

Valentina Della Fina · Rachele Cera
Giuseppe Palmisano *Editors*

The United Nations Convention on the Rights of Persons with Disabilities

A Commentary

 Springer

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of Persons with Disabilities

Valentina Della Fina • Rachele Cera •
Giuseppe Palmisano
Editors

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Editors

Valentina Della Fina
Institute for International Legal Studies
National Research Council (CNR)
Rome, Italy

Rachele Cera
Institute for International Legal Studies
National Research Council (CNR)
Rome, Italy

Giuseppe Palmisano
Institute for International Legal Studies
National Research Council (CNR)
Rome, Italy

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Foreword

The UN Convention on the Rights of Persons with Disabilities (CRPD), international human rights instrument approved by the UN General Assembly in 2006, and effective since 2008, establishes the paradigm of human rights of persons with disabilities, which provides a multifocal look at the conception on the right holder: the addition between the impairment a person can experience, including physical, sensory, intellectual and/or psychosocial levels; the interaction with various barriers; and the impact it produces as to restrictions on full and effective participation in society.

Barriers are a key factor in respect of which society as a whole must work intensively and permanently both in removing obstacles as creating necessary conditions for equal opportunities and even material equality or of results. The concomitance of both pathways will involve reducing restrictions to participation in society, in terms that the subject of law can enjoy and exercise his/her human rights and fundamental freedoms in the civil, political, social, economic, and cultural fields.

In addition, the Convention expresses various changes in the approach to human rights in the twenty-first century, which include the interdisciplinary nature in the drafting of the Treaty, determining a significant impact on its implementation, and monitoring at national and international levels.

Another change is shown by the gestation and development of the Convention with full participation of civil society of persons with disabilities. Such participation is explicitly reflected in various provisions of the Convention, and in practice it is translated into the decisive role played by persons with disabilities in the implementation of the Treaty, and in the different phases of monitoring at national and international levels.

The aforementioned transformation also shows how an international Treaty takes its own life and independence from the different lines of thought that were taken into account in drafting its articles. Thus, even though it was initially noted that the Convention would not create new rights, now the question is whether this Treaty conceived the genesis of new rights. On this analytical view, we can

examine aspects with legal impact such as accessibility, habilitation and rehabilitation, personal mobility, independent life, and being included in the community. Undoubtedly, the development of the abovementioned precepts poses deep theoretical and practical challenges to the research world. In considering the above prescriptions, we must agree that they have their own and specific elements that have given way to the regulatory interpretation even from the sphere of justiciability, as the Courts and Tribunals are admitting lawsuits in areas such as accessibility. Another example is the explicit mention of habilitation and rehabilitation as a right in national legislation.¹ Furthermore, the Committee on the Rights of Persons with Disabilities has expressly stated the right to reasonable accommodation in education, which is immediately applicable in accordance with the recommendations of the Treaty body.²

The repertoire of recommendations of the CRPD Committee provides extensive evolution and development in the interpretive look for practical implementation of the Treaty rules. The same has been done by the Committee in its opinions on individual or group complaints under the Optional Protocol to the Convention. This hermeneutics has deepened in areas such as equal recognition as a person before the law/legal capacity and accessibility, through its General Comments No. 1 and No. 2, respectively.³

The richness of a comprehensive and integral human rights Treaty, such as the Convention on the Rights of Persons with Disabilities, produces the need for the international community to have analytical texts on the rights of persons with disabilities and their international legal protection. At the same time, a text of this nature will become a useful tool for the implementation of the Convention, by the examination of the work of the CRPD Committee at international level and the identification of best practices nationally.

Accordingly, the publication of “The United Nations Convention on the Rights of Persons with Disabilities – A Commentary” is a significant contribution to the theoretical and practical universe, and in the legal and interdisciplinary field.

The work provides an introduction in three main lines: historical overview from the United Nations to promote and protect the rights of persons with disabilities, incorporating the CRPD under the umbrella of the international law of human rights; understanding the new human rights model under the CRPD, and the possibility of signature and ratification of the Treaty by regional integration organizations, such as the European Union.

¹Act 20.422 establishes Rules on Equal Opportunities and Social Inclusion of Persons with Disabilities, year 2010.

²CRPD/C/ESP/CO/1, para. 44.

³In prioritizing matters for interpretive work, the Committee adopted in 2016 a General Comment on women and girls with disabilities and a General Comment on the right to inclusive education of persons with disabilities.

The work continues with a detailed analysis of the CRPD articles, taking into account the legal obligations contained in each provision of the Convention and their practical implementation.

The study of the articles takes into account other international human rights treaties, EU legislation, and, where appropriate, national legislation. Where relevant, it takes into account the jurisprudence of the Committee on the Rights of Persons with Disabilities and of other treaty bodies.

The knowledge and experience of the authors of the work make this a must-read text in contemporary reading and requisite material in university libraries, and other public and private libraries.

Attorney-at-law, Political Scientist
Chairperson of the CRPD Committee
Santiago de Chile, Chile; Geneva, Switzerland
March 2016

María Soledad Cisternas Reyes

Preface

At the turn of ten years from the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), the time has come to enrich the international law literature with an in-depth scholarly analysis of its provisions and Protocol, in the light also of the first years of practical operation and implementation of the Convention.

This is precisely the purpose of the present Commentary, whose publication offers an opportunity not only to celebrate the 10th anniversary of the Convention but also to create new momentum towards its critical assessment and promote its sound knowledge.

The Commentary has been conceived and prepared by the Institute for International Legal Studies (ISGI) of the National Research Council of Italy as the main outcome of its multiyear researches on the rights of persons with disabilities.

As a public research Institute with specific competencies in international and European Union law, the ISGI has developed a unique scientific expertise on the implementation of international treaties within the Italian legal order. Its researches on the CRPD have, therefore, a long-standing and solid background. This may be evinced, in particular, by the Project “The 2007 UN Convention on the Rights of Persons with Disabilities: Implementation Modalities, National and Regional Adoption, Monitoring Instruments,” which was commissioned to the ISGI by the Italian Ministry of Labour, Health and Social Policy in 2008, prior to the ratification of the Convention and its Optional Protocol by Italy.⁴ The study aimed at providing guidance to the Government on the domestic legal measures necessary for adapting the Italian legal system to the obligations under the CRPD. The Project outcomes have been the point of reference for the activities of the National Observatory on the Condition of Persons with Disabilities and its working groups,⁵ in particular for preparing the initial report of Italy to the CRPD Committee and for developing the

⁴Italy ratified the CRPD and its Optional Protocol with Law No. 18 of 3 March 2009.

⁵http://www.osservatoriodisabilita.it/index.php?option=com_content&view=article&id=92&Itemid=257&lang=en. Accessed 15 February 2016.

“Biennial Programme of Action for the Promotion of the Rights and the Integration of Persons with Disabilities.”⁶

ISGI research activities in the field of disability rights went on with the publication of the volume “La Convenzione delle Nazioni Unite sui diritti delle persone con disabilità. Commentario,”⁷ which is still today the only article-by-article Commentary to the CRPD published in Italy.

On such grounds, in 2014 the ISGI has also been a partner of Autism-Europe in the European Project “Promoting equal rights for people with autism in the field of employment and education,” which was aimed at improving the understanding of the CRPD implementation in the specific fields of inclusive education and employment.⁸

And now, with the present Commentary to the CRPD and its Optional Protocol, the ISGI aims at filling a gap in international law literature, providing a legal study on the Convention that takes into account a substantial number of years of CRPD implementation, both at international and national levels.

The general purpose of the volume is to clarify the content of the CRPD, highlighting the improvements and the novelties introduced by the Convention in the international human rights law. These issues are specifically outlined in wide-ranging contributions enriching the Commentary with an academic perspective over the Convention.

The three introductory chapters deal with the drafting history of the CRPD, the new human rights model embedded in the Convention, and the EU adhesion, while the final chapter illustrates the development of human rights law through the CRPD.

The Commentary follows an article-by-article approach, with the exceptions of Articles 34–36 (concerning the CRPD Committee, the Reports by States Parties, and the Consideration of Reports) and Articles 41–43, 45–50 (final clauses of the Convention), which are covered respectively by single contributions. Also, the Optional Protocol is analyzed through a unique contribution.

Each comment generally incorporates the preparatory works of the CRPD; the references to international and domestic jurisprudence, where appropriate; the relevant practice of the UN human rights treaty bodies, *in primis* the CRPD Committee; and a short bibliography. However, no rigid approach has been imposed on authors in analyzing the scope and the content of the individual provisions, leaving a large autonomy with regard to the aspects to be treated while respecting the volume’s objectives. Only for an easy use of the Commentary,

⁶The “Programma di azione biennale per la promozione dei diritti e l’integrazione delle persone con disabilità” was adopted by the Decree of the President of the Republic on 4 October 2013. <http://www.gazzettaufficiale.it/eli/id/2013/12/28/13A10469/sg>. Accessed 15 February 2016.

⁷Edited by S. Marchisio, R. Cera, V. Della Fina, Aracne, Roma, 2010, pp. XVII-560.

⁸The scientific results of the ISGI study on the implementation of Articles 24 and 27 of the CRPD are contained in the book titled “Protecting the Rights of People with Autism in the Fields of Education and Employment,” edited by V. Della Fina and R. Cera and published with open access by Springer (2015).

all contributions follow a common format, but each comment is an expression of the author's point of view.

The CRPD provisions are examined in the framework of the relevant international human rights norms and the European Union law concerning the rights of persons with disabilities and the fight against discrimination. A special emphasis is dedicated to the States Parties' obligations in order to clarify their legal nature and scope. In this perspective, the Commentary is designed to provide a useful tool guide for the application of the Convention at domestic level and a source of consultation for the community of professionals and academics dealing with international human rights.

Having this in mind, the authors have been selected among legal scholars and academics in the field of international human rights law, practitioners of disability rights, and leading experts who took part in the negotiations of the CRPD. We are deeply grateful to the authors and extend heartfelt thanks to them for their dedication in preparing the Comments.

The editors sincerely hope that this Commentary will serve as a vehicle to improve the knowledge of the Convention, by favoring the process for strengthening the awareness of the disability rights and their international protection, in the perspective of promoting a greater social inclusion of persons with disabilities.

Rome
September 2016

Valentina Della Fina
Rachele Cera
Giuseppe Palmisano

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About the Editors and Contributors

Aurélie Baranger has been the director of Autism Europe (AE) since 2007. She is responsible for the coordination of AE's advocacy activities. She has coauthored several reports promoting a human-rights-based approach to autism.

Andrew Begg has had a career in international human rights and international criminal law, both within the New Zealand Foreign Service and the United Nations. During the negotiations to draft the CRPD, he was representing New Zealand on human rights issues at the United Nations in New York and received instructions from his Government to enthusiastically support the Convention. He provided legal advice to New Zealand Ambassador Don MacKay in his role as the Chair of the Working Group that established the first draft of the Convention and later as the Chair of the Ad Hoc Committee that negotiated the draft through to its adoption. He provides a behind-the-scene view on the negotiations and the evolution of the text.

Andrea Broderick is assistant professor at the Department of International and European Law at Maastricht University, having previously been a Marie Curie Research Fellow and a lecturer at Maastricht University. She holds a Ph.D. from Maastricht University, a BA International, an LL.B., as well as an LL.M. in International and Comparative Disability Law and Policy, with First Class Honors, from the National University of Ireland, Galway. She is also a qualified solicitor.

Giancarlo Bruno is researcher at the National Research Council of Italy (Institute for Research on Innovation and Services for Development, IRISS-CNR). His studies cover issues of public international law, international and European law of human rights, international migration law. From 2012 to 2014, he served as legal adviser for the European External Action Service (Delegation of the European Union to the Council of Europe).

Rachele Cera is researcher at the Institute for International Legal Studies of the National Research Council of Italy (ISGI-CNR), with specialization in the field of international cooperation and legal protection of vulnerable people. She took part in all ISGI researches on the legal protection of persons with disabilities and

comanaged the EU Project *Promoting Equal Rights for People with Autism in the Field of Employment and Education*. She is author of publications on disability rights and coeditor of the book *La Convenzione delle Nazioni Unite sui diritti delle persone con disabilità. Commentario* (Aracne, Roma, 2010).

Andrea Crescenzi is a technologist-researcher at the Institute for International Legal Studies of the Italian National Research Council (ISGI-CNR). He holds a Ph. D. in International Order and Human Rights from Sapienza University of Rome. Since 2004, as a Research Fellow at the ISGI-CNR, he has been carrying out his research activities in the field of public international law, with a focus on international migration law and international human rights law.

Theresia Degener is professor of law and disability studies at Evangelische Fachhochschule RWL—University of Applied Sciences in Bochum (Germany) and director of the Bochum Center for Disability Studies (BODYD). She is Vice-Chair of the United Nations Committee on the Rights of Persons with Disabilities. She studied law in Frankfurt am Main (Germany) and Berkeley, California (USA). She has been teaching law in Germany, Finland, Ireland, South Africa, and the USA. She is a board member of the German Institute on Human Rights. She is a founding member of the German association on disability studies. Her research fields are international human rights, anti-discrimination law and gender, disability studies.

Valentina Della Fina is senior researcher in international law at the Institute for International Legal Studies of the National Research Council of Italy (ISGI-CNR). She holds a Ph.D. in law of international organizations from the University of Teramo. She has a consolidated scientific background in the fields of international human rights law, disability rights, and law of international organizations. She is coeditor of the book *La Convenzione delle Nazioni Unite sui diritti delle persone con disabilità. Commentario* (Aracne, Roma, 2010) and managed the EU Project *Promoting Equal Rights for People with Autism in the Field of Employment and Education*.

Marco Fasciglione is Ph.D. and researcher at the Institute for Research on Innovation and Services for Development of the National Research Council of Italy (IRISS-CNR). His interests fall within the international law field and specifically in international human rights law mechanisms, corporate human rights obligations, migrations flows' regulation. A former legal officer of the European Court of Human Rights, he is member of the roster of experts of the EU Commission (DG Justice) on citizenship and fundamental rights.

Ornella Ferrajolo is senior researcher in international law at the Institute for International Legal Studies of the National Research Council of Italy (ISGI-CNR). She is author of numerous books and articles. She has published widely in the field of human rights, humanitarian law and international criminal law, mainly focusing on monitoring procedures, treaty bodies, and international courts.

Eilionóir Flynn is the deputy director of the Centre for Disability Law & Policy and senior lecturer in the School of Law at the National University of Ireland Galway. Her current research interests include legal capacity, advocacy, access to justice, and the intersectionality of disability, gender, and ageing. She has published widely in the fields of disability and human rights and is currently the holder of a European Research Council Starting Grant for the VOICES project, to document the narratives of people with lived experience of legal capacity denial.

Rosita Forastiero is technologist-researcher at the Institute for International Legal Studies of the National Research Council of Italy (ISGI-CNR). Her main research fields are EU law and international human rights law, with a particular focus on the rights of persons with disabilities and vulnerable groups. At ISGI-CNR, she has worked in several EU Projects. She is also member of the Editorial Board of the ISGI online publication “Italy and International Law” (www.larassegna.isgi.cnr.it).

Mary Keys is former lecturer in the School of Law, NUI Galway, specialized in mental health law and human rights. She is a founder member of the Centre for Disability Law and Policy at the Institute for Lifecourse and Society at NUI Galway. She is a member of the Mental Health Commission of Ireland as the representative of the public interest.

Anna Lawson is the director of the interdisciplinary Centre for Disability Studies at the University of Leeds where she is professor in the School of Law. She is also a member of the coordinating research team of the EU’s Academic Network of Experts on Disability. Outside her university work, she is a member of the statutory Disability Committee of Great Britain’s Equality and Human Rights Commission, a Council member of Justice and chair of CHANGE (a disabled people’s organization that focuses on the human rights of people with learning difficulties).

Janet E. Lord is an international human rights lawyer specializing in the rights of persons with disabilities. She participated in all of the negotiating sessions during the drafting of the Convention on the Rights of Persons with Disabilities and served as advisor to several lead governments, the United Nations, and Disabled Peoples International. She is currently senior researcher at the Harvard Law School Project on Disability and holds teaching affiliations at the Washington College of Law at the American University, the University of Maryland Francis King Carey School of Law, and the National University of Ireland (Galway). She holds degrees from Kenyon College, the University of Edinburgh (Scotland), and the George Washington University Law School.

Luigino Manca is researcher of international law at Sapienza University of Rome, where he teaches international human rights law. He is member of the Teaching Board of the Ph.D. course on “International Order and Human Rights” at Sapienza University of Rome.

Antonio Marchesi is Ph.D. at the European University Institute and professor of international law in the Faculty of Law of the University of Teramo (Italy). He is chairperson of the Italian section of Amnesty International (AI) and has been a

consultant for AI's International Secretariat, as well as for a number of other NGOs and IGOs such as the Council of Europe (ECPT) and the European Commission (EuropeAid). He is the author of books and articles in the fields of public international law, human rights law, and international criminal law.

Silvana Moscatelli is technologist-researcher at the National Research Council of Italy (CNR). She holds a Ph.D. in International Order and Human Rights from Sapienza University of Rome. She was contract professor of human rights law at Sapienza University of Rome. Her main research interests cover the international protection of economic, social and cultural rights, especially the right to food.

Giuseppe Palmisano is director of the Institute for International Legal Studies of the National Research Council of Italy (ISGI-CNR). He is full professor of international law and president of the European Committee of Social Rights (Council of Europe). His research activities focus mainly on international human rights, in particular social rights.

Ilja Richard Pavone is researcher of international law at the National Research Council of Italy (CNR). He holds a Ph.D. in International Order and Human Rights from Sapienza University of Rome. He is professor of environmental law at Tuscia University. At the CNR, he coordinates the research unit on International, European and National Biolaw.

