the child was represented by his mother before the European Court and subsequently, since his mother also had a serious disability, by his maternal grandmother. The court found that there had been a violation of Article 8 (Right to Respect for Private and Family Life) of the European Convention on Human Rights as the state had not fulfilled its positive obligation to provide representation, finding that the domestic courts did not strike a fair balance between the child's right to have his interests safeguarded in the proceedings and the right of his putative father not to undergo a paternity test or take part in the proceedings. Having to ascertain whether the Romanian State, in its conduct of the proceedings to establish the applicant's paternity for the child, had acted in breach of its positive obligation under Article 8 of this Convention, it observed in particular that through the guardianship office, which under the national legislation was responsible for protecting the interests of minors and persons lacking legal capacity, the authorities had neglected their responsibility to protect the child's rights and had negated participation rights by even failing to provide legal representation and had not taken part in the proceedings as it was required to do.

Another aspect of participation in decisions regarding home life is independent living. Article 19(a) of the CRPD (Living Independently and Being Included in the Community) refers to disabled persons' right to 'have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement' (United Nations 2006: 13). These opportunities are of course more relevant for disabled adults since, even within the general population, it is as adults that people choose to move out of the family home. However, for the general population it is usual for children to be afforded increasing degrees of independence even within the family home in preparation for their independent lives in the future. The extent to which disabled children are also prepared in this way is difficult to gauge because of the difficulties inherent in researching about disabled children's lives in their family homes. The literature does indicate that many parents are attuned towards enabling their disabled children to become more independent and identify the services they need in this regard as they grow up. But such parents do not necessarily constitute the majority of parents of disabled children. Furthermore, the literature and the official documentation cited above also indicates that the available services and measures are not necessarily placing the respect for and evolution of disabled children's participation rights high on their agenda.

While, as noted above, it is disabled adults who move out of the family home, there are situations where disabled children also need to take this step. Our attention will therefore now turn to residential services for disabled children and their participation rights within them.

The Disabled Child's Participation Rights in Out-of-Home Care

The decision to remove disabled children from their family home is almost invariably taken without seeking their consent. In certain circumstances it can be even taken without their own parents' consent. Much of the literature on the subject of out-of-home care for disabled children focuses on what leads to their entry into the care system, the options that best foster their development, and the safeguards that need to be in place to prevent abuse and other problems. The voice of disabled children themselves on how they view out-of-home care is very rarely heard. As with the other aspects of life investigated in this book, participation in decision-making by the disabled child in the care system can take place at different levels. The key decision is of course whether the child should remain in the family home or not. Once the decision has been taken that the child should not remain there, the next decision is where to place the child. As seen in the previous section, such decisions are often based on what type of services are available and not always on what is most beneficial for the child. Within the care system the child is placed in, there are different types of decisions to be taken ranging from the mundane to higher-level ones.

Not all of these placements in alternative care are made with the agreement of the parents and the issue is particularly pressing when the parents themselves have a disability, a right which is also addressed in Article 23 of the CRPD. In Saviny vs Ukraine (European Court of Human Rights 2008, decided on 18 December 2008) the court gave judgment in a case regarding children who had been taken into care. This case concerned the placement of children in public care on the ground that their parents, who have both been blind since childhood, had failed to provide them with adequate care and housing. The domestic authorities based their decision on a finding that the applicants' lack of financial means and personal qualities endangered their children's life, health and moral upbringing. Notably they were unable to provide them with proper nutrition, clothing, hygiene and healthcare or to ensure that they adapt in a social and educational context. The applicants had appealed against the decision unsuccessfully. The court held that there had been a violation of Article 8 (Right to Respect for Private and Family Life) of the European Convention on Human Rights, sharing its scepticism at the information on which it was based and doubting the adequacy of the evidence on which the authorities had based their finding and the extent of the danger alleged. The court found that support to the parents could have prevented a situation where the children's living conditions had in fact been dangerous to their life and health. The judicial authorities had only examined those difficulties which could have been overcome by targeted financial and social assistance and effective counselling and had not apparently analysed in any depth the extent to which the applicants' irremediable incapacity to provide requisite care had been responsible for the parents' inadequacies. Furthermore, the state had not addressed shortcomings, particularly in circumstances where the parents' efforts and motivation in caring for their children had been disregarded with relation to the children's upbringing. Indeed, as regards parental irresponsibility, no independent evidence (such as an assessment by a psychologist) had been sought to evaluate the applicants' emotional or mental maturity or motivation in resolving their household difficulties. More to the point to the subject of this book, the court also noted that the courts had not examined the applicants' attempts to improve their situation. Furthermore, the court noted that at no stage of the proceedings had the children been heard by the judges when participation should have been a standard requirement. In this case, the authorities' reaction to the parents' disability had led to the removal of the children. As a result, not only were the children separated from their family of origin but also from each other as they were also been placed in different institutions.

Similarly in A.K. and L. vs Croatia (European Court of Human Rights 2013a, decided on 8 January 2013) the court decided on a case where a child, soon after birth, had been placed in foster care. The first applicant is the mother of the second applicant, who was born in 2008. Soon after his birth, the second applicant was placed in a foster home, with his mother's consent, and then adopted without her consent, on the grounds that his mother had no income and lived in a dilapidated property without heating. The first applicant complained in particular that she had not been represented in subsequent court proceedings which had resulted in a decision divesting her of her parental rights, on the ground that she had a mild mental disability, and that her son had been put up for adoption without her knowledge, consent or participation in the adoption proceedings. The mother was alleged to have a mild mental disability which the authorities had used as a pretext to bypass her participation and objection in the adoption process. More to the point, she was 19 at the time of her son's birth and had spent all her childhood in sheltered environments. The court held that there had been a violation of Article 8 (Right to Respect for Private and Family Life) of the European Convention on Human Rights. Observing in particular that, despite the legal requirement and the authorities' findings that the first applicant had a mild mental disability, she had not been represented by a lawyer in the proceedings divesting her of parental rights and that, by not informing her about the adoption proceedings, the national authorities had deprived her of the opportunity to seek restoration of her parental rights before the ties between her and her son had been finally severed by his adoption.

Glimpses into the experiences of disabled children in the care system can be gleaned from accounts of disabled adults who grew up away from the family home. One such book is Galledo's (2007) autobiography of growing up as a disabled person in a Russian institution. Another, edited by Mitchell et al. (2006) presents testimonies of people with disability who lived in institutions mostly in the UK, but also Iceland, Canada and Australia. These accounts shed light on disabled children's situation in the care system and can help us understand the experiences, both positive and negative, that have shaped the lives of today's disabled adults. But, beyond their historical value, such accounts are of limited use. By their very nature, they reflect experiences that are years, sometimes even decades, old and so the issues they raise probably refer to systems and practices that in the meantime have changed. The fact that there is not much literature on the topic is itself significant. Researchers seem to be more concerned with the identification of disabled children's needs and the effectiveness of interventions to respond to those needs. For example, Winter (2006) remarks on the lack of research regarding the participation rights of looked-after children in healthcare settings.

To fail to do give these participation rights may – and sadly often does – result in tragic outcomes. In Nencheva and Others vs Bulgaria (European Court of Human Rights 2013c, decided on 18 June 2013) 15 children and young adults died between December 1996 and March 1997 in a home for physically and intellectually disabled young people, from the effects of cold and shortages of food, medicines and basic necessities. The court held that there had been a violation of Article 2 (Right to Life) of the European Convention on Human Rights where all of them had been entrusted to the care of the State in a specialised public facility and had been under the exclusive supervision of the authorities. In Center of Legal Resources on behalf of Valentin Câmpeanu vs Romania (European Court of Human Rights 2014, decided 17 July 2014 (Grand Chamber)) an NGO instituted proceedings on behalf of Valentin Câmpeanu, who died in 2004 at the age of 18 in a psychiatric hospital. After being abandoned at birth, diagnosed as a young child as being HIV-positive and as having a severe mental disability, the court found a violation of Article 2 (Right to Life) of this Convention, in particular: that Valentin Câmpeanu had not been accommodated appropriately according to his needs, that he had not received correct assessment prior to transfer to other facilities and his condition had not been treated with antiretroviral medication resulting in danger to life. The court also found a breach of Article 13 (Right to an Effective Remedy) of this Convention in conjunction with Article 2, considering that the Romanian State had failed to provide an appropriate mechanism for redress to people with mental disabilities claiming to be victims under Article 2. The court recommended that Romania take the necessary general measures to ensure that intellectually disabled persons in a comparable situation were provided with independent representation enabling them to have complaints relating to their health and treatment examined before an independent body.

It is also necessary for there to be direct recourse to justice for the disabled child. The European Court of Human Rights in X and Y vs the Netherlands (European Court of Human Rights 1985, decided on 26 March 1985) found that a 16-year-old girl, with an intellectual disability, had been sexually abused by the son-in-law of the woman who ran a private home for intellectually disabled children while she was living there. The court found there had been a violation of Article 8 insofar as Dutch law did not allow for proceedings to be brought in the event of sexual violence against minors with intellectual disability of 16 or more. However the court has also on occasion sympathised with actions taken to respond to parental action that may be deemed questionable. For instance, in Nielsen vs Denmark (European Court of Human Rights 1988, decided on 28 November 1998) the court found no violation of Article 5§1 in that the hospitalisation to a child psychiatric ward of the applicant, who had nervous disorders and whose custody was in dispute between his parents, had been ‘a responsible exercise by his mother of her custodial rights in the interest of the child’. However in Pleso vs Hungary (European Court of Human Rights 2012b, decided on 2 October 2012) the court found there had been a violation of Article 5 of the European Convention on Human Rights when a young man (not a child) had been detained against his will in a psychiatric hospital in order to prevent deterioration of his health.

Significantly, the criteria for identifying the needs of disabled children in out-of-home care, the interventions and the criteria for judging their effectiveness are all set by adults. It can be safe to assume that these criteria are well thought-out and are based on previous experience and the expertise of the adults taking the decisions. One can also assume that these adults are motivated by the disabled child's best interest in their decisions and actions. If a disabled child is in need of care because of shortcomings within the family home, the intervention by other adults is crucial and necessary. However, not taking the views of the disabled child into account means that the care system is missing out on an important dimension and the extent to which the system itself can be improved becomes limited.

An example cited by Knight and Oliver (2007) in their research on advocacy for disabled children who are in out-of-home care or receiving services at home illustrates this point. In one of the homes in which they conducted their research, the bathroom had a window with a curtain that was placed on the outside, so that staff could look in. The staff justified the arrangement for the purpose of health and safety but the children objected because it invaded their privacy. After a discussion facilitated by an advocate, the staff agreed that the curtain should be placed on the inside, to respect the children's privacy. Respect for privacy is in fact the subject of Article 22 of the CRPD which states that '[n]o persons with disabilities […] shall be subjected to arbitrary or unlawful interference with his or her privacy' (United Nations 2006: 15). The question is of course what constitutes 'arbitrary or unlawful interference'.

In the example presented above, it is clear that what staff took to be responsible action was seen as interference from the children's point of view. Other situations do not present such clear cut resolutions to problems of conflicting perspectives. The issue at hand may be more complex than a discussion of the position of a bathroom curtain. Mitchell and Sloper (2001) discuss the different perspectives about quality in services that are held by disabled children, families and staff. As they point out, different aspects of services are prioritised by different people. The children they interviewed, for example, focused to a much larger extent than parents or staff on positive one-to-one relationships with staff and peers as an important aspect of quality services. Other problems arise when the disabled child has little or no verbal communication. This issue is raised by Knight and Oliver (2007) and also Baines (2009) who highlights the obstacles to communication that the disabled child encounters in out-of-home care. She focuses on disabled children who have communication difficulties. Given that disabled children with complex impairments are both more likely to be cared for outside the family setting and more likely to experience difficulties with verbal communication, the points raised by Baines are highly significant. Baines reports that disabled children with communication difficulties are often seen as not being able to communicate at all because they cannot communicate verbally. Given that non-verbal communication, such as that carried out with the use of assistive technology, takes longer, care systems may not be set up in ways that leave enough time for disabled children to express themselves through the means of communication that is most appropriate for them. These means may also entail the use of technology that staff are not familiar with. As Baines points out, lack of knowledge about technology presents a hurdle for communication for these disabled children.

Ultimately, whether a disabled child in out-of-home care enjoys the opportunity to make their views heard or not depends on a number of factors arising from the environment. The disabled child's own ability to express their views verbally is of course an important factor as it means that there are fewer obstacles to being heard directly. But the disposition of the staff to enable the disabled child's participation is crucial. Knight and Oliver (2007) give an account of the difficulties they encountered in having access to some of the disabled children in one of the care homes where they conducted their research. The decision was taken by management that participation in the research would be detrimental to two of the young people. As the authors reflect, this incident mirrors the fact that prior to the disabled child being able to participate in decision-making processes, there has to be at least one adult who deems it appropriate for that child to do so.

Advocacy, Self-Advocacy and the Disabled Child's Participation Rights in Home Life

Whether they live with their biological, adoptive or foster family, or in small- or large-scale residential settings, disabled children first learn to negotiate their place in the wider world within these settings. As was seen in this chapter, there are many factors that affect the process of negotiation. Some of these factors are related to the nature and severity of the children's impairment. But it is the wider environment and adult attitudes and practices that have the most significant impact on the trajectory that a disabled child's development takes.

