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Alexander Lamplmayr, Eva Nachtschatt

Observing Legislative Processes: Implementation of the CRPD

Research Report

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Observing Legislative Processes: Implementation of the CRPD

Research Report

Alexander Lamplmayr
Eva Nachtschatt
Institut für Zivilrecht, Universität Innsbruck

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Vorwort der Herausgeber_innen

Als Herausgeber_innen der Reihe „Innsbrucker Beiträge zur Rechtstatsachenforschung“ freuen wir uns, den nunmehr achten Band zu veröffentlichen. Er bietet eine Zusammenschau der Ergebnisse des vom *FWF - Der Wissenschaftsfonds* geförderten Forschungsprojekts „Observing legislative processes: Implementation of the CRPD“ (Austrian Science Fund (FWF): P 26710-G16)).

Um die Ergebnisse über den deutschsprachigen Raum hinaus möglichst breit zugänglich zu machen, haben wir uns dazu entschieden, diesen Band auf Englisch zu publizieren. Zusätzlich wird unter www.rechtstatsachenforschung.at eine open source Variante Ende des Jahres erstellt.

Michael Ganner/Caroline Voithofer; Innsbruck, Juli 2016
Institut für Zivilrecht, Universität Innsbruck

Preface by the editors

As editors of the series “Innsbrucker Beiträge zur Rechtstatsachenforschung“ (“Innsbruck’ contributions to empirical legal studies”) are we very pleased to publish volume 8 wherein the results of the research project “Observing legislative processes: Implementation of the CRPD“ which was funded by the *FWF - Austrian Science Fund* (Austrian Science Fund (FWF): P 26710-G16)) are presented.

As the results are of potential interest for the non-German-speaking scientific community we decided to publish this volume in English. An open source edition is planned to go online by the end of the year via www.rechtstatsachenforschung.at.

Michael Ganner/Caroline Voithofer; Innsbruck, July 2016
Departement of Civil Law, University of Innsbruck

Preface by the authors

Working on this international project was exciting and challenging for both of us. We could not have gathered the necessary data, accomplished the research and written the following report without support from many great individuals and organizations on several continents.

First and foremost, we would like to thank our head of project, Prof. *Michael Ganner*, who has supported us throughout all aspects of our work, and his staff: *Caroline Voithofer*, who provided fruitful insights on a regular basis, and *Carolin Wimmer*, whose assistance regarding the English language was irreplaceable. Any remaining mistakes and linguistic inaccuracies are ours and certainly not hers. *Tanja Ulasik* always looked after us and took good care of all organizational issues. We both feel lucky and grateful to have been part of this great team at the University of Innsbruck for more than two years!

We would like to thank *Walter Hammerschick* from the Institute for the Sociology of Law and Criminology in Vienna ("Institut für Rechts- und Kriminalsoziologie"), who passionately supported the project and patiently introduced us to some methods of empirical research and their application.

Several individuals, in particular *Petra Butler* (Victoria University of Wellington) and *Sue Field* (University of Western Sydney), supported us in many ways during our stays in Wellington and Sydney.

Naturally, this research would not have been possible without great willingness to participate by countless individuals. Some of them shared their personal points of view, some of them represented their respective organizations or government agencies. All these contributors to our research in Austria, Germany, New Zealand and Australia passionately agreed to participate and shared their great expertise with us for free. We would like to thank all of them very much! To guarantee anonymity and to protect the interests of all participants, we changed the names of all interviewees in the following report.

Last but not least, we would like to thank our families and friends, who supported us throughout the last two years.

The sections B, D-F were drafted and composed by *Alexander Lamplmayr* (section E.2.5.1.-E.2.5.2. together with *Walter Hammerschick*); sections G, H by *Eva Nachtschatt*. Sections A, C were drawn up by both authors together. However, both of us feel responsible for the contents of the following report as a whole.

Alexander Lamplmayr/Eva Nachtschatt; Linz/Kassel, July 2016

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Walter Hammerschick/Alexander Lamplmayr/Eva Nachtschatt

Alexander Lamplmayr/Eva Nachtschatt

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Abbreviations

ABGB	Allgemeines bürgerliches Gesetzbuch (Austrian Civil Code)
ACT	Australian Capital Territory
ACDA	Australian Cross-Disability Alliance
AFDO	Australian Federation of Disability Organisations
AGD	Attorney-General's Department (Australia)
AHC	Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities
AHRC	Australian Human Rights Commission
AIP	Journal of the American Institute of Planners
APuZ	Aus Politik und Zeitgeschichte
Art	Article
B-VG	Bundesverfassungsgesetz (Austrian Federal Constitution)
BAG	Bundesarbeitsgemeinschaft
BBB	Bundesbehindertenbeirat (Austrian Federal Disability Advisory Board)
BGB	Bürgerliches Gesetzbuch (German Civil Code)
BMASK	Bundesministerium für Arbeit, Soziales und Konsumentenschutz (Austrian Federal Ministry for Labour, Social Affairs and Consumer Protection)
BtPrax	Betreuungsrechtliche Praxis
CALD	Culturally and linguistically diverse
CDA	Children with Disability Australia
CEO	Chief Executive Officer
COAG	Council of Australian Governments (Australia)
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CSTDA	Commonwealth, State and Territory Governments Agreement (Australia)
DBR	Deutscher Behindertenrat (German Disability Council)
DAP	Disability Action Plan (New Zealand)
DIMR	Deutsches Institut für Menschenrechte (German Institute for Human Rights)
DPO(s)	disabled people's organizations
DSS	Department of Social Services (Australia)
EAC	Every Australian Counts
e.g.	exempli gratia
ed(s).	editor(s)
EU	European Union
FaHCSIA	Department of Family, Housing, Community-Service and Indigenous Affairs (Australia)
FPDN	First Peoples Disability Network Australia
FRA	European Union Agency for

	Fundamental Rights
GA	United Nations General Assembly
HJIL	Heidelberg Journal for International Law (Zeitschrift für ausländisches öffentliches Recht und Völkerrecht)
IDA	International Disability Alliance
IDC	International Disability Caucus
IHC	Intellectually Handicapped (New Zealand organization)
iFamZ	Interdisziplinäre Zeitschrift für Familienrecht
IMM	Independent Monitoring Mechanism (New Zealand)
MA	Monitoringausschuss (Austrian Federal Monitoring Committee)
MS	Monitoring-Stelle (German National CRPD Monitoring Body)
NAP	National Action Plan (Austria)
NDIS	National Disability Insurance Scheme (Australia)
NDS	National Disability Strategy (New Zealand)
NDS	National Disability Services **or** National Disability Strategy 2010-2020 (Australia)
NEDA	National Ethnic Disability Alliance (Australia)
NESB	Non-English Speaking Background
NGO	nongovernmental organization
NHRI	National Human Rights Institution
NZ	New Zealand or Notariatszeitung (Austrian legal journal)
ÖAR	Österreichische Arbeitsgemeinschaft für Rehabilitation (Austrian National Council of Disabled Persons)
ODI	Office for Disability Issues (New Zealand)
OHCHR	United Nations Office of the High Commissioner for Human Rights
OP	Optional Protocol (to the CRPD)
OPCAT	Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment
ÖAR	Dachorganisation der Behindertenverbände Österreichs (Austrian national Council of Disabled Persons)
PWDA	People with Disability Australia
UN	United Nations
WWDA	Women With Disabilities Australia

Michael Ganner

Introduction

The following report presents the findings of a scientific project undertaken from 2014 to 2016. It examined in which way States Parties to the UN Convention on the Rights of Persons with Disabilties (CRPD) cope with their obligation to involve persons with disabilities in the process of implementing the CRPD into national law. There are different approaches and implementation results in the four compared countries (Austria, Germany, Australia and New Zealand). The main reasons for this are the different legal and social systems but also the diverse population structures in these countries.

The CRPD presents several new ideas and concepts, such as “inclusion“, “supported instead of substitute decision-making“, “informed consent“ and “products with universal design“. Therefore, the Convention is an important tool to develop our societies towards an inclusive world without barriers and with the opportunity for everyone to take part in all kinds of social and cultural activities. This is also a desirable aim for “non-disabled“ individuals.

In Australia and New Zealand, indigenous population groups play an important role which is not the case in Austria and Germany. These minorities have their own representative organisations within the disabled people’s organizations (DPOs).

Generally speaking, members of DPOs are (mainly) disabled persons, but the head representatives are still often “non-disabled“ persons. This is true in all compared countries and contradicts the idea of self-representation. However, one can certainly doubt if there is any person without a disability at all.

For me – as head of the research team – it was an impressive and insightful experience to meet a lot of players in this field and to discuss the concerned issues with them. This changed my mind during the two years of the project because I learned how capable many persons, who are described as “disabled“, actually are. Therefore, the slogan “nothing about us without us“ certainly has its rationale. When it comes to disability issues, persons with disabilities have firsthand experience and therefore are able to improve existing systems in general and can certainly help to find suitable solutions not only for themselves but for society as a whole.

This report contains an overview of the CRPD's regulations concerning the participation of persons with disabilities in general and a detailed description of Art 4 CRPD which states the obligatory participation during the implementation into national law.

To provide a general access to the topic, some theories and models of citizen participation are described at the beginning, followed by country-specific chapters, which describe recent developments and the findings of the research.

In Austria, authorities focused on the laws concerning guardianship and started a participation process consulting the federal Monitoring Committee (according to Art 33 CRPD), different DPOs, individual disabled self-representatives, scientists, service providing organizations etc. This process was concluded in May 2016 with a proposal for a big reform. The participation of persons with disabilities during the legislative process was exemplary and unprecedented. Therefore, this could be used as a model for other democratic processes too. One result of the project shows the importance of having a core group of participants who are involved throughout the whole process. If previously not involved individuals are entering the process at an advanced stage and start presenting their arguments, it could certainly decrease the workability. Learning about other stakeholders' problems during the process and trying to understand them is one of the most important matters of a participation process. A second aspect that has to be considered is that all concerned persons and organizations should be represented equally. This was not the case in the Austrian guardianship law reforming process. In general, persons with mental disabilities and specifically persons with psychiatric disorders were underrepresented as well as elderly people.

In Germany, the focus of the research was put on DPOs and alliances such as the "CRPD Alliance" (BRK-Allianz) and on the development of a Federal Act on Participation (Bundes-Teilhabegesetz) as an instrument to improve the access to support services in a self-determined way and as part of the Social Security Code (Sozialgesetzbuch). A proposal of this new Act was published in June 2016.

New Zealand focused on (political) representation structures and established an Office for Disability Issues and a dedicated Minister for Disability Issues. Aside from the CRPD, the National Disability Strategy is an important cornerstone of the country's disability policy. Contrary to the other compared countries, the national monitoring (according to Art 33 CRPD) is conducted by three institutions (Human Rights Commission, Office of the Ombudsman and the Convention Coalition, which consists of eight DPOs).

Australia has a similar federal structure to Austria and Germany and therefore has comparable problems to find nationwide solutions. However, just recently lawmakers passed federal legislation to establish a new system of financial support for persons with disabilities: the National Disability Insurance Scheme (NDIS 2013). A second crucial development was the radical change in the public funding system for DPOs. Since the beginning of 2015, only four national, cross-disability organizations, allied in the Australian Cross-Disability Alliance have been receiving government funding.

The difference between Civil Law (Austria, Germany) and Common Law (Australia, New Zealand) systems does not seem to be very important when it comes to the involvement of persons with disabilities in processes concerning the social and welfare structure of a country. However, it is rather more relevant in Civil Law systems, where legislative processes and legislation itself are of greater importance. The most crucial aspects seem to be the model and structure of the involvement process and the (public) funding of DPOs. Participation processes are money- and time-consuming but are usually worth the effort. They benefit all parties involved, which has yet to be realized by lawmakers and other officials.

This project was conducted in cooperation with the Institute for the Sociology of Law and Crininology in Vienna (“Institut für Rechts- und Kriminalsoziologie“). We would especially like to thank *Walter Hammerschick* who is mainly responsible for the sociological methodology of the research and also supported the project on a regular basis.

Furthermore, we would like to thank *Carolin Wimmer* for linguistic support (English language).

Michael Ganner
Department of Civil Law, University of Innsbruck
Innrain 52, A-6020 Innsbruck, Austria
Phone: 0043 (0)512/507-8108; michael.ganner@uibk.ac.at

Alexander Lamplmayr/Eva Nachtschatt

Research Report

A. Introduction

1. About the project

This report summarizes and presents the findings of the science project „Observing legislative processes: implementation of UNCRPD" undertaken at the Department of Civil Law at the University of Innsbruck, Austria. The research was carried out between May 2014 and June 2016.

As the title of the project suggests, the main focus of the research is not the specific contents and substantial rights established and/or reaffirmed by the Convention, but the process of implementation. As an international treaty between States Parties, the CPRD requires implementation into domestic law by these Parties.

Some of the most important provisions of the Convention include Art 5 (equality and non-discrimination), Art 9 (accessibility), Art 12 (equal recognition before the law), Art 13 (access to justice), Art 19 (living independently and being included in the community) and Art 24 (education). In Austria and Germany the most prominent discussions prompted upon the ratification of the CPRD have been around education[1] (Art 24) and guardianship law[2], especially possible restrictions of the capacity to act in case a guardian is appointed (Art 12).[3]

The two provisions that will mainly be discussed in this report are **Art 4 (3)** and **Art 33 (3)**. They deal with participation of persons with disabilities and/or their representative organizations and oblige all States Parties to involve persons with disabilities in the processes of implementing the Convention into national law as well as in the process of monitoring this domestic implementation process. Provi-

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[1] The most important question surrounding education seems to be if the CRPD requires the States Parties to establish inclusive schools or if an education for children with disabilities in a separate school or classroom is in line with the CRPD; see e.g. *Monitoring-Stelle* (2011) 1. Accordingly, the UN plans to publish a General Comment on Art 24, see http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GCRightEducation.aspx (Feb 8, 2016).

[2] In Austria: *Sachwalterrecht* (§§ 268ff ABGB [Austrian Civil Code]); in Germany: *Betreuungsrecht* (§§ 1896ff BGB [German Civil Code]).

[3] The FRA stated in 2015 that "[…] legal capacity remains one of the areas with the largest number of reforms at the national level linked to CRPD ratification"; see *FRA* (2015) 1.

sions that oblige lawmakers or governments to involve the governed people into such processes are rarely found in legally binding documents.

The concept of citizen participation first became popular in the late 1960s, when social movements demanded involvement in governments' decision-making processes. Supporters point out the benefits of citizen participation and argue that it strengthens democracy, improves trust in the government, increases government accountability and produces more effective policy.[4] Moreover, it helps to engage marginalized groups of society – such as disabled persons – in political processes.[5]

Participation of persons who are affected by the CRPD already played an important role in the process of developing the Convention as well as engagement with civil society in general.[6]

Two core questions were the main focus of the research that was undertaken from June 2014 to May 2016. The findings are described and summarized in this report:

1. How are persons with disabilities involved in the process of implementing the CRPD into domestic law (Art 4 [3])?
2. How are persons with disabilities involved in the national mechanisms that independently monitor these implementation processes (Art 33 [3])?

Some voices argue that the obligations for States Parties in Art 4 (3) and Art 33 (3) to involve the persons affected by the Convention and their representative organizations are paramount to the ideas of the CRPD and overarch all other specific obligations laid out in the Convention.[7] The Preamble (lit o) explicitly states that "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them".

Even though these principles are crucial to the CRPD as a whole, there is a lack of scientific discourse and research regarding the conditions, which legislative and monitoring processes have to meet in order to fulfil the requirements of Art 4 (3) and Art 33 (3) CPRD.

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[4] *Moriarity/Dew* (2011) 684.

[5] *Arnstein* (1969) 216.

[6] See e.g. *von Bernstorff* (2007) 1041ff; *Flynn* (2011) 16.

[7] See *Schulze* (2010) 59.

2. Research approach and methods

From May 2014 to April 2016, several processes were observed in four different countries to get a broad view over the implementation and monitoring processes. The research was carried out in Austria, Germany, New Zealand, and Australia. These are countries with different legal and political systems which especially have different approaches towards legislation.

In order to find answers to the research questions mentioned above, a mixture of methods was applied. This includes traditional legal approaches, interview techniques, questionnaires and participant observation. The project, although it has a legal foundation, primarily uses sociological methods such as questionnaires and semi-structured interviews. The Institute for the Sociology of Law and Criminology in Vienna ("Institut für Rechts- und Kriminalsoziologie"), particularly *Walter Hammerschick,* supported the implementation of the project with his comprehensive expertise regarding methods of empirical research and their application.

The empirical research in **Austria** focused on the process of amending the current regime of legal guardianship ("*Sachwalterrecht*"), as it is one of the crucial ongoing legislative projects in Austria prompted by the CRPD.[8] Fortunately, the **Federal Ministry of Justice** (**BMJ**, *Bundesministerium für Justiz*) agreed to enable and support the research. Therefore, it was possible to get a deep insight into the whole process. Regular working group sessions were held from December 2013 to May 2016. These working groups were attended by project staff, the attendants were observed and the progress documented. On three occasions throughout the process, a standardized questionnaire was handed out to all participants. The questions focused on the information policy of the BMJ, the design of the legislative process as a whole and the possibilities for each participant to take part effectively within the working group. Furthermore, semi-structured interviews with selected working group members (primarily self-advocates) were carried out to get a more detailed insight from their point of view. Interviews with BMJ officials were conducted as well to include their experience with the process.

As mentioned, the CRPD is a major human rights treaty with a large number of States Parties, which led to the idea to compare the findings in Austria to other countries. Three additional CRPD States Parties were selected to be part of the research. The reasons for the selection of the particular countries of Germany, New Zealand and Australia will be described briefly.

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[8] See e.g. *Monitoringausschuss* (2012).

The adult guardianship system in **Germany** ("*Betreuungsrecht*") shares strong similarities with the Austrian regulations. Therefore, this country was chosen to compare ongoing legislative changes in this field. During the course of the project, no legislative process particularly focused on guardianship law was underway in Germany. However, German lawmakers are currently drafting a "Federal Act on Participation" (BTHG, *Bundesteilhabegesetz*) that aims to get Germany closer to an inclusive society by strengthening self-determination of persons with disabilities and shifting away from paternalistic and patronizing approaches.[9] The legislative process itself was preceded by an interdisciplinary working group. This working group held nine sessions from July 2014 to April 2015 and included persons with disabilities and representatives of organizations from the disability sector. The final report was released in July 2015.[10] An online-survey was carried out by project staff after the final session and all attendants were invited to participate. The online-survey was very similar to the questionnaires handed out in paper to the participants of the guardianship reform working group in Austria. In addition to that, interviews with experts in the field of disability politics and lawmakers in the Federal Ministry of Labor and Social Affairs (BMAS, *Bundesministerium für Arbeit und Soziales*) were conducted.