Mads Pedersen holds a Master of Laws from the University of Copenhagen in 2010. He has been assistant attorney at Kammeradvokaten (the legal adviser to the Danish Government) from 2010 to 2013 and then attorney from 2013 to 2014, working with a variety of legal areas, including human rights law. A special adviser at the Department of equal treatment at the Danish Institute for Human Rights as of April 2014, he works with primarily human rights and disability.

Francesco Seatzu is full professor of international and European Union law at the University of Cagliari (Italy). He holds a J.D. (Cagliari) and Ph.D. (Nottingham). He authored *The UN Committee on Economic, Social and Cultural Rights: The Law, Process and Practice* (Abingdon: Routledge, 2012) (with M. Odello); *The World Bank Inspection Panel* (Turin: Giappichelli, 2007); *Insurance in Private International Law: A European Perspective* (Oxford: Hart, 2003).

Michael Ashley Stein holds a J.D. from Harvard Law School and a Ph.D. from Cambridge University. He is cofounder and Executive Director of the Harvard Law School Project on Disability and a long-time visiting professor at Harvard Law School. He holds an extraordinary professor chair at the University of Pretoria's Centre for Human Rights and a visiting professorship at the Free University of Amsterdam. He is an internationally recognized expert on disability law and policy.

Maria Ventegodt Liisberg is director of the department of equal treatment of the Danish Institute for Human Rights. She has a Ph.D. from Maastricht University (2011) on disability and employment in a human rights perspective. She has a master's degree in law from the University of Copenhagen (1996).

Abbreviations

ACHPR	African Charter on Human and Peoples' Rights
ACHR	American Convention on Human Rights
al.	Alias (other)
ASEAN	Association of Southeast Asian Nations
AU	African Union
CAT	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CAT Committee	Committee against Torture
CCPR	Human Rights Committee
CED	Committee on Enforced Disappearances
CEDAW	Convention on the Elimination of Discrimination against Women
CEDAW Committee	Committee on the Elimination of Discrimination against Women
CERD Committee	Committee on the Elimination of Racial Discrimination
CESCR	Committee on Economic, Social and Cultural Rights
cf.	Compare
CFI	Court of First Instance
CHR	Commission on Human Rights
cit.	Cited
CJEU	Court of Justice of the European Union (Lisbon)
CMW	Committee on Migrant Workers
CoE	Council of Europe
COSP	Conference of the States Parties
CPED	International Convention for the Protection of All Persons from Enforced Disappearance
CRC	Convention on the Rights of the Child
CRC Committee	Committee on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities

CRPD Committee	Committee on the Rights of Persons with Disabilities
DDA	Disability Discrimination Act
DESA	Department of Economic and Social Affairs
Doc.	Document
DPOs	Disabled people's organisations
EAT	Employment Appeal Tribunal
EC	Treaty establishing the European Community/European Communities
ECHR	European Convention for the Protection of Human Rights and Fundamental Freedoms
ECJ	European Court of Justice see also CJEU
ECommHR	European Commission of Human Rights
ECOSOC	UN Economic and Social Council
ECR	European Court Reports
ECSR	European Committee of Social Rights
ECtHR	European Court of Human Rights
ed	Editor
edn.	Edition
eds	Editors
edt. by	Edited by
EHRR	European Human Rights Reports
EO	European Ombudsman
EP	European Parliament
ESF	European Social Fund
et al.	Et alii (and others)
et seq(q).	Et sequens, et sequentes (and the following)
EU	European Union
EUCFR	European Union Charter of Fundamental Rights
ex p.	Ex parte
FAO	Food and Agriculture Organization
fn.	Footnote
HL	House of Lords
HRA	Human Rights Act
HRC	Human Rights Council
i.e.	Id est (that is)
I/A Court H.R.	Inter-American Court of Human Rights
IAEA	International Atomic Energy Agency
ibid.	Ibidem
IBRD	International Bank for Reconstruction and Development
IC	Constitution of the Italian Republic
ICAO	International Civil Aviation Organization
ICC	International Criminal Court
ICCPR	International Covenant on Civil and Political Rights
ICCPR-OP1	Optional Protocol to the International Covenant on Civil and Political Rights

ICCPR-OP2	Second Optional Protocol to the International Covenant on Civil and Political Rights, aiming at the abolition of the death penalty
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICESCR - OP	Optional Protocol to the Covenant on Economic, Social and Cultural Rights
ICJ	International Court of Justice
ICMW	International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families
ICTR	International Criminal Tribunal for Rwanda
ICTY	International Criminal Tribunal for the Former Yugoslavia
id.	Idem
IDA	International Development Association
IFAD	International Fund for Agricultural Development
IFC	International Finance Corporation
ILC	International Law Commission
ILO	International Labour Organization
IMF	International Monetary Fund
IMO	International Maritime Organization
ITC	International Training Centre of the ILO
ITU	International Telecommunication Union
LDCs	Least developed countries
loc. cit.	Loco citato (in the place already cited)
NGO	Non-governmental organization
NHRIs	National Human Rights Institutions
No.	Number
nyr	Not yet reported
O.J.	Official Journal
O.J. C	Official Journal of the European Union (Communications)
O.J. L	Official Journal of the European Union (Legislation)
OAS	Organization of American States
OAU	Organization of African Union
OECD	Organisation for Economic Co-operation and Development
OHCHR	Office of the High Commissioner for Human Rights
OP	Optional Protocol
op.cit.	Opus citatum (in the work already cited)
OP-CAT	Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
OP-CEDAW	Optional Protocol to the Convention on the Elimination of Discrimination against Women
OP-CRC-AC	Optional Protocol to the Convention on the Rights of the Child on the involvement of children in armed conflict

OP-CRC-CP	Optional Protocol to the Convention of the Rights of the Child on a Communication Procedure
OP-CRC-SC	Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography
OP-CRPD	Optional Protocol to the Convention on the Rights of Persons with Disabilities
p.	Page(s)
para.(s)	Paragraph(s)
passim	Frequently mentioned
PCIJ	Permanent Court of International Justice
Res.	Resolution
RP	Rules of Procedure
SG	UN Secretary General
SPT	UN Subcommittee on Prevention of Torture
TEU	Treaty on European Union
TFEU	Treaty on the Functioning of the European Union
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNDESA	UN Department of Economic and Social Affairs
UNDP	United Nations Development Programme
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNGA	UN General Assembly
UNICEF	United Nations Children's Fund
UNIDO	United Nations Industrial Development Organization
UNTS	United Nations Treaty Series
UPU	Universal Postal Union
Vol.	Volume
WBG	World Bank Group
WHO	World Health Organization
WIPO	World Intellectual Property Organization
WMO	World Meteorological Organization
WTO	World Trade Organization
WTO	World Tourism Organization

Abbreviations of Reviews and Encyclopaedia

Adel L Rev	Adelaide Law Review
Aff soc int	Affari sociali internazionali
Afr Hum Rights Law Jour	African Human Rights Law Journal
Afr Journ Int Law	African Journal of International Law
Afr J Physiother Rehabil Sci	African Journal of Physiotherapy and Rehabilitation Sciences
Am J Comp Law	American Journal Comparative Law
Am Journ Int Law	American Journal of International Law
Am Journ of Preventive Medicine	American Journal of Preventive Medicine
Am Soc Int Law Proc	American Society and International Law Proceedings
Am Univ Int Law Rev	American University International Law Review
An der int	Anuario de derecho internacional
Ann CEDH/YB ECHR	Annuaire de la Convention européenne des droits de l'homme/Yearbook of the European Convention on Human Rights
Ann dir int	Annuario di diritto internazionale
Ann fr dr int	Annuaire français de droit international
Ann Intern D H	Annuaire International des Droits de l'Homme
Ariz J Int Comp Law	Arizona Journal of International and Comparative Law
Asia Pac Disabil Rehabil J	Asia Pacific Disability Rehabilitation Journal
Austr Int Law J	Austrian International Law Journal
Austr YB Int Law	Australian Yearbook of International Law
AWR Bull	AWR Bulletin
Berkeley Journ Int Law	Berkeley Journal of International Law

Berkeley J Employ Labor Law	Berkeley Journal of Employment & Labor Law
Berkeley Technol Law J	Berkeley Technology Law Journal
Boll CE	Bollettino delle Comunità europee
Boll UE	Bollettino dell'Unione europea
Boston Univ Int Law J	Boston University International Law Journal
Br J Psychiatry	The British Journal of Psychiatry
Br YB Int Law	British Yearbook of International Law
Bull Cour	Bulletin de la Cour européenne des droits de l'homme
Bull dr homme	Bulletin des droits de l'homme
Bull quot Eur	Bulletin Quotidien Europe
BverfGE	Entscheidungen des Bundesverfassungsgericht
Cah dr eur	Cahiers de droit européen
Calif Law Rev	California Law Review
Camb Law Jour	Cambridge Law Journal
Case West J Int Law	Case Western Journal of International Law
Case W Res J Int'l L	Case Western Reserve Journal of International Law
Cass pen	Cassazione penale
Chic Jour Int Law	Chicago Journal of International Law
Chr Dalloz	Chronique Dalloz
Clin Psychol Sci Pract	Clinical Psychology: Science and Practice
CIJ Recueil/ICJ Reports	Recueil des arrêts, avis consultatifs et ordonnances de la Cour Internationale de Justice/Reports of Judgments, Advisory Opinions and Orders of the International Court of Justice
Coll Courses Ac Eur Law	Collected Courses of the Academy of European Law
Com int	La Comunità internazionale
Com st	Comunicazioni e Studi
Common Mark Law Rev	Common Market Law Review
Comm Tech L Rev	Communication, Technology and Law Review
Crit Soc Policy	Critical Social Policy
Dermatol Clin	Dermatologic Clinics
Dir com sc int	Diritto comunitario e degli scambi internazionali
Dir comm int	Diritto del commercio internazionale
Dir int	Diritto internazionale
Dir pub comp eur	Diritto pubblico comparato ed europeo
Dir umani, dir int	Diritti umani e diritto internazionale
Dir Un eur	Il diritto dell'Unione europea
Dir uomo	I diritti dell'uomo. Cronache e battaglie
Disabil Handicap Soc	Disability, Handicap and Society
Disabil Soc	Disability and Society
Disabil Rehabil	Disability and Rehabilitation
Disabil Stud Q	Disability Studies Quarterly

DR	Decisions and Reports of the European Court of Human Rights
Drake Law Rev	Drake Law Review
Duke J Comp Int Law	Duke Journal of Comparative & International Law
E Afr J Peace & Hum Rts	East African Journal of Peace and Human Rights
Emory Law J	Emory Law Journal
Enc dir	Enciclopedia del diritto
Enc giur	Enciclopedia giuridica Treccani
Entertain Sports Law J	Entertainment and Sports Law Journal
ERA Forum	ERA Forum
Equal Rights Rev	Equal Rights Review
Eur Anti-Discrimination Law Rev	European Anti-discrimination Law Review
Eur For Aff Rev	European Foreign Affairs Review
Eur Hum Rights Law Rev	European Human Rights Law Review
Eur Hum Rights Rep	European Human Rights Reports
Eur Intellect Prop Rev	European Intellectual Property Review
Eur J Migr Law	European Journal of Migration and Law
Eur J Health L	European Journal of Health Law
Eur Journ Int Law	European Journal of International Law
Eur J Women Stud	European Journal of Women's Studies
Eur Law Journ	European Law Journal
Eur Law Rev	European Law Review
Eur Pub Law	European Public Law
Eur YB Disability L	European Yearbook of Disability Law
Eur Yearb Minor Issues	European Yearbook of Minority Issues
Fam dir	Famiglia e diritto
Fordham Int Law Journ	Fordham International Law Journal
Foro it	Il Foro italiano
Geo Immigr LJ	Georgetown Immigration Law Journal
Germ YB Int Law	German Yearbook of International Law
Giur cost	Giurisprudenza costituzionale
Giur it	Giurisprudenza italiana
Giust pen	Giustizia penale (La)
Harv Hum Rts J	Harvard Hum Rights Journal
Harv Int Law Journ	Harvard International Law Journal
Harv Law Rev	Harvard Law Review
Hum Rights	Human Rights
Hum Rights Brief	Human Rights Brief
Hum Rights Law Journ	Human Rights Law Journal
Hum Rights Law Rev	Human Rights Law Review
Hum Rights Quart	Human Rights Quarterly
ICJ Reports	v. CIJ Recueil
Indian J Glob Leg Issues	Indian Journal of Global Legal Issues

Innov Issues Approaches Social Sci	Innovative Issues and Approaches in Social Sciences
ILSA J Int Comp Law	ILSA Journal of International & Comparative Law
Int Comp Law Quart	International and Comparative Law Quarterly
Int J Constitutional Law	International Journal of Constitutional Law
Int J Disabil Commun Rehabil	International Journal of Disability, Community & Rehabilitation
Int J Discrimination Law	International Journal of Discrimination and the Law
Int J Law Psychiatry	International Journal of Law and Psychiatry
Int J Law Context	International Journal of Law in Context
Int Law Rep	International Law Reports
Int Leg Mat	International Legal Materials
Int Org	International Organization
Int Pol	International Politics
Int Rehabil Rev	International Rehabilitation Review
Int Soc Sci J	International Social Science Journal
Int'l J H R	International Journal of Human Rights
Int J Incl Educ	International Journal of Inclusive Education
Int Organ Law Rev	International Organizations Law Review
IPRax	Praxis des Internationalen Privat-und-Verfahrensrecht
Iowa Law Rev	Iowa Law Review
Is LR	Israel Law Review
It YB Int Law	Italian Yearbook of International Law
J Am Med Assoc	Journal of the American Medical Association
J Common Market Stud	Journal of Common Market Studies
J Contemp Health Law Policy	The Journal of Contemporary Health Law Policy
J Disabil Policy Stud	Journal of Disability Policy Studies
J Hum Rights	Journal of Human Rights
J Hum Rights Pract	Journal of Human Rights Practice
J Int Crim Justice	Journal of International Criminal Justice
J Int Spec Needs Educ	Journal of International Special Needs Education
J Law Med Ethics	Journal of Law, Medicine & Ethics
J Law Med Health	Journal of Law, Medicine & Health
JCP	Juris-Classeur périodique-La semaine juridique
Jour Pr Int Law	Journal of Private International law
Jour Refug St	Journal of Refugee Studies
J Soc Welf Fam Law	Journal of Social Welfare Family Law
Journ dr int	Journal du droit international
JT	Journal des tribunaux
Jus	Jus
Lang Policy	Language Policy
Leg Iss Eur Int	Legal Issues of European Integration

Leiden Journ Int Law	Leiden Journal of International Law
Maastricht Journ Eur Comp Law	Maastricht Journal of European and Comparative Law
Max P Enc Pub Int Law	Max Planck Encyclopedia of Public International Law
Max P YB Un Nat Law	Max Planck Yearbook of United Nations Law
McGeorge Law Rev	McGeorge Law Review
Med Law	Medicine Law
Melb Jour Int Law	Melbourne Journal of International Law
Ment Phys Disabil Law Rep	Mental and Physical Disability Law Reporter
Michigan J Int Law	Michigan Journal of International Law
Modern Law Rev	The Modern Law Review
Neth Int Law Rev	Netherlands International Law Review
Neth Q Hum Rights	Netherlands Quarterly of Human Rights
Neth YB Int Law	Netherlands Yearbook of International Law
Neue Jur Woch.	Neue Juristische Wochenschrift
Nor Jour Hum Rts	Nordic Journal of Human Rights
Nor Jour Int Law	Nordic Journal of International Law
Nov.mo dig it	Il Novissimo Digesto Italiano
Nuove leggi civ comm	Le nuove leggi civili commentate
Open Med	Open Medicine
Öst Zeit öff Recht	Österreichische Zeitschrift für öffentliches Recht
Öst-Eur Recht	Öst-Europe Recht
Oxford Journ Leg St	Oxford Journal of Legal Studies
Pediatr Transplant	Pediatric Transplantation
Philos Public Aff	Philosophy & Public Affairs
Phys Med Rehabil J	Physical Medicine & Rehabilitation Journal
Polit Perspect	Political Perspectives
Pol dir	Politica del diritto
Pol Int	Politique internationale
Pol Sc Quart	Political Science Quarterly
Psychiatry Psychol Law	Psychiatry, Psychological and Law
Pub Law	Public Law
Racc uff sent ord Corte cost	Raccolta ufficiale delle sentenze e ordinanze della Corte costituzionale
Raccolta	Raccolta della giurisprudenza della Corte di giustizia (fino al 1958: Raccolta della giurisprudenza della Corte di giustizia CECA; dal 1990: e del Tribunale di primo grado)
Rass parl	Rassegna parlamentare
Rec Dall	Recueil Dalloz Sirey—Recueil périodique et critique de doctrine, de jurisprudence et de législation en matière civile, commerciale, criminelle, administrative et de droit public