Within the context of home life, parents or other primary caregivers can easily place themselves in the role of advocates for the disabled child for whose care they are responsible. Indeed, as seen in various examples from the published research cited in this book, it is often necessary for them to do so. Parents of disabled children find themselves in situations where they have to fight for their children to be given medical treatment, to be included in mainstream education settings or to participate in mainstream sport and leisure activities with other children. These parents therefore often have to intervene in their disabled children's lives to a greater extent than they do in the lives of their non-disabled children. After all, they are legally responsible for the wellbeing of their own children and, in the case of disabled children, ensuring that wellbeing often entails the procurement of services and securing benefits in addition to the services and benefits that parents with dependent non-disabled children are usually entitled to. For the majority of disabled children, it is their parents who have been with them from birth and from the moment of diagnosis. It is their parents who know the intricate details of their life history. And it is their parents who are aware of which types of support are most effective for their disabled child. It is therefore natural for parents to see themselves as being best placed to act as advocates for their child. And given that many impairments entail the provision of lifelong support in activities of daily living, it is easy for parents to feel obliged to continue being advocates long into their disabled child's adulthood. This is especially the case for those disabled children whose impairments are profound and multiple (De Geeter, Poppes and Vlaskamp 2002). While such interventions may indeed be necessary, parent advocacy should not be inimical to the growth of the disabled child's opportunities and capacities for self-advocacy. These capacities may eventually cover all or most aspects of life, or they may be restricted to decisions related to the immediate environment (eating, sleeping, engaging in an activity) for children with profound and multiple disabilities. But, as Edge (2001) shows, even these children can be in control of at least some aspects of their lives.

Where parents feel that they are ready to let go of their disabled adult child, they should not be made to feel that they are going against the current. This is the feeling expressed by Ware (2006) whose article about her son's quest for independence was cited earlier. It is a feeling echoed by one of the parents interviewed by Callus (2013: 89) who 'portrays herself as relinquishing control over her son's actions against her own maternal instincts […] talks about cutting the [umbilical] cord'.

Increasing the scope for the disabled child's self-determination within the family home has repercussions beyond the home. It is a way of ensuring that interactions between the family and health professionals, educators and staff working in different services include the disabled child's voice as well as that of their parents. Parents need to be aware of how their role as advocates for their disabled child can be transformed into a more empowering role so that their child becomes well equipped with the skills needed for them to be able to voice their opinions and stand up for their own rights at home, at school, and in other settings. After all, the notion of independence as it is understood by disabled people is not restricted to the narrow meaning of being able to do everything on your own, but incorporates the wider sense of being able take decisions about your own life and about the support that you need to enact those decisions (Morris 1993).

What counts for parents (biological, adoptive or foster) in the family home is of course also valid for staff in residential services. The staff play a dual role as primary caregivers and as service-providers. The former role is one which positions staff as advocates for the disabled children entrusted to their care in interactions with those working in education, health, leisure and other settings. In these interactions, it is important that these do not speak on behalf of the disabled children to the exclusion of these children's voices. Just like parents, they should foster the children's independence and their participation rights by allowing scope for participation in decision-making processes within the residential service. It is vital for these disabled children to develop the ability to speak and stand up for themselves as they prepare to leave care once they reach adulthood. Unlike disabled children who continue to live with their family well into adulthood, disabled children in out-of-home care lose the support network they have grown up in once they move out of the care system for children (Rabiee, Priestley and Knowles 2001).

The second aspect of the role played by staff in residential settings for disabled children is that of service-providers. They need to listen to what the disabled children have to say about the services that they themselves provide. Begum (2006) speaks of the needs for independent advocates for disabled children in residential settings, a need that the disabled children interviewed themselves identified. Such advocates act as intermediaries between disabled children and staff in residential services in the same way that the latter act as intermediaries between children and staff in other services. Needless to say, these advocates must be conscious of the need to enable disabled children to exercise their participation rights. It can be argued that in their own interactions with the children this enablement is an integral part of what they do. After all, their role is specifically to hear what disabled children have to say for themselves and to create a context for them to voice their opinions. But independent advocates need to ensure that disabled children can do this not only in their one-to-one interactions with them, but also in interactions with service-providers. They should ensure that, while they continue to provide disabled children with the advocacy support that they need, they also allow these children to speak for themselves in discussions with staff and support them to do so where necessary.

Conclusion

The research evidence presented in this chapter indicates that the disabled child's ability to exercise their participation rights in the home where they live depends on various factors, including the disposition of their family or other caregivers to give them the opportunities to do so. This is a situation which is also found in other contexts – including health settings, schools and leisure and sport facilities. As has been argued in this chapter, given that it is the parents or those acting *in loco parentis* who very often speak on behalf of disabled children, it is vital that they themselves listen to what the disabled child has to say for themselves. It is equally important for these primary caregivers to actively ensure that the child with disability has the space to voice their own opinions and participate in the decision-making process in the different settings they find themselves in. The exercise of the disabled child's participation rights in hospitals, clinics and other health settings as well as in schools has been dealt with in the previous two chapters. Participation rights in leisure and related activities are considered in the next chapter. These are activities which should provide the disabled child with the best opportunities for developing relationships with others on their own terms.

Chapter 5

Relationships

Introduction

A focus on the disabled child's participation rights within relationships entails first of all looking at the different relationships that disabled children foster in their daily lives. There are no specific articles in the Convention on the Rights of Persons with Disabilities (CRPD) or the Convention on the Rights of the Child (CRC) which deal directly with rights to relationships. But it can be argued that all those articles in these two conventions that are concerned with different aspects of life are also relevant to the relationships that the disabled child develops with others. After all, these relationships are built within the family and the local community, in schools and other educational settings, when using health services, and in activities engaged in during leisure time. These relationships can be long- or short-term, and can be either formal or informal. They are very important in the lives of the disabled child as relationships are the key to their enjoying 'full and effective participation in society on an equal basis with others' (United Nations 2006: 2). Indeed, 'with others' does not only mean that full and effective participation in society is enjoyed on the same basis as others (i.e. non-disabled people) enjoy them. 'With others' therefore also means that participation in society can only be enjoyed fully and effectively by a person when the disabled person interacts with others (whether disabled or non-disabled people) in relationships that place them on an equal basis with each other. Participation takes place in *society*, a term in which the idea of people living and acting together and sharing the same spaces and resources is inherent.

This chapter first focuses on those articles in the CRPD and CRC which were not referred to in the previous chapters and which deal with rights which impinge on relationships. It then considers the different aspects of life through which the disabled child comes into contact with other people with whom they can build relationships, especially in education and in leisure settings, and the scope for exercising participation rights in these relationships. Issues related to the participation rights of older children with regards to relationships are also considered. The chapter then shifts attention to the role that adults play in the development of the disabled child's relationships. This leads to a discussion of how adults can create inclusive structures which support the development of the disabled child's agency and of more equitable relationships among disabled and non-disabled children and between disabled children and adults.

The CRPD, the CRC and the Disabled Child's Relationships

In its Preamble, the CRC takes into consideration the fact that 'the child should be fully prepared to live an individual life in society' (United Nations 1989: 1). There is an interesting contrast here between the child as an individual, separate and distinct from others, and the child as a full and equal member of the society in which they live. These two aspects are complementary and the statement safeguards the child's right to develop their own identity as an individual while at the same time also safeguarding their right to participate fully in their society.

This participation, as seen above, comes through relationships with others. Some CRC articles are particularly relevant, including Article 14 (which focuses on freedom of thought, conscience and religion) and Article 15 (freedom of association and peaceful assembly). These articles are relevant to the participation rights of each individual child as they assert the child's right to develop their own opinions while at the same time also asserting the right of the child to assemble and associate with others in contexts where they can share those opinions. Similarly, the right of the child to preserve their own identity without unlawful interference (as asserted in Article 8 of the CRC) is complemented by Article 29 which refers to 'the preparation of the child for responsible life in a free society' (United Nations 1989: 9). Even within the family, the child has the right 'for the full and harmonious development of his or her personality' (United Nations 1989: 1), while Article 27 links the right to an adequate standard of living with both the individual and the social development of the child. Therefore, while the child has a right to interact and develop relationships with others, they also have a right to do so without their individuality being engulfed by social pressures. The child thus retains those characteristics which distinguish them from others, while at the same time ensuring that these characteristics do not lead to their being isolated.

These rights of course extend to the disabled child. The CRC specifically safeguards disabled children's rights in Article 23 while the CRPD makes direct reference to the CRC in its Preamble. Furthermore, like the CRC, the CRPD also pays attention to the right of children with disabilities to develop their own identity as individuals in their own right as well as the right for them to then participate fully in society as individuals. Indeed, the CRPD adds a further layer to these rights as it also recognises in the Preamble 'the diversity of persons with disabilities' (United Nations 2006: 3). 'Diversity' can be taken to refer to both the differences among disabled people and the differences between them and non-disabled people. The CRPD therefore recognises the disability itself as part of the person's identity, while attending to the heterogeneity of the phenomenon of disability. It goes even further in Article 3 (General Principles) which asserts '[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity' (United Nations 2006: 6).

The disabled child, therefore, has a right to participate in society and develop relationships with others while at the same time maintaining their identity not only as a child in their own right, but also as a *disabled* child. The child is thus entitled to develop all aspects of their identity, including those which are linked to their disability, rather than being made to conform to notions of non-disabled normalcy. Furthermore, the disabled child is entitled to assistive means and reasonable accommodation that are necessary for them to develop both individually and socially (Preamble and Article 20 (Personal Mobility)). The child therefore has a right to access to the physical environment (especially buildings that are open to the public), to transport and to information and communication (CRPD Article 9 (Accessibility)).

Some articles may be more relevant for adult life – for example Article 19 (Living Independently and Being Included in the Community) and Article 23.1 (Respect for Home and the Family) which refers to the right of disabled persons to marry and to found a family. However, preparation for the enjoyment of these rights must start from childhood, as is made amply clear in both the CRPD and the CRC in their emphasis on the right of the child to develop into an individual who can freely participate in their society. In the case of the CRPD, this right is explicitly recognised in Article 24 (Education) which also makes reference to both the academic *and* the social development of the disabled child. There are also other rights included in the CRPD which emphasise social and community aspects which are directly relevant to the disabled child. Article 24 refers to the right of the disabled child to be educated in their own community, while Article 25 (Health) asserts the right of both children and adults with disability to health services which are based in their own communities. The emphasis on access to education and health services within the community implicitly recognises the risk of disabled children (and adults) being isolated from their communities on the basis of their disability. This risk is recognised more explicitly in Article 14 (Liberty and Security of the Person) which states 'that the existence of a disability shall in no case justify a deprivation of liberty' (United Nations 2006: 12). The CRPD also caters for the provision of services that actively enable the disabled child to develop both on an individual and a social level. This can be seen in Article 24, which was dealt with extensively in Chapter 3, as well as in Article 26 (Habilitation and Rehabilitation), referred to in Chapter 2.

In their totality, these CRPD articles seek to strike a balance between various positions. Three such positions can be identified. The first entails ensuring that the disabled child (and adult) are able to maximise their physical and mental potential and to be assisted to reduce impairment-related effects as much as possible, thus avoiding the use of assistive equipment or assistance. The second focuses precisely on the provision of assistive means that make up for difficulties experienced by the disabled person because of their impairment. The third position entails celebrating disabled people's diversity and accepting their difference, including the need for live assistance, as natural. In the right circumstances, these three positions complement each other perfectly and provide a context in which the disabled child can develop equal relationships with others. Take, for instance, a disabled boy who has a speech impairment which makes it difficult for him to communicate his needs and his opinions. That boy has the right to communication therapy services which enable him to maximise the potential he has to communicate verbally. He also has the right to assistive and augmentative means of communication that supplement his limited ability to communicate verbally. Finally, he also has a right to be accepted as he is, which entails other people adapting to the way he communicates.

Needless to say, the child with disability should be able to exercise these rights in all contexts in which they come into contact with other people. These contexts include health settings, educational settings, and the family home or other residential settings. It also includes settings in which the child engages in leisure, sport or cultural activities, all of which have been considered in the previous chapters. The right to access to such activities is recognised in Article 31 of the CRC and Article 30 of the CRPD (Participation in Cultural Life, Recreation, Leisure and Sport), with the latter specifically mentioning 'that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system' (United Nations 2006: 24).

Article 23.1 of the CRPD asserts disabled persons' rights not only to marriage and founding a family, but also to 'relationships, on an equal basis with others' (United Nations 2006: 16). Although there is just this one mention to the right to form relationships in the CRPD, it can be considered as fundamentally necessary for participation rights to be fully exercised. This is because it is through engaging in relationships in which they are considered to be equal participants that disabled children can make their voice heard in a context which provides the support that they may need in order to do so and in which other people listen to that voice, take it seriously and act upon it. As has been mentioned above, dealings with other people occur in different contexts. They also change during the life course and in the child's development from infancy to adolescence. The next section looks at the salient issues of relationships in the different stages of the disabled child's life.

The Disabled Child's Relationships from Birth to Youth

From the moment of birth, it is through contact with other people that human babies develop various abilities. While the potential for reaching the various developmental milestones, such as walking and talking, is innate, it is only through imitating and interacting with others that babies actually go through the various developmental stages. The importance of the environment can be seen from studies on the development of children growing in atypical environments. For example, attachment disorder can be experienced by children who have been raised in institutions where they are given minimal attention. As Kay and Green (2013) report, the disorder can manifest itself either by excessive clinginess to others or by withdrawal from contact with others. Both these behaviours are detrimental to the disabled child's ability to form equal relationships with others as they are growing up. The situation is exacerbated by the fact that, as seen in the previous chapter, disabled children are at a higher risk of institutionalisation when compared to non-disabled children. The impact that the lack of an appropriate environment and appropriate adult role models can have on an infant's ability to reach expected developmental milestones can be seen more dramatically in the case of children who have been brought up with minimal contact with other human beings.