New Zealand (NZ) was one of the leading countries in terms of self-representation and participation of persons with disabilities during the development[11] of the CRPD. When the government decided to include representatives of persons with disabilities on its formal delegation to the UN, it was widely seen as a revolutionary decision.[12] Even before that, NZ was known to have a politically active disability community that had influenced domestic politics since the 1980s. Therefore, NZ was a clear choice to be included into the research.[13]

Austria and Germany are very similar countries in regard to their legal and political system. Both are federal states with closely-related civil law systems. Due to its similarities with NZ's legal system (common law), **Australia** was an obvious choice to be included into the research as well. However, Australia bears resemblances with Austria and Germany as well: as it is structured as a federal state, its States and Territories have their own legislative and administrative bodies.

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[9] See http://www.gemeinsam-einfach-machen.de/BRK/DE/StdS/Bundesteilhabegesetz/bundesteilhabegesetz_node.html (Sep. 22, 2015).

[10] http://www.gemeinsam-einfach-machen.de/BRK/DE/StdS/Bundesteilhabegesetz/Abschlussbericht/Abschlussbericht_node.html (Sep. 22, 2015).

[11] See *von Bernstorff* (2007) 1041ff.

[12] *Moriarity/Dew* (2011) 690.

[13] *Moriarity/Dew* (2011) 695.

The fundamental difference between a system based on **common law** (such as NZ and Australia) and a system based on **civil law** (such as Austria and Germany) is the source of law. Traditionally, the common law is being developed from court decision to court decision. It is historically case-law and not enacted law, and is therefore primarily established and developed by courts ("judge-made law"). In contrast, civil law contains abstract rules which are passed by legislative bodies. Judges are merely required to identify suitable regulations by interpretation and apply them on the specific case.[14]

As the research was carried out by two part-time researchers over the course of less than two years, there were certainly **limitations to the research**. Above all, there are organizations and persons of relevance to disability politics in all four countries who could not be included in our studies due to the limited rescources. Therefore, the results are not trying to give detailed insights into all aspects of disability politics. The outcomes are merely trying to give a broad overview over recent developments in the four countries. This is true for all included countries but especially for Australia. The country's overall size and multilayered legal and political systems are the main reasons for this.

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[14] See *Zweigert/Kötz* (1998) 69.

B. The CRPD

1. Development of the Convention

1.1. Brief history

The CRPD is the most recent major international human rights treaty and the first of the 21st century.[15] It is the first legally enforceable rights-based document[16] specifically protecting the rights of persons with disabilities on an international level.[17]

The GA established an "Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities" (AHC) in 2001 to explore the possibility of the UN adopting a disability-specific human rights treaty.[18]

The CRPD was adopted by the GA in December 2006 and came into force on May 3 2008, thirty days after the twentieth signatory state had deposited its document of ratification or accession at the UN.[19] It took less than a year for twenty parties to ratify the Convention since it was opened for signing only in March 2007.[20] Due to the current number of States Parties, the CRPD is a very significant treaty. As of April 2016, 160 countries have signed and 162 are States Party to the CRPD.[21] In Europe, the Convention has been ratified by 25 EU member states and the EU itself as well. Three member states (Finland, Ireland and the Netherlands) have not ratified yet but have already signed the Convention and are planning to complete the ratification process soon.[22]

All UN human rights treaties adopted before the CRPD provide protection for all individuals. As a consequence, their scope also includes the protection of persons with disabilities. Nevertheless, the CRPD is of grave importance to the human rights protection of persons with disabilities, as it is the first international treaty expressly protecting their rights.[23] *Sabatello/Schulze*[24] argue that persons with disa-

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[15] *de Beco* (2013) 1.

[16] See *Quinn/Degener et al* (2002) 14ff; *Kayess* (2011) 25.

[17] See *Stein* (2007) 76.

[18] UN Resolution A/RES/58/246.

[19] *McCallum* (2014) xv.

[20] *McCallum* (2014) xv.

[21] See https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en (Apr 6, 2016).

[22] *FRA* (2015) 2.

[23] *von Bernstorff* (2007) 1046.

[24] *Sabatello/Schulze* (2014) 1.

bilities had been "remarkably invisible within human rights discourse" before and are now elevated to being protected by a specific treaty. *Stein*[25] states that even though the seven older core UN human rights treaties theoretically apply to disabled persons, they are rarely applied in practice.[26] Therefore, the CRPD is widely described as a milestone,[27] the end of a long journey by civil society and the disability community[28] and the beginning of a new era[29] for persons with disabilities. Even though the CRPD does not create any new rights specifically for disabled persons, it reaffirms the already existing human rights especially with regard to people with disabilities[30] and provides details on what States Parties have to do to ensure those rights are realized.[31] *Shakespeare* however argues that the Convention creates new legal foundations and describes the CRPD as "legally innovative in several ways".[32] *Harpur* says that the CRPD creates a new rights discourse, empowers civil society and renders human rights more obtainable for persons with disabilities than any time before.[33] Others argue that the mere adoption of a specific human rights treaty for a specific group of persons already guarantees a better rights protection standard for this group of individuals.[34]

Once a state ratifies an international treaty and becomes a States Party, the treaty does not automatically become part of domestic law. This is true for the vast majority of states. The relationship between international and domestic legal regulations – in other words: the status of an international treaty within the national legal system – is usually regulated by each State's constitutional law.[35] Upon ratifying the CRPD, States Parties have an obligation under international law to implement it. Generally speaking, implementation is the process in which States Parties take action to ensure the realization of all rights contained in the respective treaty within their jurisdiction.[36] It is a basic principle of international law that a State Party to an international treaty has to ensure that domestic legal regula-

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[25] *Stein* (2007), 79; *Degener* (2006) 104.
[26] See also *Lord/Stein* (2008) 455.
[27] *McCallum* (2011) XVIIi.
[28] *McKay* (2014) XI.
[29] *Ganner* (2014) 22.
[30] See UN Resolution A/RES/58/246; *Schulze* (2011) 269; *Bielefeldt* (2009) 13f; *Moriarity/Dew* (2011) 687; *Degener* (2006) 105; http://www.odi.govt.nz/what-we-do/un-convention/index.html (June 29, 2015).
[31] *Harpur* (2012) 1.
[32] *Shakespeare* (2014) 317.
[33] *Harpur* (2012) 1f.
[34] *von Bernstorff* (2007) 1047; *Degener* (2006) 104; *Lord/Stein* (2008) 450f.
[35] See e.g. *Lord/Stein* (2008) 452.
[36] *OHCHR* (2009a) 7.

tions are consistent with the specifications of the treaty. Upon ratification, States Parties are required to make appropriate changes to domestic law to ensure its conformity with the respective treaty, except in the rare cases in which the rights and principles of the Convention are already fully protected under domestic law.[37]

1.2. Civil society's involvement

Prior to the adoption of the Convention in 2008, two decades of activism paved the way for the first disability-specific UN human rights treaty. As mentioned above, an AHC was mandated to draft the text for a new Convention. It was established by the GA of the UN in 2001 "to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities".[38] The resolution setting up the AHC refers to the involvement of persons with disabilities and NGOs in the process of drafting a Convention in numerous provisions. For example, the document expressly encourages member states to include persons with disabilities and/or other experts in the field in their delegations to the meetings of the AHC.

The developmental process of the Convention lasted for over five years. More than 600 NGOs, primarily DPOs, were involved in the process – following the slogan "nothing about us without us".[39] The international success of the Convention is often attributed to this involvement of civil society in the early stages.[40] Civil society's involvement as a "third force" in the process had an immense influence on the CRPD's final version.[41] The innovative form of interaction between UN and States officials on the one hand and civil society organizations promoting the interests of persons with disabilities on the other hand was unprecedented in its intensity prior to the CRPD drafting process. It was labelled "new diplomacy" by high-profile experts in the field.[42] Others argue that the proactive involvement of NGOs in the drafting process might have led to a "democratization" of the whole process.[43]

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[37] *OHCHR* (2009a) 10.

[38] UN Resolution A/RES/58/246.

[39] See e.g. *von Bernstorff* (2007) 1054; *Degener* (2006) 106; *Aichele* (2010) 13f; *Bartlett* (2012) 756.

[40] *Sabatello* (2014a) 13.

[41] *Degener* (2015) 56.

[42] *Sabatello* (2014b) 239; *Sabatello/Schulze* (2014) 5.

[43] *von Bernstorff* (2007) 1055.

Even though the original resolution permitted NGOs to make contributions to the AHC's work "based on the practice of the UN", some deficits showed early on: National human rights institutions (NHRIs) were not specifically addressed as possible contributors in the resolution. Additionally, many DPOs that would have liked to contribute to the drafting procedure did not have the necessary consultative status. The process of gaining this kind of status is often time-consuming; therefore the NGO community along with several NHRIs started an intense lobbying campaign in the first AHC session in 2002 to simplify the accreditation processes.

This campaigning led to the adoption of two resolutions. The first one allowed NHRIs to contribute to the AHC's work and enabled a separate accreditation mechanism that made it easier for DPOs to reach the necessary consultative status.[44] The second resolution allowed the accredited NGOs to attend all public and closed meetings as well as informal consultations held by the AHC. Furthermore, it enabled these organizations to intervene in the plenary, receive copies of all official documents and make presentations.[45]

These developments resulted in the establishment of a diversified working group tasked to draft and present a text for the proposed convention. The working group was composed of 27 government members from different continents,[46] twelve members of accredited NGOs, especially DPOs, and one representative of a NHRI.[47] NGOs were allowed to nominate their twelve representatives in the working group themselves. Additionally, several states chose to nominate representatives of civil society for their respective government seats (e.g. Germany), as it was proposed in the original resolution that set up the AHC.[48]

The CRPD process marked the first time that representatives of civil society organizations were granted formal seats in a working group mandated to draft a UN human rights treaty. The results of the working group's deliberation ("Chair's Draft") were used as a foundation for the subsequent treaty negotiations within

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[44] UN Resolution A/RES/56/510.

[45] *Sabatello/Schulze* (2014) 6.

[46] Africa and Asia had seven members each, Latin America/Caribbean and Western Europe had five members each and Eastern Europe had three.

[47] Report of the AHC to the GA A/58/118, http://www.un.org/esa/socdev/enable/rights/a_58_118_e.htm (Oct. 1, 2015); *Moriarity/Dew* (2011) 686.

[48] *von Bernstorff* (2007) 1053; *Sabatello/Schulze* (2014) 7.

the AHC.[49] NGO's participation was invaluable in the preparation of the draft and the outcome reflected their input.[50]

The AHC held a total of eight sessions lasting between two and three weeks in New York before the CRPD was adopted.[51] Civil society's influence, primarily via DPOs, on the negotiations in the AHC plenary was significant. Accredited NGOs regularly exercised their contribution rights and actively participated in the sessions. Persons with disabilities not only represented their respective organizations but also appeared as speakers before the AHC on a regular basis; a fact that had strong influence on the whole process.[52] Persons with disabilities who had been facing discrimination, were representing NHRIs and even part of state delegations, which has also been described as a "unique characteristic of the involvement of civil society" in the drafting process.[53]

Early on in the process, two alliances of DPOs emerged to ensure a structured and coordinated participation of these organizations. The International Disability Alliance (IDA)[54], founded in 1999, and took a dominant leadership role.[55] This international network was also instrumental in the establishment of the International Disability Caucus (IDC), a rather loosely structured movement that was mandated to officially represent the disabled persons' community in the CRPD negotiations. Throughout the process, the number of IDC's membership organizations was steadily rising. The IDC's work has been described as highly efficient and it had a key role in the drafting process of the Convention.[56] The IDC facilitated several committees to coordinate the work within the umbrella organization and contributed convention drafts that were subsequently discussed in the plenary during the AHC sessions in New York.[57]

DPOs from different countries were not the only non-UN organizations which had an influence on the Convention's development. For the first time, NHRIs were also contributing for the first time to the drafting of a human rights treaty

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[49] *Sabatello/Schulze* (2014) 7.
[50] *von Bernstorff* (2007) 1053; *Sabatello/Schulze* (2014) 7.
[51] http://www.un.org/esa/socdev/enable/rights/adhoccom.htm (Oct. 1, 2015).
[52] *Degener* (2006) 109f; *von Bernstorff* (2007) 1054.
[53] *Sabatello/Schulze* (2014) 7.
[54] http://www.internationaldisabilityalliance.org/en/about-us (Oct. 2, 2015).
[55] *Lachwitz* (2015) 377ff.
[56] *Degener* (2006) 109f; *von Bernstorff* (2007) 1054; *Sabatello/Schulze* (2014) 7.
[57] See e.g. http://www.un.org/esa/socdev/enable/rights/ahc4idcupdate.doc (Oct. 2, 2015).

and were given an opportunity to share their expertise and insights to affect a future treaty.[58]

All in all, civil society had a major impact on the Convention text that was finally adopted by the GA. People with disabilities and their lived experience were made visible, shifting the focus of the negotiations from dominant voices "from outside" to voices "from within" – following the slogan "nothing about us without us". IDC's daily newsletters during the sessions were always taken into consideration and frequently influenced the agenda and proposals by government representatives.[59]

Even though civil society's work in the drafting process was well organized and efficient in general, there were certainly tensions within the disability community. North-south conflicts occurred, as southern DPOs were underrepresented at the UN.[60] Problems arose around "authentic" representation of persons with disabilities. The mandate of many organizations *for* persons with disabilities' (in contrast to organizations *of* persons with disabilities) to actually represent and speak on behalf of disabled persons was questioned. While most organizations chose to participate under the umbrella organization (IDC), others negotiated from the outside.[61]

The CRPD drafting process showed that the involvement of a diverse variety of voices from civil society in negotiations on UN-level had impact on the Convention.[62] Not only were the results of the negotiations heavily influenced by civil society's engagement, but also the engagement process itself was unprecedented at an international level. It comes as no surprise that the theme "nothing about us without us", which dominated the drafting process, is also reflected in the Convention itself in numerous crucial provisions.

Civil society's involvement in the UN's CRPD-related work did not stop after the development of the Convention was concluded. Aside from the official State Reports, which are required by Art 35 on a regular basis, so-called "Parallel Reports", "Shadow Reports" or "Alternative Reports" are submitted to the UN. These are usually developed and written by NGOs or NGO alliances. During state examinations, the UN Committee usually does not only consider the official

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[58] *Sabatello/Schulze* (2014) 8.
[59] *Sabatello/Schulze* (2014) 8f.
[60] See *Toledo* (2014) 170ff.
[61] *Sabatello/Schulze* (2014) 9.
[62] *Moriarity/Dew* (2011) 686.

State Reports, but also takes the arguments of these collective civil society documents into consideration.[63]

2. Participation and the CRPD

2.1. Participation as an overarching principle

The Convention includes four overarching key themes: equality, autonomy, participation and solidarity.[64] Participation, as an overarching principle, is a significant aspect and achievement of a dynamic modern society.[65] Lit e) of the CRPD's preamble states that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others". Full and effective participation in a functional manner comprises economic, judicial, social and cultural involvement but also political involvement regarding political decision-making and choices.[66]

Stein/Lord argue that participation of persons with disabilities and participation of DPOs in all implementation and monitoring processes somehow related to the CRPD is both implicitly and explicitly "woven throughout the entire fabric of the [Convention's] text".[67]

As described above, the entire formulation and negotiation process of the Convention was conducted under the slogan "nothing about us without us", realizing an extensively including and participatory approach.[68] Various regulations in the CRPD's final text include an emphasis on including persons with disabilities in decision-making processes. Upon ratification, States Parties have the obligation to be more active towards involving persons with disabilities, which the Convention states clearly in several provisions.

The CRPD includes several innovative regulations, which have not appeared in other human rights treaties so far. Alongside the new feature of collective complaints, there is the strong emphasis on the importance of expertise and input of disabled persons and DPOs on an international and on a domestic level. Art 3 lit

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[63] See e.g. *Arnade* (2015) 96.
[64] *Flynn* (2011) 13.
[65] *Wansing* (2012) 100.
[66] *Wansing* (2012) 100.
[67] *Stein/Lord* (2010) 697.
[68] *OHCHR* (2010) 33.

c) proclaims that disabled persons' "full and effective participation and inclusion in society" is a general principle of the Convention as a whole. Inclusion constitutes a key concept of the entire Convention, especially regarding its legal interpretation and implementation into domestic law.[69] The overarching "nothing about us without us" principle may be identified in various wordings used by the Convention, such as "inclusion", "participation", "shall closely consult", "actively involve" or "shall be involved and participate".

2.2. General obligations – Art 4 (3)

The provisions in Art 4 present general obligations, which every States Party is obliged to fulfil and consider within all processes of implementation.[70] **Art 4 (3)** states: "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating persons with disabilities, States Parties **shall closely consult with and actively involve** persons with disabilities, including children with disabilities, through their representative organisations." The scope of this provision is very broad and extensive, as it is included in the CRPD's general obligations. Consequently, this provision has a crucial effect on all national fields of application, interpretation and implementation processes.[71] Art 4 (3) has to be read in conjunction with Art 4 (1) lit c) which requires States Parties to "take into account the protection and promotion of human rights of persons with disabilities in all policies and programmes".

Older human rights treaties informally suggested that States Parties consider civil society's input but no Convention included a specific obligation to involve affected persons and organizations into decision-making processes. *Stein/Lord* call this aspect of the Convention "perhaps one of the most progressive developments of human rights law provided by the CRPD".[72]

The particular obligation to involve persons with disabilities through their representative organizations resulted from the development history of the Convention, where persons with various kinds of disabilities were involved in the drafting process. The term "process" which is used in Art 4 (3) refers to all development and

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[69] *Wansing* (2012) 93.
[70] *Lachwitz* (2013) 85.
[71] *Lachwitz* (2013) 85.
[72] *Stein/Lord* (2010) 698.

implementation processes related to legislation and policies. Briefly summarized, the provision obliges States Parties to involve disabled persons through their representative organizations in all processes of developing policy and legislation, especially those somehow related to the Convention's implementation. However, the Convention does not stipulate, in which way these involvement processes shall be organized or shaped in order to be in compliance with this provision. Furthermore, the term "representative organizations" raises questions. It remains unclear which attributes an organization has to fulfil in order to be recognized as a representative organization within the meaning of Art 4 (3). Representation issues within the disability sector turned out to be a crucial issue of our whole research: some organizations' mandates to represent and speak on behalf of disabled persons are questioned by other players in the sector.