Recueil des arrêts/ décisions	Recueil des arrêts et décisions de la Cour européenne des droits de l'homme
Recueil des cours	Recueil des cours de l'Académie de La Haye de droit international
Rel int	Relazioni internazionali
Reports of Judgments	Reports of Judgments and Decisions of the European Court of Human Rights
Rev aff eur	Revue des affaires européennes
Rev arb	Revue de l'arbitrage
Rev comm int juristes	Revue de la commission internationale des juristes
Rev cr dr int pr	Revue critique de droit international privé
Rev cr jur belge	Revue critique de jurisprudence belge
Rev der com eur	Revista de Derecho Comunitario Europeo
Rev der cons eur	Revista de Derecho Constitucional Europeo
Rev dr aff int	Revue de droit des affaires internationales— International Business Law Journal
Rev dr int dr comp	Revue de droit international et de droit comparé
Rev dr pub	Revue de droit public
Rev dr Un eur	Revue du droit de l'Union européen
Rev eur der fund	Revista Europea de Derechos Fundamentales
Rev eur dr int	Revue européenne de droit international
Rev fr dr adm	Revue française de droit administratif
Rev gén dr int pub	Revue générale de droit international public
Rev Int Law Pol	Review of International Law and Politics
Rev M comm	Revue du Marché commun (from 1993: et de l'Union européen)
Rev M un eur	Revue du Marché unique européen
Rev trim dr eur	Revue trimestrielle de droit européen
Rev trim dr homme	Revue trimestrielle des droits de l'homme
Rev univ dr homme	Revue universelle des droits de l'homme
Riv coop giur int	Rivista della cooperazione giuridica internazionale
Riv dir cost	Rivista di diritto costituzionale
Riv dir eur	Rivista di diritto europeo
Riv dir int	Rivista di diritto internazionale
Riv dir int priv proc	Rivista di diritto internazionale privato e processuale
Riv dir proc	Rivista di diritto processuale
Riv int dir uomo	Rivista internazionale dei diritti dell'uomo
Riv int fil	Rivista internazionale di filosofia del diritto
Riv it dir pub com	Rivista italiana di diritto pubblico comunitario
Riv st pol int	Rivista di studi politici internazionali
Riv trim dir proc civ	Rivista trimestrale di diritto e procedura civile
Riv trim dir pub	Rivista trimestrale di diritto pubblico

Seton Hall J Dipl Int Relat	Seton Hall Journal of Diplomacy and International Relations
Sign Lang Stud	Sign Language Studies
Soc Leg Stud	Social and Legal Studies
Soc Philos Policy	Social Philosophy and Policy
Stud Soc Just	Studies in Social Justice
St integr eur	Studi sull'integrazione europea
St Jour Int Law	Stanford Journal of International Law
Stanf Law Rev	Stanford Law Review
Stud Soc Just	Studies in Social Justice
Süddeut Zeit	Süddeutsche Zeitung
Sur-Int J Hum Rights	Sur-International Journal on Human Rights
Sydn Law Rev	Sydney Law Review
Syracuse J Int'l L & Com	Syracuse Journal of International Law and Commerce
Temple Polit Civil Rights Law Rev	Temple Political & Civil Rights Law Review
Tul Jour Int Comp Law	Tulane Journal of International and Comparative Law
Tex J Civ Lib Civ Rights	Texas Journal on Civil Liberties & Civil Rights
Univ Ark Little Rock Law Rev	University of Arkansas at Little Rock Law Review
Univ Mich J Law Reform	University of Michigan Journal of Law Reform
U Mich Law Rev	University of Michigan Law Review
UC Davis Law Review	University of California Davis Law Review
Univ Tor Law J	University of Toronto Law Journal
Un Law Rev	Uniform Law Review—Revue de droit uniforme
Univ Chicago Leg For	University of Chicago Legal Forum
Univ of NSWLJ	University of New South Wales Law Journal
Vanderbilt Law Rev	Vanderbilt Law Review
Vanderbilt Journ Tr Law	Vanderbilt Journal of Transnational Law
Virginia Journ Int Law	Virginia Journal of International Law
Virginia Law Rev	Virginia Law Review
Wash Law Rev	Washington Law Review
Women Int Hum Rights Law	Women and International Human Rights Law
Women Ther	Women & Therapy
Yale Hum Rts & Dev L J	Yale Human Rights and Development Law Journal
Yale Journ Int Law	Yale Journal of International Law
YB Eur Law	Yearbook of European Law
YB Int Hum Law	Yearbook of International Humanitarian Law
YB Int Law Comm	Yearbook of the International Law Commission
YB Un Nat	Yearbook of the United Nations

ZaöRV	Zeitschrift für ausländisches öffentliches Recht und Völkerrecht
Zeit Schw Recht	Zeitschrift für Schweiz Recht
Zör	Zeitschrift für öffentliches Recht (Austrian Journal of Public and International Law)

From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations

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1 Introduction

The Convention on the Rights of Persons with Disabilities was negotiated in 4 years—in UN terms that is lightening quick. It took decades, however, to prepare the political and legal ground for the Convention. Earlier attempts to convince the General Assembly to open the gate for a convention focusing on persons with disabilities failed.¹ According to modern human rights theory, the struggle for new rights is determined by several factors, such as an organised social movement that

¹Degener (1995), p. 12.

defines collective grievance as normative claims and convincing gate keepers in major rights organisations, governments and United Nations organisations.²

When a background study commissioned by the Office of the High Commissioner for Human Rights explored the conditions with respect to a disability rights convention at the beginning of the new millennium, it found that the time was ripe for a new endeavour.³ Prior to that lie many years, indeed decades, of slowly emerging disability policy as rights policy at the United Nations. This chapter gives an overview over the different phases of this policy, which led to the adoption of the Convention on the Rights of Persons with Disabilities. Part 2 describes four historic phases from 1945 to 2001, which led up to an agreement to negotiate the Convention. Part 3 gives an overview of the drafting process of the treaty from 2002 to 2006.

2 Disability Policy in the United Nations: Before the Dawn

The adoption of the Convention on the Rights of Persons with Disabilities was a major achievement. But it took decades before disability was recognised as a human rights issue at the United Nations. In retrospect, four phases can be distinguished. The first phase, dating from 1945 to 1970, marks a time when disabled persons were invisible in United Nations policy. This changed in the second phase, from 1970 to 1980, when disabled persons became recognised as subjects of rehabilitation. The third phase comprised the two decades from 1980 to 2000, and during this time persons with disabilities became objects of human rights. Only in the new millennium, during the fourth phase, disabled persons became subjects of human rights.

2.1 Disabled Persons as Invisible Citizens, 1945–1970

Neither in the UN Charter of 1945 nor in the Universal Declaration of Human Rights of 1948 were people with disabilities mentioned. The Universal Declaration refers to disability only as an event or a condition, like unemployment and sickness,⁴ to which social security should apply to ensure the right to an adequate standard of living. This lack of recognition of disabled people is surprising, given that at least two of the nine members of the drafting committee of the Declaration had direct experience with disability. The Chair of the drafting committee was Eleanor Roosevelt, the wife of US President Franklin D. Roosevelt, who had to use a wheelchair for the last two decades of his life. And John P. Humphrey, the

²Bob (2009), p. 4 et seq.

³Quinn and Degener (2002).

⁴UDHR, Resolution A/RES/3/217A, December 10, 1948, Art. 25.

Canadian member of the drafting committee, had lost his arm at the age of six.⁵ It cannot be claimed that no person with experience of disability was present during the drafting.

The first three of the core international human rights treaties were adopted during this phase: the International Convention on the Elimination of All Forms of Racial Discrimination in 1965 and the International Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights, both in 1966. None of these treaties contain explicit references to persons with disabilities. While the General Assembly and other human rights bodies emphasised many times subsequently that disabled persons are covered by these laws, it is reasonable to say that this group was not on the radar when they were being drafted.

Disabled persons were more or less invisible citizens during this first two and a half decades of the United Nations. The UN Yearbooks from 1946 to 1970 mention persons with disabilities only in three contexts: firstly, as a specific group among refugees; secondly, as objects of rehabilitation and welfare; and thirdly, in the context of social security funds.

Just how limited this discourse on disability was can be illustrated with a few examples. Firstly, in 1950 the Secretary General submitted a report to the Social Commission on “Social Rehabilitation of the Physically Handicapped”. The report summarizes the findings of an international expert meeting, the sole subject being an international programme of rehabilitation, and it covered medical, occupational and physical therapy; manufacture and fitting of prostheses; and similar services.⁶ Following this report, the Economic and Social Council adopted Resolution 309 (XI), in which the Council requested the Secretary General “to plan jointly with the specialised agencies and in consultation with the interested non-governmental organisations a well co-ordinated international programme for rehabilitation of physically handicapped persons”. Similar recommendations were directed to Member States.⁷

The focus in these documents, however, was on the rehabilitation experts, not on the individuals with disabilities. Despite the fact that during this period Helen Keller, a famous person with disability, addressed the United Nations,⁸ disabled persons in general were regarded as objects of rehabilitation, while as citizens and rights holders, they remained invisible.

⁵Scott (2011).

⁶Social Rehabilitation of the Physically Handicapped, Report of the Secretary General to the Social Commission, E/CN.5/197, March 22, 1950.

⁷Social Rehabilitation of the Physically Handicapped, Resolution E/RES/309E (XI), July 13, 1950.

⁸<http://www.afb.org/blog/afb-blog/helen-keller-at-the-united-nations/12>. Accessed March 20, 2015.

2.2 Disabled Persons as Subjects of Rehabilitation, 1970–1980

The second phase started with two important non-binding declarations adopted by the General Assembly. In 1971, the Declaration on the Rights of Mentally Retarded Persons was adopted,⁹ followed in 1975 by the Declaration on the Rights of Disabled Persons.¹⁰ The 1971 Declaration had been drafted by an international NGO, the International League of the Societies for the Mentally Handicapped, some years earlier at their world congress in Jerusalem.¹¹ This short declaration consisted of only seven paragraphs and a preamble. While it appeared to be a rights-based document according to its title and preamble, which referenced the Universal Declaration and the International Covenants,¹² it was actually a document that adhered firmly to the medical model of disability. Persons with cognitive impairments were guaranteed the same rights as other human beings, but only “to the maximum degree of feasibility”.¹³ It saw impairment, therefore, as a potential barrier to holding and exercising rights. This is clear in the last paragraph of the Declaration. Its purpose was to guarantee due process of the law and other legal safeguards to persons with intellectual impairments, but in fact it failed to outlaw serious human rights infringements on the basis of impairment:

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for this restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capabilities of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

In other words, the denial and restriction of human rights to persons with cognitive impairments was not seen as a human rights violation, as long as it was done with proper legal safeguards to prevent abuse. Guardianship is called for as a measure of legal protection in this document.¹⁴

Another feature of the medical model of disability can be seen in the fact that the Declaration does not proclaim the whole catalogue of human rights but emphasises only economic and social rights, such as “economic security and a decent standard of living”.¹⁵ In contrast, civil and political rights are only referred to with respect to legal standards for restricting freedoms, such as prosecution and guardianship. The

⁹Declaration on the Rights of Mentally Retarded Persons, Resolution A/RES/26/2856 (XXVI), December 20, 1971.

¹⁰Declaration on the Rights of Disabled Persons, Resolution A/RES/30/3447 (XXX), December 9, 1975.

¹¹Mittler (2003), p. 37; Herr (2003).

¹²A/RES/26/2856 (XXVI), cit., Preamble.

¹³A/RES/26/2856 (XXVI), cit., para. 1.

¹⁴A/RES/26/2856 (XXVI), cit., para. 5.

¹⁵A/RES/26/2856 (XXVI), cit., para. 3.

most operational part of the declaration calls for “proper medical care and physical therapy and...rehabilitation...as will enable [the person with intellectual impairment] to develop his ability and maximum potential”. For this reason, it is fair to qualify it as a soft law instrument according to which disabled persons are seen as subjects of rehabilitation.

The 1975 Declaration on the Rights of Disabled Persons similarly demanded that persons with disabilities were to be granted all the human rights that non-disabled persons enjoy. It stated that “Disabled persons have the inherent right to respect for their human dignity”.¹⁶ It further stipulated that “Disabled persons have the same civil and political rights as other human beings”.¹⁷ The Declaration also called for the right of disabled persons “to enjoy a decent life, as normal and as full as possible”,¹⁸ which is described as “the right to live with their families or with foster parents and to participate in all social, creative or recreational activities”.¹⁹

But these equality promises were subject to caveats. First, equality rights were limited for persons with intellectual impairments by referring to the Declaration on the Rights of Mentally Retarded Persons and in particular its restriction clause in paragraph 7.²⁰ This restriction is referred to despite the proclamation that “Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age”.²¹ Second, for some situations, institutionalisation of persons with disabilities was deemed as “indispensable”.²²

For these cases, the Declaration pronounced a ‘normalisation’ principle: “The environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.”²³ While the reference to the normalisation principle was clearly a step towards a human rights approach, the underlying philosophy of this Declaration was still determined by the medical model of disability. Prevention of disability is referenced twice as a necessary measure,²⁴ integration is demanded “as far as possible”²⁵ and disability is defined not as a result of environmental and individual factors. Instead, a disabled person is defined as “any person unable to ensure by himself or herself, wholly or partly,

¹⁶A/RES/30/3447 (XXX), cit., para. 3.

¹⁷A/RES/30/3447 (XXX), cit., para. 4.

¹⁸A/RES/30/3447 (XXX), cit., para. 3.

¹⁹A/RES/30/3447 (XXX), cit., para. 9.

²⁰A/RES/30/3447 (XXX), cit., para. 4: ‘Paragraph 7 of the Declaration of the Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally retarded persons.’

²¹A/RES/30/3447 (XXX), cit., para. 3.

²²A/RES/30/3447 (XXX), cit., para. 9.

²³A/RES/30/3447 (XXX), cit., para. 9.

²⁴A/RES/30/3447 (XXX), cit., Preamble.

²⁵A/RES/30/3447 (XXX), cit., Preamble.

the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capacities”.²⁶

Despite these shortcomings, the Declaration was one of the first documents of the United Nations that acknowledged the importance of consultations with organisations of disabled persons.²⁷

The second phase ended in 1976 with the General Assembly proclaiming that 1981 would be the International Year of Disabled Persons and calling for a Plan of Action that would emphasise “Full participation and Equal Opportunities”.²⁸ Disabled persons in this second phase were increasingly seen as agents in their own affairs. But these affairs were mainly rehabilitation affairs, with the focus on fixing the impaired individual.

2.3 Disabled Persons as Objects of Human Rights, 1980–2000

The third phase spanned two decades from 1980 to 2000 and was kicked off by the International Year of Disabled Persons in 1981. While the International Year did bring attention to disability as a policy issue, at the UN, a year is not enough time to achieve very much. It was the beginning, however, of a much more active period.

2.3.1 The World Programme of Action Concerning Disabled Persons

The main outcome of the International Year of Disabled Persons was the adoption of a detailed action plan: the World Programme of Action Concerning Disabled Persons²⁹ remained the main UN strategy to enhance disability prevention, rehabilitation and equalisation of opportunities well into the new millennium.³⁰

The Programme of Action is a lengthy document of more than 200 paragraphs. While still based on the traditional three-tier approach to disability (definition, prevention and rehabilitation of disability), it added a new dimension by calling for equalisation of opportunities. It contains a long list of recommendations for national actions in order to achieve equalisation of opportunities for disabled persons. These actions pertain to issues such as legislation, physical environment, income maintenance and social security, education, employment, recreation, culture, religion and sports.³¹ In addition, the Programme of Action has a small chapter

²⁶A/RES/30/3447 (XXX), cit., para. 1.

²⁷A/RES/30/3447 (XXX), cit., para. 12.

²⁸International Year for Disabled Persons, Resolution A/RES/31/123, December 16, 1976.

²⁹World Programme of Action Concerning Disabled Persons, Resolution A/RES/37/52, December 3, 1982.

³⁰Keeping the promise: Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond, Report of the Secretary General to the General Assembly, A/65/173, July 26, 2010.

³¹A/RES/37/52, cit., paras. 108–137.

on human rights, which calls upon United Nations organisations, governments and other stakeholders to pay due attention to the human rights of disabled persons.³²

In adopting the Programme of Action, the General Assembly clearly recognised that it was an ambitious document, and to ensure continued focus on its implementation, the General Assembly proclaimed at the same time the International Decade of Disabled Persons (1983–1992).³³ During that Decade, a number of other instruments dealing with disability emerged from the United Nations.

2.3.2 ILO Convention 159

First off the block was the adoption in 1983 of the International Labour Organization Convention 159 on the Vocational Rehabilitation and Employment of Disabled Persons. ILO Convention 159 was the first legally binding human rights treaty to mention persons with disabilities—all the previous documents were non-binding. It was also the first UN instrument to specifically mention women with disabilities, providing that “Equality of opportunity and treatment for disabled men and women workers shall be respected”.³⁴

While the Convention is significant in that it introduced the principle of equality of opportunity in the workplace for persons with disabilities, its narrow scope meant its impact was limited. Its main purpose was to create an obligation on States Parties to implement vocational rehabilitation policies for persons with disabilities to promote their employment opportunities in the open labour market.³⁵ But it did build on the 1975 Declaration’s recognition of the importance of consultation with organisations of persons with disabilities. Clearly forecasting the way forward, it included a legally binding obligation that in implementing vocational rehabilitation policies, “representative organisations of and for disabled persons shall also be consulted”.³⁶

2.3.3 Breaking Onto the Agenda of the Commission on Human Rights

The United Nations Commission on Human Rights issued two important reports on disability-related human rights issues during the International Decade.

The first was a study by Erica-Irene A. Daes, a Special Rapporteur of the Sub-Commission on the Prevention of Discrimination and Protection of Minorities, on the situation of persons with psycho-social impairments. This study was initiated more with a view to draw attention to political prisoners detained on grounds of

³²A/RES/37/52, cit., paras. 162–169.

³³Implementation of the World Programme of Action Concerning Disabled Persons, Resolution A/RES/37/53, December 3, 1982, para. 11.

³⁴Convention (No. 159) concerning vocational rehabilitation and employment (disabled persons), entered into force June 20 1985, UN Treaty Series, Volume 1401, 23439, Article 4.

³⁵Convention (No. 159), cit., Articles 2 and 3.