One of the most well-known cases is that of Kasper Hauser, who lived in nineteenth-century Germany. Cavalli (2007) recalls this case in her analysis of one of her patients: a boy, whom she calls Casper, who was referred to her when he was nine. Casper was growing up with parents who could not look after him because of their own physical and mental difficulties. Cavalli recounts how when she first met the boy she noted '[h]is incontinence, his language and his lacking sense of balance of a very young child in the body of a nine or ten year old' (2007: 3). Her article traces the first year and a half of intensive analysis that she carried out with him. In a postscript, she describes how Casper, who was 15 at the time of her writing the article, had developed into an affectionate boy who could make some friends with the children in the special school he attended. This improvement had come about at least partly through the purposeful intervention of the adults caring for and working with him.

Other disabled children face relationship problems not within the family home but in their immediate community. In Đorđević vs Croatia (European Court of Human Rights 2012, decided on 24 July 2012), a mother and her son, who is both physically and intellectually disabled, brought a case before the court complaining of harassment and attacks by the neighbourhood children for over four years, and of a lack of action by the authorities to protect the mother and her disabled son. The mother stated that the two of them experienced severe anxiety and fear not only from the attacks but also from the failure by the authorities to take any action. Despite being informed on numerous occasions through the filing of reports, the police did not take any action and when they did it was too late and it was only to tell the children not to be noisy. There was also the issue of the children being too young to be prosecuted. The case treated the issue that the State has a positive obligation towards people with disabilities which went beyond the undertaking expected within criminal law. The court found a violation of Article 3 (Prohibition of Inhuman and Degrading Treatment) of the European Convention on Human Rights (Council of Europe 1950) as the State had neglected to take effective action to end the harassment even though they were aware that the disabled child had been systematically targeted and that there was a founded fear of future abuse. Harassment in the community is experienced by many disabled people, including children (Hunter et al. 2007). In the case of the child with disability, the experience of harassment is particularly deleterious since it compromises their ability to foster relationships within their immediate community. Furthermore, the fact that, as Hunter and her colleagues note in their report, some of the perpetrators of this harassment are themselves children, such circumstances make the fostering of relationships between disabled and non-disabled children impossible.

For typically developing children growing in more nurturing environments, the first relationships are developed with the adults who are primarily responsible for their care: mothers, fathers and other primary caregivers. As the child gains self-awareness, they build relationships with the extended family and with people in their neighbourhood. Once the child starts leaving the family home to access childcare and educational services they also come into contact with other children and learn how to build relationships with these children and eventually form friendships with them which in some cases may last for years and possibly decades. These relationships are of course mediated through the agency of other adults, especially child care workers and educators, who are paid to be in the children's lives and who themselves develop relationships with the children even if for the year or so in which they are working directly with them. Disabled children also follow this general trajectory, although the paths they take may differ significantly from those of their non-disabled peers. Obviously, every child follows their own particular trajectory, for the simple reason that different children live in different family structures and are placed in different types of child care arrangements and educational set-ups. However, there are some characteristics in disabled children's trajectories and relationships which arise from the reaction to the children's impairments.

Niedecken (2003) takes a psychoanalytic approach to describe how the relationship between the child with intellectual disability and the adults around them changes the moment the diagnosis of disability is made. Niedecken focuses on the mother–child dyad, since in most cases this is the most basic of relationships for babies. However, her observations can be applied to the other adults in the disabled child's life, whether they are family members or staff working with them. They can also be applied to children with different impairments. As Niedecken argues, after diagnosis the disabled child's actions tend to be scrutinised for signs for development. There is also a tendency for every activity that the child engages in to be viewed as therapeutic. For example, as Goodley and Runswick-Cole (2010a) state, play activities are provided for the disabled child to engage in as part of their therapy. The intention of course is to enable the child to develop its potential to the maximum through early intervention which, as pointed out in Chapter 2, is very important. However, it is also important to ensure that the various therapies and interventions engaged in do not address the disabled child's difficulties in reaching typical developmental milestones at the expense of preventing that child from developing informal social relationships with those around them on their own terms.

For some disabled children, the impairment itself can impact on the development of relationships. V. Lewis (2002) traces the developmental pathways that are typical of children with mobility, hearing, visual and intellectual impairments, as well as those who have developmental co-ordination disorder and those who are on the autism spectrum. She points out that the parents of a disabled child may be at a loss, especially because they do not have any readily available reference points, since the incidence of disability in babies and infants is low (most disabled people acquire their impairments in adulthood). Furthermore, cultural references tend to promote negative stereotypes of disability (Darke 2004) and parents unwittingly draw from these stereotypes when handling their reaction to the news that their child has a disability. In fact, as pointed out in the previous chapter, parents' reactions to this news has been likened to the grieving process as they adjust from an idealised image of their child to one in which the child is expected to experience developmental difficulties (Perryman 2005).

Lewis (2002) describes how the situation is further complicated by difficulties encountered in gaining an accurate assessment of the disabled child's abilities and potential, especially because it can be hard to distinguish between difficulties that the child experiences which arise directly from the impairment and difficulties that arise from the child's environment. As a result, it is easy to either overestimate or underestimate a child's potential. Lewis argues that it is important for professionals to keep an open mind about that potential and guide the parents accordingly. She further points out that while disabled children with the same impairments have much in common, no two disabled children with the same condition are the same, because of the myriad individual and environmental factors that impinge on a child's development, whether they are disabled or not.

All these factors impinge on the relationships that the disabled child fosters with adults (especially family members and staff in the different services) as well as with other children (disabled and non-disabled). Impairment-related factors may themselves also have a direct effect on these relationships. This is especially the case for those children whose impairments affect their ability to develop and use spoken language in a fluent manner, such as children who are born profoundly deaf, those who have cognitive impairments, children who have cerebral palsy or other conditions which affect the way they speak, and those who are on the autism spectrum. In addition, the severity of each of these conditions (or the presence of more than one condition) is also a contributing factor to the development of the disabled child's communication abilities, abilities which are so fundamental for them to be able to build relationships with those around them. However, it is ultimately the decisions that are taken by adults which have the most significant impact on these abilities. Difficulties which are the direct consequence of an impairment (such as the inability to hear or to articulate words clearly) can seldom be rectified (although cochlear implants improve the deaf child's hearing significantly). But the treatments, therapies and assistive equipment that are chosen by parents and professionals can have an impact and decisions about these choices are informed first of all by what is actually available, what is affordable and practical for the family, and what is believed to be best for the disabled child.

For the child whose disability is congenital or appears early on in life, the choices and decisions made by the adults most closely involved in their life can have a lasting impact on their development, including their social development. As was stated in Chapter 3, the disabled child tends to spend more time with adults and less with other children than the non-disabled child. This tendency adversely affects the way the child relates with their peers. As the disabled child grows up, difficulties in relationships with other children begin to have more pronounced consequences. In the case of typically developing children, relationships with peers tend to take increasing importance in later childhood and even more so in adolescence when relationships are not exclusively of a social nature but may involve sexual interest as well. In their vast majority, disabled adolescents also develop sexual interest but their efforts to develop both social and sexual relationships with their peers may be fraught with difficulties. The next sections deal with the participation rights of disabled children and young people in developing relationships with others in different settings.

The Disabled Child, Leisure and Relationships

Article 31 of the CRC recognises the right of the child 'to rest and leisure, [and] to engage in play and recreational activities' (United Nations 1989: 9). These are important components of a child's life for the development of both intrapersonal and interpersonal skills. The disabled child of course also has this right, which is reinforced by Article 30 of the CRPD. And, like other children, the disabled child has a right to have a say in the kind of play and leisure activities they engage in and the children with whom they play. In fact, play is the area where the disabled child should be most able to exercise their participation rights. In the areas of health, education and other services, adults (especially parents and professionals) can rightfully reserve the right for taking final decisions because of the perspectives and expertise they possess which children, especially young ones, cannot be expected to have. However, when it comes to play and engaging in leisure activities, it is children who are the experts and it is their perspective that counts. For it is they who know what they enjoy doing most, and who they would like to do various activities with. The time reserved for play, rest and leisure should therefore be the disabled child's time to decide what to do with.

There are of course restrictions to this ideal scenario. Some are inevitable: regularly going to the seaside is highly impractical for a child living in a land-locked region; playing in the snow is impossible in warmer climates. Other restrictions arise from the choice of activities that are available in the disabled child's own community. After all, the disabled child has a right to engage in play and leisure activities on an equal basis with other children and therefore they can only choose from the range of choices available to other children. The main obstacle is the extent to which in reality the disabled child can choose from the same range of activities as non-disabled children. The research literature strongly indicates that the disabled child and their parents experience a lot of restrictions in this regard especially when it comes to structured play and leisure activities such as sports and activities held by different organisations. Such restrictions are related to, among others, lack of physical access; the fear that playing with non-disabled children will expose the disabled child to bullying; the assumption that the child's physical or mental impairments will hinder them from keeping up with their non-disabled peers; and lack of knowledge or ability of the staff in charge of how to include disabled children. Galvin, Froude and McAleer (2010) in Australia and Cooper (2010) and Hodge and Runswick-Cole (2013) in the United Kingdom are among the many researchers who have documented such participation restrictions. Similar obstacles are reported by Rapp, Meine and Thyen (2010) and by Michelsen et al. (2009) in their studies involving children with cerebral palsy in Germany and across Europe respectively. Michelsen et al. (2009) also highlight the lack of accessible transport to venues where mainstream leisure activities are held.

The following is recorded in the research carried out by Hodge and Runswick-Cole in the United Kingdom. The authors quote a worker from a voluntary organisation as saying:

> I mean, we've had cases where we've had, we had a young woman who was very articulate, she had a physical disability, she was a wheelchair user, she had moving and handling needs to assist to go to the toilet, and she very much wanted to go to her local youth club and went and staff said, "Oh, well when you need the loo your mum'll have to come down and take you to the loo if you're in the club" and she said to me, "Well nobody else's mum has to come down" and you know, and it's issues like that that I think really do need to be addressed. (Hodge and Runswick-Cole 2013: 318–19)

The situation depicted here encapsulates the difficulties that the disabled child faces in accessing mainstream leisure opportunities that are available for other children their own age. For this young woman, going to her local youth club gives her the opportunity to mix and foster relationships with other young non-disabled people. On the other hand, her impairment-related requirements (in her case being assisted to use the toilet) need to be taken into consideration. The solution offered by the youth club, that her mother attends to these needs, is unacceptable both for the mother (who would experience restrictions in her own life) and for the young woman – having her mother regularly coming to the youth club would make the young woman stand out among the other youths and hinder her from developing an equal relationship with them, especially because she herself feels uncomfortable about the arrangement.

Because of these difficulties and restrictions, children with disabilities tend to engage in leisure activities which are organised specifically for them through what Hodge and Runswick-Cole (2013: 231) aptly call 'diagnostic apartheid', a term which recalls Goggin and Newell's (2004) use of the concept of apartheid to describing the segregation of disabled people in Australia. Some disabled children may prefer to associate and build friendships with other disabled children anyway. Others may prefer activities that are tailored to cater for their impairment-related requirements. While it is well within the right of the disabled child to make these choices, one must ask whether these preferences come about not as a result of informed choice but because the options that are available are either remaining within the family sphere or taking part in these disability-specific leisure activities. For a disabled child to decide what to do with their leisure time, they must first of all be given the opportunity to sample different age-appropriate activities in different settings which are available to non-disabled children. The relevant research, including that quoted above, strongly indicates that these opportunities are not readily available for disabled children, a situation which severely restricts their ability to participate in decisions regarding how to spend their leisure time and who to foster friendships and relationships with outside the family circle. Given that leisure is the time when an individual should be most able to express choices and act on their preferences, it is particularly deplorable for the disabled child not to be able to exercise their participation rights on an equal basis with other children in this area.

The opportunities, or lack of them, for the disabled child to freely build relationships do not only come from organisations that provide structured leisure activities for children of different age groups. They can also arise, or fail to do so, from family-generated activities that many children experience as part of their growing up. One such activity is the birthday celebration, and especially the practice of parents organizing a party for their child for which they invite that child's classmates. For disabled children attending mainstream schools, receiving an invitation is not a foregone conclusion. Kramar (2008) describes the dilemma she faced when she was with her disabled son at McDonalds and one-by-one his classmates from the daycare centre started streaming in for a birthday party which she did not know about. Kramar's dilemma stems from her doubt as to whether the invitation was sent but never received, or whether the parents of the child whose birthday was being celebrated never sent her son an invitation. Her doubt as to what could have happened draws on and reflects the experiences of many disabled children who find themselves left out of social activities with their classmates even if they are included in mainstream educational settings.

Kramar also refers to a friend of hers whose son, who is on the autism spectrum, was left out of a school trip. As she says, 'well-intentioned people may succumb to stereotypes and fear when confronted with people with disabilities' (Kramar 2008: 34). The reasons for the disabled child to be left out of mainstream activities may be based on unjustified fears or on valid concerns. But, whatever the basis, unless non-disabled people address the issues by speaking to the disabled child and their parents, the end result is the social marginalisation of that child. Some disabled children are at a higher risk of experiencing marginalisation because of relational difficulties that are associated with certain conditions, especially those pertaining to autism spectrum disorders. These difficulties lead others to assume that children (and adults) who are on the spectrum prefer to be alone and not to relate to others. But it is much more likely that their solitariness does not result from any preference that they express, but from a lack of opportunity to build relationships with other people on their own terms. Giles Duley, the disabled photographer, refers to how Nick, a young man with very severe autism, talks about his life:

> He's described his life as living downstairs at a party. He said he could hear the party in the kitchen but he felt like he was always trapped in the basement in his own little world, wanting to be part of the party but not able to walk upstairs. (Duley 2012: 2.55–3.09 minutes)

Nick's description of his life challenges the stereotype of people with autism as loners who prefer solitude to other people's company. The inaccuracy of this stereotype is confirmed by the research literature, including the study by Bauminger and Kasari (2000) carried out in the United States with 22 children with high-functioning autism which concludes that many of these children experience loneliness and dissatisfaction with their friendships.