2.3. National implementation and monitoring – Art 33

The provision of Art 33 stipulates that States Parties are required to establish three individual mechanisms, which are significant for the implementation and monitoring the Convention's implementation into domestic law. According to Art 33 (1), States Parties have to nominate "one or more **focal points** within the government for matters relating to the implementation of the present Convention" and "give due consideration to the establishment or designation of a **coordination mechanism** within government". The latter institution shall support and facilitate various actions in different sectors and on different levels. The focal point shall facilitate coordination across and between ministerial institutions and departments, additionally between local, regional, or federal authorities if necessary. It also should gather information, data and statistics. The national focal point is expected to cooperate with civil society, in particular persons with disabilities and their representative organisations. Consequently, focal points and coordination mechanisms shall complete and coordinate government activities in the field of educating the general public, raising awareness, training and capacity building.[73] In Austria, for instance, the same Ministry serves as focal point and coordination mechanism. In other countries, both roles are assumed by different government agencies or departments.

Additionally, according to Art 33 (2), States Parties shall nominate or install an **independent monitoring mechanism**, a framework to promote, protect, and

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[73] *Schulze* (2014) 215.

monitor the national implementation. In the process of developing the provisions regarding the monitoring mechanism, there was aspiration towards changing the system compared to other human rights treaty monitoring systems, as there were several points of criticism, such as “overlapping and burdensome reporting obligations, backlogs in consideration of reports by treaty bodies, late submissions by state parties, and resource limitations”. Creating a legal foundation for an effective monitoring mechanism was a crucial challenge for the CRPD drafters. *Stein/Lord* argue that the outcome of the discussion regarding the negotiation on monitoring is a “conservative result”. According to them, the intended reform should have led to a fundamentally different system compared to the existing monitoring mechanisms from other human rights treaties. However, the final provisions on the CRPD monitoring mechanism again resemble those of existing treaty bodies.[74]

Art 33 (2) states that States Parties shall be aware of “the principles related to the status and function of national institutions for protection and promotion of human rights” when establishing a “monitoring facility”. This provision refers to the so-called **Paris Principles**.[75] These Principles are legally enshrined in the Resolution 48/134, adopted by the GA on December 20, 1993. The Resolution describes fundamental attributes, which are relevant to guarantee independence of national human rights bodies from national governments. They describe the areas of competences and responsibilities of NHRIs and include provisions regarding the composition of such institutions. The resolution also gives a framework, in which the national institutions shall operate and states the principles for the status of commissions (national institutions) with quasi-jurisdictional competence.[76]

The Paris Principles put a strong emphasis on pluralistic representation within the respective institutions. Involvement of civil society in the protection and promotion of human rights is an important cornerstone of the Principles. The Resolution specifically mentions NGOs operating in the human rights field, universities, qualified experts, representatives of the parliament, government departments (in an advisory role), and persons who take philosophical and religious thoughts into account. The institution shall be provided with infrastructure and equipped with adequate funding. Appropriate funding enables these institutions to recruit staff and to rent premises at their discretion. All these factors are important to ensure

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[74] *Stein/Lord* (2010) 692.

[75] *Schulze* (2014) 216.

[76] UN Resolution A/RES/48/134; see http://www.ohchr.org/EN/ProfessionalInterest/Pages/StatusOfNationalInstitutions.aspx (Mar. 18, 2016).

(financial) independence from national governments, which is a crucial aspect, as these NHRI's usual objectives include critical monitoring of government activity.

Similar to Art 4 (3), Art 33 (3) requires civil society's involvement in the monitoring system, in particular persons with disabilities and their representative organizations.

2.4. UN Committee members and State Reports – Art 34, 35

The Convention's Art 34 refers to Art 4 (3) in a very important context. This provision regulates the **establishment and composition of the UN Committee on the Rights of Persons with Disabilities**, which carries out important functions under the Convention, such as examining and considering the State Reports under Art 35, 36.[77] The Committee monitors the States Parties' implementation on an international level.[78] Art 34 (3) refers to Art 4 (3) regarding the candidate who a States Party intends to nominate for a seat on the Committee. It invites States Parties to "give due consideration" to the provision set out in Art 4 (3).

Art 35 (4) includes a corresponding provision for the process of **preparing State Reports**: "States Parties are invited to consider doing so [preparing the Reports] in an open and transparent process and to give due consideration to the provision set out in Art 4 (3) of the present Convention".

Both these provisions merely "invite" States Parties to consider the provision of Art 4 (3), which leads to the conclusion that these regulations only present suggestions and do not include legally binding obligations for States Parties. As the mandatory involvement of people with disabilities into national implementation and monitoring processes is expressly prescribed in the CRPD, it is somehow surprising that there is no corresponding legal obligation for States Parties in the process of developing and submitting the State Reports (Art 35) and in the process of nominating UN Committee members (Art 34).

Even if there is no legally binding obligation for States Parties under these provisions, they are certainly well advised to consider involving civil society when fulfilling these obligations. The potential benefits of engaging with DPOs and other

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[77] See *Stein/Lord* (2010) 694f.

[78] *Flynn* (2011) 21f.

civil society stakeholders to include their observations and points of view are definitely there – a participatory approach can certainly benefit both sides.[79]

2.5. Participation in political and public life – Art 29

According to Art 29, States Parties shall guarantee that persons with disabilities can enjoy their political rights and opportunities on an equal basis with others. This includes the right to participate in decision-making processes, directly or through freely chosen representatives, as well as the right to vote and to be elected. For instance, States Parties are required by this provision to design accessible voting procedures, so that persons with disabilities can exercise their right on an equal basis with others.[80]

Art 29 lit b) specifically protects the rights of persons with disabilities to fully participate in the conduct of public affairs on an equal basis with others. It further requires States Parties to "encourage their participation in public affairs". This includes encouragement to form NGOs and other organizations concerned with public and political issues as well as forming and joining of DPOs to represent persons with disabilities at international, national, regional and local levels.[81]

Thus, Art 29 includes several important obligations for States Parties. The provision aims at States Parties to encourage disabled persons to organize themselves. This is a crucial prerequisite to enable effective participation. For instance, active involvement and close consultation with disabled persons **through their representative organizations** as specified in Art 4 (3) **requires the existence of a functioning DPO system**.

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[79] *Kallehauge* (2009) 207.

[80] *Trenk-Hinterberger* (2013) 304f.

[81] *Trenk-Hinterberger* (2013) 301ff.

C. Models of citizen participation

As described in the previous section, the CRPD views participation of persons with disabilities as a major principle. States Parties to the Convention are required to involve disabled persons into the implementation and monitoring processes.

Throughout the past decades, questions around citizen participation have become an important scientific and practical issue. The following section depicts *Arnstein's* fundamental model "A Ladder of Citizen Participation" which was published almost 50 years ago and gives a brief overview over some subsequent models and theories based on *Arnstein's* foundation.

1. A Ladder of Citizen Participation (*Arnstein*)

1.1. Overview

The widespread article "A Ladder of Citizen Participation"[82] serves as a theoretic base, published by *Sherry Arnstein* in 1969. Many subsequent theories and models of participation are built on this model.

Arnstein describes a stirred up controversial discussion about misleading euphemistic and exacerbated rhetorical terms concerning participation at that time. These terms cover "citizen participation", "citizen control" and "maximum feasible involvement of the poor". *Arnstein* tries to offer a definition of the term "citizen participation". She writes that "citizen participation is a categorical term for citizen power“ and describes it as "distribution of power that enables the have-not citizen, presently excluded from the political and economic process, to be deliberately included in the future“. By the term "have-not citizen" she primarily refers to members of minorities who are excluded from political and economic processes. This definition may as well fit persons with disabilities in today's society who are not only excluded from decision-making processes, but even marginalized and subject to discrimination on a regular basis. "Citizen Participation" in general means applying a concept or strategy, which includes rules of cooperation between officials and citizens. Furthermore, the strategy provides guidelines on sharing of information, organizing goals and policies, allocating financial resources and practicing of programs. According to *Arnstein*, genuine participation requires a shift of power balance between the haves and the have-nots.[83] It is a

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[82] *Arnstein* (1969) 216ff.

[83] *Arnstein* (1969) 216f.

significant aspect of the model that participation requires a redistribution of power: without this shifting of the existing power, involvement of citizens is merely a blank and frustrating process for people without power.

Arnstein establishes and depicts a vivid model of eight different rungs on a ladder. Higher steps mean a higher degree of participation. These eight stages can be summed up in three bigger categories: **"Non-Participation"** (includes the stages of "Manipulation" and "Therapy"), **"Degrees of Tokenism"** (includes "Informing", "Consultation" and "Placation") and **"Degrees of Citizen Power"** (includes "Partnership", "Delegated Power" and "Citizen Control").

1.2. Non-Participation

In *Arnstein's* model, Manipulation and Therapy are the lowest levels and are framed by the concept of Non-Participation. According to her, they merely constitute substitution for genuine participation. There is no actual empowerment for citizens to participate in creating or implementing programs. In this scenario, the persons in power are able to "educate" and "cure" the so-called participants.[84]

1.2.1. Manipulation

Arnstein illustrates the first level of **Manipulation** with several examples, such as advisory committees or advisory boards. Members of the social elite of citizens are asked to participate in various programs as supporters with special knowledge. However, in fact, the powerful officials are the ones who convince, parent and give advice to the citizen participants. *Arnstein* provides possible names for such boards and strategies – most of them include negative connotations, such as "information-gather", "public relations" and "support". Within these advisory committees and advisory boards, the persons in charge use the citizen participants (so called "grassroots people") to verify the actions and decisions of the committee or board to the outside, without giving these people information or involving them in the actual decision-making processes. After a decision is made without the involvement of the "grassroots people", they nevertheless feel proud because they "participated" in something important. In case the outcome of the process does not work out and something goes wrong, these people have to live with the

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[84] *Arnstein* (1969), 217.

engrained shame about a decision they actually did not make. A positive effect of this type of non-participation might be that some citizens may have learned from their frustrating experience and will demand genuine forms of participation in future processes.[85]

1.2.2. Therapy

Arnstein argues that **Group Therapy** constitutes an "invidious form of participation", as citizens are engaged in a "masquerade". Several citizens who often face common issues (such as marginalization based on ethnicity or disability) are invited to join a group. While participants think they are actually working on a solution for the underlying issue, they are merely used by experts. The experts are only focused on "curing them [the participants] of their pathology" but they are not keen on solving the fundamental problems that create this pathology in the first place. *Arnstein* views this form of participation as both dishonest and arrogant and therefore suggests that it can even be put on a lower rung of the ladder of participation.[86]

1.3. Degrees of Tokenism

Arnstein states that the degrees of tokenism should be viewed critically. She argues that there is an absence of any guarantee that the ideas and views of the participants will actually be considered by the decision-makers, while feigning absolute participation to the participants. Even the fifth level, Placation presents merely a higher form of tokenism. The applied rules merely offer the participants (have-nots) to hear and to have a voice. Nevertheless, the right to make decisions remains only to the powerful.[87]

1.3.1. Informing

Arnstein argues that **Informing** citizens of their rights, opportunities and responsibilities is a crucial first step of participation. However, she criticizes that there is often only a one-way flow of information (from officials to the citizens). There

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[85] *Arnstein* (1969) 218.
[86] *Arnstein* (1969) 218.
[87] *Arnstein* (1969) 217.

are no possibilities for citizens to give feedback or negotiate with officials. Relevant information is often shared with citizens only at a very late stage of a process. Consequently, there is little time for citizens to react in a meaningful way and influence the outcome of the process. Popular tools for one-way communication are news media, pamphlets, posters, and responses to surveys. Officials offer superficial information and give meaningless responses to questions raised by citizens. The officials' answers include long, highly sophisticated technical explanations, which most participants do not understand. Intimidated by this information, most citizens accept it and support the officials' decisions.[88]

1.3.2. Consultation

At the stage of **Consultation**, people are asked for their opinion. Similar to the stage of informing, *Arnstein* states that it can be a legitimate step towards actual participation. However, she argues that consultation would be deception without any combination with other forms of participation. Mere consultation guarantees no consideration of the peoples' aspirations and needs. Consultation tools are attitude inquiries, meetings, and public hearings. Citizens are often asked to fill in questionnaires without knowing what their options are, as they do not have sufficient information to make an informed decision. The powerful restrict the contributions and the impact of the citizens' suggestions. *Arnstein* calls this "window-dressing" participation.[89]

1.3.3. Placation

On this level, tokenism is still present but citizens begin to have influence to some extent. One possibility to decorate the **Placation** strategy is to handpick some "worthy individuals" as representatives and place them on boards or other public bodies. Even if handpicked participators are invited to hold a number of seats in such bodies, the powerholders hold the majority of seats. Thus, the "less important" members of the board may easily be outvoted and outfoxed. *Arnstein* states that even if citizens are involved in strategic planning extensively, the decisions are made by officials alone. Furthermore, *Arnstein* mentions that some institutions may put standards for citizen participation in place. Their provisions can

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[88] *Arnstein* (1969) 219.

[89] *Arnstein* (1969) 219f.

often be misleading: The phrase “citizens have clear and direct access to the decision-making process” may be misinterpreted by citizens who might think they have actual voting powers. Frequently, the established boards and councils themselves have misleading names which might suggest that they have influential authority or actual decision-making power whereas they actually have only very limited authority. Actual decisions are made elsewhere and the role of the participatory boards is reduced to approving these decisions in a formalistic way.[90]

1.4. Degrees of Citizen Power

The three highest rungs on the ladder of participation include different types of citizen involvement where “have-nots” actually hold decision-making capabilities and can influence the outcome of a process. *Arnstein* distinguishes between three levels: at the level of Partnership, negotiating and engaging in compromises with the powerful takes place. At the levels of Delegated Power and Citizen Control, citizens hold a majority of decision-making seats or “full managerial power”.[91]

1.4.1. Partnership

Contrary to the lower rungs, power is actually redistributed on the **Partnership** level. This takes place through a negotiation process between citizens and power-holders. Partnership may be organized in forms of structured joint policy boards, planning committees or other problem solving mechanisms. *Arnstein* mentions the importance of an “organized power-base” in the community for which the citizen leaders, who are directly involved, would be responsible. Financial aspects play a significant role, especially for the capacity of the citizen group, which has to be able to pay its leaders adequately for their work and to hire lawyers, experts and necessary supporters. With actual negotiating power, citizen groups may have impact on the outcome of the process. This impact, of course, depends on both parties finding the partnership approach useful and wishing to continue working together.[92]

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[90] *Arnstein* (1969) 220f.

[91] *Arnstein* (1969) 217.

[92] *Arnstein* (1969) 221f.

1.4.2. Delegated Power

According to *Arnstein*, the stage of **Delegated Power** means transferring competences from public officials to citizens. On this level, citizens have a ”dominant decision-making power” regarding specific plans or programs. The citizen participants hold significant cards in their hands to guarantee accountability of the plan to them. On this stage, financial aspects are again of grave importance because citizen groups usually seek external counsel and have to pay for this expertise. A possible form of the delegated power model is to have two separated and parallel groups of citizens and powerholders, with provision of a citizen veto in case a disagreement cannot be solved through discussion and negotiation. Clear areas of responsibility have to be defined within the delegated power arrangements.[93]

1.4.3. Citizen Control

Citizen Control does not mean, as the term might suggest, that all responsibilities are handed over to citizens. This level of power or control merely ensures that citizen participants manage and administer a program or a project related institution on their own. They are in full charge of all financial, policy and management processes. Additionally, they are in a position to negotiate the conditions under which outsiders may change the citizens' responsibilities, thus guaranteeing independence. The particular role of money and funding should not be underestimated because citizens will regularly need expertise and support from the outside.[94]

1.5. Influence

Arnstein's ladder model laid the groundwork for countless models of citizen participation. Most of these models and theories pick up on her categorization depending on the intensity level of participation. In the following section, models and guidelines for involving citizens into political processes shall be depicted. Some of these models are generic and cover all areas of policy. Others, such as NZ's "Principles of Engagement", are specifically designed to ensure effective participation of persons with disabilities and explicitly refer to the relevant CRPD provisions (Art 4 and 33).

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[93] *Arnstein* (1969) 222f.

[94] *Arnstein* (1969) 223f.

2. Austria – Standards of Public Participation

The Austrian federal government adopted the **"Standards of Public Participation"** ("*Standards der Öffentlichkeitsbeteiligung*") in 2008 and recommends them to be applied by all federal administrative bodies.[95] The document was prepared by an inter-ministerial working group with the participation of legally established representations of interest, NGOs and external experts as part of a project commissioned by the Austrian Federal Chancellery.[96] An appendix to the document includes a list of all government agencies and NGOs who participated in the working group.[97]

These guidelines are thought to be comprehensive and include all kinds of processes in all fields of policy (not restricted to disability-related issues). They are addressed to all administrative staff of the federal government.[98] The Standards of Public Participation shall be applied in all processes where policies, plans, programmes and general legal instruments are developed.[99] Even though this extensive and detailed document has been available for almost eight years, its existence and contents are widely unknown to the persons it is addressed to. No Ministry official that was involved in our research has knowledge that this government publication even exists.[100] An official English translation was released in 2011.

The document includes five main sections:

1. *Objectives:* This section briefly describes why participation by citizens is important and what the key objectives, benefits and goals are (e.g. mutual exchange of information, enhancing quality, transparency and acceptance of decisions).[101]
2. *Principles:* Key principles shall be applied in all participatory processes. These include fundamental concepts such as transparency, joint responsibility, mutual respect, fairness, information, use of clear language and so on.[102]

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[95] See http://www.partizipation.at/standards_oeb.html (Feb. 2, 2016).
[96] *Bundeskanzleramt* (2011) 3.
[97] *Bundeskanzleramt* (2011) 31.
[98] *Bundeskanzleramt* (2011) 6.
[99] *Bundeskanzleramt* (2011) 27.
[100] See Chapter D. Austria 2.2.1.
[101] *Bundeskanzleramt* (2011) 6.
[102] *Bundeskanzleramt* (2011) 8ff.

3. *Standards of Public Participation:* This section describes the actual Standards, which include guidelines for preparation, implementation and monitoring/evaluation of the participatory process. The Standards are structured as a list of questions such as: "Do you know exactly what you want to achieve by means of public participation (clear-cut goals)?"[103]

4. *Definitions:* This section provides clear and practical definitions of important phrases and concepts such as "public", "information" or "cooperation".[104]

5. *Benefits:* This concluding section depicts the benefits of involving civil society in decision-making processes. While participatory processes require commitment, time and financial resources, they also produce a number of benefits and "in the output the investment may pay multiple dividends".[105]

Similar to *Arnstein's* model of a ladder featuring eight rungs, the Standards of Public Participation distinguish between three intensity levels of participation. They are described in the document:

1. *Informative Public Participation (Information):* Participants merely receive information on the planning of a project or a decision. However, they do not have influence on the process. Communication is only one-way, from decision-making body to the public. There is no possibility for the public to give feedback.

2. *Consultative Public Participation (Consultation):* Participants can submit answers to an asked question or give feedback to a presented draft. Thus, there is a possibility for them to influence the decision, even though the extent of influence may vary strongly. Communication is in both directions, from decision-making body to the public and back. Comments may be collected already at very early stages of the process, e.g. via interviews.