³⁶Convention (No. 159), cit., Article 5.

mental illness (particularly behind the “iron curtain”), but it did also take a closer look at the situation of persons with disabilities in psychiatric institutions. The study proposed a set of “Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental–Ill Health or Suffering from Mental Disorder”.³⁷

The report was one of the first to consider medical professionals as potential human rights violators, a groundbreaking normative gain.³⁸ However, the draft Principles left ample discretion to medical personnel on forced treatment and detention. For this reason, they soon attracted criticism from legal commentators and organisations of disabled persons.³⁹ (This is the reason why the Principles are not referenced in the preamble of the Convention on the Rights of Persons with Disabilities). Nevertheless, the Daes report needs to be recognised as a first step of the Commission on Human Rights and its Sub-Commission to put disability on its agenda.

The second study commissioned by the Sub-Commission was undertaken by Special Rapporteur Leandro Despouy between 1984 and 1991 and covered all persons with disabilities. His report, published in 1993, on “Human Rights and Disabled Persons”⁴⁰ gave evidence of widespread human rights abuses against persons with disabilities all over the world. The report, which was tabled before the Commission on Human Rights and the General Assembly, has been instrumental in placing disability on the agenda of several human rights bodies of the United Nations.

During the preparation of the study, two attempts were undertaken to adopt a human rights treaty for disabled persons. Following a 1987 Global Meeting of Experts to Review the Implementation of the World Programme of Action in Stockholm, Italy presented a draft outline for a text at the forty-second session of the General Assembly, and another endeavour was made by Sweden during the forty-fourth session of the General Assembly.⁴¹ Both attempts failed to get off the ground. The Despouy report comments on this lost opportunity:

It must be said that at the end of the period (since the adoption of the World Programme of Action) persons with disabilities are going to find themselves in a legal disadvantage in relation to other disadvantaged groups such as refugees, women, migrant workers, etc. The latter have the protection of a single body of binding norms. . . . However there is no

³⁷Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental–Ill Health or Suffering from Mental Disorder, Report of the Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, 1986, E/CN.4/Sub.2/1983/17/Rev.1, Annex II.

³⁸E.g., Principle 11 (Consent to treatment) para. 12 reads: “Sterilization shall never be carried out as a treatment for mental illness.”

³⁹Minkowitz (2007), p. 407, Lord (2009), p. 87.

⁴⁰UN publications, Sales No. E.92.XIV.4.

⁴¹Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Resolution A/RES/48/96, Annex, December 20, 1993, para. 9. Interestingly, Italy was represented by Maria Rita Saulle according to Nagase (1995), pp. 36–40.

specific body in charge of monitoring respect for the human rights of disabled persons and acting, whether confidentially or publicly, when particular violations occur. It can be said that persons with disabilities are equally as protected as protected as others by general norms, international covenants, regional conventions, etc. But although this is true, it is also true that unlike the other vulnerable groups, they do not have an international control body to provide them with particular and specific protection.⁴²

2.3.4 The Standard Rules

The International Decade of Disabled Persons instead ended with the adoption of a non-binding instrument: the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities.⁴³ The Standard Rules consist of four sections with twenty-two rules. Section I deals with the preconditions of equal participation: awareness raising (Rule 1), medical care (Rule 2), rehabilitation (Rule 3) and support services (Rule 4). Section II identifies target areas for equal participation, such as accessibility (Rule 5), education (Rule 6) or employment (Rule 7). Section III deals with implementation measures, focusing on actions like information and research (Rule 13), policymaking and planning (Rule 12) or legislation (Rule 13). Section IV addresses issues of monitoring.

The Standard Rules were drafted against the backdrop of the World Programme of Action, but the spirit and language were more based on a rights-based approach to disability and included some terminology of the emerging international disability rights movement such “independence” or “personal assistance services”.⁴⁴ Another important feature was its focus on non-discrimination and equality. While commentators criticised shortcomings with respect to civil and political rights, legislative demands⁴⁵ and its legal character,⁴⁶ the Standard Rules remained the main human rights instrument for the next decade to come. They had a significant impact on the emergence of disability-based anti-discrimination legislation in many countries around the globe.⁴⁷

One feature that distinguishes the Standard Rules from the Programme of Action is a group of provisions for its monitoring. The Rules were monitored until 2014 by a Special Rapporteur who was advised by a panel of experts. The first Special Rapporteur was Bengt Lindqvist, a blind former minister of Sweden and a member of the international disability movement. He served from 1992 to 2002. He was followed by Sheikha Hessa Al-Thani of Qatar (2003–2005). As the third Special Rapporteur on Disability, Shuaib Chalklen (2009–2014) served as a prominent disability rights leader and wheelchair user from South Africa.

⁴²Dito Despouy (1993), paras. 280–281.

⁴³Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Resolution A/RES/48/96, December 20, 1993.

⁴⁴A/RES/48/96, cit., Rule 4; for a more detailed analysis in this regard, Degener (1995), pp. 14–15.

⁴⁵Degener (1995), p. 15; Quinn and Degener (2002), p. 23.

⁴⁶Michailakis (1999), p. 122.

⁴⁷Quinn and Degener (2002); Soledad Cisternas Reyes (2011).

The panel of experts consisted of representatives of six international organisations from the disability field.⁴⁸ They advised the Special Rapporteur on his monitoring mandate. Thus, with the Standard Rules and its monitoring mechanisms, persons with disabilities became experts at the United Nations and agents of their own cause.

2.3.5 The Emergence of the Disability Rights Movement

The creation of a UN panel of experts made up of disabled persons' organisations was possible because of the emergence of disability rights movements internationally during the International Year and the International Decade. Persons with disabilities around the world, inspired by other social movements such as the civil rights movement and the women's movement, became politicised and started to speak up for themselves.

As a result, the traditional welfare and rehabilitation-oriented organisations were criticised for being made up by a majority of delegates who were non-disabled "experts", or parents of the disabled. Disabled Peoples' International was founded in 1980 as an alternative to Rehabilitation International for this very reason.⁴⁹ Yet it took some time before these young organisations became professional players in the human rights machinery of the United Nations.

While Disabled Peoples' International and other organisations of (rather than for) disabled persons were involved in the drafting of the World Programme of Action and the Standard Rules,⁵⁰ they were outnumbered by experts without life experience of disability. The first draft of the Programme of Action, for example, was produced by Rehabilitation International.⁵¹ While the medical model of disability had been replaced by the social model of disability, persons with disabilities were still objects, rather than subjects, of human rights.

In addition to non-disabled experts taking the lead in policy and lawmaking, persons with disabilities were still not mainstreamed in the United Nations human rights machinery. Discussion at the Commission on Human Rights was still limited, and for the most part persons with disabilities were segregated as a social policy question, apart from any rights-based discussion. The Special Rapporteur, for example, reported to the Commission for Social Development in New York and not to the Commission on Human Rights in Geneva. While in theory the two commissions had equal status, the Commission for Social Development was in reality a poor cousin. Its annual meeting each year was one and a half weeks, while the Commission on Human Rights met for six. Human Rights experts and NGOs from capitals all over the globe descended on Geneva each year for the Commission

⁴⁸Disabled Peoples' International, Rehabilitation International, the World Federation of the Deaf, the World Blind Union, and Inclusion International, cf. Michailakis (1999).

⁴⁹Driedger (1989); Groce (2002).

⁵⁰Driedger (1989).

⁵¹Groce (2002), p. 75.

on Human Rights, where meetings were crowded and often standing room only. The Commission for Social Development, on the other hand, barely attracted attention in capitals, was attended mainly by junior delegates from New York Missions, and numerous empty seats signified that many delegations simply did not bother to turn up. Likewise, Secretariat support to the Special Rapporteur came from the Department for Policy Coordination and Sustainable Development in New York, whereas all the human rights bodies and their associated resources, experts and energy were located in Geneva.

During this third phase, however, the disability rights movement was gaining strength and experience in political advocacy, and by the dawn of the new millennium, disabled persons' organisations had become articulate policy advocates, no longer prepared to allow others to speak on their behalf.

2.4 Disabled Persons as Agents of Human Rights in the New Millennium

The fourth phase started with the new millennium, which marks the time when disabled persons and their organisations became agents of human rights on a broader scale. By now organisations 'of' persons with disabilities took the lead in political trend setting and organisations 'for' persons with disabilities were relegated to take a secondary role in international disability policy. After much internal debate, some of these organisations for disabled persons also elected persons with disabilities as their presidents or representatives to international conferences.⁵² Others changed their names to indicate a new policy era.⁵³

The main characteristic of this phase is that international disability policy became a rights-based policy. By claiming access, equality, freedom, solidarity and participation as rights, disability advocates made normative claims against long-felt disadvantages. This rights-based approach put disabled persons on the agenda as citizens with equal rights and as persons to be recognised before the law. It was associated with a new understanding of disability with respect to rights status. Impairment, according to this new notion of disability, cannot serve as the basis of denial or restriction of rights. To deny or restrict rights on the basis of impairment is a form of disability-based discrimination.

It was a rather logical step that at the dawn of the new millennium disabled persons' organisations realised that in order to be fully mainstreamed into the United Nations human rights machinery, a convention on the human rights of disabled persons needed to be adopted.

⁵²E.g., Rehabilitation International; see Groce (2002), 66 et seq.

⁵³Inclusion International, for example, changed its name from the International League of Societies for Persons with Mental Handicap.

One of the major players in this regard was the International Disability Alliance, which was founded in 1999 by seven international disability organisations⁵⁴ that had learned to work together on the Panel of Experts to the Special Rapporteur on Disability.

2.4.1 Calls for a Convention Grow Louder . . .

During a World Summit on Disability in March 2000 in Beijing, the Declaration on the Rights of People with Disabilities in the New Century was adopted, which called for a legally binding convention and urged disability organisations to strive for it. It stated:

5. We share the conviction that the full inclusion of people with disabilities in society requires our solidarity in working towards an international convention that legally binds nations . . .

6. We believe that the inception of the new century is an opportune time for people with diverse disabilities and their organizations. . . members of the United Nations system. . . to collaborate closely in an inclusive and wide consultative process aimed at the development and adoption of an international convention . . .

7. We therefore urge all heads of state and government . . . to immediately initiate the process for an international convention . . .

9. We hereby send out a call to action. . . to ensure the adoption of an international convention on the rights of all people with disabilities.

10. We commit our respective organizations to strive for a legally binding international convention. . .⁵⁵

Within a year, disabled persons' organisations had mobilised, and at the World Conference against Racism in Durban, in September 2001, they succeeded in lobbying for the inclusion of a call for a disability convention in the outcome document. The Programme of Action invites the United Nations General Assembly to consider elaborating an integral and comprehensive international convention to protect and promote the rights and dignity of disabled people, including, especially, provisions that address the discriminatory practices and treatment affecting them.⁵⁶

At the same time some governments seemed to be ready for a third attempt to initiate a process for a disability-focused human rights treaty. While an Irish effort to table a resolution to the Commission on Human Rights in early 2000 had failed,⁵⁷ in 2001 Mexico successfully introduced a resolution to the General Assembly calling for a discussion on the possibility of drafting an international convention. The Mexican President, Vicente Fox, gave a high level political commitment to this resolution, calling for a convention in his address to the General Assembly's

⁵⁴Disabled Peoples' International, Rehabilitation International, the World Federation of the Deaf, the World Blind Union, Inclusion International, the World Federation of the Deafblind and the European Disability Forum.

⁵⁵Quinn and Degener (2002), p. 181.

⁵⁶Report of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, December 8 2001, A/CONF.189/12, Programme of Action, para. 180.

⁵⁷Quinn (2009), p. 96.

annual General Debate that year.⁵⁸ The Mexicans successfully pushed other delegations, ready or not, into adopting a resolution creating an Ad Hoc Committee of the General Assembly to “consider proposals for a comprehensive and integral convention to promote and protect the rights and dignity of persons with disabilities”.⁵⁹ In that same year the New Zealand Government adopted a national Disability Strategy that included a national commitment to investigate and support efforts to develop a Convention at the United Nations.⁶⁰ With both Mexico and New Zealand having committed at the political level to pushing for the convention, their delegations in New York began to work closely in partnership, publicly and behind the scenes, to push the process along.

Three months later, a further milestone on the path to the Convention was published. In February 2002, the Office of High Commissioner for Human Rights published a study on the use and future potential of human rights instruments in the context of disability.⁶¹ It was financed by the Irish government and carried out by disability rights scholars who had long been involved in the international disability rights movement.

The study presented a comprehensive review of the then six core human rights conventions and their application with respect to persons with disabilities. Not surprisingly, it found that while persons with disabilities were not invisible anymore, the medical model of disability still prevailed in most countries. The study also made several practical recommendations to improve the visibility of disability within the United Nations and among States Parties. It also provided arguments in favour of drafting a new human rights convention with relation to persons with disabilities.

From that point, things moved very quickly.

While disabled persons’ organisations were turning themselves into human rights organisations, the mainstream human rights community was also taking some first small steps to look at disability as a wider human rights issue, beyond the narrow scope of individual issues such as detention on the grounds of mental health. The seeds for this were planted much earlier, including an important step at the 1993 Vienna Conference on Human Rights. That Conference recognised explicitly the universality, interdependence, interrelation and indivisibility of all human rights, a principle that eventually underpinned the comprehensive approach to the Convention on the Rights of Persons with Disabilities. The Conference also included specific references to people with disabilities in the outcome document,

⁵⁸Address of President Vicente Fox to the General Debate, 56th Session of the General Assembly, 10 November 2001.

⁵⁹Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, December 19 2001, Resolution A/RES/56/168, para. 1.

⁶⁰New Zealand Disability Strategy, Action 2.5, Minister of Social Development, April 2001.

⁶¹Quinn and Degener (2002).

the Vienna Declaration and Programme of Action. Disabled persons were specifically mentioned as a focus group, next to migrant workers, children and women. It read:

The World Conference on Human Rights reaffirms that all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities. Every person is born equal and has the same rights to life and welfare, education and work, living independently and active participation in all aspects of society. Any direct discrimination or other negative discriminatory treatment of a disabled person is therefore a violation of his or her rights. The World Conference on Human Rights calls on Governments, where necessary, to adopt or adjust legislation to assure access to these and other rights for disabled persons. The place of disabled persons is everywhere. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers, be they physical, financial, social or psychological, which exclude or restrict full participation in society.⁶²

The Vienna Conference also greatly strengthened national and international human rights machinery. It created the Office of the High Commissioner for Human Rights and was the catalyst for the creation of National Human Rights Institutions in many countries and consequently more human rights dialogue at national levels.

Together with the emergence of the Internet, new opportunities for a global international human rights advocacy appeared, which eventually led to a “new diplomacy” in the international arena.⁶³

Other important factors that enabled disabled persons’ organisations to take a lead and demand that disability become mainstreamed in the human rights regime were expert meetings that helped to create networks between human rights scholars and disability rights advocates. Two such seminars were organised by the United Nations in 1998 at the University of California, Berkeley, and in 1999 at the University of Hong Kong.⁶⁴ Both meetings focused on international norms and standards related to disability and resulted in elaborated recommendations for a new thematic convention and reforms within UN system organisations.

Another important meeting in this regard took place outside the United Nations in April 2002. Mainstream human rights organisations met with disability rights activists in order to address the long-standing disregard of disabled persons’ rights in the mainstream human rights movement. According to a legal commentator, this meeting helped the disability community to get the support of the major human rights organisations, such as Amnesty International and Human Rights Watch.⁶⁵ Those traditional human rights organisations, however, remained at arm’s length

⁶²Vienna Declaration and Programme of Action, A/CONF.157/23, June 25, 1993, para. 63–64.

⁶³Sabatello (2014).

⁶⁴Degener (1999).

⁶⁵Lord (2009), p. 90.

during the Convention negotiating process, and Amnesty International and Human Rights Watch only ever gave the Ad Hoc Committee cursory attention.

2.4.2 ...but Old Attitudes Remain a Stumbling Block

These factors at the dawn of the new millennium empowered persons with disabilities to become subjects of human rights. But as negotiations to draft a convention were about to begin, the old medical model of disability was proving persistent, and disabled person organisations had their work cut out for them to change attitudes.

In May 2001, for example, the World Health Assembly, the governing body of the World Health Organization, approved the International Classification of Functioning, Disability, and Health.⁶⁶ This document was intended as an international standard to describe and measure health and disability. While disabled people's organisations were involved in its drafting, and the Classification focuses on all aspects of life and not just the medical diagnosis, it still very much approaches disability from a medical perspective. (Like the 1991 Principles for the Protection of Persons Detained on the Grounds of Mental Disorder, the WHO Classification was for this reason left out of the preamble of the CRPD).

The disability movement greeted the new Classification with scepticism and focused on their goal of overcoming the medical model of disability by all means.

3 Asserting Rights: Drafting the Convention on the Rights of Persons with Disabilities

After years of lobbying for a convention by the disability community, the Ad Hoc Committee tasked with examining proposals for a convention was scheduled to have its first meeting in July 2002. It was open to all Member States of the United Nations, and Ecuador's Ambassador, Luis Gallegos, was elected Chair,⁶⁷ with Vice Chairs from South Africa, the Philippines, Sweden and the Czech Republic.⁶⁸

⁶⁶International Classification of Functioning, Disability and Health, Resolution WHA54.21, May 22, 2001.

⁶⁷Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, A/57/357, August 27, 2002, para. 5.

⁶⁸The Chair and Vice-Chairs collectively formed the Bureau of the meeting responsible for setting the agenda, organising the programme of work and the general running of the Ad Hoc Committee. Later in the process, Sweden resigned as Vice Chair to allow New Zealand to assume the Chair, Costa Rica assumed a Vice Chair role to replace Ecuador and the Philippines was replaced by Jordan.