Many disabled children find themselves in situations where they are not able to join the party, literally or metaphorically, not out of choice but because of the physical or attitudinal barriers that they encounter. The exclusion that ensues leads to their experiencing a restricted scope for building relationships with other people and end up being able to do so only with members of their family, disabled children with whom they engage in leisure activities, and the people they spend their school day with.

The Disabled Child's Relationships in School Settings

When it comes to building relationships at school, restrictions on the disabled child's participation rights stem partly from the formal and structured nature of most educational settings. However, even within these settings there is scope for the disabled child to exercise choice in their relationships with other children, both within the classroom and during breaks and extra-curricular activities. The focus here is mostly on the disabled child in inclusive education settings. This is not to say that children in special schools, or other separate educational arrangements, do not also build relationships with other children. However, the segregated nature of these settings and the fact that the day in a special school tends to be much more rigidly structured than that in a mainstream school impose restrictions on options for building relationships. And, insofar as schools serve as a preparation for 'persons with disabilities to participate effectively in a free society' as specified in Article 24.1(c) of the CRPD (United Nations 2006: 17), it is in inclusive settings that the disabled child can more realistically benefit from this preparation. This applies not only for the academic aspects of education but also in the skills and experiences that children acquire in their interactions with each other. Given that children within the age range of compulsory schooling spend a considerable part of their day at school, a place where they can have plenty of chances to socialise with other children, it is important to consider the options available for disabled children to exercise their autonomy when fostering relationships with their peers in inclusive education settings.

Despite the potential in inclusive education settings for the disabled child to develop relationships with other children, research indicates that very few have the opportunity to do so. Apart from the harassment mentioned earlier in this chapter, the disabled child may experience bullying in their interactions with other children (Cappadocia, Weiss and Pepler 2012). On the other hand, they may be treated with a degree of condescension by other children who treat them like the teachers do (Rossetti 2014, Watson et al. 1999) or they may form equitable friendships with non-disabled children which are however interpreted by teachers as the latter being kind and generous to 'less fortunate' children (Cardona 2006). Writing about research carried out in inclusive Greek schools, Vlachou and Papananou (2015: 83) report on 'relationships ranging from steady, supportive friendship and full acceptance to systematic victimisation and exclusion'. While bullying is obviously more negative than being patronised, both attitudes lead to contexts in which the disabled child cannot place themselves on the same footing as their non-disabled peers and cannot exercise their agency in building relationships with them.

Evidence from the literature indicates different types of experiences for the disabled child in schools in the realm of relationships. Mundhenke, Hermasson and Nätterlund (2010) report about Swedish disabled children's opportunities to participate in activities with other disabled children but not with non-disabled children. Yalon-Chamovitz et al. (2006), who conducted their research with children with intellectual disability in special schools in Israel, correlated the students' preferences for leisure activities during breaks with the activities they actually participated in. They found that most of the students did not engage in the activities they showed preference for. Significantly, they tended to opt for dynamic activities that would entail interaction with the teachers or the other children. By contrast, most of them only engaged in passive activities, especially just sitting around. Back to relationships in mainstream schools, Wendelborg and Kvello (2010) researched the interactions between non-disabled children and children with different types and levels of severity of disability in Norway. Their main conclusion is that the type of impairment has a greater effect on these interactions than the level of severity, with children with more severe physical impairments enjoying better relationships with their non-disabled peers than those who had more moderate intellectual impairments.

Hodge and Runswick-Cole's research, which was quoted earlier, also records an incident which is typical of most other studies that focus on the relationships between disabled and non-disabled students.

> Mainstream schools might, perhaps, offer significant opportunities for mainstream leisure activities. Break times and lunch times offer opportunities for children to "hang out" together or to play. However, Greg, a young person aged 11 with a physical impairment, told us: Like in football at school today I did get about three touches but not much. They just didn't pass me it. So it's

> kind of annoying because you're like "Come on, I'm in!" and they just like pass it to someone else. (Hodge and Runswick-Cole 2013: 319)

One of the difficulties that Greg's story highlights is how to get non-disabled children to include disabled classmates in play. Presumably, Greg's classmates did not pass him the ball because their aim was to win the football match. It would take adult intervention to encourage them to include him by passing the ball to him more frequently, even if they see this as a risk of losing the ball to the opposing team. Such intervention would enable Greg to participate directly in the game of football and to exercise his participation rights in choosing his friends and who to play with during break times at school. The potential effect of adult intervention in the disabled child's relationships on the latter's participation rights is dealt with later in this chapter, after considering issues that are pertinent to adolescents and young adults with disability.

The Relationships of the Disabled Older Child

One of the markers of adolescence and of growing up is the decreased attachment to one's family, especially parents, and the concomitant development of relationships with children in one's age group. These relationships may be platonic friendships or take on a sexual nature. Disabled adolescents experience difficulties in developing these relationships. Their continued reliance on others for activities of daily living very often means that they remain attached to their parents, or primary caregivers, long after their non-disabled peers have become physically independent of theirs.

The situation described in the earlier quotation by Hodge and Runswick-Cole (2013), regarding the need of the presence of an adult to assist the young woman with her toileting needs at the youth club, is a good illustration of this predicament. Such situations often lead to disabled young people choosing to frequent segregated places which cater for their needs and thus to befriend each other. There is of course nothing inherently wrong in this. Friendships tend to be formed among people who share similar experiences and it is quite likely for older children with disability to have gone through similar experiences, especially if they have similar impairments. But these friendships should develop from free and conscious choices on the part of disabled children. Disabled children do not necessarily have the same interests even if they have similar impairments. As Young (1966: 7), an adult with a physical impairment, puts it '[w]e do not want to be segregated into insulated groups of individuals who may have nothing in common except their physical condition'.

The child with disability therefore should be able to develop relationships with other disabled children as they grow older. But they should do this out of choice and not because it is the only option available for them. And when disabled adolescents befriend each other, no matter what the reason is, their friendships should be valued as much as those of their peers. Salmon (2013: 352) researched situations in Ireland where disabled teenagers struck friendships between themselves. She describes their relationships as reciprocal, 'vibrant and meaningful' but remarks how the adults still 'believed these friendships were about care giving and helping on the part of the "less disabled teen"'. Ytterhus's (2012) Norway-based research sheds light on another issue – the way that young people with certain impairments are at more risk of social isolation. She concludes that the challenges of children with intellectual disability increase with age to a greater degree than those of children who have physical disabilities. As a result, children with mobility difficulties find it easier to foster relationships with other children than do those who have cognitive impairments. Significantly, children with severe mobility difficulties found it easier to develop friendships than children with more moderate cognitive impairments. The latter therefore have even more restrictions to exercising their agency in developing relationships with their peers.

When it comes to developing relationships of a sexual nature, the pathways available for the disabled adolescent are fraught with even more difficulty. First of all, they have to deal with common misconceptions about the asexuality of disabled people (Esmail et al. 2010). It is therefore quite likely that their status as a disabled child is seen as more important than their status as adolescents who are developing sexually, both physically and emotionally. Furthermore, disabled children, especially those who have an intellectual disability, are prone to be seen as eternal children, people who never really outgrow a childlike state (Wolfensberger 1972). Bjarnason (2005: 124) describes how Icelandic special schools put disabled children on a trajectory which carries with it 'the risk of remaining in the limbo of "eternal youth" within segregated settings subjected to a degree of paternalism and diminished personal freedom'.

Even if they are not seen as children, disabled people tend to be seen in terms of their disability, rather than their gender and sexuality. The research carried out by Deepak (2002) with mostly young disabled people in Italy is aptly named 'Male, female or disabled: barriers to expression of sexuality'. Without ignoring the role that disability plays in the lives of disabled young people and while attending to the support needs brought about by disability, it is equally important to attend to these young people's needs as girls and boys who are discovering their sexual natures as they grow older. Such sexual development occurs simultaneously with the obstacles that the disabled child faces in developing relationships, regardless of the child's age and of the type of relationships, especially those related to physical and attitudinal barriers. Consequently, the disabled older child is quite likely to experience significant restrictions in their ability to participate, on their own terms, in relationships with other children. The various restrictions that they are likely to experience mean that the ability to exercise participation rights in developing relationships may remain unattainable. Adults can be the key to whether or not the disabled child, regardless of age or impairment, can make choices in developing relationships. It is to this theme that the chapter now turns.

The Disabled Child's Relationships with Adults

Adults play very significant roles in the lives of the child with disability. It is adults who diagnose impairments and medical conditions and prescribe the appropriate treatment, therapy or other intervention. It is adults who administer these interventions, whether they be staff or family members. And it is adults who provide disabled children with day to day support at home, in school, in different types of services and even during leisure activities. The disabled child therefore can develop strong bonds with the adults that play significant roles in their life. These bonds are formed in relationships in which the disabled child is dependent on the adult. There are therefore inherent power differentials that make it difficult for the disabled child to exercise their participation rights within these relationships. There is, however, another aspect of the disabled child's relationship with adults that needs to be considered. This is the extent to which adults can hinder or facilitate the development of relationships between a disabled child and other children. Adults very often hold the key to these relationships and can either promote or stifle the disabled child's own agency in relationships.

Adult roles in inclusive education settings provide an excellent illustration of this influence. In Chapter 3, it was shown how disabled children are eager to develop good relationships with their educators. This is especially relevant with regards to their learning support or personal assistants, because of the amount of time they spend working in proximity with them. These assistants are a very necessary bridge for disabled children to access the curriculum and receive their education in mainstream settings. However, interventions that may be vital during lessons may then have detrimental effects on disabled children during the less formal periods of the school day as these adults' physical presence can easily act as a barrier to disabled children developing reciprocal relationships in interactions in between lessons, just before and after the school day starts and finishes and, even more so during breaks (Giangreco et al. 1997).

The increased surveillance of the disabled child in mainstream settings is noted by different researchers, among them De Schauwer et al. (2009) and Watson et al. (1999). For relationships between disabled and non-disabled children to develop, educators need to know when to intervene and when to take a step back. Buddy systems, such as the ones researched by Sylvester et al. (2014), can ensure that non-disabled children are made aware of how they can befriend their disabled peers. Such systems are set up by adults. But for these system to work, adults must allow scope for children to interact with and relate to each other spontaneously. The same pattern is found time and again in different studies, namely that when adults create contexts for disabled and non-disabled children to interact, friendships develop between them which the children themselves can then continue to foster on their own (Bunch and Valeo (2004) in Canada; Evans and Meyer (2001) in New Zealand; and Ring and Travers (2005) in Ireland). Adult intervention in the area of friendship may be more necessary for some disabled children than for others. As Carter and Hughes (2005) assert, adolescents with intellectual disability are particularly at risk of not having friends in mainstream settings and they benefit from interventions that encourage interactions between them and their non-disabled peers. Opportunities for encouraging these interactions may come from unexpected sources, as Rossetti (2012: 1270) reports from his research:

> One of the bigger surprises in the data was the effect of a family member acting as a mentor to a student without disabilities. Both Stephanie and Jocelyn learned how to respectfully and naturally interact with someone with a disability from their mothers who each worked in related fields. They were privy to insider information that answered practical questions about interacting together and overcame potential effects of stigmatisation and ableism.

The initial nudge may be structured or even dictated by adults, but used in the right manner it can lead to providing the disabled child with the options they need to eventually make up their own minds as to the children they want to befriend, and to non-disabled children considering friendships with their disabled peers as an option. In the example quoted above from the research by Hodge and Runswick-Cole (2013), Greg's schoolmates could have benefitted from being made aware of ways in which they could include him in their games.

These systems are of course also valid for settings outside the school. In fact, Sylvester et al.'s (2014) research in Scotland focuses on the use of buddy systems in social and leisure activities organised by statutory and voluntary organisations. The authors refer both to support groups for disabled children to be able to come together and share their experiences, and to facilitating the full inclusion of disabled children in mainstream activities. Jeanes and MacGee's (2012) research in Australia and the United Kingdom also supports this idea. The following quotation from one of the mothers interviewed in their research encapsulates how adults should strike the right balance between intervention and non-intervention:

> Here they would help Andrea (severe physical and learning disabilities) to maybe get on the swing but they'd also help a non-disabled child do something as well and they don't follow the disabled children around all the time, once they know they are comfortable and set they will leave them to do their own thing. At a couple of other things we've gone to staff seem to think they have to stick to the disabled child like glue and they don't get any freedom. Plus it's another thing that singles them out as different. (Jeanes and MacGee 2012: 204)

It is significant to note that, while Greg has a physical disability which still allows him to be able to run around in the schoolyard, he enjoys a lesser degree of social inclusion with his peers than Andrea, whose impairments are reported as being both more complex and more severe. As argued above, disabled children can only effectively exercise their participation rights in relationships if they can interact with other children in different settings. In these two examples from the research, therefore, Andrea has potentially more opportunities to do so than Greg. Time and again, the examples from the research cited in this book point to a situation where obstacles to participation rights are correlated to a greater extent to the presence of adults who ensure that through their actions they are 'facilitating equal status' (Devine 2004: 154), than to the disabled children's type or degree of impairment.