3. *Cooperative Public Participation (Cooperation):* Participants have a say in the decision, for example at round table meetings, in mediation procedures or in stakeholder processes. The public may have a high influence,

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[103] *Bundeskanzleramt* (2011) 11ff.
[104] *Bundeskanzleramt* (2011) 23ff.
[105] *Bundeskanzleramt* (2011) 29ff.

> which may even include joint decision-making with the political decision-making bodies. “[D]ecision-making bodies and the public communicate intensively with each other.”[106]

Strong similarities between this model and *Arnstein's* ladder model can be found very easily. The guidelines list several stages of participation and distinguish between the different degrees of citizen influence on decision-making procedures. The terminology used in the government document shows strong resemblances to *Arnstein's* model.

Even though the Standards of Public Participation present easy ways of engaging with civil society, they are rarely applied. During the course of our research, we talked to numerous representatives of Ministries and other federal agencies. Most of them have never even heard of the document. Thus, promoting and distributing the document throughout government departments would be a first step in order to raise awareness for the importance and benefits of public participation in decision-making processes.

3. New Zealand – Principles of Engagement

After ratifying the CRPD, NZ has set up several institutions tasked with implementing the CRPD and coordinating government work. The role and composition of these institutions will be described in a separate section of this report.[107] NZ's efforts of strategically implementing the CRPD also included the adoption of fundamental rules on how to engage with civil society organizations in this process.

At a very early stage of developing the new Disability Action Plan, the Chief Executives' Group on Disability Issues agreed on fundamental principles – the **“New principles of Engagement”** – to guarantee a practice of involvement of disabled persons in line with NZ's interpretation of Art 4 (3). The summarizing five core principles reflect the idea of **including disabled persons via the DPO system:**

1. The government will engage with DPOs as representatives of disabled people.

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[106] *Bundeskanzleramt* (2011) 25f.

[107] See below chapter F.1.

2. We involve the right people, at the right time, in the right work.
3. We value the contribution of each party and make it easy to engage.
4. We will be open, honest, transparent and creative in our engagement with each other.
5. We jointly learn about how to engage with each other.[108]

These principles reflect the general idea of participation and reaffirm that participatory approaches have to be taken in disability politics. However, they do not include any guidelines or suggestions, which DPOs shall be included in which way. The processes of (joint?) decision-making are also not depicted in the release.

The illustration on the next page was published by the ODI and gives an overview of government's arrangements to ensure that all disability-related activities of government departments and agencies are in line with Art 4 (3) and Art 33 (3). It is in use since 2016.

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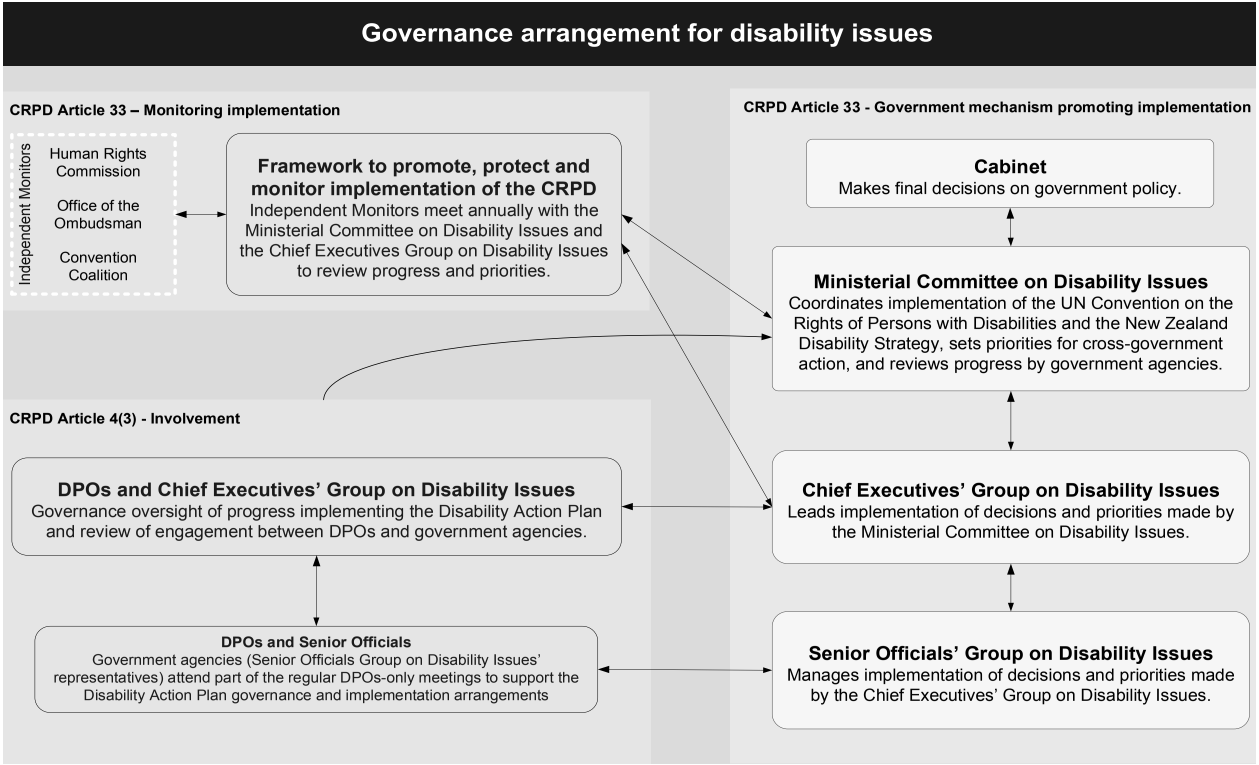
[108] *Office for Disability Issues* (2014) 3.



Governance arrangement for disability issues

CRPD Article 33 – Monitoring implementation

Framework to promote, protect and monitor implementation of the CRPD
Independent Monitors meet annually with the Ministerial Committee on Disability Issues and the Chief Executives Group on Disability Issues to review progress and priorities.

CRPD Article 4(3) - Involvement

DPOs and Chief Executives' Group on Disability Issues
Governance oversight of progress implementing the Disability Action Plan and review of engagement between DPOs and government agencies.

DPOs and Senior Officials
Government agencies (Senior Officials Group on Disability Issues' representatives) attend part of the regular DPOs-only meetings to support the Disability Action Plan governance and implementation arrangements

CRPD Article 33 - Government mechanism promoting implementation

Cabinet
Makes final decisions on government policy.

Ministerial Committee on Disability Issues
Coordinates implementation of the UN Convention on the Rights of Persons with Disabilities and the New Zealand Disability Strategy, sets priorities for cross-government action, and reviews progress by government agencies.

Chief Executives' Group on Disability Issues
Leads implementation of decisions and priorities made by the Ministerial Committee on Disability Issues.

Senior Officials' Group on Disability Issues
Manages implementation of decisions and priorities made by the Chief Executives' Group on Disability Issues.

4. Bulgaria – problematic "institutional participation"

Mladenov published a paper in 2009, which presents the findings of a critical study undertaken in Bulgaria. The study examined the effects of DPOs being involved in policy-making processes on a national level. According to the findings of the study, the involvement of DPO representatives in these processes through institutions (such as the "National Council on the Integration of People with Disabilities") has several negative effects.[109]

Mladenov maintains that "such an instance of 'participation' [through institutions] actually helps sustaining the status quo of underdevelopment and dependency" of disability organizations. His findings include that the professionalization and institutionalization of NGOs by involving them through institutions alienates them from their social base. Furthermore, he states that a shift from donor support to more funding from EU funds will negatively affect the "civil character" of the NGO sector, as the organizations' independence from the EU and state will be jeopardized.[110]

Mladenov argues that these "side-effects" are not specific to the area of disability politics but that similar consequences occur in other fields as well. He refers to another study published by *Dakova* which reaffirms this statement: "There is a paradox for the NGOs in countries in transition – if they want to influence the state, they have to 'come closer to it' and then they are easily coopted and distanced from their functions as civil society; if they remain firm on their civil society positions, they are easily marginalized and are not allowed access to the process of defining the development policies."[111] Additional international studies prove that this phenomenon does not only occur in "transitional" countries such as Bulgaria at that time, but show that it is a typical occurrence in today's society. As soon as representatives of social movements are involved in policy-making through institutions set up by the government, it leads to a "shrinking and eventual extraction from the agenda of the groups which have initiated it". Terms like "constructive dialogue" and "participation of people with disabilities" have to be considered with caution, especially if the participation processes are institutionalised.[112]

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[109] *Mladenov* (2009) 33ff.

[110] *Mladenov* (2009) 33.

[111] *Dakova* (2003) 44.

[112] *Mladenov* (2009) 37.

Mladenov describes this difficult challenge for DPOs and refers to findings by other scholars: On the one hand, disability organizations have to build a relationship with government authorities to receive financial and institutional resources. On the other hand, the organizations should remain independent, critical and keep a close relationship with their base.[113]

He distinguishes between four levels or degrees of participation and expressly states that the categories reflect the foundations laid by *Arnstein's* ladder model of eight rungs:

1. *participation as accepting and supporting predetermined decisions*, which inevitably leads to their one-way legitimation;
2. *participation as choosing between predetermined alternatives,* which, although providing more opportunities for reaction, still leads to one-way legitimation of an already made decision;
3. *participation as developing alternatives within the framework of a predetermined system of relationship,* where the process sustaining the status quo may initiate change;
4. *participation as changing a particular system of relationship* and, therefore, specific pattern of power distribution – the status quo might be successfully overturned on this level.[114]

Mladenov concludes his paper by restating the most important finding that "incorporation of civil participation into established institutional structures bears a significant risk of increasing state power at the expense of disempowering civil organisations." He calls for a much needed "radical change", which can only be achieved if DPOs succeed in "climbing up the ladder of participation".[115]

Forrest/French describe their observations of the work and the disability sector's perception of the Australian Federation of Disability Organizations (AFDO) in the mid-2000s. Their conclusions strongly resemble the findings described by *Mladenov* in a totally different part of the world: "The [AFDO] is now regarded by the Australian government, and describes itself, as 'the' national representative voice for persons with disabilities, but in reality it is still struggling to achieve legitimacy among the wider community of persons with disabilities and their organ-

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[113] *Mladenov* (2009) 34ff.
[114] *Mladenov* (2009) 43.
[115] *Mladenov* (2009) 42f.

izations in Australia. Suspicion and resentment of the Federation, which was perceived as created by the government, was particularly acute during the CRPD negotiation process. Yet as the negotiation process progressed, it was positioned by the Australian government as the principal coordination mechanism and ultimate representative body for channeling the sector's views."[116]

5. Other models

As mentioned above, countless models and theories of participatory approaches have been developed by either scholars or government entities all over the world. Some of them focus on specific demographic groups (such as children, youths or disabled persons) others deal with particular ways of participation (such as online participation).

There are several compilations of participation models and theories available online. The website nonformality.org features an impressive report which includes a total of 36 different models of citizen participation. These models have been developed either by UN organizations, private organizations or scholars. All the theories are presented and briefly summarized in the release. It starts with *Arnstein's* ladder model from 1969. The most recent model featured in the list deals with children and young persons participating in policy-making processes in Nicaragua and was published in 2012. Some of the important models listed in the report include:[117]

- Ladder of Citizen Participation (*Arnstein*, 1969),
- Ladder of Children Participation (*Hart*, 1992),
- Active Participation Framework (*OECD*, 2001),
- Strategic Approach to Participation (*UNICEF*, 2001),
- Participation 2.0 Model (*New Zealand*, 2007),
- Spectrum of Public Participation (*International Association for Public Participation –IAP2*, 2007): This model is particularly interesting, as it takes a comprehensive and all-encompassing approach and includes detailed in-

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[116] *Forrest/French* (2014) 197.

[117] http://www.nonformality.org/wp-content/uploads/2012/11/Participation_Models_20121118.pdf (Mar. 23, 2016).

formation on citizen involvement. IAP2 also offers a training program for decision-makers.[118] A chart depicting the Spectrum of Public Participation is also available online. As most other models, it strongly resembles *Arnstein's* ladder model.[119]

- Six Principles of Online Participation (*Davies*, 2011).

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[118] See http://www.iap2.org/ (Mar. 23, 2016).

[119] http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/Foundations_Course/IAP2_P2_Spectrum.pdf (Mar. 23, 2016).

D. Austria

In 2008, Austria ratified the CRPD and it came into force on October 26th of the same year.[120] The Parliament ratified the Convention with a constitutional reservation ("*unter Erfüllungsvorbehalt*", Art 50 [2] Z 3 B-VG). This means that the **Convention cannot be directly applied** by courts and administrative bodies. It does not award any rights to individual persons, as long as national legislators have not implemented the CRPD into national law.[121] In other words, domestic legislation is absolutely essential for the Convention to be implemented into Austrian law.

Austria was very fast in ratifying the Convention. The federal government very soon came to the conclusion that domestic law was in line with the CRPD anyway and therefore saw no immediate need for action with the exception of establishing an independent monitoring mechanism. The government's view was reflected in the official Austrian "Disability Report 2008" ("*Behindertenbericht 2008*"). The Report expressly states that the paradigm shift of the CRPD had already been implemented in Austria and that all rights stipulated in the Convention had already been embodied in the domestic legal system. Therefore, **the government saw no need for implementation** under substantive law after Austria became a States Party to the CRPD.[122] This conclusion by the government seemed premature and was criticized by key stakeholders in disability politics.[123] Shortly afterwards the government acknowledged the fact that there was still work to be done towards full implementation of the CRPD requirements into domestic law.

The following sections describe Austria's institutional framework in disability politics and disabled persons' involvement in the process of implementing the CRPD. The ongoing process of amending the guardianship laws in the light of Art 12 was closely monitored. It serves as an exemplary process for the whole research. The results of the empirical studies conducted will be described.

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[120] Federal Gazette III 2008 No 155.

[121] *Schulze* (2013) 174.

[122] *BMASK* (2009) 73.

[123] See e.g. *Schulze* (2013) 171; *ÖAR* (2013) 7.

1. Institutional framework

1.1. Focal points, coordination mechanism (Art 33 [1])

Over the past decades the **Federal Ministry of Labor, Social Affairs and Consumer Protection** (**BMASK**, *Bundesministerium für Arbeit, Soziales und Konsumentenschutz*) has been the driving force in the area of disability politics in Austria.[124] Shortly after Austria became a States Party to the CRPD, the BMASK was designated to serve as the coordination mechanism and the focal point within the government under Art 33 (1).[125] *Schulze* argues that the CRPD's intention was for the States Parties to establish focal points throughout various government departments and criticizes a lack of discussion of this issue in Austria.[126] Other countries have different approaches: In NZ, for example, a committee comprising eight important ministers serves as the coordination mechanism. This sort of composition of the national coordination mechanism increases the institution's ability to coordinate policy and other aspects across different government departments.[127]

In Austria's federal system, transparency within the often **confusing administrative setup** of both the federal and provincial bureaucratic systems remains a major issue. This fact is regularly used as an excuse or justification for not fully implementing the CRPD (as well as in other fields of law, where competences are split between federal and provincial levels).[128] The Concluding Observations, released in 2013 after Austria's first state examination, clearly state that Austria's federal system has led to an "undue fragmentation of policy". The Committee refers to Art 4 (5), which clearly states that "administrative particularities of a federal structure do not allow a State party to avoid its obligations under the Convention".[129]

After extensive search, no official document enlisting all provincial focal points and monitoring mechanisms was to be found online. The leaked draft of the "Objective Agreement Towards Inclusive Disability Politics" proposed by the

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[124] *Schulze* (2013) 176.
[125] *de Beco* (2014) 17.
[126] *Schulze* (2013) 176; *Schulze* (2014) 215.
[127] See below chapter D.2.3.
[128] *Austrian NGO Delegation* (2013) 1.
[129] *Committee on the Rights of Persons with Disabilities* (2013) point 10.

BMASK provides a list of all provincial focal points that had been set up until early 2015.[130]

1.2. Monitoring mechanisms (Art 33 [2])

Austria is a federal state composed of nine provinces (*Länder*). A federal monitoring mechanism was set up in 2008. As of 2015, all nine provinces have established monitoring mechanisms.

1.2.1. Federal committee

The **Monitoring Committee** (MA, *Monitoringausschuss*) was established under Section 13 Federal Disability Act (*Bundesbehindertengesetz*) and has served as the independent monitoring mechanism under Art 33 (2) since December 2008. It is tucked into the **Federal Disability Council** (**BBB**, *Bundesbehindertenbeirat*), an advisory board[131] to the BMASK.[132] The BBB was established in 2001 and its functions and composition are regulated in Sections 8-12 Federal Disability Act. Members of the Council include representatives of significant federal Ministries, members of all political parties represented in parliament and representatives of the provinces. Following an amendment[133] of the Federal Disability Act in 2014, the chairperson of the MA and eight representatives of the "disabled persons' organizations, self-advocacy organizations as well as war victims' organizations" are additional voting members of the Council.

Shortly upon the establishment of the MA, the Austrian government proudly announced[134] that the setup of the MA was fully in line with the requirements of the Paris Principles.[135] This declaration by the government was criticized from various sides. In public statements, the MA itself[136] and its long-term chairperson (*Marianne Schulze* served from 2008-2015) strongly opposed the government's

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[130] *BMASK* (2015) 10.

[131] *Mladenov* (2009) 35f describes the restrictions usually imposed on these kinds of institutions by the law, which set it up. Consultation and advisory boards are generally very weak bodies in terms of their abilities to actually change policy.

[132] *Schulze* (2013) 178.

[133] Federal Gazette I 2014 No 66.

[134] *BMASK* (2009) 73.

[135] *OHCHR* (2009b) 10f; see UN Resolution A/RES/48/134, http://www.un.org/documents/ga/res/48/a48r134.htm (Feb. 2, 2016).

[136] See e.g. *Monitoringausschuss* (2009a) 1.

opinion in that regard.[137] Several reasons are given for the alleged **lack of independence** from the BMASK, especially insufficient financial resources and the absence of a constitutional guarantee of this independence.[138] Domestic criticism was backed by the Concluding Observations in 2013. The UN Committee noted that the federal MA "does not have its own budget and appears to lack the independence required by the principles relating to the status and functioning of national institutions for protection and promotion of human rights (the Paris Principles)."[139]

The composition[140] of the federal MA is regulated in Section 13 Federal Disability Act. There is a total of seven members:

- four representatives of disabled persons' organizations,
- one representative of a NGO in the field of human rights,
- one representative of a NGO in the field of international development,
- one representative of academia.

A substitute member is nominated for each of the seven members. All members are to be nominated by the ÖAR and appointed by the Minister of Social Affairs for a period of four years. They elect a chairperson for the same period. By law, all members of the MA act independently. Members of any Austrian Ministry are allowed to participate in sessions of the MA to provide consultation but do not have any voting rights.