3.1 The First Meeting: Still No Agreement on the Need for a Convention

Disabled persons' organisations came to the United Nations from all over the world for the first meeting, ready to start drafting. But it was clear from day one of the meeting that there was, as yet, no agreement on the need for a convention. Articulating views typical of those with doubts, the European Union had submitted a paper noting that while the mandate of the Ad Hoc Committee mentioned a specific legal instrument, that did "not exclude the Committee from considering other options as well".⁶⁹

At the other end of the spectrum, Mexico was not only convinced of the need for a convention, but it had also submitted an entire draft convention as a working paper.⁷⁰ Mexico continued to push strongly for the process of negotiating a text to begin as soon as possible, with statements of support being made by Chile, Norway, South Africa and Brazil.⁷¹ The delegates of Sierra Leone and Croatia also strongly supported a convention, noting its relevance to the significant number of their citizens disabled by recent conflicts in their countries.⁷²

The United States, on the other hand, urged caution and questioned the wisdom of a new treaty as the most effective way to strengthen the rights of persons with disabilities. Canada was also cautious, noting that while a proposal for a convention had merit, greater and more targeted use could be made of the existing human rights treaties.

Part of the hesitation displayed by some of the more cautious delegations arose from a suspicion that such a convention could end up focusing on social development. There was some irony to this, given how long disabled persons' organisations had struggled to make disability a rights issue. Some delegates from developed countries privately expressed a fear that it would become a convention where the obligations were placed on donor countries, undermining the traditional obligations on governments to protect the rights of their own citizens.

Feeding into that fear were statements of the sort contained in a working paper submitted to the meeting by China. The paper noted that because the majority of persons with disabilities lived in developing countries, the convention "should focus on the special situation and difficulties of persons with disabilities in developing countries and should reflect the just demands of...developing coun-

⁶⁹Position paper by the European Union, A/AC.265/WP.2, July 31, 2002.

⁷⁰Working Paper by Mexico, A/AC.265/WP.1, July 15, 2002.

⁷¹Disability Negotiations Daily Summary, Vol. 1 No. 1, July 29, 2002, and Vol. 1 No. 2, July 30, 2002.

⁷²Disability Negotiations Daily Summary, Vol. 1 No. 2, July 30, 2002, and Vol. 1 No. 3, July 31, 2002.

tries”.⁷³ It went on to say that developed countries “should take concrete steps to provide the developing countries with support and financial assistance”. Similar statements were made by India and Indonesia.⁷⁴

If lack of agreement on the need for a convention was one characteristic of the meeting, lack of preparation was another. Less than a quarter of Member States addressed the general debate, and some of those did so only to express concerns that they had not yet received instructions from their capitals. Disabled persons’ organisations issued a bulletin expressing their “deep disappointment” at the lack of progress and their “frustration” at the lack of preparation.⁷⁵

Given the range of views at the meeting, the Committee was only able to agree on a limited number of outcomes. These included a recommendation that it meet again the following year and a request to the Secretary General to improve accessibility of the United Nations headquarters. While architecture buffs admired the virginal state of the 1950s modernist design of the complex, the feature most noticed by persons with disabilities was that its accessibility standards also remained firmly stuck in the 1950s.

3.2 The Second Meeting: Securing the Participation of Persons with Disabilities

The Ad Hoc Committee met again for its second session nearly a year later in June 2003. In the interim, those in favour of the convention had been busy, and many regional meetings had been held to consider proposals. Working Papers submitted to the second session included the Bangkok Recommendations,⁷⁶ the Beirut Declaration and Recommendations,⁷⁷ a compilation of proposals made by governments and disabled peoples’ organisations⁷⁸ and no less than four reports of the

⁷³Position paper by the People’s Republic of China, A/AC.265/WP.3, August 1, 2002.

⁷⁴Disability Negotiations Daily Summary, Vol. 1 No. 3, July 31, 2002.

⁷⁵Disability Negotiations Bulletin Vol. 1 No. 3, August 1, 2002.

⁷⁶Bangkok recommendations on the elaboration of a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, A/AC.265/CRP.10, June 4, 2003.

⁷⁷Beirut Declaration and Recommendations on the elaboration of a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, A/AC.265/CRP.12, May 29, 2003.

⁷⁸Compilation of proposals for a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, A/AC.265/CRP.13, Add.1 and 2.

Secretary General.⁷⁹ In addition, Venezuela had submitted its own proposed draft convention.⁸⁰

In the year that had passed, the tide of opinion had clearly turned in favour of a convention, and the debate now focused on what the scope of the convention should be and which of the drafts before the Committee should be used to begin its work.

Discussion centred around three possible models for a convention. The first was a comprehensive or holistic convention, which covered a broad range of human rights, including civil, political, economic, cultural and social rights. The Convention on the Rights of the Child was cited as a model to follow. An alternative approach was a narrower convention focused on non-discrimination, based on the model of the Convention on the Elimination of All Forms of Discrimination against Women. The third approach suggested was a hybrid of the two.⁸¹

The Venezuelan and Mexican drafts followed the first model, as did the Bangkok recommendations and the compilation of proposals from disabled persons' organisations. Mexico noted in the debate that the mere affirmation of human rights and the elimination of discriminatory barriers "is not sufficient" and that a "comprehensive" approach was most appropriate.⁸² This position was echoed by the newly formed International Disability Caucus,⁸³ which rejected calls for a narrowly focused non-discrimination treaty.

Kick starting a debate on process, the European Union submitted a draft resolution on the third day of the meeting. The draft would have established a group of 15 experts, serving in their personal capacities, to be given the task of drafting a text for presenting to the next session of the Ad Hoc Committee.⁸⁴

The reaction of other delegates to the European Union's draft, however, was immediately negative. Mexico, with some pique, commented that it would be "strange" to need experts to draft a first text of a convention when Mexico had

⁷⁹Issues and emerging trends related to the advancement of persons with disabilities, A/AC.265/2003/1, April 7, 2003; Overview of issues and trends related to the advancement of persons with disabilities, A/AC.265/2003/2, April 7, 2003; Progress in the equalization of opportunities by, for and with persons with disabilities, A/AC.265/2003/3, April 7, 2003; Views submitted by governments, intergovernmental organisations and United Nations bodies concerning a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities, A/AC.265/2003/4, Corr.1 and Add.1, May 6, 2003.

⁸⁰Letter dated 18 June 2003 from the Deputy Permanent Representative of Venezuela to the United Nations addressed to the Secretary of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, A/AC.265/2003/WP.1, June 18, 2003.

⁸¹Disability Negotiations Daily Summary, Vol. 2 No. 1, June 16, 2003.

⁸²Disability Negotiations Daily Summary, Vol. 2 No. 3, June 18, 2003.

⁸³The International Disability Caucus was formed by disabled persons' organisations specifically to coordinate positions for the drafting of the Convention.

⁸⁴Austria, Belgium, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Italy, Ireland, Luxembourg, Malta, Netherlands, Poland, Portugal, United Kingdom of Great Britain and Northern Ireland, Slovenia, Slovakia, Spain, Sweden: draft resolution, A/AC.265/2003/L.3, June 19, 2003.

already tabled one.⁸⁵ Disabled persons' organisations were dismayed that the draft text would be prepared by a group of experts, without their explicit involvement. They saw it as a "stalling tactic to thwart the process".⁸⁶

Sensing the mood of the room, New Zealand proposed instead that a small working group of states and disabled persons' organisations should prepare a first draft. In including disabled persons' organisations at the table on the same basis as Member States, the New Zealand proposal was unprecedented at the United Nations. Given the demands from disabled persons' organisations that there be "nothing about us without us",⁸⁷ New Zealand made it clear that the participation of disabled persons' organisations was a prerequisite for beginning negotiations.

Securing participation of non-governmental organisations in General Assembly negotiations, however, is notoriously difficult, where they are traditionally observers, not participants. A few states, such as Iran and Nepal, raised concerns about creating such a precedent.⁸⁸ But, remarkably, aside from a few such comments, the issue of participation by non-government organisations in the working group was not whether they should be at the table, but how many seats they should have. The number of seats allocated to disabled persons' organisations grew from the original proposal of seven, to ten, and then to twelve, in order to ensure a fair geographic balance of disabled persons' organisations from around the world.

Eventually, and with only minutes to spare before the end of the meeting, the Committee agreed to create a working group to meet "...with the aim of preparing and presenting a draft text which would be the basis for negotiation by Member States and Observers at the Ad Hoc Committee of the draft convention, taking into account all contributions. . .".⁸⁹

3.3 The Working Group: Drafting Begins

When the Working Group met early in January 2004, under the leadership of New Zealand Ambassador Don MacKay, there was an air of excitement and anticipation in the room. Member States and disabled persons' organisations were finally sitting down, after years of lobbying, to begin drafting a convention. For the first time, disabled persons' organisations were sitting at the same table as governments to negotiate a legally binding text. Disabled persons' organisation were clearly no longer just subjects of human rights, but were actors in shaping those rights.

⁸⁵Disability Negotiations Daily Summary, Vol. 2 No. 3, June 13, 2003.

⁸⁶Disability Negotiations Bulletin Vol. 2 No. 6, June 23, 2003.

⁸⁷Disability Negotiations Bulletin Vol. 2 No. 6, June 23, 2003.

⁸⁸Disability Negotiations Daily Summary, Vol. 2 No. 8, June 25, 2003.

⁸⁹Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, A/58/118, July 3, 2003, para. 15.

The task in front of the delegates, however, was daunting. The Working Group had only been allocated ten working days to develop the draft. In addition, the amount of documentation had ballooned since the second session of the Ad Hoc Committee. As well as the Mexican and Venezuelan drafts, the Working Group now had in front of it draft conventions from China, the European Union and India, as well a draft submitted by the Chair of the Committee and a draft submitted by a regional meeting of national human rights institutions in Bangkok. Additional position papers had also been submitted by Australia, Costa Rica, Japan, New Zealand and the United States, as well as by a wide range of disabled persons' organisations such as Disabled Peoples' International, the International Disability Alliance, the World Blind Union and the World Network of Users and Survivors of Psychiatry.⁹⁰

The scale of the task was evident from the first day of the discussions, when it became clear that there were two different languages being spoken—that of the human rights lawyers sent by governments and that of the disability movement. Many of the first interventions of disabled persons' organisations, for example, asked for the right to self-determination to be included in the convention. For the disability movement, the right to self-determination was a term that was used frequently to encapsulate many of their demands. It was a catch-all term that included ideas such as autonomy for persons with disabilities, a right to make their own decisions and the right to be included. For international lawyers, however, the right of self-determination was a term that meant something else entirely. They understood it to be a group right that was traditionally applied to colonies and territories under foreign occupation. Proposals elsewhere to expand it to other groups, such as indigenous peoples, were hotly disputed. The suggestion that it be included in the disability convention made government lawyers shift uncomfortably in their seats.

The language of international human rights law, on the other hand, caused its own problems for disabled delegates. The original draft of the article on equality and non-discrimination included a paragraph on “special measures”. This was a concept that has a long history in international human rights law and that had been borrowed from the Convention on the Elimination of Racial Discrimination and the Convention on the Elimination of All Forms of Discrimination against Women. The word “special” in the disability community, however, had attracted derogatory overtones due to its misuse over the years, and disabled persons' organisations rejected a proposal to use it in their own convention.

The first few days of the meeting, therefore, saw much confusion over the difference in language. There was debate about how to, and whether to, translate terms and concepts used by the disability community into the language of

⁹⁰These contributions were not issued as official UN documents, but were listed in paragraph 7 of the report of the Working Group (A/AC.265/2004/WG.1), issued in an informal compilation at the meeting in hard copy and CD Rom, and made available on the UN Enable website, <http://www.un.org/esa/socdev/enable/rights/comp-element0.htm>. Accessed April 30, 2015.

international human rights law, or whether to use them as they were understood by the disability movement.

Negotiations proceeded, despite the initial misunderstandings, at a fast pace. Each draft article was drawn up by informal drafting groups working late into the evenings at the New Zealand Mission, with the assistance of anyone who wished to attend. The results of the discussions were issued the next morning for discussion by the Working Group.

By the time the overall text was being pulled into shape towards the end of the meeting, the major issues that would come to dominate the negotiations in the Ad Hoc Committee over the next three years had become apparent. These were the questions of the legal capacity of persons with disabilities, institutionalisation and forced interventions, a raft of social, religious and cultural values, a debate over inclusion versus segregation, and the treatment of women and children with disabilities. These are all discussed in more detail in the next section.

The Working Group was able to complete a text in two weeks because it did not need to solve any of these difficult issues. It focused on concluding a text that had the widest possible support, and by reflecting any major disagreements in footnotes to the text. The draft convention that it forwarded to the Ad Hoc Committee was one that had significant support and buy-in from governments as well as disabled peoples' organisations. The Working Group draft was seen as a strong and robust text that would give negotiations in the Ad Hoc Committee the strongest possible start. There was some hope that a lot of progress could be made by the end of that year and the convention would soon become a reality.

3.4 The First Reading of the Draft: Momentum Stalls

Optimism, however, soon evaporated when the Ad Hoc Committee met for a third time four months later for the first read through of the Working Group draft. Rather than focus on the key issues that had been identified by the Working Group in its extensive annotations, delegations proposed amendments to every part of the text. Secretariat officials were barely able to keep up with the suggestions as they flooded in. Additions were marked with round brackets and deletions with square brackets, resulting in a Gordian Knot of overlapping proposed amendments.

By the end of the meeting, the 25-page Working Group draft had ballooned to a 66-page document that was so heavily bracketed that it was, in places, virtually unreadable. Many delegations expressed concerns privately that the Working Group's efforts had been undone because the text had essentially been turned back into a compilation of all proposals, without any attempt to identify levels of support, common themes, points of consensus or to weave similar and duplicative proposals together.

These frustrations led to a behind-the-scene tussle over how the Committee should respond to the proposed amendments. Mexico thought informal negotiations should begin right away to prepare revised draft articles, and sought to lead this

work by holding invitation-only meetings in the evenings, starting with articles one and two.

In response, the Chair of the Ad Hoc Committee asserted his control by issuing his own revised “clean” drafts for articles one and two. This rendered the Mexican meetings irrelevant, and it was not a popular move. Delegations were unsure who had done the drafting of the Chair’s drafts, and the bureau asked him not to issue any more.

With both attempts to hurry the process along stymied, it was not clear how the Committee was to proceed. Even worse, the participation of disabled persons’ organisations was in doubt. The Chair proposed to use a spare day at the end of the meeting to begin informal negotiations on a second reading. He announced that the informal negotiations would be private meetings for states only, consistent with the practice of the General Assembly. His ruling was immediately challenged by Yemen, the European Union, Israel and Thailand. New Zealand and Canada announced that they would refuse to participate any further if disabled persons’ organisations were shut out.

The meeting concluded in confusion, with its working methods in disarray, and the text of the draft convention in a shambles.

3.5 The Second Reading: The Ad Hoc Committee Gets Down to Business

Between the May and August meetings of the Ad Hoc Committee that year, there were constant negotiations by New York based diplomats, who spent much of the summer discussing how to pull the process back on track.

The Working Group had been successful because it had adopted unprecedented working methods allowing for the full participation of disabled persons’ organisations who were, after all, key to the discussions. The Mexican and New Zealand delegations brokered an eventual compromise to return, as much as possible, to the Working Group model, where all discussions happened in the main room in public meetings. To ensure consistency with the Working Group methods, delegates requested that the second reading negotiations be coordinated by Ambassador MacKay of New Zealand.

Based on this consensus the second reading proceeded relatively smoothly; slowly and cautiously at first during the fourth session, but with increasing pace at the fifth and sixth sessions as the positive atmosphere returned. Ironically, any suggestion that negotiations relocate to private meetings in small rooms became impossible because the number of delegates from governments and disabled person’ organisations continued to grow from one session to the next. There was no chance of the Ad Hoc Committee fitting in any room except Conference Room Four—the largest meeting room at UN headquarters besides the General Assembly Hall itself.

The core themes of the debate that had emerged during the Working Group were a focus of much of the discussion during the second reading. These are detailed below.

3.5.1 Legal Capacity

The question of legal capacity is at the core of many of the rights in the text, and historically the denial of legal capacity had led to many violations of individual rights. Most prominent in the text was a draft article on equal recognition as a person before the law. It provided that states should recognise persons with disabilities as individuals with rights before the law equal to other persons and that they had full legal capacity on an equal basis to others.

The article was key to achieving the shift from the medical to the rights model of disability. Rather than being seen as objects of the law, without the capacity to exercise their own rights, the article would deem them to be subjects of the law, like everyone else. It promoted a shift to a model of supported, rather than substituted, decision-making. Rather than envisaging a cutoff point where people who need support are deemed not legally capable, that model recognised that people with disabilities may require varying degrees of support to exercise their legal capacity.

Many government delegations, however, sought to make an allowance for exceptions. They argued that in some cases, persons with disabilities would not be able to exercise their legal capacity. In such situations, governments wanted the article to retain the possibility of substitute decision-making where someone would be appointed to make decisions on behalf of the person with the disability.⁹¹ For this reason, they insisted that the draft article contain safeguards to prevent misuse and abuse in such situations, much like earlier instruments.

The Working Group had fudged the issue by including in the article the concept of safeguards but without specifically mentioning any ability for states to allow for substitute decision-making. A footnote in the Working Group draft noted that the safeguards “should apply only in exceptional circumstances”.⁹²

During the first reading, amendments were proposed that would have expressly allowed for the “appointment of third parties as legal guardians”, as suggested by Canada, or a “legal representative”, as suggested by India.⁹³ Similarly, Morocco proposed to add to the article on the right to health the ability for a “guardian or legal representative” to be able to give consent to medical treatment.⁹⁴

Many states had struggled to reconcile the need to promote a rights-based approach on the one hand, and their wish to maintain some ability to exercise coercive power to force medical interventions on the other. China, for example,

⁹¹Disability Negotiations Daily Summary, Vol. 3 No. 8, January 14, 2004.