That said, it is important to keep in mind that the support needs of some disabled children may pose significant challenges to facilitating the creation of equal relationships with other children, disabled or non-disabled. In their research, Rossetti et al. (2008) focus on adolescents and adults with autism who type to communicate. As the authors argue, because the typing itself is often facilitated by other adults, it is assumed that these persons lack agency and communication competence. Significantly, Rossetti and his colleagues focus on the viewpoints of their eight research participants with autism. What emerges from this research is how these individuals see support as an integral part of how they communicate. Rather than being a sign of their lack of agency, the support they receive is in fact the means for them to exercise that agency.

In the hustle and bustle of the school playground and informal leisure settings, fostering relationships between children who use facilitated communication and their peers may prove to be difficult, but not necessarily impossible. However, it is only considered impossible if the success of the outcomes of any attempts to facilitate these relationships is measured according to standards and norms that are set a priori by adults. The exercise of participation rights by the disabled child in developing relationships is not only about enabling them to make informed choices about the children and adults they want to spend their time and develop relationships with. It is also about respecting the level and kind of interaction that the child wants to engage in with different people.

Ultimately, it is adults who have the responsibility of acting as agents to facilitate the participation rights of the disabled child in relationships and then knowing when to take a step back to allow those rights to become a reality. It is also within their responsibility to listen to what the disabled child has to say about their relationships and respect the choices that the child makes.

Promoting the Disabled Child's Participation Rights through Relationships

The foregoing sections have shown how the disabled child develops relationships with others, especially adults, in different settings – with medical professionals in clinical settings, with educators in schools, with service-providers in residential, leisure and other services, and of course with their parents and other family members at home. These relationships are an essential and also an inevitable part of the disabled child's development – interaction with other people on a regular basis (the pupil with the teacher, the child patient with the physiotherapist, and so on) inevitably leads to the fostering of a relationship between adult and child, even if these relationships are not always long-term and even if they have a power imbalance which is very much in favour of the adult. Attending to that power imbalance and finding means of correcting it is an important way of ensuring that the disabled child can relate with those around them on an equal basis with other children. It is also an important way of making the exercise of participation rights a more common reality for disabled children.

Time and again throughout this book, there has been a discussion of the key role that adults play in the trajectories taken by disabled children in different stages of their lives. A recurrent theme of this book is in fact the way that barriers to the disabled child's participation rights arise not so much from the nature of their impairments as from the environment. Given that it is adults who mostly structure and shape the environment in which the disabled child develops, it is adults' behaviour and attitudes that must be the focus of any efforts to promote the disabled child's participation rights. It has been seen how health professionals, educators, staff in different service settings and parents themselves need to become more aware of these rights, their importance and of how to make them happen. The issue of providing training on participation rights is taken up in the final chapter.

Initiatives taken by adults to actively promote the disabled child's participation rights are important as these can address the environmental barriers that prevent the child from taking a meaningful part in decision-making processes that affect them. However, this focus on the adults' attitudes and their behaviour must not be made at the expense of ignoring the contribution that the disabled children make to the process. That is to say that while it is important for the necessary changes to be made for existing structures to allow more comprehensive scope for the disabled child to have their voice heard and to participate in decisions, it is equally important to attend to the ways in which they exercise their agency in different settings and relationships in their lives. Children cannot be held responsible for the difficulties they face in their lives – they grow up and develop in a world shaped by adults. The Universal Declaration of Human Rights recognises that childhood is 'entitled to special care and assistance' (United Nations 1948: 7) and policies and services are informed by this important and very necessary principle. But removing responsibility and placing an emphasis on care and assistance risks ignoring the ways that the child can and does take responsibility for their own life. For instance, the emphasis in State Reports in connection with both the CRC and CRPD is almost entirely on the provision of services and care for children and disabled people, with provisions for the exercise of their participation rights being given scant attention. In research, the same situation obtains. As Davis and Watson (2000) remark, most research is *about* children not *with* children. For the disabled child, the risk of being seen only as a passive recipient of services and as a passive subject in interactions with others is even greater because of the association of the state of being disabled with the need for lifelong care and assistance.

These needs do not prevent the disabled child from exercising agency in relationships with others. It must be emphasised that the focus here is on disabled children's relationships with adults rather than their friendships with each other and with non-disabled children. As seen above, adults can play a vital role in fostering these friendships. But it is in the disabled child–adult dyad that conscious steps must be taken for the former to have a voice which is considered valid and which is listened to. The disabled child plays an active part in their interactions with adults, not only by responding to what adults say and do, but also in taking the initiative themselves. A remark in the research report by Watson et al. (1999) illustrates this point. Participant observation research with 300 children was carried out in 14 secondary schools in England and Scotland, with 165 disabled children being interviewed. The researchers report that they gained access to the disabled children's homes through invitations by the children. The researchers contrast this informal way of gaining access to the children's family homes to the process 'of obtaining consent to enter schools where local authorities, head teachers, parents and classroom teachers all acted as gate keepers' (Watson et al. 1999: 11).

From a participation rights perspective, what is interesting is the process by which the disabled children took the initiative and opened up the scope of the research themselves, thus subtly reversing roles with the adults. Disabled children can likewise open up the education system and make it more inclusive. As Vlachou and Papanou (2015), cited earlier, point out, listening to the views of disabled children in mainstream schools can provide an effective way of ensuring that these schools are truly inclusive, because no one is better placed than disabled children themselves to point out what barriers exist to their effective inclusion. The same of course applies to other health, leisure and other service settings.

Adults must therefore be sensitive to the ways in which disabled children make their own way and find a place in the world. They need to take into account the fact that each disabled child is an individual in their own right, with their different characters, temperament, preferences, aptitudes and family and socioeconomic backgrounds. While impairment-related requirements need to be attended to, a child's disability should not be seen as the one and only salient factor in their life. Participation rights should therefore not simply be exercised on terms set out solely by adults but through the fostering of relationships in which the disabled child has a more equitable place. Furthermore, these rights are not there to be granted after a disabled child has been assessed as being competent to make their views heard, as Davis and Watson (2000) assert. They inherently belong to each and every child.

Conclusion

This chapter has been based on the premise that the nature of the disabled child's relationships with others – whether they are adult or children, disabled or non-disabled – are the key to their enjoyment of full and effective participation in society on an equal basis with others as envisioned in the CRPD. The disabled child's rights to exercise agency in interactions with different adults and children whom they encounter in their daily lives, and to make choices especially with regards to fostering friendships are a crucial part of their ability to exercise their participation rights. It is thus that reciprocal and equitable relationships can be fostered. However, the disabled child does not necessarily have a free hand in choosing friendships and fostering relationships with other children, even during their free time. This lack of choice is partly due to a number of restrictions for them to participate in mainstream leisure activities, as seen in this chapter. It was also seen how the same situation often obtains in schools where disabled children do not necessarily have the option of socialising with other children during breaks and may even be actively ostracised through bullying and other antagonistic behaviour. On the other hand, this chapter has shown how successful social inclusion can come about when adults recognise when to take a step back to allow disabled and non-disabled children to associate freely with each other and when and to what extent to intervene in order to create environments in which such associations can then occur. The importance of acknowledging the disabled child's ability to exercise agency on their own initiative was also considered, an issue which is taken up in more detail in the next chapter. Furthermore, it has been seen how the theme of relationships cuts across the other themes that were analysed in the previous three chapters. In the next, and final, chapter, the common issues discussed in these four chapters will be summarised and ways forward towards the fuller realisation of the disabled child's participation rights presented.

Chapter 6

Conclusion: Realising Disabled Children's Participation Rights

Introduction

Both the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) establish the right of disabled children to have their views heard and participate in decision-making processes in everyday life as well as at the levels of service-provision and policy-making. In chapters 2–5 many examples were presented of how disabled children can and do exercise their participation rights. However, one of the recurrent themes that emerge from these chapters is that exercising these rights does not happen in a comprehensive or systematic manner and is very often contingent on the attitudes and dispositions of adults. Effective access to rights also remains a challenge, notwithstanding public attention to child-friendly justice by both the Council of Europe and the European Commission.

This concluding chapter brings together the themes and issues discussed in the previous chapters and then makes recommendations that are aimed at making participation rights a reality for every disabled child. The chapter starts with a focus on the importance of recognising how the disabled child can become a causal agent in their own life, before moving on to highlighting examples of good practice in order to gauge the scope that disabled children actually have to exercise their agency. Most of these examples are about the disabled child participating in decisions that affect them directly in their daily life. The chapter then shifts its focus to the role that disabled children can and do play in research and policy development. The chapter then looks at the importance of adults (staff in service-providing organisations as well as parents and other family members) becoming aware of disabled children's participation rights and to be trained in how to make them happen. The comprehensive realisation of disabled children's participation rights cannot come about without ensuring that there is a shared understanding of what these rights are and what is entailed in making them a reality. This chapter therefore presents a detailed description of what is entailed in participation rights.

The Disabled Child and the Exercise of Agency

Together with the Universal Declaration of Human Rights, the CRC recognises children as being in need of special care and attention. In fact, the whole Convention can be seen as forming the basis for a programme of policies and measures that specifically address the needs of children in their enjoyment of their fundamental rights and freedoms. As Freeman points out, 'taking children's rights more seriously has certain consequences, including that it demands of us that we adopt policies, practices, structures and laws which both protect children and their rights' (Freeman 1992). The recognition of children as a population group with its own specific needs is also present in the CRPD. As seen earlier in this book, disabled children are specifically mentioned in the Preamble of the CRPD and in several of its articles, in relation to freedom from ill treatment, liberty of movement and nationality, family life, education, health and cultural and leisure activities.

It is of course adults whose responsibility it is to ensure that the requirements of these different articles are adhered to and implemented. To state that it is adults, rather than children, who are policy-makers and service-providers, is such an obvious statement that it seems absurd to be making it at all. However, within the scope of this book, it is an important observation to make. Discussion between children and adults strengthens the processes of democracy, while creating openings for children to appreciate and assimilate democratic principles (UNICEF 2003). It is also an expectation of the United Nations from its members states who 'must respect their [children's] right to express themselves and to participate in all matters affecting them, in accordance with their age and maturity' (United Nations 2002: 3), which translates into the positive obligation referred to by the European Court of Human Rights whose judgments have been cited throughout this book.

As seen in the previous four chapters, where disabled children are afforded participation rights, it is always within structures that have been pre-determined by adults. Significantly, the CPRD obliges these adults to ensure that the disabled child can have their views heard and that these views are given due weight. Control is still in the hands of adults, for it is also they who decide what is 'due weight' and it is adults who very often ultimately have the authority to decide what is in the best interest of the child. Both the CRC and the CRPD link the concept of 'due weight' to the child's age and level of maturity. Again, it is of course adults who decide on the level of maturity that a child, whether disabled or not, has reached, using the best interests principle as a criterion which has its own limitations, but is used as there does not seem to be any other alternative agreed upon by all.

The capacity of the child to exercise their participation rights is seen as evolving in both the CRC and the CRPD. As the child grows older, they are assumed to become more capable of taking decisions and that capacity can then be exercised more fully once the child has become an adult. This, at least, is the trajectory followed by most non-disabled children. As seen in this book, when it comes to disabled children, adults tend to continue to exert a significant influence in their lives, very often well into adulthood. There can be said to be three broad groups of people who can take decisions that directly affect disabled children's lives: their parents or those acting *in loco parentis*, professionals and other staff providing various services, and of course the children themselves. In some areas, parents are the key decision-makers, in others staff are. Who takes the key decisions varies according to the context in which the decision is being taken, the type of decision being taken, and the aspect of life it refers to, and also according to the established policy and practice.

Thus, in Chapter 3 it was seen how in some European countries it is parents who decide on the choice of school for their child, in others it is the educational authorities who take the ultimate decision. In the area of health, dealt with in Chapter 2, it is parents who have the right to consent to medical treatment on behalf of their child. On the other hand, as seen in Chapter 4, professionals may decide to remove children from their family home if it is not seen as being in the best interests of the child to remain there. These various chapters have also shown how the most fundamental decisions are taken early on in the disabled child's life and, regardless of whether they are taken by parents or professionals, they can have long-lasting effects on the child's present and future wellbeing and determine the types of choices that the child can have. The decision to use early intervention services, referred to in Chapter 2, is one such example. Early intervention is aimed at maximizing the capabilities of the disabled child, and parents who are able and willing to use these services will also be enabling the evolving of their child's decision-making capacities.

There can therefore be said to be a hierarchy of decision-makers with parents and staff ranking first or second depending on the type of decision being taken and the context in which it is taken. Disabled children, inevitably, come third in this hierarchy. This is because, as seen above, even when they *can* enjoy their participation rights and exercise agency in their own lives, children very often do so within structures set up by adults. Participation in decision-making by all children is largely dependent on adult decisions and within parameters set by adults so it is hardly surprising that disabled children's actions similarly follow on from decisions made by adults within structures set up by them. Furthermore, opportunities for participation are also contingent on adults' perceptions of disabled children's ability to engage in this participation. The preconceived stereotypes attached to many adult judgements regarding child capacity carry through into the assumptions made about disabled children. Adults who are reluctant to include children in decision-making processes seem to be even more apprehensive about including disabled children. As seen in the previous chapters, this perception is mostly affected by the disabled child's age and the nature of their impairment, with children who have intellectual or communication difficulties having fewer opportunities to engage in participation, regardless of their age.

Because of their legal status as minors, and because of their impairments, disabled children do not tend to have many opportunities to be causal agents in their own lives.