Austrian legislators, recognizing the importance of Art 33 (3), were eager to include people with disabilities directly into the monitoring mechanism. That is reflected in the fact that **four of seven members** of the federal MA **represent persons with disabilities** within the Committee.

The federal MA has set up its own rules of operation (which can be found online), in which the duties and responsibilities of the members as well as the procedures of decision-making are described in detail.[141]

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[137] *Schulze* (2013) 182.

[138] *Monitoringausschuss* (2009a) 1; *Schulze* (2013) 181f.

[139] *Committee on the Rights of Persons with Disabilities* (2013) point 52.

[140] For the current composition see http://monitoringausschuss.at/ueber-uns/zusammensetzung/ (Feb. 2, 2016).

[141] http://monitoringausschuss.at/download/documents-in-english/MA_GO_2009_04_01_EN.pdf

The Austrian MA has taken a very **proactive role** in recent disability politics by regularly publishing critical statements on current issues and holding a number of public sessions all over the country. Thereby, the MA hopes to enable civil society to participate and have their say in the monitoring process. The subject of one of the recent public sessions[142] in October 2014 was the wide field of political participation of people with disabilities in Austria. This session's lively discussion and results led to the publication of an extensive statement on the issue by the MA in April 2015.[143]

Minutes[144] of all public and closed sessions as well as annual reports[145] to the BBB and the UN Committee are available online. A number of comments[146] on existing law and statements[147] concerning drafts of laws are available and regularly updated on the MA's website. Several important reports by the MA can be found in sign language on the MA's own YouTube channel.[148]

All in all, the federal MA has made strong efforts to include civil society and especially persons with disabilities into their work. Furthermore, the Committee tries to design their work transparently by regularly publishing results on their website. Any shortcomings with regard to the involvement of civil society in the federal monitoring mechanism are most likely caused by the MA's lack of resources.[149]

1.2.2. Provincial mechanisms

Austria is composed of nine provinces (*Länder*), which have their own executive and legislative bodies and therefore have their own administrations as well. By early 2015 all provinces finally managed to establish their own monitoring mechanisms as stipulated in Art 33 (2). By September 2012 only the provinces of Carinthia and Vienna had designated monitoring bodies.[150] Even though all prov-

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(Feb. 2, 2016).

[142] http://monitoringausschuss.at/sitzungen/wien-30-10-2014-politische-partizipation/ (Mar. 8, 2016); see *Naue/Wegscheider* (2015) 86.

[143] *Monitoringausschuss* (2015).

[144] http://monitoringausschuss.at/protokolle/ (Feb. 2, 2016).

[145] http://monitoringausschuss.at/dokumente/berichte/ (Feb. 2, 2016).

[146] http://monitoringausschuss.at/stellungnahmen/ (Feb. 2, 2016).

[147] http://monitoringausschuss.at/begutachtungen/ (Feb. 2, 2016).

[148] https://www.youtube.com/channel/UC3PN0C3KtVd1c57sg8iQo3A/feed (Feb. 2, 2016).

[149] Aside from the chairperson, all members exercise their position in the Committee without pay.

[150] *Schulze* (2013) 179.

inces have established monitoring mechanisms,[151] the majority of them are not newly set up entities. Provincial legislators often decided to extend the competences of existing administrative bodies. Monitoring the CRPD's implementation was simply added to their existing portfolio. Therefore, their independence from other administrative and legislative entities is highly questionable.[152]

As an example, the **Tyrolean Monitoring Committee** (*Tiroler Monitoringausschuss*) shall be described briefly. It is tucked into the "Service Department for Equal Treatment and Non-Discrimination" (*Servicestelle Gleichbehandlung und Antidiskriminierung*) and was established in January 2014.[153] As mentioned above, the Committee is not a newly established body but an existing body with extended competences.

The composition of the Committee according to the rules of operation[154] is quite similar to the federal MA's composition but has an even stronger emphasis on persons with disabilities representing the lived experience within the Committee. The Tyrolean Committee has nine members and an additional nine substitute members:

- the "Tyrolean Commissioner for Anti-Discrimination" serves as the chair-person,
- one member represents academia,
- one member represents the field of human rights,
- six members are people with disabilities (they have hearing or visual impairments or restricted mobility or learning difficulties or mental illnesses).

According to the rules of operation, the Tyrolean committee holds at least four closed sessions annually. Additionally, public sessions are held at least once a year to discuss various topics of special public interest. The purpose of the first public session in July 2014 was to introduce the committee and its members to the public and to gather priorities and ideas from the public. Due to the ongoing public

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[151] *BMASK* (2015) 11.

[152] *Schulze* (2013) 178f.

[153] https://www.tirol.gv.at/meldungen/meldung/artikel/mehr-rechte-fuer-menschen-mit-behinderungen/ (Feb. 2, 2016).

[154] https://www.tirol.gv.at/fileadmin/themen/gesellschaft-soziales/UN-Konventionen/downloads/Geschaeftsordnung_MA_Okt_2014.pdf (Feb. 2, 2016).

discussion and the obvious importance of the issue, both the second (November 2014) and third public session (April 2015) featured the issue of inclusive education. Minutes of all public sessions are available online in different formats, e.g. in visualized or plain language versions.[155]

1.3. Other important institutions

The **Ombudsman's Office** (**VA**, *Volksanwaltschaft*) has historically been the most important human rights institution in Austria. The office is chaired by three former politicians. Its main objective is to follow complaints by individuals related to unfair treatment in an administrative decision by an Austrian authority.[156] Additionally, the VA serves as a "National Prevention Mechanism" with a constitutional mandate under two UN human rights treaties (OPCAT and CRPD). Under the CRPD (see Art 16 [3]), the VA is specifically tasked with preventing any form of exploitation, violence and abuse against persons with disabilities. The VA fulfils his or her duty by regularly visiting various facilities and programmes designed for persons with disabilities. Findings of these inspections are regularly reported to Austrian parliament.

There are several other entities in Austria that aim to improve and preserve human rights protection.[157] Among them, the **Ombudsman for Disabilities** (*Bundesbehindertenanwalt*) plays an important role in disability politics. The Ombudsman regularly reviews existing laws and drafts to ensure equal opportunities for persons with disabilities. Aside from that, the Ombudsman offers support with disability-related complaints by individuals facing discrimination by an administrative body. The Ombudsman provides assistance in these cases and the office offers a mediation and arbitration service in cases of discrimination.[158]

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[155] https://www.tirol.gv.at/gesellschaft-soziales/gleichbehandlung-antidiskriminierung/un-konvention-behindertenrechtskonvention-brk/monitoringausschuss/protokolle/ (Feb. 2, 2016).

[156] http://volksanwaltschaft.gv.at/en/problems-with-authorities (Feb. 2, 2016); *Schulze* (2013) 177.

[157] See *Schulze* (2013) 177f for a brief description of various entities and their competences.

[158] http://www.behindertenanwalt.gv.at/behindertenanwalt/ (Feb. 2, 2016); *Schulze* (2013) 178.

1.4. Disability sector

Similar to most other countries, Austria's disability sector features a broad variety of different organizations. This section tries to give a brief overview over some of the most important players in the sector.

The **Austrian National Council of Disabled Persons** (**ÖAR**, *Österreichische Arbeitsgemeinschaft für Rehabilitation*) was founded[159] in 1950 and serves as an umbrella organization for 78 member organizations[160] with a total of over 400.000 individual members.[161] The ÖAR's goal is the realization of an inclusive society in Austria, which is underpinned by the CRPD.[162] As an umbrella organization, the ÖAR aims to represent the interests of their membership organizations to the outside world and is doing publicity and awareness raising work. As mentioned above, the ÖAR is tasked to nominate members of the federal MA by law (Section 13 Federal Disability Act). Furthermore, the ÖAR offers a wide range of services to their member organizations, individual members and other partners.[163] Their website lists their main activities as following:

- "Development and upkeep of various documentations (technical aids, specialised literature, social services and institutions); […]
- The preparation of various – political – proposals and demands of disabled persons and consequently the attempt to realise these proposals and demands; especially in the areas of building and engineering, justice, labour market, social affairs, education and vocational training;
- The operation of an European department so as to inform the Austrian Disability Organisations on disability related issues in the European Union and so as to co-ordinate their according activities as well as to enable their participation in projects of the European Union;
- Collaboration in various panels and commissions: for instance Standards Committees, the Vienna school authority, various panels in Federal ministries (education, social affairs etc.), panels on long term care, panels of

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[159] A brief history of the ÖAR can be found on http://www.oear.or.at/publikationen/archiv/monat/monat-2006/mai-2006/oar-30-jahre-jung (Feb. 2, 2016).

[160] A list of member organizations is available online http://www.oear.or.at/oear-info/Verein/mitglieder-und-partner/mitglieder-und-partner/mitglieder-und-partner-adressen (Feb. 2, 2016).

[161] http://www.oear.or.at/startseite/english (Feb. 2, 2016).

[162] http://www.oear.or.at/oear-info (Feb. 2, 2016).

[163] http://www.oear.or.at/english/the-organisation (Feb. 2, 2016).

the Federal disability authorities, European Disability Forum in Brussels etc.

- Contact to all scientifically active institutions […];
- The Convention on the Rights of persons with Disabilities is from mayor importance for our work."[164]

In practice, the ÖAR should work as an interface between legislative and administrative bodies on the one side, and the broad variety of member organizations on the other side. However, the ÖAR's mandate to speak on behalf of Austria's disabled persons is questioned by some DPOs.[165]

The **Independent Living Austria movement** (**SLIÖ**, *Selbstbestimmt Leben Initiativen Österreich*) is "a network of organizations, networks and individuals" from all parts of Austria.[166] Their goal is to achieve true equality of persons with disabilities and the full application of their citizen and human rights following the principles of self-advocacy, independence, equality, non-discrimination and accessibility. Their motto "nothing about us without us" is reflected in their organizational structure, as all initiatives, projects and working groups consist of and are led by disabled persons.[167] Two members of SLIÖ were part of the NGO delegation that presented the status quo of Austria's implementation to the UN Committee in 2013 prior to Austria's first assessment in September 2013. The written statement, presented by the delegation, is available online.[168]

The Austrian self-advocacy movement has become more present and influential in recent years. The Tyrolean organization **WIBS**[169] ("*Wir informieren beraten bestimmen selbst*") is part of the People First network and serves as a pioneer organization within the self-advocacy movement in Austria. Other regional branches of People First in several provinces have been established, such as **Vienna People First**[170] or **People First Vorarlberg**[171].

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[164] http://www.oear.or.at/english/activities (Feb. 2, 2016).

[165] See below chapter D.2.3.1.

[166] A list of member organizations can be found on the SLIÖ's website, http://slioe.at/wer/mitglieder.php (Feb. 2, 2016).

[167] http://slioe.at/aboutus.php (Feb. 2, 2016).

[168] http://slioe.at/was/stellungnahmen/2013-04_Presentation_UN-CRPD.php (Feb. 2, 2016).

[169] http://www.wibs-tirol.at/ (Feb. 2, 2016).

[170] http://www.viennapeoplefirst-gaw.at/ (Feb. 2, 2016).

[171] http://www.mensch-zuerst.at/ (Feb. 2, 2016).

Aside from the organizations mentioned above, there are many other organizations and entities in Austria's disability sector. It would go beyond the scope of our research to describe them all at this point of the report.

2. Involvement of persons with disabilities

2.1. Overview

In Austria, persons with disabilities and their organizations are regularly invited to submit statements to proposed law amendments affecting them. Nevertheless, there are no legally binding and comprehensive guidelines or standards on how to involve persons with disabilities into legislative processes. As mentioned above, the Austrian federal government adopted the **"Standards of Public Participation"** ("*Standards der Öffentlichkeitsbeteiligung*") in 2008 and recommends them to be applied by administrative bodies. Even though these guidelines are thought to be comprehensive and include all kinds of processes in all fields of policy and the document has been available for almost eight years, its existence and contents are widely unknown to the persons it is addressed to. No Ministry official that was involved in our research has knowledge that this government publication even exists.

Therefore, actual practices of different government agencies on federal and provincial level in terms of participation vary strongly.[172] As several interviewees confirmed, it depends on the specific persons in charge of the respective process whether it is designed participatory or not. Aside from the little known CRPD, there are no legal regulations that require participatory processes. Accordingly, the Concluding Observations after Austria's first State Report recommend that Austria should ensure that "federal and regional governments consider adopting an overarching legislative framework and policy on disability in Austria, in conformity with the Convention. It further recommends that such policy include frameworks for real and genuine participation by persons with disabilities through their representative organizations with respect to the development and implementation of legislation and policies concerning persons with disabilities […]."[173]

The development of the **Federal Act on Insurance Benefits for Nursing** (**BPGG**, *Bundespflegegeldgesetz 1993*) during the early 1990s is often referred to as an

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[172] *Austrian NGO Delegation* (2013) 8f.

[173] *Committee on the Rights of Persons with Disabilities* (2013) point 11.

example for good practice in recent history. Persons with disabilities were involved throughout the process and working group sessions were held.

Shortly upon the CRPD's ratification, Austria's government realized – contrary to earlier statements[174] – that the CRPD's principles had not been fully implemented into domestic law and amendments to domestic law were needed. Austria's first State Report to the UN Committee was due in late 2010. During a consultation process prior to the adoption of the report by the federal government, the BMASK announced the establishment of a national strategy for the implementation of the CRPD until 2020.[175] The **"National Action Plan"** (**NAP**, "*Nationaler Aktionsplan Behinderung 2012-2020*") lists a number of measures deemed necessary in order to reach full implementation by 2020. In the introduction to the NAP, the Minister of Labor, Social Affairs and Consumer Protection expressly states his satisfaction that civil society and especially organizations of persons with disabilities were closely involved in drafting the NAP.[176] However, the Austrian Alternative Report to the UN (published by the ÖAR) describes this process of consulting with NGOs less enthusiasticly: "In the drafting process of the NAP, two work forums (at the beginning and at the end of the drafting process) were organized by the Federal Ministry of Labour, Social Affairs and Consumer Protection in order to inform civil society about the progress made. The first draft of the NAP was sent out to the NGOs for written consultation. Some ideas from about 70 statements made by NGOs were taken into account by the Ministry. However, important arguments were not considered, supposedly because of the financial expenditures that would be necessary. The finalization of the NAP was neither sufficiently transparent nor participative."[177]

A leaked draft of an "Objective Agreement Towards Inclusive Disability Politics" (*Zielvereinbarung "Inklusive Behindertenpolitik"*) proposed by the BMASK in 2015 has been heavily criticized for similar reasons. The document lists the importance of full participation of persons with disabilities (in all decision-making processes affecting them) as a major principle.[178] Thus, it comes as a surprise that the document itself, which proclaims to be aiming at changing Austria towards an inclusive society, was drafted without any involvement of DPOs. The fact that a

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[174] *BMASK* (2009) 73.

[175] *ÖAR* (2013) 3.

[176] *BMASK* (2012) 3.

[177] *ÖAR* (2013) 3; the lack of involvement of people with disabilities in the development of the NAP is also criticized by other stakeholders, see e.g. https://www.bizeps.or.at/news.php?nr=13405 (Feb. 2, 2016); *Naue/Wegscheider* (2015) 86.

[178] *BMASK* (2015) 12.

document that declares participation as an important cornerstone in the Austrian society and politics was created without any participation by relevant stakeholders from civil society has been described as a "paradox".[179]

Another aspect that has been raised by participants of our research is the fact that persons with disabilities are still vastly under-represented in decision-making positions all across government, legislative and administrative bodies – on both federal and provincial levels. Apparently, these observations are not only an Austrian phenomenon. Similar facts were also pointed out by a scientific study that was carried out in Norway a few years back.[180]

Legislators in the province of Tyrol have started an ambitious participatory legislative process in early 2016. The development of a new disability support system shall be preceded by an extensive consultative process which is designed as a "Legislative Theatre".[181] This form of participation is based on the concept of "Theatre of the Oppressed", developed by Brazilian theatre director, politician and activist *Augusto Boal*. It enables citizens to raise their voice in the setting of a stage play. The objective is to start an open dialogue between citizens and governmental and administrative institutions. Citizens can take the stage and share their opinions and lived experience with legislators, thereby helping the legislative process. According to officials, a number of these events are planned in all districts of Tyrol over the course of 2016. An estimated 10.000 persons who received disability support in recent years are invited to the information events which are also held in all districts. This proposed plan marks an unprecedented participatory approach in Tyrol. Unfortunately, the process will start just after the conclusion of this project.

2.2. Empirical studies and methods

Over the course of our research in Austria, different empirical methods were applied. Through the support of the BMJ, it was possible to examine the process of amending **guardianship** laws very closely. Therefore, this process was the main focus of the research in terms of Art 4 (3). The methods applied in this area will be described in a separate subsection below.

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[179] https://www.bizeps.or.at/news.php?nr=19 (Feb. 2, 2016).

[180] See *Guldvik/Lesjø* (2014) 516ff.

[181] See https://en.wikipedia.org/wiki/Theatre_of_the_Oppressed#Legislative_theatre (Apr. 22, 2016).

Additional empirical data collection undertaken in Austria can be summarized as follows:

- A set of questions was sent via e-mail to the ÖAR (as the umbrella organization) to get a broader perspective on their involvement in legislative activities in Austria.
- Several public sessions of the federal MA and the Tyrolean MA were attended to assess civil society's involvement in the monitoring activities.
- Semi-structured interviews were conducted with 2 members of the federal MA who both have long-time experience in disability politics.

Guidelines with bullet points were sent to all interviewees in advance in order to allow them to prepare for the meetings. Thus, the interviews were semi-structured. Two different sets of interview guidelines were used, one for the interviewees on the "government side", and one for those on the "non-government side".

All interviews were conducted by two researchers, recorded and transcribed shortly afterwards. The data gathered during the interviews was evaluated by establishing categories in order to identify significant themes, such as "problems regarding representation within the disability sector" or "issues caused by Austria's federal structure". Relevant categories were established *after* the interviews were conducted; therefore the risk of imposing preconceived categories or theories on the data was reduced.[182]

2.3. Key findings

Representatives of the Austrian disability sector identified issues with some Austrian officials' way of involving persons with disabilities. The following section describes the main issues that were identified by participants of our research aside from the guardianship process, which will be described in a separate section of this report.

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[182] *Moriarity/Dew* (2011) 688.

2.3.1. Different interpretations of "participation"

As shown in previous sections (models of citizen participation), there are **different understandings of the concept of participation**. Lawmakers and administrative bodies in Austria often have a different understanding of participation than various stakeholders in the disability sector; a fact that was not only pointed out in several interviews conducted for our research but had also been established in academic papers before.[183]

Today's selective participation of people with disabilities is considered a **hard-fought achievement** by the disability sector and not something that was enabled or promoted by officials. *Paul*, a DPO representative, said:

"The Independent Living movement in Austria was kind of the thorn in the flesh of politics. Participation was something that had to be fought for. […] That fight was the beginning of our movement. […] The premise by officials has to be that participation improves legislative processes and is not something that just has to be done to fulfill international obligations. […] Today it is all about raising awareness on what participation is and what its benefits are."