⁹²A/AC.265/2004/WG.1, Annex I, cit., Article 9, para. (c) (ii).

⁹³Report of the third session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, A/AC.265/2004/5, Annex II, June 9, 2004, Article 9.

⁹⁴A/AC.265/2004/5, Annex II, cit., Article 21, para. (j).

proposed the use of safeguards for the use, in exceptional circumstances, of unwanted medical interventions.⁹⁵

At the second reading Canada led discussions to reorganise the article on equality before the law to base it more clearly on existing human rights law. The Canadian redraft was modelled on Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women.⁹⁶

Although this had the welcome effect of focusing the article, it opened up a debate on the meaning of “legal capacity” that was to remain unresolved for the duration of the negotiations. Both China and Russia argued that when the term was translated into their languages, it was understood to mean the capacity to hold rights rather than the capacity to exercise them.⁹⁷ This would allow a slight of hand where states could remove legal capacity in practice while maintaining a legal fiction that the right still existed.

Minutes before the end of the fifth session of the Committee, China insisted on the addition of a footnote to the report of that meeting that said “In Chinese, the term ‘legal capacity’ refers to ‘legal capacity for rights’, rather than ‘legal capacity to act’”. Russia and Syria seized the opportunity to add “Arabic” and “Russian” to the footnote also, and the report was adopted before anyone could object, let alone consider the implications.⁹⁸

The meeting also included in the redraft of that article a new paragraph, based on the proposals that had been made during the first reading, which provided for a procedure and safeguards for personal representation. The report, however, noted that there was still no agreement to the paragraph, with disabled persons’ organisations arguing that any mention of personal representation might encourage its overuse by states, undermining the concept of supported, instead of substitute, decision-making.⁹⁹

3.5.2 Forced Intervention and Institutionalisation

There was a general acknowledgement during the debate that many practices around the world in relation to forced interventions and institutionalisation have been abhorrent, amounting to the most intrusive and appalling abuse of human rights. The World Network of Users and Survivors of Psychiatry was a particularly loud critic of the ability of the state to commit persons with disabilities to institutions and to receive forced medical interventions.¹⁰⁰ There was widespread

⁹⁵ A/AC.265/2004/5, Annex II, cit., Article 21, para. (k).

⁹⁶ Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its fifth session, February 23, 2005, A/AC.265/2005/2, Annex II, para. 15.

⁹⁷ Disability Negotiations Daily Summary, Vol. 6 No. 2, January 25, 2005.

⁹⁸ A/AC.265/2005/2, Annex II, cit., note b.

⁹⁹ A/AC.265/2005/2, Annex II, cit., para. 22.

¹⁰⁰ Disability Negotiations Daily Summary, Vol. 3 No. 8, January 14, 2004.

acknowledgement in the room that the convention as a whole must address that situation and allow persons with disabilities to live in the community rather than in institutions.

But the Working Group had struggled to find a way of dealing with the issue clearly. The article on liberty and security of the person clearly negated the state's ability to detain people based on a disability.¹⁰¹ But while the deprivation of liberty of persons with disabilities has most often been based on civil commitment, states have traditionally interpreted the right of liberty and security of the person narrowly, to apply only to the criminal justice system and not to mental health institutions. The Working Group was essentially trying to fit a square peg into a round hole, despite the fact that the Human Rights Committee has held that this right applies to all deprivations of liberty, not just to those in the criminal justice system.

More clearly, the right to health in the Working Group draft stated that medical interventions should not be imposed, and should only occur with the free and informed consent of the person with a disability.¹⁰²

But in both articles, many governments were reluctant to agree to proposals that would completely remove their ability to detain and treat those persons who may pose a danger to themselves or society. They argued that they needed to retain the ability to compulsorily treat some people and that this meant an express provision should be made in the convention, along with safeguards.

At the second reading, the Committee agreed to separate out the issue of involuntary medical treatment into its own article on protecting the integrity of the person.¹⁰³ The Network of Users and Survivors of Psychiatry, however, maintained that forced interventions were tantamount to torture and should be dealt with in the article on torture.¹⁰⁴

Efforts were made to find a compromise where forced intervention and institutionalisation would be considered illegal except in exceptional circumstances prescribed by law. Furthermore, compulsory treatment should be provided in the least restrictive setting possible, and states should ensure that its use be minimised. A paragraph acknowledging that there could be exceptions to the rule, and providing for safeguards where there was no alternative to involuntary treatment, was included in the report of the meeting.¹⁰⁵

¹⁰¹ A/AC.265/2004/WG.1, Annex I, cit., Article 10, para. 1 (b) said that "any deprivation of liberty shall be in conformity with the law, and in no case shall be based on disability."

¹⁰² A/AC.265/2004/WG.1, Annex I, cit., Article 21, paras. (j) and (k).

¹⁰³ A/AC.265/2005/2, Annex II, cit., para. 58.

¹⁰⁴ Disability Negotiations Daily Summary, Vol. 4 No. 3, May 26, 2004.

¹⁰⁵ A/AC.265/2005/2, Annex II, cit., para. 67.

3.5.3 Social, Religious and Cultural Values

Emerging out of the debates on the right to respect for privacy, the home and the family, and the right to health were some age old UN debates on differences over social, religious and cultural values.

Disabled persons' organisations listed a long litany of discrimination, such as being denied the opportunity to marry and found a family due to an ill founded assumption that they would not make good parents. The practice of forced sterilisation was particularly highlighted as a routine and ongoing violation of the rights of persons with disabilities.¹⁰⁶

The Working Group had included in the draft article on the right to privacy, therefore, the right to marry, the right to experience parenthood and an obligation on states to ensure that persons with disabilities are not denied the equal opportunity to experience their sexuality. Many delegations from more conservative states were uncomfortable with including these issues.

More difficult still was the debate over sexual and reproductive health in the article on the right to health. The debate in the United Nations on sexual and reproductive health has long been hijacked by right to life lobby groups, which see in the phrase—despite all evidence to the contrary—a hidden promotion of abortion. Many delegations did not, therefore, want to bring such a phrase into the convention.

Delegates with disabilities, however, resisted being sidetracked by the politics of the issue and focused their statements on the need to highlight what was, for them, one of the most neglected and invisible aspects of their right to health. South Africa, for example, pointed out the “humiliating” perception that persons with disabilities are, or should be, asexual and do not need to avail themselves of reproductive health care.¹⁰⁷

Subsequently, the rest of the negotiations in the Ad Hoc Committee were shadowed closely by right to life groups, whose single focus was to delete any reference to sexual and reproductive health, and who showed no interest in any other aspect of the rights of persons with disabilities.

At the first reading there were many proposals to remove the most sensitive parts of the text. Some states sought to re-cast the article on privacy, home and the family to be more explicitly focused on family life. Qatar, for example, suggested language to “encourage the full participation in family life by persons with disabilities”.¹⁰⁸ In addition, there were many proposals to either delete the reference to sexuality or to place it squarely “within the framework of legitimate marriage”, as proposed by Libya, or “in accordance with various religious and social conventions and traditions”, as proposed by Yemen.¹⁰⁹

¹⁰⁶Disability Negotiations Daily Summary, Vol. 3 No. 5, January 9, 2005.

¹⁰⁷Disability Negotiations Daily Summary, Vol. 3 No. 6, January 12, 2004.

¹⁰⁸A/AC.265/2004/5, Annex II, cit., Article 14, para. 2.

¹⁰⁹A/AC.265/2004/5, Annex II, cit., Article 14, para. 2 (a).

At the second reading, very little progress was made, but there was general agreement that people with disabilities should be treated on an equal basis with others.¹¹⁰ This was not enough, however, to bridge the divide, and the calls to delete the references to sexuality and sexual and reproductive health continued.¹¹¹

3.5.4 Inclusion versus Segregation

The move from segregation to inclusion was woven through numerous articles, including living independently and being a part of the community, participation in political and public life, and participation in cultural life, recreation, leisure and sport. For the most part there was little controversy, and all delegates agreed on the need to promote inclusion for persons with disabilities. But in two areas, the debate over segregation versus inclusion became drawn out and protracted.

On the right to education, at issue were the differing expectations of various communities within the disability movement. Some delegates argued that children with disabilities should be included in the mainstream schooling system as the rule, with the existence of specialist education services only as the exception. Inclusion International, for example, pointed out that once children with intellectual disabilities are segregated in a special school, they almost always end up in sheltered workshops, in a pattern of moving from one segregated environment to the next.¹¹²

Others argued that educating children with disabilities in general schools would result in them missing out on specialised education. The World Blind Union, for example, criticised UNICEF's promotion of inclusive education, arguing that blind children find themselves mainstreamed in classes with no support. The World Federation of the Deaf, in particular, linked its stance to the right of linguistic minorities to be educated in their own language, pointing out that specialised education is not the same as segregated education.¹¹³

There was considerable debate over which approach was most appropriate and how to strike a balance. Thailand had suggested that the text should not favour one model over the other, and persons with disabilities should have the right to choose general or specialised education.¹¹⁴ The debate was a heated one, and the Working Group had not been able to do more than agree to a basic text, annotated with extensive footnotes setting out the positions of all major points of view in the debate.¹¹⁵

¹¹⁰A/AC.265/2005/2, Annex II, cit., para. 94.

¹¹¹A/AC.265/2005/2, Annex II, cit., paras. 96 and 124, and Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its sixth session, A/60/266, Annex II, August 17, 2005, para. 85.

¹¹²Disability Negotiations Daily Summary, Vol. 3, No. 6, January 12, 2004.

¹¹³Disability Negotiations Daily Summary, Vol. 3, No. 6, January 12, 2004.

¹¹⁴Disability Negotiations Daily Summary, Vol. 3, No. 6, January 12, 2004.

¹¹⁵A/AC.265/2004/WG.1, Annex I, cit.

At the first reading, contradictory proposals were inserted into the text. A proposal by the European Union, for example, made it clear that while the ultimate aim was inclusion, “where the general education system does not yet adequately meet the needs of person with disabilities”, specialist facilities could continue in the meantime.¹¹⁶ On the other side of the debate, Costa Rica had submitted a new paragraph that explicitly provided that “deaf and deaf blind persons have the right to receive education in their own groups”.¹¹⁷

At the second reading, the Committee agreed that the core issue of inclusion versus segregation needed to be dealt with up front. The first paragraph on the Right to Education was amended to include a statement committing states to the “goal of inclusiveness in their general education systems”. It also included a provision to allow for alternative forms of education in exceptional cases “bearing in mind the goal of full inclusion”.¹¹⁸

The World Blind Union, the World Federation of the Deaf and the World Federation of the Deafblind, however, continued to insist that their needs for separate education be taken into account,¹¹⁹ and a new paragraph was proposed setting out that deaf, blind and deafblind children had the right to choose education in their own groups.¹²⁰ The Coordinator’s report diplomatically noted that the proposal “received some support”, but it was clear that deep divisions still existed over the issue.

For the draft article on the right to work, a similar debate took place. The main focus of the debate was to ensure that persons with disabilities were guaranteed equality of treatment in the work place, were granted reasonable accommodation, and had access to the same labour rights as others. The debate focused, therefore, on the rights of persons with disabilities in the mainstream workforce. A minority of delegations, however, argued that the article needed to contain explicit provisions for fair treatment in sheltered workshops.

Others viewed sheltered workshops as characterising precisely the sort of segregation that the convention was meant to outlaw. They pointed out that sheltered workshops had an unhappy history, which included meaningless work, exploitative conditions and segregation. They considered that including a mention of them—even to outline safeguards to protect against exploitation—would be inconsistent with one of the main aims of the convention.

In the first reading, for example, most proposals related to ensuring labour rights and participation in the open workforce. But Bahrain, Namibia and Israel proposed

¹¹⁶A/AC.265/2004/5, Annex II, cit., Article 17, para. 3.

¹¹⁷A/AC.265/2004/5, Annex II, cit., Article 17, para. 4.

¹¹⁸A/60/266, Annex II, cit., para. 36.

¹¹⁹Statement on Inclusive Education for Persons who are Deaf, Blind and Deafblind: The rational for choice in education, issued by the World Federation of the Deaf, the World Blind Union and the World Federation of the Deafblind, August 2, 2005.

¹²⁰A/60/266, Annex II, cit., para. 40.

language to encourage and regulate sheltered workshops, and Chile suggested supporting “modalities of protected work”.¹²¹

The majority opinion clearly shifted away from segregation by the second reading. There was a clear preference expressed for the article to deal only with the rights of persons with disabilities in the open labour market. The report of that meeting noted that “The balance of views in the Committee on sheltered workshops was that such settings were undesirable because of the potential for segregation from the community and their conditions of employment”.¹²² Only Israel and the International Labour Organisation continued to swim against the tide, arguing that the convention should not ignore the reality of persons with disabilities who were working in sheltered workshops, or for whom there are no other options.¹²³

3.5.5 Women and Children with Disabilities

The Working Group had not had time to adequately tackle the issue of women with disabilities and had only had a preliminary discussion of children with disabilities. Both issues received many proposals during the first reading.

The Republic of Korea proposed a whole new article on women with disabilities that sought to centralise in one article many issues of specific relevance to women with disabilities that could be found elsewhere in the text, such as maternal health, labour rights during pregnancy, and sexual exploitation and abuse.

On children, the Working Group had included in its text an almost exact replica of Article 23 of the Convention on the Rights of the Child. Delegates had suggested that simply replicating the article from one treaty into another would not be an advance on existing human rights protections.¹²⁴ But the discussion had been rushed, and there was no time to consider the issue further.

The article was, not surprisingly, subject to extensive proposals during the first reading. The EU proposed deleting it altogether. Sierra Leone proposed a wholesale redraft. Canada, India and Uganda proposed eight new paragraphs between them. Japan proposed that instead of repeating the substance of Article 23 of the Convention on the Rights of the Child, there could simply be a cross reference to it.¹²⁵

Many delegations supported separate articles pointing to the need to highlight the issues. But in both debates, others pointed out that separate articles would have the result of “compartmentalising” those two groups so that people would look to apply the relevant article on children or women with disabilities but neglect to

¹²¹A/AC.265/2004/5, Annex II, cit., Article 22.

¹²²A/60/266, Annex II, cit., para. 96.

¹²³Disability Negotiations Daily Summary, Vol. 7 No. 8, August 10, 2005.

¹²⁴Disability Negotiations Daily Summary, Vol. 3 No. 5, January 9, 2004. It was noted, in fact, that because the Convention on the Rights of the Child had almost been universally ratified, with only Somalia and the United States not already bound by it, there would be no practical effect in repeating it.

¹²⁵A/AC.265/2004/5, Annex II, cit., Article 16.

notice that the rest of the Convention applied to those groups also.¹²⁶ They proposed instead that issues relevant to women and children should be mainstreamed throughout the text. During the first reading, for example, Canada, Mexico, Costa Rica and Norway had all proposed that equality between men and women be made a general principle of the convention in article two.¹²⁷

Out of the second reading arose a suggestion from the women's wing of the International Disability Caucus for a "twin track" approach—to have separate articles on women and children and also specific mentions throughout the text.¹²⁸ But the issue was left to be resolved at a later date.

3.5.6 Conclusion of the Second Reading

The second read through of the text concluded at the end of the sixth meeting in August 2005. It produced a set of reports that contained updated text and extremely detailed written commentaries that form what is perhaps the most meticulous set of *travaux préparatoires* of any human rights treaty. The reports began to sift common ground from the debate into new text, mostly free of brackets. Proposals were captured that had gathered a good deal of support, while those that did not were quietly dropped.

Midway through the second reading, at the conclusion of the fifth meeting, Ambassador Gallegos concluded his posting as Ecuador's Ambassador to the United Nations, regretfully announcing that he would step down as Chair.¹²⁹ To ensure continuity in the discussions, Ambassador MacKay stepped into the position and continued through to the end of the negotiations.

3.6 The Third Reading: The Chair Issues a Clean Text

Debate had gone about as far as it could, and the results of the second reading needed to be shifted into a clean text to serve as the basis for the next reading. Ambassador MacKay, therefore, produced a "Chair's text", using much of the language that had already been generally agreed during the second reading. The Chair's approach was to identify the common ground and, in some places, to suggest possible ways of bridging the differences. The Chair also restructured the convention into a new order,¹³⁰ based on the order used in other human rights treaties, and weeded out inconsistent use of language and a certain amount of duplication that had survived the second reading.

¹²⁶Disability Negotiations Daily Summary, Vol. 7 No. 2, August 2, 2005.

¹²⁷A/AC.265/2004/5, Annex II, cit., Article 2.

¹²⁸Informal proposal distributed by the International Disability Caucus, August 4, 2005.

¹²⁹Disability Negotiations Daily Summary, Vol. 6 No. 10, February 4, 2005.

¹³⁰Letter dated 7 October 2005 from the Chairman to all members of the Committee, A/AC.265/2006/1, Annex II, October 14, 2005.

The text was also accompanied by a letter from the Chair providing a detailed commentary on the draft. It encouraged delegates to come to the seventh session prepared to be flexible.¹³¹

The Ad Hoc Committee enthusiastically began to review the Chair's text in January 2006 at its seventh meeting, and it made good progress in narrowing down differences on the remaining issues. The most difficult questions, however, were left for its last meeting.

The Ad Hoc Committee met for its eighth meeting in August 2006. The message that the eighth session was to be the last was clearly taken seriously, but with an unwelcome result. Sensing it was their last chance to secure national positions, many delegations ignored the exhortations of the Chair and made a flurry of proposals during the first week. They proposed over 150 amendments to the text that had otherwise been agreed to, including to virtually every substantive article of the convention. Many were last ditch attempts to revive proposals that had been rejected at previous meetings. Others were clearly intended as negotiating capital to create leverage for issues that remained in square brackets.