> A causal agent is a person who makes or causes things to happen in the person's own life; people who are causal agents are actors in their own lives, rather than being acted on. The component elements of self-determined behavior include self-advocacy, goal setting and attainment, self-awareness, problem-solving skills, and decision-making skills. (Shogren and Wehmeyer 2015: 20)

They may not even be seen as having the capability to be causal agents. In fact, even in this book, the emphasis on the key roles played by adults in the disabled child's lives runs the risk of constructing the latter as being merely a passive recipient of care and services who can only participate in decisions or air their views at the behest of adults. This is certainly not our intention and throughout this book every opportunity is taken to question those attitudes which deny disabled children their right to participate and attempt to excuse or justify such measures. After all, as reiterated on other occasions, the disabled child has a right to participate in all matters which impact on individual present and future wellbeing so any contrary activity would constitute a violation of those rights.

It is therefore crucial for adults to recognise disabled children as agents in their own lives. On a practical level, this recognition entails being attentive to the way that disabled children take the initiative in making their views heard, adapting to their impairment-related requirements especially for those disabled children whose impairments directly affect the way they communicate, and valuing disabled children's points of view. The latter means that when the disabled child's perspective may seem at odds with those of adults, it should still be valued. Within a court context, for instance, decisions may be made in the best interests of the child without due recourse to the opinion of that child on the basis of lack of capacity and *locus standi* and where the child is disabled it may be argued that establishing the wishes of the child may prove too great a challenge for the administration of justice to address. However such an approach is flawed at source as it negates basic principles of rights to participation which place the onus to attempt effective communication on the authority rather than the disabled child.

To take children's views on therapy as another example (referred to in chapters 2 and 3), the way that disabled children may evaluate them in terms of whether they enjoy them or not, should not be dismissed as irrelevant. After all, as Hahn-Markowitz, Manor and Maier (2011) point out, when children enjoy their therapy sessions, the benefits reaped are greater especially because the children are motivated to learn. The corollary to this is that when disabled children express dissatisfaction with therapy or certain aspects of therapy, or any other activity that it has been deemed important for them to engage in, their perspectives should also be taken into account. They should not simply be cajoled into doing something against their will because it is considered in their best interest to do so. Indeed, they should have a stake in determining what is in their best interest. This is not to say that therapy or education should be abandoned if the disabled child does not like it. But listening to the child's complaints and taking them on board can lead to a compromise being found which leads to educational and therapeutic goals being reached without rendering the child unhappy.

Sometimes, it may simply be a question of the intensity with which these goals are sought, without compromising the child's development. French, a disabled adult, remembers 'speech therapy as being a lot of hard work and I can remember getting extremely fed up' (French, cited in French and Swain 2008: 85). What annoyed French the most was that she ended up being continually supervised by the speech therapist and by her parents in how she swallowed food and drink (which sometimes is an integral part of speech therapy). This insistence rendered mealtimes, both at school and at home, an ordeal. French says 'you get to a point when you think, "Wouldn't it be nice to just sit and enjoy your food?" […] it becomes a technical exercise […] getting to a point when I dreaded mealtimes' (ibid.). A similar situation is the one cited by Parens (2009): he quotes Rousso, a prominent American disability activist with severe physical impairments, who recounts how she refused to do physiotherapy and 'practice walking more "normally" [… because it] *felt like an assault on myself, an incomplete acceptance of all of me*' (cited in Parens 2009: 22; authors' emphasis).

On the other hand, in the same paper, Parens quotes Isabelle, a girl with craniofacial differences, who decided to have surgery in order to avoid people treating her differently, and even if her own mother told her that she should be accepted as she is. Rossetti et al. (2008: 369), whose research was cited in the previous chapter, quote John, one of the persons with autism involved in their research, as saying 'ALTHOUGH I AM BESET BY THE DRUDGERY OF AUTISM I LIKE OTHERS TO NOT TRY TO FIX ME. I LIKE TO DECIDE WHAT I WANT FOR MYSELF' (block letters in the original).

Although John was 31 at the time of participating in the research and therefore a long way from being a child, it is a statement that can also apply to children. It is significant that one of John's methods of communication is through typing which is facilitated by his forearm being supported. Therefore, while John was supported to communicate and thereby exercise his own participation rights, he used this opportunity to make a statement about not wanting to participate in activities and therapies that were deemed to be beneficial for him by others.

Participation rights are grounded in the effective access to express views or wishes. Being able to participate makes no guarantee that the wish will sway the final judgement or decision but its inclusion in the consideration leading to the decision is crucial at all levels. It ensures that all parties involved are acknowledged as active participants with a contribution to be made, notwithstanding the challenges involved in making, understanding or relaying that contribution. Of course children may require support to feel they are welcome to participate. Gourley and Miles (2004) contend that to guarantee child participation, support is essential and this means that the child should be able to expect attention to skills, information, finances, emotional needs, physical needs and whatever is required by the individual child to effectively bridge the feeling or issue that threatens full participation. The need for support is experienced by a child with learning or communication difficulties as much as it may be experienced by a child dealing with emotional burdens so that the adult has a responsibility to recognise the support required and make all efforts to ensure the child is empowered to participate if to do so is the child's wish.

In the examples cited above, while the decisions taken by Harilyn Rousso and Isabelle are diametrically opposed to each other, in both cases they became causal agents in their own lives. Recognising disabled children's agency entails valuing what they have to say about different aspects of their lives and the activities they engage in and taking it on board to the extent of making adjustments where necessary. It also entails respecting a disabled child's wish not to participate. This issue needs to be approached with delicacy and sensitivity taking into account both the child's wishes and their needs. In the area of mental health, for example, disabled children may find themselves being referred to services against their will. But once the referral is made, the services provided should take the children's opinions into account. Beyond therapy and health-related services, disabled children should also be able to exercise their agency, both in terms of choosing what activities to engage in and in terms of choosing not to engage in certain activities at all. Thus, while the availability of inclusive mainstream education and leisure activities is essential, a disabled child should have the ability to opt out of certain mainstream activities if they so wish. The important thing is to discover the reason for the wish to opt out. If it is because of bullying (which, as seen in Chapter 5, is a reality for many disabled children), then it is the antagonistic behaviour of the other children which should be addressed. But if a disabled child simply prefers the company of children with the same impairments (for instance a deaf child feeling more comfortable socialising with other deaf children whose first language is sign language) that preference should be respected. Furthermore, the freedom to exercise one's participation rights also includes the freedom to choose not to exercise these rights at all in contexts where the disabled child does not feel comfortable doing so. To take one example, important as it is for disabled students to be involved in the drawing up and implementation of their Individual Educational Programme (IEP), as discussed in Chapter 3, if a disabled child prefers to stay in class to follow their lessons during the IEP meeting so as not to be singled out among their classmates, they should not be forced to attend. Other means can be found of eliciting the child's views and bringing them on board in the implementation of the decisions made.

Finding the right way for the effectively realising the disabled child's participation rights is very challenging. However it is symptomatic of the relationship between adults and children without disability too. Participation rights for children remain a barrier to be overcome. Hart's (1992) ladder of participation highlights the challenges participation entails and although the first 1992 design has been further developed, the image of a ladder starting with tokenism and decoration and culminating in full participation rings true for many working in this field (cited in McNeilly, Macdonald and Kelly (2015); see also Creative Commons (2012) for a review of the various models of participation). Reaching the upper rungs of this ladder entails redrawing the hierarchical lines between adults and children, disabled children being aware of their participation rights, and adults being aware of the nature of participation rights and ways to make them a reality. These topics are dealt with later on in the chapter, after highlights from the literature presented in the previous chapters that show how opportunities are created for the disabled child to voice their opinions and to participate in decision-making processes.

The Scope for Participation in Disabled Children's Lives

'Participation' and 'participation rights' have been used throughout this book as referring to disabled children's rights and opportunities to participate in decisions affecting their rights. These terms can of course take on a wider meaning, referring to rights and opportunities to participate in different activities – from participating in lessons in mainstream schools to participating in leisure activities for children of a similar age. In fact, most legislation, policy documents, strategies, measures and services in European countries and elsewhere are geared towards this type of participation. This practice is reflected in official reports, such as those presented to the United Nations Committee on the Rights of Persons with Disabilities, which have been referred to in the preceding chapters, as well as other reports such as those found on the website of the Academic Network of European Disability Experts (ANED), which were also cited in the previous chapters. All efforts made in the direction of increasing the inclusion of disabled children in mainstream services and activities are a crucial part of creating an inclusive society where disabled children can enjoy their fundamental rights and freedoms on an equal basis with others. Disabled children should take part in or make decisions that are based on informed choice and on real choices.

For instance, without inclusive education, inclusive sport, leisure and cultural venues and activities, and without accessibility to various services and initiatives, the disabled child would only be able to make their views heard in specialised settings which, however much they may cater for their impairment-related requirements, keep them segregated from their non-disabled peers and do not offer a real choice. Likewise, it is crucial for health services to take into account the needs of the disabled child which, in some cases, may be lifelong, and for the needs of the disabled child within the family home to be catered for and the family supported to be able to do so. Furthermore in structures which are not purposefully intended for the disabled child, such as proceedings in court where the disabled child's parents are seeking divorce or where the disabled child is the victim of a crime or a witness in a civil or criminal case or is the perpetrator or aggrieved party, the burden of responding to the needs of the disabled child must rest with the establishment which has a responsibility to ensure participation, both for its own ends but also in acknowledgment of the rights of the individual. Furthermore, a commitment to inclusion does not obviate the need for disability-specific services that cater for the particular needs of certain disabled children, especially those who have complex dependency needs.

However, the totality of inclusive and disability-specific policies and services cannot in themselves guarantee that the disabled child has scope to have their views heard, play an active part in the taking of decisions affecting their own lives, and exercise their participation rights in other ways. Neither should these rights be seen as an add-on to policies and services. The issue of participation is fundamental to the provision of true access rights to the disabled child. Until all efforts are made to ensure effective participation, the disabled child will remain unable to attain their dignity as rights holders with options to enforce or refuse to engage, according to their own individual choice. There is still a reluctance to view participation as a justiciable right for the disabled child and a predilection for transferring this right to the adults entrusted with the child's best interests. However to take this road is to deny both the CRC and the CRPD and to virtually hide away the key to status rights to which every human being is entitled. Participation must therefore be an integral part of how policies are drawn up and services provided. In his article about inclusive education, Barton (1997: 233) asserts that '[c]entral to the demands of an inclusive society are issues of social justice, equity and democratic participation'. Disabled children cannot be truly included in society if they do not also have the opportunity to participate in democratic processes as equal citizens. This participation needs to start in everyday contexts from a young age.

The previous chapters have provided examples of good practice in terms of the disabled child exercising their participation rights. In Chapter 2, examples of how this happens in health settings were seen. Of particular salience is the review carried out by Shilling et al. (2012) in which the authors identify hospitals and health settings where disabled children's participation rights are respected. As they point out, the key is communication – health professionals and parents communicating information *to* the disabled child and also communicating *with* the child in order to discuss treatments and other health-related matters. These authors, however, also conclude that there is scope for more involvement of the disabled child in health-related decisions. Shilling et al., as well as other researchers referred to in Chapter 2, point to the link between the involvement of the disabled child in these decisions and improved health outcomes, not least because children who have been involved in decisions are more likely to adhere to treatment regimes.

However, improvement in health is not the only, or even the main, reason why the disabled child should be able to take part in decisions and have their views heard in health settings. At a deeper level, the disabled child should exercise their participation rights simply because it is their right to do so. While that statement may seem tautological, it is nonetheless an important one to make – the exercise of these rights should not be seen only as a means to an end (for example that of achieving better outcomes) or out of fear of possible legal repercussions should those rights be withheld, but as an end in itself. This of course applies not only to health settings but to all aspects of life.

When it comes to education, which was considered in Chapter 3 of this book, the most basic decision, that of whether a disabled child is educated in a mainstream or a segregated setting, is not one in which the child participates. In fact, as was seen in that chapter, in many countries the decision is even taken away from the parents and it is educational authorities who assess what is the optimal setting for the disabled child. The problems inherent in even considering the option of segregation and the way this undermines the inclusive education project were considered extensively in Chapter 3 and need not be entered into again here. However, one point that merits restating is that the way these decisions are taken and the basis on which they are taken mean that any participation rights exercised by the disabled child in educational settings can only take place within structures that have been pre-determined by others. That said, even within this limitation, there is plenty of scope for the disabled child to have their views heard and to participate in decisions.

As seen in Chapter 3, the process of drawing up the Individual Education Programme (IEP) provides a context in which the disabled child can take an active part in meetings and present their own thoughts and opinions. It is also a context in which the disabled child can become more informed about their own individual educational needs and therefore be better placed to participate in decisions about their education. As with health-related decisions, involvement by the disabled child in decisions about their IEP can result in better education outcomes since they are more likely to adhere to the decisions made, even if what the child proposed is different from the final decision taken (see Goepel 2009). And, as with health-related decisions, better outcomes should not be the sole or even the main reason for enabling the disabled child to exercise their participation rights. These rights are important in themselves and not simply a tool for adults to be better able to achieve their own ends, regardless of how well thought-out those ends are and how beneficial they are for the disabled child concerned.

A school that stands out as an example of good practice is among the ones included in the research carried out by Pawley and Tennant (2008), cited in Chapter 3. This was a school where disabled children were very much aware of the targets in their IEPs and their awareness was not related to the children's cognitive abilities or communication skills. It stemmed rather from the school giving importance to this aspect of the disabled children's education. Another aspect of good practice noted in the research literature cited in Chapter 3 is the appreciation shown by disabled children when their teachers (De Schauwer et al. 2009) or therapists (Connors and Stalker 2003) listen to their concerns and adapt their working methods to cater for the children's needs.