Matt, another long-time activist, said:

"You do not just get negotiating power from somebody; you really have to fight for it. All the participation that is happening nowadays is a result of years and years of struggle."

There is general consensus among all interviewed persons that Austrian officials have yet to realize the benefits of including those affected by the respective regulations into legislative processes. The participatory process preceding the BPGG during the early 1990s regularly comes up as a prime example for how participation improves legislative processes and outcomes. The final draft of the proposed act reflected the influence of all parties involved. Even though the outcome was not considered perfect by either side, the **involvement** of the disability sector led to a different degree of **acceptance by persons with disabilities**. The new act was not viewed as new regulations imposed on civil society by politicians ("*their* law") but as **a joint product** ("*our* law") of officials and various interest groups.[184]

Matt, who is a long-time representative of an Independent Living organization and already participated in these processes decades ago, shared his memories of the development of the BPGG:

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[183] See e.g. *Schulze* (2013) 186.

[184] See *Moriarity/Dew* (2011) 689.

"You win some, you lose some. That is just part of making a compromise. However, after [you have participated] you view it as your own *draft as well. Even if the new act is not perfect, at least you have the feeling that it is partly* your work. *There is a different degree of respect for these regulations. […] The disability movement still views the BPGG as* their *success and that is why there have been emotional discussions around this act ever since."*

Nearly all participants of our research from the disability sector criticized that Austrian lawmakers still largely **exclude** persons with disabilities **from actual decision-making processes**.[185] Even if persons with disabilities and their organizations are invited to submit written statements and/or participate in working groups, officials always reserve the right to make the ultimate decision themselves. Contributions from the disability sector are accepted but their ideas are rarely reflected in the final outcome of legislative processes. Most processes also lack transparency, which makes it difficult to assess if and how civil society's input was taken into consideration.[186] This leads to the perception that the involvement of persons with disabilities sometimes merely works as an excuse for officials ("tokenism")[187] or that the outcome of the process has already been determined before the so-called participation process even starts. Participation might be used as a means to legitimize already made decisions.[188] The federal MA released a statement that comments on the status quo in Austrian disability politics:

"Working groups and other advisory boards are established in order to create the impression that the opinions and ideas of the people, who are invited, are relevant, but the actual decisions are made by somebody else and the results of these bodies are completely ignored by decision-makers."[189]

Matt, an Independent Living activist, said:

"[Participation] means to be included right from the beginning. It does not mean to just receive information during an ongoing process. […] You reach a situation, where you are allowed to share your opinions and where you are listened to [by officials]. […] But there are no results. We have no negotiating power and we are not involved at the actual decision-making level. […] It is typical for Austrian participatory processes that – even if you are invited to participate in working groups – you do not negotiate with the persons that ultimately make the decisions."

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[185] *Austrian NGO Delegation* (2013) 8f.
[186] *Monitoringausschuss* (2015) 1f.
[187] *Monitoringausschuss* (2015) 1.
[188] *Mladenov* (2009) 43.
[189] *Monitoringausschuss* (2015) 2.

Claire, a self-advocate who regularly participated in the guardianship reform working group sessions, also shared a pessimistic view:

"I think it is a good thing that officials ask for my opinion at all. But in the end I cannot influence the final outcome. The officials will make the ultimate decisions themselves and they do not care what was agreed upon beforehand in the working groups. But I think it is a good first step that they at least ask for outsiders' opinions."

During the course of our research, we also spoke to *Dan*, a political scientist who is a renowned expert in the field of participation. He also emphasized the importance of participation throughout the whole process as opposed to selective participation at certain stages of the process:

"Effective participation in the long-term requires involvement of all parties right from the beginning. […] This starts with sharing necessary information even before *the start of the process itself."*

Critics argue that lawmakers in Austria regularly use the fact that they "allowed" participation in the respective process to legitimize legislative outcomes to the public. *Paul*, a DPO representative, critically evaluated the role of the ÖAR:

"The ÖAR is only noticed by Ministries if they need legitimation for something. […] After the process is over and the results are criticized, they simply say that the disability sector was asked to share their opinion. That is their actual understanding of participation. […] You should not just let someone participate to be able to say afterwards: 'Well, we asked them about their opinion – what else do they want now?'"

Representatives from all over the disability sector complain that participation was "granted" to civil society in order to squish criticism. Therefore, the fact that civil society was in any way involved in the process somehow precludes them from criticizing the new act and is sold to the public as a participatory process. The process preceding the release of Austria's NAP in 2012 serves as a good example: While officials[190] praise the participatory development of the NAP, practically every participant of our research criticized the lack of participation and transparency throughout this process. Paul, an involved DPO representative, said:

"The NAP as a whole is a total failure. It already started with the development process. There was a first draft, to which some organizations were allowed to submit statements. The second draft was not even shown to these groups. It was not until after the adoption and the public re-

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[190] *BMASK* (2012) 3.

lease of the NAP that we saw it again. […] Nevertheless, the NAP is viewed by officials as an example for best-practice in regard to participation."

All in all, most interviewees noted that there have been **improvements** regarding the involvement of disabled persons in political processes **in recent years**; most likely prompted by the CRPD's influence. Many officials do not yet perceive participation as an important element of policy-development and legislation in a democracy. Civil society however perceives participation as something that has to be fought for and is being granted by officials subsequently.

Several participants of our research stressed that there are severe differences with regard to the understanding of participation between officials and other stakeholders in the disability sector. A clear and uniform definition of the term is viewed as a necessary requirement for effective participation in the future.

Even though most representatives from the disability sector found critical words to describe past and current practices, they all see overall improvement in recent years. All of them highlighted the **current process to amend the Austrian guardianship law** as an **outstanding positive example** in terms of participation. It remains to be seen if the final outcome will actually reflect the input and know-how of the disability community.

2.3.2. Lack of resources

Most participants of our research from the disability sector addressed the general problem of **insufficient resources and funding for DPOs**. They also criticized the fact that officials view participation by civil society as honorary work. DPO representatives mentioned that officials expect organizations and individuals to participate without being payed for their expertise and not even being reimbursed for their expenses.

As an umbrella organization, the ÖAR is supposed to fulfil the role of representing the interests of their member organizations in political processes in Austria. Their membership includes some of the most important players in the sector. When asked about their way of fulfilling this role, a representative of the ÖAR stated:

"We do most of our work on the federal level. We submit statements regarding all drafts and law amendments affecting persons with disabilities. Only in very important processes we submit

statements in provincial matters. In urgent matters we coordinate our actions with our member organizations throughout the whole country."

Critics argue that even the ÖAR as an umbrella organization of some of the biggest players does not have enough resources to effectively participate in all crucial political processes throughout Austria. Nevertheless, according to critics from the DPO sector, the ÖAR itself is not to be blamed for these shortcomings, as it seems to have been knowingly installed as a weak body without any actual powers. *Paul*, speaking on behalf of his DPO, shared his view of the ÖAR:

"Practically every small Independent Living organization has more employees than the ÖAR has. […] Even the ÖAR is not invited to participate in working groups or similar processes most of the time. The ÖAR is only used by the BMASK to legitimize their work but is very little noticed and respected by other Ministries. A few weeks back, I talked to a very senior official at the Federal Chancellery of Austria who had never even heard of the ÖAR in his life. […] Outside of Vienna [Austria's national capital], the ÖAR is practically non-existent. […] That is particularly bad in the field of disability politics, as most competences lie with Austria's provinces."

The fact that the ÖAR and other organizations in the field do not have sufficient resources to effectively participate in all federal and provincial legislative processes was also picked up by the Committee in its Concluding Observations on Austria's State Report. The Committee points out that Austria's provinces are the main providers of social services but are insufficiently included in important processes, such as the development of Austria's NAP.[191]

If the concept of participation is taken seriously, additional financial resources are required in order to enable civil society to contribute effectively. This may include reimbursements for participants, such as travel and accommodation costs or fees for personal assistants, if needed. Expenses for travel and accommodation are an important issue in Austria, as most important events such as conferences, workshops or working group sessions are held in Vienna.

Additional financial resources are needed for all events to be arranged accessible for everybody. This requires various costly expenditures, such as expenses for hiring sign language interpreters during working group sessions or renting accessible facilities.

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[191] *Committee on the Rights of Persons with Disabilities* (2013) point 10.

Several interviewees criticized the fact that civil society is expected to participate in legislative processes without any reimbursement of expenses. They noted that this practice leads to financially weak and independent organizations being precluded from participating, which results in a dominance of service providing organizations in most processes.[192] *Paul* (DPO representative) said:

"Big service providing organizations can afford to send some of their numerous employees to working groups. However, if I run a small organization with e.g. three members with learning difficulties – […] who pays for possible personal assistance, travelling or accommodation? No wonder, that no representatives of small organizations attend working group meetings even though they are invited. The only representatives from the disability sector there are those that are financially dependent on powerful organizations."

Mary, another DPO member, said:

"They do not pay you for attending the working group sessions. Maybe they actually do not want self-advocates to be there speaking up for themselves."

2.3.3. DPOs vs service providing organizations: representation issues

Various participants of our research critically addressed the fact that there is no clear distinction between DPOs and service providing organizations (organizations *for* disabled people) in Austria.

The ÖAR sees itself as an "umbrella organization *of* disabled people"[193], even though the vast majority of its member organizations are organizations providing services *for* disabled people, such as running special institutions. Therefore, the ÖAR's self-perception is criticized by several DPO representatives. *Paul* said:

"The ÖAR views itself as a DPO. This is simply not true. The ÖAR is a conglomerate of service providing organizations as well as organizations of and for disabled people. […] This is the reason, why it is just unthinkable for our organization to become an ÖAR member: We simply cannot form an alliance with the organizations that run institutions for disabled people – they are our opponents. […] Of course, we work together with them occasionally, as we share some common goals."

Matt, a long-time activist of the Independent Living movement, said:

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[192] *Austrian NGO Delegation* (2013) 9.

[193] See http://www.oear.or.at/publikationen/archiv/monat/monat-2006/mai-2006/oar-30-jahre-jung (Feb. 2, 2016).

"The ÖAR is a strange hybrid-system because it shelters for-profit organizations and organizations of persons with disabilities. The group that I represent, the Independent Living movement, has nothing to do with that."

This shows a crucial problem in Austrian disability politics: Politicians and representatives of the public administration make no clear distinction between (DPOs) and other organizations and players in the field.[194] This sometimes leads to strange incidents, as *Paul* described:

"Some Ministries do not even distinguish between monitoring institutions and civil society. This resulted in the fact that the federal MA was actually perceived as a DPO by officials and its members were invited to participate as representatives of disabled persons. However, actual DPOs were not invited."

These statements paint a rather negative picture of Austrian officials' knowledge of the disability sector and the Convention's ideas of participation. It seems to be regular practice to just invite someone who is somehow associated with "disability". A clear distinction has to be made between groups who actually represent disabled persons' interests (DPOs) and other organizations, which include groups who primarily pursue financial interests such as service providing organizations.

2.3.4. Participation in the monitoring mechanism

The federal MA in Austria is taking the requirement of Art 33 (3) to involve civil society, in particular persons with disabilities, in the monitoring process very seriously. It identified at very early stages that participation of people with disabilities (and civil society in general) solely based on the composition of the Committee (by law, four of the seven members of the MA have to be DPO representatives) was insufficient.[195]

The MA's current **information policy** can be seen as an example for **best practice.**[196] Their website provides detailed information on their composition and work. All publications as well as preparation papers and minutes of all closed and public sessions are accessible there. The most important documents are available

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[194] *Austrian NGO Delegation* (2013) 9.

[195] *Schulze* (2013) 185.

[196] Compare *Mladenov* (2009) 34. He describes the rather dubious information policy of the National Council of People with Disabilities in Bulgaria.

in plain language. An online dictionary provides explanations for crucial technical and legal terms.[197]

The challenges that the MA had to face at the early stages can be largely attributed to the fact that it has always had very little resources. *Schulze*, the MA's long-time chairwoman, describes the **challenges during the evolution of the Committee** in a paper: According to her, the MA proposed to hold regular public sessions very early on. The first session "featured many shortcomings due to the lack of resources". As there was no website yet, the announcement of the public session did not reach many organizations and the documents relevant to the session could not be distributed beforehand.[198]

So far (late 2015), the MA has held **12 public sessions** on various crucial issues such as inclusive education, supported decision-making, reasonable accommodation and political participation of persons with disabilities. The sessions were held in accessible rooms with sign language interpreters being present. To increase the possibilities of participation for people all over the country, the public sessions of the federal MA alternate between the federal capital Vienna and a capital city of one of Austria's provinces.[199]

Accessibility of information and publishing all documents in various formats are recognized as key criteria for effective participation in the monitoring system. This is reflected e.g. in Section 12 of the Rules of Operations. They clarify that this document has to be made available in accessible formats, in particular "Braille, sign languages, easy-read and auditive forms".[200] As far as possible, plain language is used during the public sessions. If technical or complicated terms are used during discussions, they are immediately explained by the chairperson of the MA in plain German.

Political participation of persons with disabilities is viewed as a paramount principle of the CRPD by the MA. In October 2014, the committee held a public session on this issue in Vienna. The inputs and results of this session led to the publication of an extensive written statement on "Comprehensive Participation" in April 2015.[201] The publication of this paper shows that the MA not only embraces important principles of participation in its own work but also shows the proac-

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[197] http://monitoringausschuss.at/glossar/ (Feb. 2, 2016).

[198] *Schulze* (2013) 185f.

[199] *Schulze* (2013) 186.

[200] *Monitoringausschuss* (2009b) 6.

[201] *Monitoringausschuss* (2015).

tive approach of the Committee in Austrian politics. The MA proposed various ideas to officials and tried to lay out foundations for **efficient participation of persons with disabilities in all areas of life**, which is a necessity for effective political participation: "In order to make political participation possible, we have to ensure participation in everyday life."[202]

2.4. Guardianship reform

2.4.1. Overview

Self-determination of persons with disabilities is a paramount principle of the CRPD. The area of **guardianship law** is of **prime importance** to this, as it usually limits and restricts self-determined and independent everyday decision-making for persons under guardianship. Many disabled persons are currently under guardianship in Austria. In order to create an inclusive society on all levels, the CRPD requires all States Parties to eliminate substitute decision-making in their domestic guardianship systems as an element of the outdated paternalistic approach as far as possible.[203]

The amendment to the Austrian guardianship laws currently underway was primarily prompted by the realization that the laws regarding possible restrictions of legal capacity are not in line with the requirements of the CRPD (especially Art 12). Following Austria's first State Report, this fact was pointed out by the UN Committee in the List of Issues as well as in the Concluding Observations.[204]

Even before the UN Committee indicated **possible legal conflicts** between the **current guardianship regulations** and **Art 12**, legislative changes in this area were demanded by several domestic actors in disability politics. In 2012, the federal MA issued a statement on the subject of self-determination of persons with disabilities. Among other matters, the paper describes problems of the current guardianship regime in Austria and the restrictions it imposes on each person under guardianship (ward).[205] The Austrian Alternative Report to the UN (published by the ÖAR) on the occasion of the first State Report also criticized both the legal foundations and practices in the field of guardianship.[206] Furthermore, these

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[202] *Monitoringausschuss* (2015) 1; *Naue/Wegscheider* (2015) 86.

[203] See e.g. *Degener* (2015) 59.

[204] See *Committee on the Rights of Persons with Disabilities* (2013) point 27.

[205] *Monitoringausschuss* (2012) 2ff.

[206] *ÖAR* (2013) 32f.

issues and possible breaches of the CRPD had already been mentioned and discussed in several scientific legal papers before.[207]

As pointed out by most critical voices, the system of guardianship seems incompatible with Art 12 because it specifies full or partial incapacitation of the ward. By automatically restricting the capacity to act as soon as a guardian is appointed, the current system limits self-determined decision-making. Moreover, Austrian guardianship laws do not reflect the principle of supported decision-making but are solely based on the principle of substituted decision-making.

Recognizing the need for change, the responsible federal Ministry (BMJ) started a process in late 2013 to bring the Austrian guardianship laws in line with the CRPD. In establishing a working group including persons with disabilities at the Ministry, the BMJ also fulfilled a demand of Austria's Alternative Report to the UN.[208]

2.4.2. Design of the process

Historically, persons with disabilities and their organizations were included in legislative processes in Austria by inviting them to submit written statements in response to concepts. However, there has never been a comprehensive and structured consultation process that included persons with disabilities from the beginning.[209]

The process to amend guardianship laws stands as a prime example for an improvement in this regard, as officials tried to **involve all important players** in the sector right from the beginning. Several participants of our research expressed hope that this process could be the start of a paradigm shift taking place; if other Ministries followed this path as well. *Paul* (DPO representative) who was involved throughout the process said:

"The process could and should serve as a role model for other processes to come."

There is a high level of awareness by the officials in charge that the guardianship laws have to be brought in line with the CRPD and the process itself has to be

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[207] See e.g. *Schauer* (2011) 260ff; *Barth/Ganner* (2010) 204ff; *Gruber/Palma* (2015) 88ff.

[208] *ÖAR* (2013) 33.

[209] *Austrian NGO Delegation* (2013) 8f.

designed accordingly. *Ted*, a senior BMJ official, who had already observed the process preceding the last amendment in 2006, said:

"We did not want to amend the law without including all people concerned by the regulations, so we initially asked ourselves: Who are the people that are most affected? […] The CRPD certainly paved the way for our process. […] I feel like we are doing real pioneering work, as there has never been a similar process in Austria."

The Ministry made significant efforts to involve all parties affected and especially persons with disabilities in the process right from the beginning. These efforts by certain officials at the BMJ are appreciated throughout the DPOs and other organizations. *Paul* (DPO representative) said:

"The guardianship reforming process is absolutely unique. Therefore, it should not be seen as just an example. It should be viewed as the *model of best-practice in Austria."*

Daniel, a long-time member of the monitoring process said:

"The guardianship process at the BMJ is quite astonishing because the people in charge seem really open-minded for these participatory processes. […] Senior officials at other Ministries still show reluctance to try. […] It always depends on the specific person who is in charge."

The officials in charge appeared to be very keen on reaching a maximum number of people who would possibly be interested in participating in the working groups. Trying to gather contact information of different DPOs, the Ministry reached out to the federal MA before starting the working group.

Invitations to sessions were sent out in various formats, e.g. in plain language. All invitations included a remark addressed to all recipients to forward the invitation to all other people who might take an interest in participating as well. Thus, the number of members and the composition of the working group changed throughout the process.