The slew of new proposals derailed the Chair's intention that the meeting focus chiefly on those few issues that remained in square brackets and cast in doubt the possibility of concluding the negotiations. At the close of the first week, the Chair declared the meeting to be in a crisis and called on delegations to exercise restraint in insisting on their proposals. A somber mood settled over the room. Further proposals, meanwhile, continued to be emailed to the secretariat over the weekend.

The following week, the Chair announced that if delegations really wanted to conclude the negotiations, unusual working methods would need to be adopted. He suggested that any delegation could object to a proposed amendment, and if it did, the amendment would be dropped unless the delegation that had proposed it could strike a deal with who that had objected. These were certainly unorthodox working methods for the United Nations, but they reflected the strong desire to finish the convention quickly.

The Committee read through the compilation of proposals at a fast clip, and delegations settled into a pattern of deal making and trade-offs. Proposals that had not received support were steadily withdrawn, and the Committee was able to re-focus its attention on the serious disagreements that remained. The bureau members from South Africa, Jordan, Costa Rica and the Czech Republic, along with the New Zealand and Mexican delegations, put aside their own positions and fanned out across the room brokering deals and suggesting compromises wherever they could.

The difficult issues that had persisted throughout the negotiations were predictably the last to be solved. The solutions to these questions are discussed below.

¹³¹ A/AC.265/2006/1, cit., paras. 6 and 7.

3.6.1 Legal Capacity

On the question of “legal capacity” versus “capacity to act”, the Chair had included both phrases in his text in square brackets. He noted in his covering letter, however, that “legal capacity” was the term used in other conventions and suggested that the Committee should, therefore, stick to that.¹³² But China had other ideas, and not only did the Chinese delegation insist on retaining the phrase “capacity to act”; it also insisted on re-inserting the footnote it had asked to be attached to the report of the fifth meeting.¹³³

The Chair had also included in his text the disputed paragraph providing for personal representation but, again, in square brackets. In his covering letter, he pointed out that paragraph (a) of the article “clearly envisages a wide spectrum of ‘assistance’ depending on the circumstances of each case”.¹³⁴ Personal representation was clearly one end of the spectrum, so did not need to be explicitly spelled out. The Chair suggested, therefore, that it be deleted.

The compromise had begun to emerge at the previous meeting. The New Zealand delegation proposed an alternative paragraph that retained the safeguards that had accompanied the provision for personal representation—but without mentioning personal representation. The proposal would neither explicitly provide for substitute decision-making, nor explicitly outlaw it.¹³⁵

At the final meeting, consensus was forming around the New Zealand proposal, but China remained unmoved, continuing to demand the inclusion of the footnote from the previous report in the final text.

On the very last day of the meeting, it became clear that no further progress would be made on other outstanding issues unless an agreement was found on legal capacity—and the only way to secure China’s agreement was to include the footnote along with the compromise text. The language was, therefore, gavelled through with the footnote included. During the rush to conclude the issue, several delegations were clearly caught by surprise. After the convention had been adopted, the European Union, Canada and Australia objected to the footnote and announced that they would seek to reopen the issue when the convention would be put before the General Assembly for final adoption.

3.6.2 Forced Intervention and Institutionalisation

On the question of the integrity of the person, the Chair’s text had retained the paragraph that provided for safeguards for involuntary interventions but, again, in

¹³²A/AC.265/2006/1, cit., para. 53.

¹³³Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its seventh session, A/AC.265/2006/2, February 13, 2006, Article 12, para. 2.

¹³⁴A/AC.265/2006/1, cit., para. 54.

¹³⁵A/AC.265/2006/2, cit., Article 12.

square brackets. Despite strenuous efforts to find a compromise, views had remained firmly polarized between those who wished to delete and those who wished to retain the offending paragraph. The International Disability Caucus continued to maintain that there should never be any exception for forced interventions, so there should be no need for safeguards.¹³⁶

At the final meeting, the Committee was close to agreeing to a compromise proposal similar to the compromise on legal capacity—to retain mention of safeguards, but without specifically mentioning forced intervention. But time ran out before all delegations could be convinced. An alternative text, containing only a short one-sentence principle on the right to physical and mental integrity, was put forward by the International Disability Caucus. Consensus quickly coalesced around it, given the lack of time remaining to consider anything more complicated, and the rest of the article was discarded.

3.6.3 Social, Religious and Cultural Values

On the issues to do with sexuality, the Chair's text had attempted to capture the middle ground by including a new phrase, "in accordance with national laws, customs and traditions of general application".¹³⁷ This proposal did not prove a success, satisfying neither side of the debate.¹³⁸ At the seventh meeting, the Committee took the concept, inverted it and inserted it into the opening paragraph, creating an obligation on States Parties to "ensure that national laws, customs and traditions relating to family and personal relationships do not discriminate on the basis of disability".¹³⁹

Discussions on the gender language, sexuality, sexual and reproductive health, as well as unresolved language on the family, had clearly become an overall stumbling block in the negotiations affecting a large number of articles. In a fitting re-enactment of the Working Group process, the New Zealand Mission was opened up to interested delegates on the final evening of the meeting. In talks that went until 4 am, a compromise package covering all of those issues was hammered out.

The package included strengthened references to the family in the preamble to the convention, retention of some of the references to "gender" and the inclusion of sexual and reproductive health. The references to sexuality and sexual relationships became, simply, "relationships".

¹³⁶Disability Negotiations Daily Summary, Vol. 8 No. 4, January 19, 2006.

¹³⁷A/AC.265/2006/1, cit., para. 86.

¹³⁸Disability Negotiations Daily Summary, Vol. 8 No. 6, January 23, 2006, and Vol. 8 No. 7, January 24, 2006.

¹³⁹A/AC.265/2006/2, Annex II, cit., Article 23, para. 1.

3.6.4 Inclusion versus Segregation

The Chair had used in his text for the article on education a restructured version that had been developed in discussions during previous meetings led by the Australian delegation. While general agreement was getting closer at the seventh meeting, the article still retained the controversial statement that alternative measures should be provided in “exceptional circumstances” where the general education system could not meet the needs of persons with disabilities.¹⁴⁰

At the final meeting, Australia tirelessly worked the room searching for compromise language, and believed several times to have found it, only to have the agreements fall through shortly before they could be adopted. The final compromise, however, is a strong one. It neither expressly permits nor excludes separate education. But it does commit States Parties to ensure an inclusive education system, and at the same time to facilitate the learning of Braille and sign language, and to promote the linguistic identity of the deaf community.

The compromise on the right to work was somewhat easier to reach. Delegations agreed that the article should continue to focus on the protection of labour rights of persons with disabilities in general. The article was, however, tweaked, so that it applied to “all forms of employment”. The compromise meant that while sheltered workshops were neither specifically permitted nor prohibited, the protections of the article would cover them and, if they continued to exist, they would need to meet the same employment conditions as the open market.

3.6.5 Women and Children with Disabilities

The Chair had included in his text both an article on women and an article on children. But given the disagreement that was still evident during the second reading, he left both articles blank. In his covering note, he issued a gentle rebuke to the Committee. Noting in both respects that the issue was “mainly with respect to placement rather than substance”, he urged delegations to come to the meeting with flexible instructions because the Committee “cannot afford to be held up by such differences of approach”.¹⁴¹

The German and Kenyan delegations had been given the responsibility of working out a compromise solution. Much lobbying and cajoling of delegations in the margins of the meeting produced an agreement that short separate articles on women and children would be included in the general section of the convention. They would briefly cover general principles for the purposes of awareness raising and would be reinforced by specific references in the body of substantive articles where relevant.

¹⁴⁰ A/AC.265/2006/1, Annex I, Article 24, para. 2 (d).

¹⁴¹ A/AC.265/2006/1, paras. 41 and 44.

3.6.6 Monitoring

The final meeting was the first to discuss actual text on monitoring provisions for the convention. The Mexican delegation had hosted intercessional meetings during the summer, and three broad positions emerged. The first was to have no monitoring mechanism (and some delegations suggested that the treaty bodies of the existing human rights treaties could monitor the disability convention). The second was to have a traditional monitoring mechanism based on the committee system developed by the other core human rights treaties. The third option was to create an innovative new monitoring body.¹⁴²

There was limited support for the first and third options, and only the second looked capable of forming the basis of consensus. It became apparent at the final meeting that the most likely compromise was to duplicate what had been adopted in the past. The Committee eventually agreed to a monitoring body that looks more or less like the committees tasked with monitoring the other core human rights treaties.

The biggest stumbling block in getting there was over the question of whether to include a right of individual petition to the committee—a feature of several of the other core human rights treaties. Many delegations were not convinced, however, as to the justiciability of economic, social and cultural rights.

Those in favour were adamant, however, arguing that the disability convention should have no lesser rights of appeal than other core human rights treaties, glossing over the fact that an appeal mechanism would actually be a groundbreaking innovation for economic, social and cultural rights. (One has subsequently been adopted for the Covenant on Economic, Social and Cultural Rights, but at that point it was still under negotiation).

The solution, proposed by Liechtenstein, appeared in the last days of the meeting and was to separate out the appeal mechanism into a separate optional protocol. Once it was apparent that an optional protocol was the only way out, the compromise was agreed to in record time. The Liechtenstein delegation drafted the protocol overnight, and it was agreed to in the space of two hours the following morning—perhaps the fastest negotiated human rights instrument of all time.

3.6.7 The Last Day

Negotiations went right to the wire. When the Friday afternoon session began on the last day of the meeting, many of the difficult issues had not yet been agreed. The Chair gavelled the meeting open with several issues unresolved, and negotiations still proceeding frantically at the back of the room and in the corridors outside.

¹⁴²Informal compilation of proposals on monitoring, prepared by the Mexican Mission, May 18, 2006.

The compromises on legal capacity, integrity of the person and education were all forged in those last hours. Following the adoption of the last article, the Chair put the text as a whole to the room and gavelled it through to a standing ovation.

Speaking following the adoption, the President of the General Assembly said that he had sensed that he was about to enter “a room where history was going to be made”. He pointed out that “You are sending a message, a message that we want to have a life in dignity for all, and that all human beings are equal”. Noting that the quality of a society is measured by how it treats its most vulnerable citizens, he congratulated the delegates for their years of work. “You have done it!” he said, “You should celebrate!”¹⁴³

3.7 Adoption by the General Assembly

The convention was not, however, out of the woods yet. There was a technical step still to be completed. UN treaties are usually referred to a ‘drafting committee’ following their adoption, which ensures that the treaty is internally consistent, it uses terminology consistently, and the various language versions have harmonized translations. The drafting committee was chaired by Liechtenstein and was to report back to a resumed meeting of the eighth session of the Ad Hoc Committee for final adoption and referral to the General Assembly.

This technical step would not normally feature in a negotiating history since it is entirely editorial in nature. But in this case, it gave delegations the opportunity to continue to contest the presence of the footnote on legal capacity. The International Disability Caucus wasted no time in mounting a lobbying campaign to have the footnote removed. The Caucus wrote to all delegates pointing out the harm the footnote did to the integrity of the text—for both substantive and linguistic reasons—and urged them to press for the removal of the footnote.¹⁴⁴

Negotiations continued to that end in the succeeding months in the margins of the drafting committee. The arguments put forward by the International Disability Caucus proved to be persuasive. Given that all language versions of UN treaties are equally authentic, and all States Parties are equally bound by each language version, a footnote purporting to guide the interpretation of three of the six UN languages would not have any real effect. The face-saving way out was to use the Arabic, Russian and Chinese translations of “legal capacity” that already existed in the Convention on the Elimination of Discrimination against Women (since it was language already accepted in that treaty) and to delete the footnote. Syria, Russia and China all agreed to the compromise.

¹⁴³Disabilities and Rights, UNTV, August 25, 2006, UN Audiovisual Library, <http://www.unmultimedia.org/avlibrary/asset/U060/U060825c/>. Accessed 30 April, 2007.

¹⁴⁴Removing Article 12 Footnote, Letter from the International Disability caucus to Government delegates to the Ad Hoc Committee, September 5, 2006.

With the last disagreement finally tidied away, the Ad Hoc Committee met for the last time in December 2006 to adopt the final text. Speaking before the adoption, Louise Arbour, UN High Commissioner for Human Rights, paid tribute to the Committee. She said that “I believe that this Committee has been one of the most successful collaborations between states, civil society organisations, national human rights institutions and inter-governmental organisations in any UN forum”.¹⁴⁵

The Convention was then adopted by the Ad Hoc Committee and sent to the General Assembly, where it was adopted a week later on 13 December 2006 as the first comprehensive UN human rights treaty of the new millennium. The success of the Committee in forging a strong consensus document can be seen in that fact that when it opened for signature a few months later on 30 March 2007, it was signed by 81 states on the first day—a record for any UN treaty.

4 Conclusion

Years of lobbying by the disability movement for a convention, and then their participation in its development, saw disabled persons’ organisations transform themselves into human rights groups. During the negotiations of the Convention, persons with disabilities were active at all levels: as representatives of NGOs (of which more than 400 were accredited to the Ad Hoc Committee), as members of government delegations, as representatives of United Nations organisations and as delegates of National Human Rights Institutions.¹⁴⁶ Never before in the history of the United Nations have so many persons with disabilities been active and influential in international lawmaking. The time was finally ripe for persons with disabilities to become true subjects of human rights.

The result is a convention that differs considerably from earlier disability instruments. Unlike the declarations of the 1970s, the Convention contains no caveats relating to the possibility of enjoying human rights under impairment conditions. To the contrary, the Committee on the Rights of Persons with Disabilities made a point of making Article 12 the subject of its first General Comment, noting that every person with a disability must be regarded as legally capable and that Article 12 outlaws substitute decision-making regimes.¹⁴⁷

All those who participated in the process contributed to one of the richest, least politicised and most inclusive human rights debates at the United Nations for some years. The Ad Hoc Committee, spurred on by the demands of the disability community, managed to set aside the usual working methods of the General

¹⁴⁵Statement by Louise Arbour, UN High Commissioner for Human Rights, General Assembly Ad Hoc Committee, Resumed 8th session, New York, 5 December 2006.

¹⁴⁶Sabatello (2014); Quinn (2009); Trömel (2009); Lord (2009).

¹⁴⁷CRPD Committee, General comment No. 1, Article 12: Equal recognition before the law, CRPD/C/GC/1, May 19, 2014.

Assembly and created a new model of openness, participation and transparency. Despite all of the differences of opinion on the details, there was a unity of purpose in the Committee and a clear dedication to recognizing the rights of persons with disabilities.

The international disability community had convinced national governments across the spectrum of the United Nations to take their demands seriously and to negotiate with them as rights-holding individuals. The commitment of the International Disability Caucus and the quality of its arguments, as well as the many talented advocates for disability rights on government delegations, was an essential part of the process. Their candid and informative contributions consistently served to reaffirm the need for the Convention, to educate governments and to underscore why the task was so crucial. It also meant that the Convention is closely informed and influenced by the experiences of persons with disabilities worldwide. As they had said from the beginning, “Nothing about us without us”.

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A New Human Rights Model of Disability

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Disability studies provide the theoretical background for what we call the shift from the medical to the social model of disability. The social model of disability was developed as a critique to the medical model of disability. However, within disability studies, the social model of disability has been almost as strongly criticized as the medical model of disability. Michael Oliver, one of the founding fathers of the social model of disability, has recently called for a halt to this criticism, unless someone can come up with a better alternative.¹ The CRPD offers such an alternative: the human rights model of disability. It is by no means the only alternative to the social model of disability (many models have been developed, among them recently the capability approach model²), but the human rights model is an improvement on the social model of disability, and it is a tool to implement the CRPD.

¹Oliver (2013), p. 1026.

²Mitra (2006).

1 Understanding the Human Rights Model of Disability

The majority of States Parties' reports to the CRPD reveal an understanding of disability that follows the traditional medical model of disability. As it has often been stated, this model regards disability as an impairment that needs to be treated, cured, fixed, or rehabilitated. Disability is seen as a deviation from normal health status. Exclusion of disabled persons from society is regarded as an individual problem, and the reasons for exclusion are seen in the impairment. Michael Oliver, one of the founding fathers of the social model of disability, has called this the ideological construction of disability through individualism and medicalization, the politics of disablement.³ Further, the medical model of disability is that it is based on two assumptions that have a dangerous impact on human rights: (1) disabled persons need to have shelter and welfare, and (2) impairment can foreclose legal capacity. The first assumption legitimizes segregated facilities for disabled persons, such as special schools, living institutions, or sheltered workshops. The second assumption has led to the creation of mental health and guardianship laws that take an incapacity approach to disability.⁴ During the negotiations of the CRPD, the medical model served as a deterrent. While it was difficult to reach consensus among stakeholders on which way to go in terms of drafting the text of the Convention, there was overall agreement that the medical model of disability had to be overcome.⁵ Rather, the social model of disability was supposed to be the philosophical basis for the treaty. The paradigm shift from the medical to the social model has often been stated as the main achievement of the CRPD. However, it can be argued that the CRPD goes beyond the social model of disability and codifies a human rights model of disability.⁶

The social model of disability explains disability as a social construct through discrimination and oppression. Its focus is on society rather than on the individual. Disability is regarded as a mere difference within the continuum of human variations. The social model differentiates between impairment and disability. While the impairment relates to a condition of the body or the mind, disability is the result of the way environment and society respond to that impairment. Exclusion of disabled persons from society is politically analyzed as the result of barriers and discrimination.

The following six arguments elucidate the difference between the social and the human rights model of disability and explain to what extent the CRPD is a manifestation of the latter model.

³Oliver (1990).

⁴Dhanda (2007), pp. 429–462.

⁵Kayess and French (2008), pp. 1–24; Trömel (2009), pp. 115–138.