Another aspect of participation rights that was considered in this book concerns opportunities for the disabled child to build and develop relationships with others on their own terms. Chapter 5 showed how, even in this area, the disabled child tends to face significant restrictions. At the most fundamental level, the child does not get to choose the type of settings in which to be, and the type of people they can be with. Some of the research referred to, on the other hand, highlights examples where these restrictions are reduced as much as possible by the adults in charge. Jeanes and MacGee (2012), cited in Chapter 5, describe how in one mainstream children's leisure facility, the staff tend to the needs of both disabled and non-disabled children in such a way as to provide the former with the support they require without singling them out and without reducing their freedom to choose for themselves what to do. Adults sometimes take on a more active role in facilitating relationships between disabled and non-disabled children, as with the buddy system in mainstream schools reported by Sylvester et al. (2014).

One of the common factors found in these examples of good practice is the way that different adults take steps to facilitate the exercise of the disabled child's participation rights and to foster more equitable relationships with these children. The problem, as mentioned earlier in this book, is that there are not enough of these examples to create a paradigm shift in how adults and disabled children interact. While, as pointed out earlier, disabled children can play an active role in bringing about this shift, it is often adults who hold the key to change. The next section considers how training for and awareness-raising among adults can itself be a factor in bringing about the necessary changes.

Training and Awareness-Raising

The fact that there are settings in which the disabled child's voices is actively listened to, as chronicled in the research literature cited in this book, shows that there are adults who believe in disabled children's ability to take part in decision-making processes and take steps to enable them to do so, albeit to different extents and at different levels. The research does not focus on what motivates these adults to take these steps and why it is that this motivation is not more widespread – and indications from the research literature are that opportunities for disabled children to exercise their participation rights are an exception rather than the rule.

The reasons for this lack of opportunities are probably multiple and complex. They may include the view of children in general as incomplete adults and as not being mature enough to be able to take certain decisions. The struggle to accord participation rights to children without disability remains an ongoing issue and there are numerous examples at all levels to highlight just how inaccessible participation rights continue to be for most children, regardless of their ability. As seen in Chapter 1, the law itself makes a clear distinction between people who attain the age of majority and reach adulthood and those persons under that age – usually 18. The fact that there is legally-backed authority to respond to children differently and to accord them inferior rights based on their immaturity and expected lack of understanding permeates dealings with children at most levels. The authority invested in adults is placed there to the benefit of the vulnerable and in the best interest of the child but at times this power is used to ignore children’s rights and may be employed to hasten decisions which participation rights may be perceived as complicating.

In addition, there is the tendency to perceive *disabled* children in terms of their lack of functional abilities. These children therefore may be seen as doubly incapable of taking decisions or even of taking part in the decision-making process. It is therefore vital to ensure that adults who work with disabled children are aware of the capacity that the latter have to participate in decisions and have the necessary skills to enable these children to do so effectively. Realising the disabled child’s participation rights cannot be left to chance encounters with adults who happen to be open to it and have the competence to bring it about. Stephenson (1998: 7) identifies child participation in the context of adult partnership, offering the following definition: ‘children influencing issues affecting their lives, by speaking out or taking action in partnership with adults’. Although we do not fully endorse this sentiment, the notion of partnership is often vital to the successful participation of the disabled child in particular. While it is true that the enlightened individual who promotes the disabled child’s rights is an invaluable ally, child participation in general and more specifically participation for the disabled child is a matter of rights and should be seen as a justiciable, enforceable matter.

For the purposes of this section, a clear distinction is being made between two types of adults who are directly involved in disabled children’s lives: parents and other family members acting as primary caregivers on the one hand, and adults who work with service-providers and are paid to work with disabled children on the other. The latter thus includes those who work in residential services for disabled children who are in out-of-home care. Family members on the one hand and staff on the other have different responsibilities and making this distinction in the context of a discussion about training and awareness-raising is useful because of the different approaches needed, as seen below. Family members also typically have far longer-term connections with the disabled person over their lifetime, while paid workers often come and go.

The CRPD envisages the need for various professionals to receiving training in different aspects of disability. This includes for example training for educators and for health and rehabilitation professionals in techniques and practices relevant to their work. Significantly, the CRPD goes beyond this type of training and obliges States Parties to also promote training that increases the awareness of disability issues by professionals and staff. This requirement is first set out in Article 4 (General Obligations) which requires the promotion of training in the rights recognised by the CRPD itself ‘so as to better provide the assistance and services guaranteed by those rights’ (United Nations

2006: 6). Given that one of these rights is the disabled child's participation rights, it is not enough for professionals and staff to provide assistance and services on the terms that they believe best serve the interests and needs of the child. The disabled child's views about their own interests and needs have to be sought and be factored into decisions taken. Many of the studies cited in this book show that it can and that it does happen. However, the localised nature of the studies indicates that the participation of disabled children in decision-making processes is at best sporadic and uneven. For it to become systemic and thereby more consistent, it needs to be an explicit part of policy which is then implemented in a comprehensive manner.

The process of drawing up policies also needs to take into account disabled children's views. Then, for the aims of a policy to become a tangible reality, those who are meant to implement it need to be made aware of the importance of the disabled child's participation rights and to be trained in how to bring them about. The administrators of children's homes themselves need to be knowledgeable about the consequences of ignoring these rights and about the potential legal suits which may be initiated against them should they knowingly act in violation of the rights. This knowledge is important because once training is given it becomes impossible to plead ignorance and the implementation of basic minimum standards becomes a salient part of expected policy. Obviously, the wish to be observant of participation rights for the disabled child should primarily be motivated by the commitment towards each individual child's dignity and self-expression.

The need for increasing this awareness is addressed in Article 8 of the CRPD, which deals with awareness raising, as well as in Article 24 (Education) which, apart from giving inclusive education its much deserved importance, also tackles the issue of incorporating disability awareness in training programmes for professionals and staff. The same sub-article (Article 24.4) also requires training in the use of alternative and augmentative forms of communication – an essential prerequisite for the disabled child with various communication difficulties to assert their participation rights.

Training programmes aimed at the promotion of the disabled child's participation rights need to include various components for the training to lead to effective participation by the disabled child. These components build on the training mentioned above, that is awareness of disabled people's rights as set out in the CRPD, awareness of the accessibility issues experienced by disabled people and training in various means of communication. Adults who work and live with disabled children also need training which is specifically about the principles of participation rights and how to create contexts in which disabled children can exercise them effectively.

First of all, they need to know about the disabled child's participation rights. As seen in Chapter 1, thanks to the achievements of the disabled people's movement, to anti-discrimination legislation in many countries, and to international treaties like the CRPD, there is much more awareness of disabled people's (including disabled children's) rights in the twenty-first century than there ever was in any preceding century. The right to education, to employment, to relationships and to adequate social protection on an equal basis with others is rarely if ever contested, at least in principle. There is also wide consensus on the importance of equal opportunities for disabled people. However, awareness and acceptance of the importance of disabled people to be in control of their own lives and to receive services on their own terms, rather than on terms set by others, is not so widespread. This lack of control is experienced to an even greater extent by the disabled child.

Having learnt about participation rights, professionals and other staff working with disabled children need to understand how these rights are translated into practice. It is important for them to understand that participation in decision-making need not always be a formal process connected with major life-decisions. As cited in Chapter 2, Alderson, Hawthorne and Killen (2005) argue that even premature babies can contribute to their interaction with adults, if those adults are attentive enough to 'listen' to what these babies are communicating. Within a school setting, allowing disabled children to decide who to spend their breaks with, and facilitating their interactions with non-disabled children if this is what they choose, can be another way of enabling disabled children to have a say in their lives. In Chapter 4, the issue of privacy in residential settings was discussed and an example presented (from Knight and Oliver (2007)) of one disabled children's home where the resident children objected to there being a window with a curtain on the outside in the bathroom, an objection that was heeded by the management.

These are just some examples of facilitating participation rights in simple but nevertheless important ways. And their importance is twofold – first of all, sharing decision-making with the disabled child in everyday things can help build a more reciprocal adult–child dyad; secondly, this practice can help both adult and child learn how to participate together in more important decisions. The aspect of reciprocity in the exercise of participation rights is very important. Professionals and staff need to understand that it is not enough to listen to what disabled children have to say and then take decisions without directly involving the child concerned. Effective participation in decision-making can only occur if the power inherent in being able to take decisions is shared between child and adult. Such sharing means that it is important for staff to appreciate that it is not just the disabled child whose ability to participate in decision-making evolves. It is also the ability of adults to include disabled children in different types of decision-making processes that must develop.

Participation by the disabled child in decisions also needs to take place in formal settings. When the steps to taking a decision are defined in a structured manner, canvassing the opinion of the disabled child to whom that decision refers should be built in. To take examples from the different settings analysed in this book, health protocols should include informing the child about the treatment needed and eliciting their views about it. Educational planning meetings should include questions that are directed to the disabled child to gain their opinion about their aspiration and support needs and their opinions about the support they are receiving. Assessments of the disabled child carried out by educators or those providing any type of other service from residential to leisure activities should not simply be a catalogue of the child's functional abilities and impairments, as assessed by professionals and those working closely with the child. Such assessments should also include what the disabled child has to say about their life – including what they like and dislike about their life, and their aspirations and concerns for the present and the future. This input then should form an integral part of the information upon which decisions are taken.

Training, therefore, must also include a component about how to actively foster and promote the disabled child's participation rights in both formal and informal settings. The adults involved in taking decisions must be attentive to the fact that they need to learn how to bring participation about, first of all by taking the disabled child's capacity to participate as a given. That is to say, the disabled child should not be placed in a position where they have to prove their capacity to form and express opinions before they can do so. Rather, adults should ensure that impairment-related needs are catered for so that the disabled child can use and develop the capacity that they do have. Needless to say, guidance in identifying these needs and catering for them should also be part of the training received. But impediments to communication because of impairment-related difficulties should lead to increased support for the disabled child concerned to make their views heard, not to a decreased effort on the assumption that the child cannot realistically articulate their views.

Such training therefore includes the provision of assistive equipment, especially that related to facilitating communication, and using discussion-methods and meeting styles which are child-friendly. It also includes awareness on the part of professionals and of other staff of when to step forward to facilitate participation and when to take a step back and give the disabled child the freedom they need to express themselves, make choices and act on those choices. It even includes knowing when to respect a disabled child's wish not to participate in a decision-making process, a point discussed earlier in this chapter. More or less, these replicate the requirements pertaining to participation rights for all children with the added need to factor in the individual impairment-related requirements which render additional awareness and support essential.

Adults must also be attentive to how the disabled child's participation rights can be exercised in different ways in different contexts. In the same way that the disabled child's needs change across their lifecourse, (they generally become more mature as they grow older), so their level of participation in decision-making can and should change according to context. For instance, the preschool child cannot be expected to decide on the type of support that they require when they start their formal schooling. But once the child has started school, they should be involved in the decisions that are taken about their education. If the child is always present at IEP meetings, they can gradually learn about the process and soon be in a position to contribute to the proceedings themselves. Then, during leisure time, the disabled child should be allowed more scope for choosing activities and the settings in which to engage in those activities. In the same way that the child without disability is expected to mature and develop as they get older, so the disabled child should be given the benefit of similar expectations even when their transitional development may happen at a different pace.

Furthermore, professionals and other staff working with the disabled child, whether in mainstream settings or in segregated services, need to be aware of how their own attitudes, decisions and practices can hinder the exercise of the disabled child's participation rights. This awareness is even more important when one considers the fact that this hindrance can occur in the process of adults taking decisions or acting in ways which they are convinced are in the best interests of the disabled child concerned. The research by Vehkakoski (2008), cited in Chapter 3, is a good illustration of just such a situation. In one of the extracts presented by the researcher, the mother of William, a two-year-old boy with a hearing impairment, is discussing her son's school placement with various professionals. Using a discourse analysis approach, Vehkakoski comments on how the professionals talk about William in passive terms and 'produce an image of the child who has to earn his place at school through proving his abilities, which he either owns or does not own' (Vehkakoski 2008: 500). Service-providers, professionals and other staff working with disabled children need to be made aware of how even the way they talk about them can deprive the disabled child of their participation rights. It is also reflected in the way they take decisions and the decisions that they take. Being aware of practices which are deleterious to the realisation of the disabled child's participation rights is therefore an essential part of training for staff.

The focus thus far has been on professionals and staff, which is also the case with the references to training in the text of the CRPD. But the type of training and awareness-raising that is necessary for those working with the disabled child can also be beneficial for parents and other family members who are primary caregivers, even if the approach used may need to be different. This is because parents are in a rather paradoxical situation. Unlike professionals and other staff, they have not chosen to work with the disabled child, they do not get remunerated for their work, and they cannot opt out of it unless they are so overwhelmed that their disabled child has to be removed from the family home. Indeed, insofar as they are an important part of the disabled family (as discussed in Chapter 4), they are also people whose needs disability-related services should address.

Parents very often act as mediators between their disabled child and various service providers, and take on the role of their child's advocates. In the normal course of things, they are the ones who have been with their child from the moment of birth and, more pertinently, from the moment the child's impairment is diagnosed. Not valuing their opinions and not taking them into account is likely to result in a disservice being rendered to the disabled child. This is not only because parents' views and opinions about their child are valid in themselves but also because parents often act as gatekeepers for their disabled child and not listening to the parents makes the probability of listening to their child more remote. Parents themselves also need to listen to their disabled child.

As advocates for their child, parents need to be attentive to the extent to which the views and opinions that they present are not only their own but also take into account the views and opinions of their child. In their encounters with professionals and staff in health, education, leisure and other service-provision settings, the parents of a disabled child take on this advocacy role in order to stand up for their child's rights to inclusive education, adequate support and social protection, the necessary health services and so on. In so doing, they may ironically impinge on their child's participation rights, despite the best of intentions. Consequently, parents of disabled children may themselves need to be made aware of their disabled children's participation rights in addition to their other rights. And of course, just like professionals and other staff, they need to be aware of how their actions and decisions may hinder the exercise of participation rights by their disabled children.