The process was organized in a working group that met regularly – mainly on the premises of the BMJ in Vienna. There was a distinction made between **"big working group sessions"** and **"small working group sessions"** which were held alternately, approximately every two or three months. The smaller sessions usually comprised around 20 participants (depending on the issues being discussed) and big working group meetings featured up to 70 participants. The Ministry's approach to a participatory process included two crucial steps:

1. *Small working group sessions:* The purpose of these sessions was to gather ideas for the proposed new draft and discuss possible al-

ternatives subsequently. Participants in this type of sessions typically have professional experience in the field of guardianship (e.g. judges, notaries, attorneys, representatives of guardianship associations,[210] service providing organizations and law professors with a scientific background in the matter at hand).

2. The second step was to *share the progress and results* of the small working group sessions with all participants in a bigger session and gather feedback from a more diversified group of people. In order to make it easier for everybody to follow the sessions, the BMJ regularly hired a professional presenter who ran the discussion in plain language and occasionally an illustrator who summarized the results in small sketches and drawings. Both BMJ officials who took part in our research explicitly stated during the interviews that the big working group sessions were especially designed in order to enable persons with disabilities to participate effectively. During these sessions, smaller circles of participants (roundtables) were formed regularly to discuss specific problems. The results of these discourses were then presented to the auditorium and discussed by all participants subsequently.

Additionally, **three special working group sessions** were held in January 2015, June 2015 and February 2016, to which **primarily persons with disabilities and supporting persons** were invited. This setting was supposed to encourage them to share their lived experience concerning the current guardianship regime with Ministry officials and present the proposed changes to a number of persons who were under guardianship themselves at that time. The Ministry hoped that a discussion in a smaller circle of people would encourage participants to contribute even more. The initial idea was to always include everyone in the big working group sessions but throughout the process, officials realized that some people felt a bit left out of the discussion and maybe a bit intimidated by the setting. This shows that individual needs and wishes were taken into consideration by officials.

Currently, the goal of the process is to finish a draft of relevant sections of the ABGB before the summer of 2016.

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[210] The most important guardianship association in Austria is the „Representation Network" (*Vertretungsnetz*), see http://www.vertretungsnetz.at/ (Feb. 2, 2016).

2.4.3. Empirical methods

Overall, we tried to include a broad range of involved officials and representatives of civil society into our research to gain a view on the whole process from various angles.

The BMJ held **17 working group meetings** during the process of amending the Austrian guardianship laws. They were all attended by at least one member of our project staff between December 2013 and May 2016. The aim was to monitor the progress and assess the involvement of persons with disabilities and their organizations throughout the process.

Thanks to the support of the research by Ministry officials, we were able to carry out **questionnaire surveys**. After three of the working group sessions, all participants of the respective sessions were asked to participate in this survey in which they were asked to anonymously share their experience regarding the specific session and the process as a whole:

1. At a meeting in December 2013, about 70 persons were present, 42 completed the questionnaire.
2. At a working group session in September 2014, about 65 persons were present. The questionnaire was filled in by 45 participants.
3. In January 2015, about 20 persons were present. 17 of them completed the questionnaire. This session was mainly attended by persons who identified themselves as disabled and/or self-advocates (10 of them).

The questionnaires were designed in easy-read German in order to be comprehensible for all participants. As the composition of the group regularly changed depending on the matters that were discussed, the results of the survey cannot be considered representative for all participants in the working group. They can, however, provide a wide range of impressions by the participants. Additionally, some suggestions for improvements can be deducted from the outcomes.

All in all, the three sets of questionnaires for the sessions were roughly identical; the third one, of course, focused even more on the direct involvement of persons with disabilities. Each set of questionnaires started off with questions for socio-demographic information such as gender, age, place of residence and organizational affiliation. These questions were followed up by inquiries into the motivations of the addressees to participate and their expectations of the participatory process. Several questions focused on the information provided for participants by the BMJ before, during and after the sessions and the degree of satisfaction with this information (whether it was accessible, comprehensible and sufficient). Other questions focused on whether the respondents actively participated in the respective session and whether they felt they were listened to and their statements were taken seriously by officials and other participants. An open question was included and the respondents were asked which aspects of the current guardianship regulations they wished to change. The questionnaire concluded with an open question, where respondents were able to make general comments towards the Ministry and proposals for future participatory processes.

Additionally to the questionnaire surveys, **semi-structured interviews** with five selected **participants** of the process were conducted:

- 3 of them represented DPOs,
- 1 of them considered himself an independent self-advocate,
- 1 of them represented a guardianship association.

Semi-structured interviews with two key **BMJ officials**, who supervised the whole process, were conducted to include their point of view as well. Naturally, these two interviews featured a different set of questions than those conducted with working group participants. The questions aimed at gaining insight into the development and the execution of the guardianship process. As these two interviews were carried out towards the end of the working group process in late 2015, it was possible to do a retrospective analysis of the whole progress made since 2013.

2.4.4. Results of the empirical studies

2.4.4.1. Composition of the working group

The male-female ratio of participants was roughly balanced, with men being slightly better represented than women (between 55 and 60 per cent).

Generally speaking, residents of Vienna are represented very well in all working group sessions. This comes as no surprise, as the vast majority of all meetings were held in Vienna. The opening workshop that started the whole process off was held in Salzburg in December 2013 and during 2015 three sessions were held in each of the three major court circuits outside of Vienna (in Wels, Graz and Innsbruck). At these sessions, presumably, other provinces outside of Vienna were better represented. Two sets of questionnaires that were handed out after sessions in Vienna included the question regarding the place of residence. In both cases, **more than 60 per cent of the participants** stated that they currently reside in **Vienna**. The majority of participants from other provinces come from provinces near Vienna (Lower Austria, Upper Austria). **Western provinces** (Tyrol, Vorarlberg) are therefore **underrepresented** at most working group sessions. At the specific sessions, when the questionnaires were handed out, almost two thirds of the participants came from *one* of Austria's nine (!) provinces. This should give some cause for concern to officials.

The vast majority of participants, who filled in the questionnaires, stated that they lived in an **urban area** (between 75 and 91 per cent of participants). Conversely, rural areas seem to be underrepresented in the working group.

Participants were asked to categorize themselves and their organizational affiliations in the questionnaires. The results show that the group of **participants** was actually very **diversified**, as it included representatives of:

- guardianship associations,
- DPOs,
- service providing organizations,
- the medical sector and nursing facilities,[211]
- legal professions such as lawyers, judges and notaries,
- representatives of other Ministries (e.g. BMASK) and of national social security agencies occasionally joined the working group, depending on the issue at hand.

As an example, the composition of the big working group that met in September 2014 is shown in the chart below. On other occasions, the working group composition seemed to be fairly similar.

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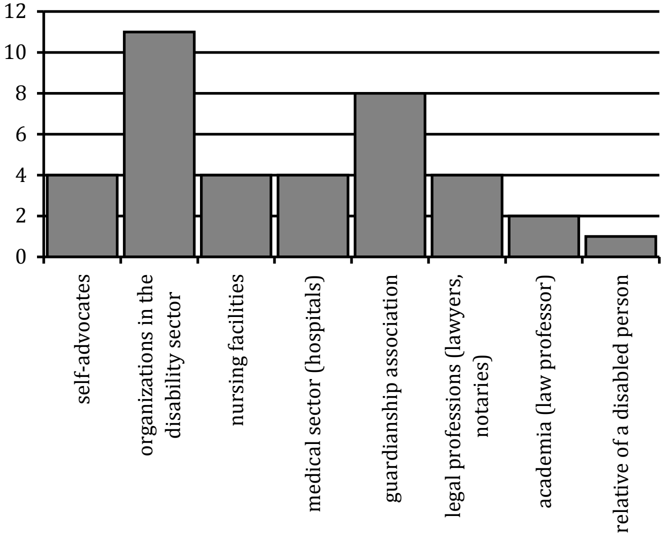
[211] Medical treatment of people under guardianship and consent of possibly incapacitated patients were crucial issues discussed throughout the process.



The fact that the BMJ tried to include most important actors in the sector right from the beginning was widely appreciated by working group participants. Even at the first session that kicked off the whole process, nine respondents explicitly applauded the BMJ for this approach.

Most of the participants stated that they contributed in the working groups on behalf of their respective organizations and not as individuals and therefore did not stand up for their personal views there. A slight majority of participants said that they were also invited to the working group through their organization, as opposed to being invited as an individual.

Self-advocates, who were invited personally and did not identify themselves as representatives of any organizations, were also present but outnumbered by representatives of various organizations. According to questionnaire responses, **roughly ten per cent of participants identified themselves as disabled**:

- At the meeting in December 2013, four of 42 persons, who filled in the questionnaire, identified themselves as disabled.
- At the session in September 2014, four of 45 questionnaire respondents identified themselves as disabled.

2.4.4.2. Information policy of the BMJ

The information policy of the BMJ, in general, is viewed positively. The issues discussed at the working group sessions are often rather difficult to understand for persons without legal training or professional background in the field of guardianship law. Providing the diversified range of working group participants with comprehensible and accessible information at all stages was a crucial challenge for the officials in charge.

Throughout the process, officials were aware that most of the issues would **require participants to prepare** for the sessions. Accordingly, they tried to schedule each session about two months beforehand and sent out information material alongside the invitations. The fact that information sheets and agendas for the respective session were regularly attached to the invitation e-mails was viewed very positively by working group members. More than 90 per cent of participants stated that they felt "sufficiently prepared" or "well prepared" going into the sessions by the materials handed out beforehand. Half of them stated that even more information would have been good, nevertheless.

However, there is **criticism regarding the transparency of the process as a whole**. Three questionnaire respondents and two interviewed persons stated that the progress in between meetings of the working group was difficult to follow. The main reason for this was that there was no focal point where all information concerning the process (such as agendas and/or minutes of previous sessions) was retrievable. This issue was also pointed out by two interviewees. Even though brief summaries of recent developments are presented by BMJ officials at the beginning of the sessions, participants stated that the process as a whole lacked transparency. *Paul* (DPO representative) stated:

"Often it is not clear what the next steps by the Ministry will be. They [Ministry officials] should share their plans with the working group participants; whether there are upcoming meetings with the Minister or other plans for the time in between working group sessions."

Participants were regularly invited to sessions but it remained unclear whether the input of the previous working group meetings was considered and in which way, as the Ministry usually did not reach out to the working group participants in between meetings. When interviewed, two of the officials who were closely involved however stated that the results of the working group sessions actually shaped and directly influenced various aspects of the upcoming draft. *Ted* said:[212]

"The new concept that we developed is not something that we [within the Ministry] came up with before the process started. The whole concept was actually developed and shaped throughout the working group sessions. (…) It is definitely a joint product of all participants. […] Certain aspects of the new concept can, in fact, be traced back to single statements by working group participants and subsequent discussions."

A recurring wish by a number of working group participants was for the Ministry to not only send out information material before the sessions but to also distribute **summaries of the results** *after* each session. This would have increased transparency and made it easier for working group members to follow the process.

One participant of our research, who is a long-time DPO representative, suggested that officials should establish a **website**, where all relevant **information** and documents regarding the process are collected and **available to everybody**. A similar website was created by German lawmakers in order to make the process of creating a Federal Act on Participation (*Bundesteilhabegesetz*) transparent to the public.[213]

2.4.4.3. Feedback to the BMJ by working group participants

Especially the last question of the questionnaires, which invited members of the working group to generally comment on the situation was used by a number of participants to give feedback to the BMJ officials. The overall feedback given by all different groups of participants was **predominantly positive**, as a large number of them expressed gratitude towards BMJ officials for the opportunity to participate. All participants recognized the involvement of persons with disabilities in the working group as "very important".

Nearly all participants stated that the sessions were, all in all, well-organized and easy to follow. The BMJ's efforts to design the whole process barrier-free and easily accessible were praised. The design of the big working group sessions was

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[212] At this stage, it cannot be assessed if this is a true statement, as no draft has been released yet.

[213] See http://www.gemeinsam-einfach-machen.de/BRK/DE/StdS/Bundesteilhabegesetz/bundesteilhabegesetz_node.html (Feb. 2, 2016).

viewed very positively, as most participants stated that the idea of forming small discussion groups within the session very much improved the discourse.

Most participants (about two thirds of the questionnaire respondents) stated that, before attending the meetings, they had planned on actively participating (= making statements), which in fact they did. This included all persons who identified themselves as self-advocates in the questionnaires. Observations by project staff during the working group meetings confirmed this result, as self-advocates and DPO representatives took a very proactive approach during the sessions and regularly made statements. Around one third of persons who filled in the questionnaire also noted that they wanted to send a signal simply by attending the sessions.

Nearly all self-advocates who filled in the questionnaire, as well as several other participants throughout the sector stated that the new guardianship regulations should strengthen self-determination of people under guardianship. They demanded a shift from a system solely based on substituted decision-making to a system embracing the model of supported decision-making.

Strong hope was expressed that the work and results of the working group will actually be reflected in the upcoming draft. Most participants believe that the design of the whole process as an interdisciplinary working group with regular meetings will in fact benefit the outcome.

However, some aspects were criticized by participants; the most common points that came up were the following:

- About one third of the respondents brought up that the **language** was **sometimes too complicated** and people were talking too fast. This was not only criticized by persons who identified themselves as disabled, but also by other participants.
- A significant number of respondents criticized that the venue of the big working group sessions in the BMJ featured very **bad acoustics**. This made it rather difficult to follow all aspects of the discussions. Observations by project staff confirmed this criticism.
- A small number of participants (most of them identified themselves as self-advocates) suggested that there should be a number of shorter **breaks during the sessions** (usually three hours) instead of one single break of 20 minutes. This would help to keep participants interested throughout the whole session.

- A small number of participants proposed that more sessions should be held and that some of them should be organized **outside of Vienna** in the future. It comes as no surprise that the vast majority of participants was satisfied with sessions being held in Vienna, as most of them stated that they currently reside in this city.

2.4.4.4. Special working group sessions for self-advocates and persons under guardianship

The idea of holding three sessions specifically designed for persons with disabilities was very well received. In January 2015, the first of these meetings was held in Vienna to gain insight into actual and everyday issues for persons under guardianship and their experience with the current system. The session was held at the BMJ in Vienna and the discussion was run by the then-chairperson of the federal MA, *Marianne Schulze*, who tried to run the meeting in easy language.

Ten persons who identified themselves as self-advocates attended the session; four of them stated that they were under guardianship at the time. Two persons who filled in the questionnaire were personal supporters, two others were members of the federal MA and one identified herself as a politician with a special interest in disability politics. Following the general trend of other sessions, ten of the seventeen respondents (59 per cent) stated that their current place of residence was Vienna.

Another question focused on self-advocates' expectations of the process. Five of them responded and the answer showed that there are various expectations, such as "general progress", "discourse and effective participation" or "strengthening self-determination".

Nine of ten self-advocates stated that they attended the session because they wanted to actively participate, three respondents wanted to be able to meet other people there to discuss their guardianship experience and three noted that they were interested to get more insight into guardianship law in general. Nine of them felt at least sufficiently prepared going into the session by the information sent out beforehand (in easy-read German) and the same number of respondents stated that the session improved their understanding of guardianship law.

Overall, self-advocates were satisfied with the working group meeting; six of them were "very satisfied", whereas four viewed it positively but saw "room for improvement"; seven suggested that sessions, which are designed primarily for self-advocates, should be held on a regular basis. Almost all self-advocates stated that they enjoyed the small circle of the working group because it was easier to actively participate in this environment.

The final question, asking for suggestions for future participatory procedures and for other comments, was answered by five self-advocates. Partially, this space was used to repeat comments already stated before but eight of the seventeen respondents (three of them self-advocates) explicitly applauded the BMJ's and Ms. *Schulze's* efforts. They especially praised the use of easy language during the session; only one respondent wrote that the discussion was too complicated at some point.

3. Summary

- The **BMASK** serves as the **focal point** and is also responsible for **overall coordination** of government policies and practices regarding CRPD implementation (Art 33 [1]).
- The **federal MA** was set up as the **independent mechanism to monitor the CRPD's implementation** in Austria on the federal level (Art 33 [2]). Most of Austria's nine provinces also established monitoring mechanisms. Their independence from governments is questioned.
- Austria's **disability sector** features a broad variety of organizations. The ÖAR identifies itself as an umbrella organization of DPOs. However, self-advocacy representatives and other organizations challenge the ÖAR's mandate to speak and act on behalf of disabled persons.
- There are **no comprehensive and legally binding guidelines on the involvement** of persons with disabilities in legislative processes. Therefore, the status of implementation of Art 4 (3) remains unclear. Actual practices and approaches of government departments in terms of participation vary strongly.
- Even if certain processes are presented to the public as participatory (e.g. the development of the NAP), DPO representatives claim that these processes were neither sufficiently transparent nor participatory, as civil society representatives are not included in the **actual decision-making processes.**

- Representatives of the disability community claim that government officials have yet to realize the **benefits** of participatory processes.
- Effective participation requires **adequate funding** and reimbursement for expenses which are directly related to acts of participation by members of organizations (e.g. travel expenses).
- The process of amending the **Austrian guardianship system** conducted by the BMJ serves as an example for **best-practice** in terms of participatory approaches. An interdisciplinary working group including persons with disabilities and DPOs was set up in order to enable participation throughout the whole process. Both participants from civil society and Ministry officials were satisfied with their progress and viewed it as a joint effort to create amendments for the existing regulations.

E. Germany

Germany signed the CRPD and the OP in 2007 and concluded the ratification process for both documents in 2009. With the "Act Approving the CRPD", the Convention's regulations were transformed and incorporated and are now part of German domestic law.[214]

The German federal government attached a memorandum ("*Denkschrift*") to the official parliamentary release in the Federal Gazette.[215] In this memorandum, the government provides guidelines and interpretation information. The government seemed to be under the impression that German law was already in compliance with the CRPD at the time of ratification. This point of view was criticized by civil society representatives.[216]

The following sections describe the most important government and non-government institutions and stakeholders in German disability politics and show disabled persons' involvement in political processes over the past years. This includes a summary of findings of the empirical studies undertaken between summer 2014 and winter 2015/16, primarily via phone interviews and online questionnaire surveys.

1. Institutional framework

1.1. Focal points, coordination mechanism (Art 33 [1])

The **Federal Ministry of Labor and Social Affairs** (**BMAS**, *Bundesministerium für Arbeit und Soziales*) was tasked with being the focal point on a federal level. Similar to Austria and Australia, Germany is a federal state consisting of 16 provinces (*Länder*) with their own legislative powers and administrative bodies. Focal points were also established in the provinces.[217] The BMAS took the leading role in drawing up an Action Plan listing measures for the implementation of the Convention.

The **Commissioner of the Federal Government for Matters relating to Disabled Persons** (*Bundesbehindertenbeauftragter*) assumed the role of state coordina-

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[214] *Kotzur/Richter* (2012) 82f; *Knospe/Papadopoulos* (2015) 77; *Germany* (2011) point 1.

[215] Available at http://dipbt.bundestag.de/dip21/btd/16/108/1610808.pdf (Mar. 15, 2016).