⁶The term 'human rights model' was already used in the run-up to the CRPD negotiations, e.g. by Degener and Quinn (2002), p. 13, and in Quinn and Degener (2002), p. 14.

2 The Difference Between the Social Model and the Human Rights Model

2.1 Impairment Does Not Hinder Human Rights Capacity

First, whereas the social model merely explains disability, the human rights model encompasses values for disability policy that acknowledge the human dignity of disabled persons. Only the human rights model can explain why all persons with disabilities have a right to be legally recognized as a person before the law.

The social model of disability was created as one explanation⁷ of exclusion of disabled people from society. It has been developed as a powerful tool to analyze discriminatory and oppressive structures of society. To use Michael Oliver's words:

[D]isability according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure to discrimination institutionalised throughout society.⁸

The social model does not seek to provide moral principles or values as a foundation of disability policy. The CRPD, however, seeks exactly that. The purpose of the treaty is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."⁹ In order to achieve this purpose, eight guiding principles of the treaty are laid down in Article 3, and following articles tailor the existing human rights catalogue of the International Bill of Human Rights¹⁰ to the context of disability. What makes human rights so special is that they are fundamental and inherent to the person. They cannot be given or taken away from an individual or a group. They are acquired by birth and are universal, i.e., every human being is a human rights subject.¹¹ Neither social status nor identity category nor national origin or any other status can prevent a person from being a human rights subject. Thus, the absence of impairment is not a prerequisite to be a subject of human rights.

The CRPD reflects this message in its preamble. The universality of all human rights for all disabled persons is reaffirmed,¹² and it recognizes that the human

⁷Other models are, e.g., the normalization principle, the minority model, or the Nordic relational model, Traustadottir (2009).

⁸Oliver (1996), p. 33.

⁹Article 1 of the CRPD.

¹⁰The "International Bill of Rights" is the collective term for the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights.

¹¹Article 1 of the UDHR says that "All human beings are born free and equal in dignity and rights."

¹²Preamble, para. (c), of the CRPD.

rights of all disabled persons, including those with more intensive support needs, have to be protected.¹³ The substantive articles put this principle into effect, such as in the article on the rights to equal recognition as a person before the law with equal legal capacity.¹⁴

Thus, the human rights model of disability defies the presumption that impairment may hinder human rights capacity. The social model of disability also acknowledges the importance of rights¹⁵ and has often been associated with a rights-based approach to disability as opposed to needs-based or welfare approach to disability policy.¹⁶ But scholars of disability studies have emphasized that the social model is not a rights-based approach to disability. Rather, it extends beyond individual rights to social relations in society to the broader system of inequality.¹⁷

2.2 The Human Rights Model Includes First and Second Generation Human Rights

Second, while the social model approach to disability policy supports anti-discrimination policy and civil rights reforms, the human rights model is more comprehensive in that it encompasses both sets of human rights, civil and political, as well as economic, social, and cultural rights.

The social model served as a stepping stone in struggles for civil rights reform and anti-discrimination laws in many countries.¹⁸ Meanwhile, the social model has become officially recognized by the European Union as the basis for its disability policy.¹⁹ Within disability studies, this approach was characterized as a tool for stipulating citizenship and equality.²⁰ To demand anti-discrimination legislation was a logical consequence of analyzing disability as the product of inequality and discrimination. In the US, where the social model of disability was conceptualized as the minority model,²¹ the fight for civil rights was similarly seen as a way to disclose the true situation of disabled persons as members of an oppressed minority. The focus on rights was perceived as an alternative to needs-based social policy that portrayed disabled persons as dependent welfare recipients. The ideology of dependency was coined by Michael Oliver as an essential tool of social construction of disability.²² Thus, anti-discrimination legislation was seen as a remedy to a welfare

¹³Preamble, para. (j), of the CRPD.

¹⁴Article 12, paras. 1 and 2, of the CRPD.

¹⁵Oliver (1990), p. 63.

¹⁶Waddington (2006); Degener and Quinn (2002); Lawson (2008); Lawson and Gooding (2005).

¹⁷Finkelstein (2007); Priestley (2005), p. 23.

¹⁸Degener and Quinn (2002), p. 6; Gooding (1994), pp. 10–13; Barnes (1991).

¹⁹European Disability Strategy 2010–2020.

²⁰Oliver (1990), p. 112.

²¹Davis (1997).

²²Oliver (1990) p. 83.

approach to disability. Disabled persons could thus be described as citizens with equal rights. Architectural barriers could be defined as a form of discrimination. Segregated schools could be described as apartheid. The shift from welfare legislation to civil rights legislation in disability policy became the focus of disability movements in many countries.²³ “We want rights not charity” was and still is a slogan to be heard around the world from disability rights activists.

However, anti-discrimination law can only be seen as a partial solution to the problem and is not in itself enough to move to a human-rights-based model of disability. Even in a society without barriers and other forms of discrimination, people need social, economic, and cultural rights. People need shelter, education, employment, or cultural participation. This is true for all human beings and particularly for disabled persons who have historically been excluded. Because impairment often leads to needs for assistance, it is especially true that disabled persons need more than civil and political rights. While welfare policies and laws in the past have failed to acknowledge and empower disabled persons as citizens,²⁴ laws on personal assistance services or personal budgets proved that even classical social laws can give choice and control to disabled persons.²⁵ It is thus illustrative that the global independent living movement has always phrased their demands in terms of broader human rights rather than in terms of pure anti-discrimination rights. The human rights model of disability includes both sets of human rights: civil and political, and economic, social, and cultural rights. These two categories of human rights, which were both included in the 1948 Universal Declaration but were then separated into two separate legally binding Covenants in the 1960s for political reasons,²⁶ are fully incorporated in the CRPD. The legal hierarchy of civil and political rights over economic, social, and cultural rights is slowly but steadily decreasing through international jurisprudence and the strengthening of monitoring and implementation of the International Covenant on Economic, Social and Cultural Rights (ICESCR).

The CRPD is a good example of the indivisibility and interdependence of both sets of human rights. It not only contains both sets of human rights, the text itself is evidence of the interdependence and interrelatedness of these rights. Some provisions on rights cannot be clearly allocated to one category only. For instance, the right to be regarded as a person before the law²⁷ is a right commonly regarded as a civil and political right.²⁸ However, Article 12, para. 3, of the CRPD speaks of support measures that disabled persons might need to exercise their legal capacity. These support measures are realized by social services, which fall into the

²³Breslin and Yee (2002); Lawson and Gooding (2005); Vanhala (2011).

²⁴Hvinden (2009), pp. 5–28.

²⁵Degener (1991); Power et al. (2013); Townsley (2010).

²⁶For an illustrative account of the political history of human rights, see Normand and Zaidi (2008).

²⁷Article 12 of the CRPD.

²⁸Article 16 of the ICCPR, Article 6 of the UDHR.

economic, social, and cultural rights sphere. Another example would be the right to independent living.²⁹ The right to independent living and being included in the community is an answer to human rights violations against disabled persons through institutionalization and other methods of exclusion, such as hiding in the home or colonizing at distant places. The concepts of independent living and community living are not rooted in mainstream human rights philosophy. They derive from the disability rights movement and other social movements such as the deinstitutionalization movement,³⁰ which came into being in the 1960s and 1970s in the United States, Scandinavia, Italy, and many other countries.³¹ The common catalogue of human rights of the UDHR does not contain a right to independent or community living. If at all, the right to independent living can be traced back to the freedom to choose one's residence, which in other treaties is usually linked to the freedom of movement and considered as a pure civil right.³² However, independent living can require—among others—personal assistance services, which are measures to realize social rights. Thus, the CESCR Committee has interpreted the right to an adequate standard of living³³ to include a right to independent living for disabled persons. But it has also linked the issue to anti-discrimination measures. Its General Comment No. 5 interprets Article 11 of the ICESCR as a right to “accessible housing” and to “support services including assistive devices,” which enable disabled persons “to increase their level of independence in their daily living and to exercise their rights.”³⁴ During the last 15 years, there has been an influx of publications on deinstitutionalization, the right to independent and community living, and States Parties' obligations under Article 19 of the CRPD.³⁵ Most legal publications characterized this article as a social right with strong freedom and autonomy components.³⁶

The CRPD Committee has not qualified the right to independent living as either a civil or a social right, yet. At the time of writing, a draft general comment on Article 19 is on the Committee's agenda. While the CRPD contains the progressive realization clause usually applied to state responsibility regarding social, economic, and cultural rights, it also includes a reminder that even economic, social, and

²⁹Article 19 of the CRPD.

³⁰Which in some countries was part of the disability rights movement; in other countries, it was not.

³¹Degener and Koster-Dreese (1995); Parker (2011); Quinn and Doyle (2012).

³²Article 13, para. 1, of the UDHR: “Everyone has the right to freedom of movement and residence within the border of each State.” See also Article 12, para. 1, of the ICCPR, Article 5, para. (d) (i), of the CERD, Article 15, para. 4, of the CEDAW.

³³Article 11 of the ICESCR.

³⁴CESCR, General Comment No. 5: Persons with Disabilities, E/1995/22, December 9, 1994, para. 33.

³⁵For example: Townsley (2010); Quinn and Doyle (2012); Parker (2011); Mansell et al. (2007); FRA European Union Agency for Fundamental Rights (2012).

³⁶Parker (2011); Quinn and Doyle (2012).

cultural rights are immediately applicable under some circumstances in public international law.³⁷

2.3 The Human Rights Model Values Impairment as Part of Human Diversity

A third argument is as follows: whereas the social model of disability neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life, and early death due to impairment and dependency, the human rights model of disability acknowledges these life circumstances and demands them to be considered when social justice theories are developed.

The social model of disability has been criticized for neglecting the experience of impairment and pain for disabled people and how it affects their knowledge and their identity. Both the dichotomy of impairment and disability as well as the materialist focus of the social model have been criticized, especially by feminist disabled writers such as Jenny Morris. In her famous book *Pride Against Prejudice*, she claims:

[T]here is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. A feminist perspective can help to redress this, and in so doing give voice to the experience of both disabled men and disabled women.³⁸

In a later publication, she writes:

If we clearly separate out disability and impairment, then we campaign against the disabling barriers and attitudes which so influence our lives and the opportunities which we have. This does not justify, however, ignoring the experience of our bodies, even though the pressures to do this are considerable because of the way that our bodies have been considered as abnormal, as pitiful, as the cause of our lives not being worth living. . . . In the face of this prejudice it is very important to assert that autonomy is not destiny and that it is instead the disabling barriers ‘out there’ which determine the quality of lives. However, in doing this, we have sometimes colluded with the idea that the ‘typical’ disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment.³⁹

³⁷Article 4, para. 2, of the CRPD reads: “With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.”

³⁸Morris (1991), p. 10.

³⁹Morris (2001), p. 17.

Other writers followed this path of criticism. Marian Corker and Sally French, who brought discourse analysis to disability studies, added that besides neglecting the importance of impairment, the social model fails to “conceptualize a mutually constitutive relationship between impairment and disability which is both materially and discursively (socially) produced.”⁴⁰ Many other disability study scholars have shared this critique. Bill Hughes and Kevin Paterson proposed to develop a sociology of impairment based on poststructuralism and phenomenology as a response to this dilemma of impairment/disability dichotomy.⁴¹ Tom Shakespeare has challenged the dichotomy on the basis that both are socially constructed and inextricably interconnected.⁴² The founders and advocates of the social model have emphasized that the social model of disability was never meant to ignore impairment. Michael Oliver states: “This denial of the pain of impairment has not, in reality, been a denial at all. Rather it has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than professional and medical treatment.”⁴³ However, he also contends that the social model is not a social theory of disability, which when developed should contain a theory of impairment.⁴⁴

The CRPD does not make any statement regarding impairment as a potential negative impact on the quality of life of disabled persons because the drafters were very determined not to make any negative judgement on impairment. However, persons with higher support needs are mentioned in the preamble⁴⁵ as a reminder that they must not be left behind and that the CRPD is meant to protect all disabled persons, not only those who are “fit” for mainstreaming. Impairment as an important life factor is also recognized in two of the principles of the treaty, though both principles do not mention impairment explicitly. Article 3, para. (a), introduces “respect for the inherent dignity . . . of persons,” while para. (d) refers to “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.” Respect for human dignity is one of the cornerstones of international human rights and domestic constitutional law today. It was introduced into many human rights catalogues after World War II as a response to the atrocities of the Nazi Regime and today is recognized as a core value of the United Nations.⁴⁶ The CRPD relates to the concept of human dignity more than any other human rights treaty. Respect for the human dignity of disabled persons is the purpose, and one of the eight guiding principles, of the treaty.⁴⁷ In addition, it is referred to five times in such various contexts such

⁴⁰Corker and French (1999), p. 6.

⁴¹Hughes and Paterson (1997).

⁴²Shakespeare (2014), pp. 72–91.

⁴³Oliver (1990), p. 38.

⁴⁴Oliver (1990), p. 42.

⁴⁵Preamble, para (j), of the CRPD.

⁴⁶Petersen (2012), pp. 1–9.

⁴⁷Articles 1 and 3, para. (a), of the CRPD.

as discrimination,⁴⁸ awareness raising,⁴⁹ recovery from violence,⁵⁰ inclusive education,⁵¹ and care delivery by health professionals.⁵² Further, recognition of the “inherent dignity and worth and the equal and inalienable rights of all members of the human family” is regarded as the “foundation of freedom, justice and peace in the world.”⁵³ All of these strong statements emphasize that impairment does not diminish human dignity. Never again may persons with disabilities be regarded as *lebensunwertes Leben* (life not worth living).

The international disability rights movement has fought for the CRPD for more than two decades. The long struggle for a human rights treaty was not only a fight of disabled persons’ organisations for political change but also an individual struggle of disabled people for recognition and respect in the sense of Axel Honneth’s recognition theory.⁵⁴ According to Honneth, political struggles of social movements always have a collective and an individual dimension. The individual dimension relates to the struggle as a process of identity formation that needs to be facilitated by self-respect, self-confidence, and self-esteem. The struggle for human rights of disabled persons is thus a struggle for the global collective of disabled people and also a fight for respect and recognition of the individual disabled by society. The human rights model of disability clarifies that impairment does not derogate human dignity, nor does it encroach upon the disabled person’s status as rights bearer. Therefore, the human rights model is more appropriate than the social model to encompass the experience of impairment, which might not always be bad but certainly can be. It also allows us to analyze politics of disablement as the denial of social and cultural recognition, which is an aspect of the critique of the social model of disability.⁵⁵ The human rights model of disability demands that impairment is recognized in theories of justice. Whether these are social contract theories, take a capability approach or take an ethics of care as their basis is another matter.⁵⁶

2.4 The Human Rights Model Acknowledges Identity Issues

Fourth, the social model of disability neglects identity politics as a valuable component of disability policy, whereas the human rights model offers room for minority and cultural identification.

⁴⁸Preamble, para. (h), of the CRPD.

⁴⁹Article 8, para. 1 (a), of the CRPD.

⁵⁰Article 16, para. 4, of the CRPD.

⁵¹Article 24, para. 1 (a), of the CRPD.

⁵²Article 25, para. (d), of the CRPD.

⁵³Preamble, para. (a), of the CRPD.

⁵⁴Honneth (1996).

⁵⁵Watson (2004), pp. 101–117; Danermark and Gellerstedt (2004).

⁵⁶For a combination of capabilities and other approaches, see Stein (2007).

The social model has also been criticized for neglecting identity politics as a valuable component of emancipation. Identity politics can be defined as politics that values and cares for differences among human beings and allows persons to identify positively with features that are disrespected in society. Gay pride, black pride, feminism, and disability culture are manifestations of these identity politics. The social model of disability does not provide much room for these issues because its focus is not on personal emancipation but on social power relations. Identity politics in the context of disability can have several meanings. The term might relate to impairment categories or impairment causes. Deaf people have created their own culture (as language shapes culture), and deaf studies have become an important strand of disability studies in which deaf identity plays an important role.⁵⁷ Like deaf or hard of hearing persons, blind and deafblind people were among the first groups that created their own organizations that are still operative today,⁵⁸ as are many other impairment-related organizations.

Another identity factor in the context of disability might be the difference between acquired and congenital impairment. To be born blind or deaf or physically or intellectually impaired is very different from becoming disabled through illness, accident, violence, or poverty. Further, some impairments or “disorders” may come along with unique experiences of exclusion and identity. For example, Peter Beresford argued for a social model of madness, long before the CRPD came into being.⁵⁹ Finally, identity may be shaped by more than impairment but by gender, “race,” sexual orientation and gender identity, age, or religion. Disabled women were among the first to criticize the disability rights movement (and the women’s movement) for neglecting other identity features.⁶⁰ Disabled people of color followed,⁶¹ and others like Ayesha Vernon raised the issue of intersectional discrimination and multidimensional oppression.⁶² Impairment-related identity policy also has been seen with suspicion by social model proponents.⁶³

Human rights instruments are at least partly the political response to collective experiences of injustice. The history of human rights law as it developed after World War II shows that identity-based social movements were strong players in the making of international law.⁶⁴ The current core human rights treaties are a manifestation of this process. The International Convention on the Elimination of All Forms of Racial Discrimination (CERD) of 1965, as well as the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (CRMW) of 1990, are responses to colonization and racism; the

⁵⁷Ladd (2003); Corker (1996).

⁵⁸WBU (<http://www.worldblindunion.org/English/Pages/default.aspx>), WFD (<http://wfdeaf.org/>).

⁵⁹Beresford (2004).

⁶⁰Asch and Fine (1997); Wendell (1997); Garland Thomson (1997); Morris (2001).

⁶¹Bell (2011).

⁶²Vernon (1998).

⁶³Silvers (1999); Shakespeare (2014), pp. 92–110.

⁶⁴Burke (2010); Bob (2009).