Just like some professionals and other staff, some parents are already disposed towards promoting their disabled child's participation rights, and actively do so, while others may need guidance in this regard. They need to be aware that their child's ability to participate in decisions is not simply equivalent to any innate capacity to do so but comes about and evolves in their interactions with others, primarily in the family home and later in other contexts as well. Parents and other familial primary caregivers also need to be attentive to how they themselves can learn to promote the participation rights of their own disabled child, and how this participation can be brought about through the fostering of reciprocal relationships which address the power differentials that are usually inherent in any parent–child dyad. They also need to acknowledge that some children may experience unease at the interaction and may fear misunderstanding or rejection if they do participate (Lansdown 2001). Power differentials may be more pronounced when the child has a disability because, as observed earlier in this book, the disabled child tends to remain dependent on their parents for longer and to a larger extent than their non-disabled siblings (see for instance Antle, Montgomery and Stapleford's (2009) research about the relationships between young people with spina bifida and their parents).

Parents of disabled children and other primary caregivers do not receive formal training like professionals and other staff in service-providing organisations. Getting the message across regarding the issues set out above therefore needs to be approached in a different way. Parents' support groups can be ideal settings for raising awareness among the parents and primary caregivers of disabled children about these children's participation rights and how to make them a reality, as the guidance would be provided by those who live the day to day reality of raising a disabled child. In addition, meetings can be held by service-providers to talk to parents about these issues. These encounters can be taken a step further and the training provided for staff can also include parents, so that together they learn how to include the disabled child in decisions in the different contexts in which they care for them. In some instances, training that is carried out with staff and family members jointly is particularly beneficial. One such instance is when the disabled child uses augmentative and alternative means of communication (AAC). AAC involves developing a means of communication for disabled children who do not use verbal or sign language. The type of communication developed takes into account the disabled child's way of communicating, and information about this is gleaned from those living and working closely with the child (Simeonson, Björck-Åkessön and Lollar 2012). Collaboration between these two sets of adults is thus essential in ensuring that an effective means of communication is developed. Likewise, it is important for the two to learn how to use the AAC device or protocol established so that it is used with the disabled child in a consistent manner that promotes and enhances communication. For the disabled child who uses AAC, this consistency is vital in ensuring that they can exercise their participation rights.

Training for professionals and staff should also include awareness of the importance of listening to what parents have to say about their disabled children and about the situation of the family, and taking it into account when taking decisions. Listening to the disabled child can be done in both formal and informal ways. Increased awareness and training can help ensure that even simple day-to-day encounters between family members and those who provide services happen in ways which take into account the needs of the disabled child and their families, and safeguard all their rights including their right to participate in those encounters as well as in more formal encounters where important decisions are made. Summers et al. (2014) discuss the need for educators to recognise the role that families play in the child's development and to seek ways to work with them in fostering the disabled child's self-determination skills. These skills are very important for the child to have in order to be in a good position to take part in decision-making processes themselves. The fact that these authors speak of the need 'to equalize the balance of power between families and practitioners so there is an equal and respected exchange of ideas' (Summers et al. 2014: 191) is significant. This respect is necessary in order to avoid situations where parents who speak up for their disabled child's rights are labelled by professionals as 'troublemakers', for example as reported by one of the fathers interviewed for the report published by the Care Quality Commission (2012). Such situations reflect a hierarchy prioritising professionals and other staff, followed by parents and other primary caregivers, and then disabled children. Equalising the power relations between the first two members of this hierarchy is crucial in achieving more equitable relations with disabled children themselves.

Increasing awareness of the disabled child's participation rights and providing training to all those adults directly involved in these children's lives in how to make these rights a reality can give a much-needed impetus to a paradigm shift in the provision of disabled children's services in the areas of health, education, residential services, leisure services and others. They can put into motion a process through which adults learn the value of the disabled child's views and how to make it possible for these views to be heard and taken into account. Eventually, the process should also lead to the disabled child taking a more active role in the actual decision-making. For this to happen, adults and children need to have confidence in their ability to work together and learn how to make it happen. However such training and the need for sensitivity and awareness regarding rights in general and participation rights in particular is necessary for each member of the community to which the child belongs. Although the requirement described in the context of care-givers is more immediate, any person who forms part of the community has a role to play in furthering inclusion and genuinely responding to enabling the exercise of rights. Law makers, policy developers and judicial professionals are all guided by the rights of the vulnerable and the minorities they serve. Children are perceived to be part of such a group and disabled children even more so, leading to the conclusion that training is a necessity for all.

Participation in Research and Policy-Making

Apart from participating in decisions taken at an individual level (those decisions that concern them directly) the disabled child can and should also be involved in decisions at a higher level, including policy-making. Apart from achieving self-determination, they should also be able to represent the collective interests of disabled children. In fact, the CRPD places an obligation upon States Parties to 'consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations' in the implementation of the requirements of the Convention (United Nations 2006: 6).

The views of disabled children should therefore also be taken into account when drawing up policies (including legislation), when developing strategies and measures to implement these policies, and when monitoring their implementation (Carpenter and McConkey 2012). Many of the studies referred to in this book involved disabled children as direct respondents in research. As seen in these studies, disabled children bring their own viewpoints to the table and these viewpoints can in turn inform policy. The participation of disabled children can be more direct. In the field of health, Sloper and Lightfoot (2003) and Lightfoot and Sloper (2003) involved disabled and chronically ill children and young people in the development of the health services that they themselves use. Very importantly, the children (most of whom were older children) involved also had a say on the topics that were chosen for discussion and received feedback about how and where their ideas were being implemented. While not all those who took part could clearly identify benefits from their involvement in the project, there were those who felt they had gained from the experience as it presented an opportunity for them to grow personally and become more self-confident and to make a difference in the services they receive. The staff involved also reported becoming more critical of the decisions they take and more aware of their young patients' needs. Lightfoot and Sloper's research can be replicated in other settings as well. Therefore, promoting participation rights of the disabled child not only increases their wellbeing but contributes to the improvement of the services they use and makes a contribution to society.

While evidence-based policy and practice are not without shortcomings and are certainly not a panacea for all the problems encountered in the drawing up and implementation of policies and measures (Stanhope and Dunn 2011), the views of disabled children should inform policy making and the development and implementation of practical measures. The disabled child should not be seen only as a service-recipient but also as an active agent in their own life and in the services they use. As seen above, research carried out with them can give disabled children a more active role and the opportunity to put forward views and opinions that then help shape policy.

The theory and practice of doing research specifically with disabled children is well documented and it is beyond the scope of this book to go into the details (see for example Abbott 2013, Beresford 1997, Cavet and Sloper 2004, Davis and Hogan 2004, M.M. Lewis 2001, among others). However, it is important to consider the principles of emancipatory disability research which provide valuable guidance that can help ensure that research with disabled children reflects their needs and opinions rather than simply the adult researcher's concerns, thereby also respecting their participation rights. As explained by Barnes (2002) and Oliver (1992), emancipatory disability research is, first of all, research that is based on the social model of disability. This means that the focus is on socially-created disabling barriers not on the disabled child's impairments. Additionally, emancipatory disability researchers are accountable to disabled people. In his paper, Barnes describes emancipatory processes in which advisory groups made up of disabled people were set up to discuss the findings and approved the final research report.

Disabled children can be involved in similar ways by being given the opportunity to discuss research findings and provide feedback on how these will be presented in the report, paper or other documents. This involvement also enables disabled children to be involved in research at a higher level than simply as research participants. Barnes also states that in emancipatory disability research, researchers should make their standpoint in favour of disabled people's lives clear. Therefore, far from pathologising disabled children's lives and analysing these lives in terms of deficits and impairments, the emancipatory disability researcher doing research with disabled children should declare his standpoint in favour of the participation rights of their research subjects and seek ways of enabling them to speak. Furthermore, in emancipatory disability research, the research methods used are planned in a way to ensure that the research process is accessible. This entails taking into account impairment-related needs and includes, among others, choosing physically accessible venues for interviews, focus groups and other consultations involving children with mobility impairments, and ensuring that any information and communication is also provided in accessible formats especially for children with print disabilities or hearing impairments. It also includes ensuring that disabled children who have communication difficulties are able to participate in research projects. An example of how these children can also participate is presented below.

Barnes (2002) also stresses that emancipatory disability research gives a great deal of value to the role of experience, in this case recording the experiences of disabled children and giving them the opportunity to voice their opinions about it. Disabled children will be reflecting on their own experiences in the process of formulating their opinion, thereby becoming more empowered into seeing themselves as potential causal agents in their own lives. Finally, emancipatory disability research requires that the research findings are disseminated widely so that disabled activists themselves can use the knowledge gained. Disabled children then should also be informed, in child-friendly and accessible formats, about the outcomes of the research about their own lives.

As Barnes (2002) observes, living up to these principles is not easy to achieve. But the researcher who sets out to do emancipatory disability research should adhere to them to the maximum extent possible. The study by Rabiee, Sloper and Beresford (2005) provides an excellent example of how to follow one of these principles – choosing methods that are suitable for disabled children. Their young research participants were disabled children whom they describe as 'difficult to reach' (p. 387), that is children with complex dependency needs, children with autism spectrum disorders, those with degenerative conditions and children with communication impairments. The researchers devised a method which went beyond eliciting the views of these disabled children about their likes and dislikes in their immediate surroundings and which enabled them to express opinions about more complex issues. The researchers first obtained views from sources which are easier to tap into – the opinions of disabled children who are more articulate and of parents of disabled children who do not use speech. The analysis of the data generated from these preliminary consultations was used to elicit the themes to be explored with the disabled children who do not use speech. Specific statements presenting different views on these themes were then prepared for these children to choose from.

The disabled children involved in this study played different roles in the research process, with some responding to pre-set statements that were presented to them and others providing input into the themes and content of this structure. The role of disabled children in research in fact is not only related to responding to research questions but also to identify issues that need to be researched. The research results can, in turn, inform policy and the development of services. Given that the children involved in the research by Rabiee, Sloper and Beresford (2005) tend to use not only mainstream services that are provided for all children, and not only those provided specifically for disabled children, but also to use services specifically designed for them to address their communication needs, it is particularly important to ensure that the development of these services is also informed by research with disabled children who are less articulate and do not communicate through conventional methods.

The promotion of the disabled child's participation rights can and should therefore happen not only in daily life but also through consultations with them about the services they use which then directly inform the development of policies and services. In order for consultations to be effective, there needs to be a common understanding of what constitutes participation rights for disabled children. Consequently, we end this book by presenting a detailed definition of what constitutes disabled children's participation rights as a basis for this common understanding.

Defining the Disabled Child's Participation Rights

Article 12.1 of the CRC asserts the right of 'the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (United Nations 1989: 4). The wording of this sub-article leaves plenty of scope for interpretation as it is in the hands of adults to decide on which children are capable of forming their own views and what weight to give to these views. The preceding chapters in this book have shown very clearly that what happens is that different adults give different interpretations and varying degrees of importance to the exercise of these rights. The result is that while some disabled children are able to air their views and even to participate in decision-making, others are not. The existence of such opportunities or the lack of them was seen not to depend on the nature of the impairment of the disabled children involved, their age or level of maturity, or their ability to articulate their opinions easily. The common factor in the examples of good practice cited is the motivation by the adults to ensure that these children can assert their participation rights.

The comprehensive realisation of the disabled child's participation rights needs to start with acknowledging the disabled child's agency and recognising the ways in which they act as causal agents in their own lives. It also entails the assumption that all disabled children have the capacity to exercise these rights. Furthermore, the ability of the disabled child to participate in decisions should not be taken to be synonymous with capacity to do so. Ability refers instead to the availability of opportunities for them to do so. It is incumbent upon adults to provide these opportunities and to ensure that the disabled child's support needs are catered for. Once these opportunities are in place, the views of the disabled child should be considered as intrinsically valuable and used as an opportunity for adults to understand the disabled child's life from the latter's perspective. Furthermore, the notion of the exercise of the disabled child's participation rights as an evolving process applies to both disabled children and to adults. In the same way that the disabled child can become increasingly involved in decisions as they mature and as they gain experience and develop the necessary skills, so must adults evolve in their ability to make the disabled child's participation rights a reality. The exercise of these rights can happen in both formal and informal ways and in everyday as well as life-changing decisions. And it is important for the different permutations possible within these parameters to be present in the disabled child's life so that they can truly exercise their participation rights to the maximum within their own particular environments, and to the extent that the child wishes to do so. Finally, taking decisions, airing views and forming opinions can only happen effectively if the disabled child has the necessary information. The exercise of participation rights is therefore also contingent on information being made available in formats which they can access.

Ultimately, the exercise of the disabled child's participation rights is about the child being party to decisions about what is in their own best interest and therefore about achieving more equitable power relations between the disabled child and the adults who directly or indirectly play important roles in their life:

> […] participation of children is crucial in influencing the conditions of their own lives, in that participation is not only involvement in institutions and decision-making but above all a general pattern of democracy relevant to all areas of family and social life. (Council of Europe 1998: 2)

It is in this way that disabled children can be equal to all other children without disability who can access their rights and enjoy their individual autonomy, leading to the freedom to make their own choices as set out in Article 3(a) (General Principles) of the CRPD. This is a salient element of the disabled child's right to a childhood, including their right to enjoy their present wellbeing. It also places the disabled child in a good position to be able to access their full rights as adults, such as the right to continue with their education throughout their life, the right to work, the right to vote and participate in political life and the right to form a family of their own and, above all, to live their life on their own terms on an equal basis with others.

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