[216] See e.g. *Degener* (2009a) 282; *Degener* (2009b) 212; http://www.inklusion-online.net/index.php/inklusion-online/article/view/80/80 (Mar. 15, 2016).

[217] *Germany* (2011) point 284; *Knospe/Papadopoulos* (2015) 79.

tion mechanism under Art 33 (1). According to Germany's first State Report to the UN Committee "the coordination mechanism is one of the most important tools for the monitoring and support of the implementation of this Convention. Its main task consists of guaranteeing the inclusion of persons with a disability and their associations and organisations, as well as of the broader civil society, in the implementation process."[218] The Commissioner published a report in 2014, which describes the work of the entity between 2011 and 2013. It views itself as an interface between the government and civil society and tries to fulfil this role primarily via public relations work and raising awareness. Additionally, persons with disabilities play an important role in various councils and committees established around the Commissioner.[219]

On its website, the Commissioner defines three main tasks regarding the implementation of the CRPD in Germany:

- "Inclusion of the civil society, in particular persons with disabilities as well as other relevant stakeholders in different fields of action into the implementation process (providing a forum for information and discussion);
- Interface between the civil society and the state level;
- PR and awareness-raising campaigns in order to have a multiplier function at different levels."[220]

In order to fulfil these tasks, the Commissioner established an **Advisory Council on Inclusion** (*Inklusionsbeirat*). This Council is the decision-making body within the national coordination mechanism under Art 33 (1). It is chaired by the Commissioner of the Federal Government for Matters relating to Disabled Persons and its membership consists "by majority" of persons with disabilities. According to the 2014 report, the Advisory Council comprised 13 members at the time. Seven of them represent organizations of and for persons with disabilities; the others primarily represent federal or provincial government agencies. The national Monitoring Body is also represented. The current head holds a consultative role within the Council.[221]

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[218] *Germany* (2011) point 285.

[219] *Behindertenbeauftragter* (2014) 3.

[220] http://www.behindertenbeauftragte.de/EN/Englisch.html?nn=2950120#doc2967342bodyText6 (Feb. 2, 2016).

[221] *Behindertenbeauftragter* (2014) 10.

The Council is supported by four Special Committees ("*Fachausschüsse*"), each with a different focus of work:

1. Committee: e.g. health, nursing, rehabilitation,
2. Committee: e.g. liberal rights, family and women issues,
3. Committee: e.g. labor and education,
4. Committee: e.g. mobility, construction, accessible information and communication; social participation.[222]

There are **clear guidelines and areas of responsibility** within the German coordination mechanism. The Advisory Council on Inclusion is the only decision-making entity. It decides on the membership, composition and areas of work for the Special Committees. Various government and non-government agencies and organizations are invited to participate in the Special Committees, depending on the issues at hand. According to the Council's report, organizations will be selected to become a member of a Special Committee if they support the CRPD's implementation "in a distinguished way" and are expected to provide "constructive criticism" in subsequent processes.[223] As of 2014, **more than 100 actors and organizations** are involved in the work of the Council and the Special Committees. The role of these institutions as an interface between the government and civil society is working fairly well.[224]

As soon as an issue has been discussed in a Committee, it reports back to the Council. The members of the Council then release a public statement if they are satisfied with the Committee's work on the issue or they can send the results back to the respective Committee for further revision.

1.2. Monitoring mechanism (Art 33 [2])

Germany's federal government tasked the **German Institute for Human Rights** (**DIMR**, *Deutsches Institut für Menschenrechte*) with carrying out the role of the independent monitoring mechanism under Art 33 (2). Accordingly, the **National**

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[222] *Behindertenbeauftragter* (2014) 9; for detailed information on the composition and fields of activity of the Councils see *Arnade* (2015) 94ff.

[223] *Behindertenbeauftragter* (2014) 15.

[224] *Behindertenbeauftragter* (2014) 27; *Germany* (2011) point 286; *Arnade* (2015) 94.

Monitoring Body for the CRPD (**MS**, *Monitoring-Stelle*) at the DIMR was set up in 2009.

The DIMR's website features a detailed description of the MS's work: "By carrying out scientific studies, regularly meeting with disability advocacy organizations and people with disabilities, visiting care facilities and consulting with experts, the National CRPD Monitoring Body generates a broader picture of the situation of people with disabilities in Germany."[225] Additionally, the MS fulfils an advisory role for politicians and officials on all levels as well as organizing public events and publishing statements on various CRPD-related issues.[226]

As opposed to the Austrian MA, there is no question that the DIMR in general and the MS are established in line with the **Paris Principles**.[227] Funding is provided by the BMAS but the government cannot interfere with the Institute's work. There are legal guarantees to ensure **independence**. As of Jan. 1, 2016, the Federal Act on the Institute for Human Rights declares the Institute an independent institution and explicitly refers to the Paris Principles (Section 1).[228] As of now, there are no official plans to establish additional monitoring bodies on a provincial level.

The MS regularly publishes reports and statements on various issues. On the occasion of Germany's state examination following the first State Report, the MS released an extensive **"Parallel Report"** to the UN Committee and submitted a separate paper commenting on the List of Issues subsequently.[229]

The CRPD's requirement (Art 33 [3]) to involve disabled persons in the monitoring seems to be taken seriously by the MS. So-called **"civil society consultations"** are held three times per year.

1.3. Disability sector

Germany's disability sector features a **broad variety of organizations** of all sizes pursuing different goals and interests. These organizations have taken a very pro-

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[225] http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/ (Feb. 2, 2016).

[226] http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/ (Feb. 2, 2016).

[227] See *Aichele* (2015) 86; UN Resolution A/RES/48/134.

[228] The Act is available at http://www.institut-fuer-menschenrechte.de/das-institut/struktur/dimr-gesetz/ (Feb. 2, 2016).

[229] All publications are available at http://www.institut-fuer-menschenrechte.de/en/publications/suche/ (Feb. 2, 2016).

active stance on disability politics, especially since the CRPD was ratified by Germany. Aside from organizations with nationwide activities, there are countless provincial and local groups. Therefore, the following section merely tries to give an overview over the most important organizations, groups and alliances that have recently been playing a major role in Germany's CRPD implementation process.

Several networks of disability organizations were formed in recent years, the most important being the **"CRPD Alliance"** (**BRK-Allianz**, *Allianz zur UN-Behindertenrechtskonvention*). The BRK-Allianz was formed in January 2012 and was composed of **nearly 80 organizations**. According to its statutes[230], the purpose of the BRK-Allianz was accompanying Germany's first state examination before the UN Committee. The Alliance fulfilled this task primarily by developing and publishing the so-called **"Parallel Report"** to the UN Committee, in which civil society's views on the status of CRPD implementation in Germany are presented to the UN Committee.

The Alliance's mandate ended in June 2015, after the Concluding Observations of the UN Committee were released and the state examination was concluded (Section 2 of the Alliance's statutes).[231]

The statutes of the BRK-Allianz regulate decision-making processes within the Alliance and stipulate that only non-profit NGOs that do not have contractual or other obligations to public entities are allowed to join the network (Section 3 of the statutes). The Alliance was composed of a broad variety of self-advocacy and self-help groups, charity organizations, labour unions and other initiatives.[232] The majority of member organizations emerged from the fields of self-representation of persons with disabilities, disability self-help associations, and social associations.[233]

One of the most important unions of disability organizations is the "**German Disability Council"** (**DBR**, *Deutscher Behindertenrat*), which was founded in 1999. According to its statutes,[234] which are available online, the DBR is open for membership to all organizations that identify themselves as NGOs advocating for

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[230] The statutes are available online at http://www.brk-allianz.de/attachments/article/73/Statut%20-%20Abgestimmte%20Fassung%20vom%202-11-2011-s.pdf (Feb. 2, 2016).

[231] http://www.brk-allianz.de/ (Feb. 2, 2016).

[232] *Arnade* (2015) 96.

[233] *BRK-Allianz* (2013) 3.

[234] Available at http://www.deutscher-behindertenrat.de/ID25199 (Feb. 2, 2016).

disabled persons, chronically sick people and their relatives (Section 3.1 of the statutes). The statutes also try to ensure that the DBR's structure is fairly representative of all types of disabilities (Section 4.1). The DBR views itself as a platform for joint action and mutual exchange of experience and **not an umbrella organization**. It does not represent its member organizations to the outside in a collective way.[235] A list of membership organizations is available on the DBR's website. It shows that some of Germany's most influential groups and organizations are members of the Council.[236] **BAG Selbsthilfe**, which itself is an umbrella organization comprising 113 groups of disabled persons, is also a member of the DBR.[237]

A significant number of Germany's influential DPOs formed an alliance called **"Network Article 3 – Association for Human Rights and Equality for Disabled People"** (**NW3**, *Netzwerk Artikel 3*). It was founded in 1996. The name of the network refers to Art 3 of the German Constitutional Basic Law (*Grundgesetz*), which stipulates that all persons are equal before the law. Aside from running a complaint department, the NW3 lists coordination of their membership organizations, particularly in legislative processes, as their main task.[238] In recent years, NW3 has taken a prominent role in two crucial processes prompted by the CRPD's ratification:

- Shortly upon the release of the **CRPD's official German translation**, civil society organizations pointed out numerous **critical inaccuracies**.[239] The crucial term "inclusive" was translated into "Integration" or "Einbeziehung", both of which have fundamentally different conceptual meanings than the CRPD's idea of inclusion.[240] In 2009, the NW3 decided to publish a so-called **"Shadow Translation"** of the CRPD, which eliminates these inaccuracies and is more aligned with the CRPD's English version in terms of terminology.[241] The Shadow Translation is available online in various formats.[242]

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[235] http://www.deutscher-behindertenrat.de/ID25034 (Feb. 2, 2016).

[236] http://www.deutscher-behindertenrat.de/ID25209 (Feb. 2, 2016).

[237] http://www.bag-selbsthilfe.de/ (Mar. 14, 2016).

[238] http://www.nw3.de/index.php/profile-englisch (Feb. 2, 2016).

[239] *Heiden* (2013) 2.

[240] See e.g. *Wansing* (2015) 43ff.

[241] *Arnade* (2015) 93f.

[242] http://www.nw3.de/index.php/vereinte-nationen (Feb. 2, 2016).

- NW3 had an important role within the **BRK-Allianz**. As nearly 80 organizations worked together in the development of the Shadow Report, NW3 took over the duties of **coordinating** the work being done by the Alliance.

2. Involvement of persons with disabilities

2.1. Overview

Germany's first State Report to the UN Committee already mentions the importance of involving disabled persons into policy-making processes in the very first paragraph: "The Federation, the *Länder* [provinces] and local authorities, as well as social benefit agencies and other institutions dealing with the circumstances faced by persons with disabilities, work under the umbrella of the Convention to refine the equal participation of persons with disabilities. Civil society is included in this process and makes a valuable contribution. The work of the associations and organisations of persons with disabilities, charity associations, as well as church facilities, employers and trade unions, should be mentioned here."[243] Furthermore, the State Report mentions disabled persons' involvement in the development of Volume 9 of the Social Security Code (*IX. Teil des Sozialgesetzbuchs*), which came into force in 2001.[244] Three interviewed persons from different organizations also pointed out that this process had been a good example for a functioning participatory process before the CRPD was developed.

Interviews with several representatives of the German disability sectors were conducted during the course of our research. They showed that there has been **improvement** in terms of participation **in recent years**, even though the overall situation is far from perfect.

The "Coalition Contract" of the German federal government currently in power includes the intention to improve the access of persons with disabilities to public benefits.[245] Thus, the federal government started a process to develop a new

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[243] *Germany* (2011) point 1.

[244] *Germany* (2011) point 29.

[245] https://www.cdu.de/sites/default/files/media/dokumente/koalitionsvertrag.pdf (Feb. 2, 2016), see page 78.

Federal Act on Participation (**Bundesteilhabegesetz**)[246], which aims to **improve access to support services** in a self-determined way.[247]

The following sections try to give an overview over some recent developments in Germany's disability politics, with a special focus on the involvement of disabled persons.

2.2. Empirical studies and methods

Over the course of the research in Germany, two different empirical methods were applied between 2014 and 2016.

The participation of persons with disabilities in the process of developing a Federal Act on Participation was explored via an **online-questionnaire**. A set of questions was sent out to all participants of the working group after the process was concluded.

All other data was gathered via **interviews** with experts in the field of disability politics. Between November 2014 and January 2016, 12 interviews were conducted:

- 3 interviewees represented the BMAS,
- 3 interviewees represented disability organizations,
- 3 interviewees are long-time academic experts in the field of guardianship and/or disability law,
- 1 interviewee was a member of Germany's monitoring body,
- 1 interviewee was a judge specializing in guardianship law,
- 1 interviewee represented a guardianship association.

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[246] Draft of the Federal Act on Participation see https://www.google.at/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwiIk7f_647OAhVHPBQKHftGAwYQFggbMAA&url=https%3A%2F%2Fwww.bmas.de%2FSharedDocs%2FDownloads%2FDE%2FPDF-Meldungen%2F2016%2Fbundesteilhabegesetz-entwurf.pdf%3F__blob%3DpublicationFile%26v%3D4&usg=AFQjCNGxjjF2n2EbwMXfGfhDTth3tzz6XQ&sig2=X0KYJV3wYgc6vIC41kaLYw (July 25, 2016).

[247] See also *Germany* (2011) point 2.

Guidelines with bullet points were sent to all interviewees in advance in order to allow them to prepare for the meetings. Thus, the interviews were semi-structured. Different sets of interview guidelines were used, in particular one for the interviewees from the "government side" and one for those from the "non-government side".

All interviews were conducted by two researchers, recorded and transcribed shortly afterwards. The data gathered during the interviews was evaluated by establishing categories in order to identify significant themes. Relevant categories were established *after* the interviews were conducted; therefore the risk of imposing "preconceived categories or theories on the data"[248] was reduced.

The results of the interviews and questionnaire surveys are the prime source for the deductions in the following sections. Additionally, there are various reports available that have been published by different entities over recent years. These other sources include the **Parallel Report published by the BRK-Allianz** in 2013, which provides fruitful insights from civil society's perspective. An additional **Parallel Report** was developed and released **by the MS** in 2015, in which the German government's and civil society's stances are summarized. It also includes recommendations by the MS. Therefore, there are two reports aside from the official State Report, which describe the situation in Germany from different angles and from which conclusions can be deducted.

2.3. Development of the NAP

The 2009 Coalition Contract of the then new German federal government specified that the government planned to develop a National Action Plan (NAP) to implement the CRPD.[249] The process of creating this plan started with a workshop in March 2010, where the structure and overall paradigms of the future NAP were discussed by officials and representatives from the disability sector. In June 2010, a **workshop** with a total of more than 300 participants, a large number of them representing the disability sector, was held. Additionally, officials established a **website**, where members of civil society could share their thoughts and wishes. This measure aimed at enabling those disabled persons who are not

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[248] *Moriarity/Dew* (2011) 688.

[249] *Germany* (2011) point 31.

members of any organizations in the sector and therefore have very limited resources to participate in workshops to share their ideas as well.[250]

During our interviews, two officials of the BMAS, who were part of this process, confirmed that **civil society's involvement actually had an influence** on the structure and contents of the plan. According to them, statements and ideas of persons from the disability sector shaped the subsequent discussions within the Ministry that led to the first draft of the NAP.

This draft was then sent out again to disability organizations and other relevant players and via submissions, feedback was gathered. In June 2011, the NAP was passed by the federal government.[251] As mentioned, BMAS officials viewed the participatory approach very positively. This assessment is strongly **contradicted in the Parallel Report** to the UN published by the BRK-Allianz in 2013: "[…] many civil society associations issued statements regarding the NAP, but this did not result in any changes [to the original draft]."[252] It seems to be not a German phenomenon that there are contradicting statements by government officials on the one side and civil society representatives on the other side. During the course of our research, this occurred on several occasions: While officials praise the success of their participatory approach, civil society claims that, even if their opinion was asked, their input was not considered at all by officials and they were precluded from the actual decision-making process.

2.4. Parallel Report

Aside from participating in legislative processes, there are other ways of including civil society's voice in political processes. Developing Parallel Reports (or Shadow Reports or Alternative Reports) has proven to be a proper way to do so. The process of developing these reports is not only viewed as a good example for participation in general, but also as an example for a broad variety of diverse civil society organizations working together towards a mutual goal.[253] A German Parallel Report was published by the BRK-Allianz in 2013.[254]

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[250] *BMAS* (2011) 108f.

[251] *BMAS* (2011) 109.

[252] *BRK-Allianz* (2013) 9.

[253] *Arnade* (2015) 96.

[254] *Heiden* (2013) 1.

As mentioned above, the BRK-Allianz was primarily founded to accompany Germany's first state examination and to publish a Parallel Report from the **disability sector's perspective**. In order to ensure that the Report would be given serious consideration by the UN Committee, the BRK-Allianz tried to compile a single report as a joint product of all member organizations, as opposed to many smaller reports being drawn up by individual organizations.[255]

The preface of the Parallel Report reads: "The BRK-Allianz compiled this joint report on the implementation of the CRPD in order to lay it before the UN Committee on the Rights of Persons with Disabilities. The associations involved made a strong effort to build their arguments with extensive consideration of all persons with disabilities, and to deliver a well-balanced account of issues to ensure equal participation."[256] Accordingly, **more than 70 organizations** from all parts of Germany were involved in the development of the Report. A list of these groups can be found in the appendix to the Report.[257]

The development of the Parallel Report was supervised and coordinated by NW3. Ten sub-groups with different main focuses worked on different areas of issues relating to the CRPD's implementation status in Germany.[258] Each provision of the CRPD is discussed in a separate section of the Report and the current status of implementation in German law is analysed. Most sections conclude with **calls for specific actions** on behalf of all members of the BRK-Allianz. It comes as no surprise that the Parallel Report takes a rather **critical stance** compared to the official German State Report.

The Parallel Report touches the issue of participation in several sections. It **criticizes an overall lack of participation** by disabled persons. The Report specifically refers to the process of developing the official State Report: "The introduction of the first State Report mentions the 'inclusion of civil society […] under the umbrella of the CRPD' with regard to equal participation. However, in contrast to Art 35 (4) CRPD, the State report was not compiled with close consultation or active involvement of organizations representing disabled persons […]. Civil society was presented with a nearly finished draft of the State report, and was asked to submit their contributions and suggestions for change in written form, within a period of approximately two weeks. In the opinion of the BRK-

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[255] *Arnade* (2015) 96.
[256] *BRK-Allianz* (2013) 3.
[257] See *BRK-Allianz* (2013) 96ff.
[258] *Arnade* (2015) 96.

Allianz, these proceedings do not represent a target-oriented contribution to the State report by civil society. During a hearing of the associations, most suggestions from the civil society regarding the NAP were not taken into consideration. Therefore, most civil society organizations decided to refrain from such statements, and to compile a parallel report instead."[259]

Thus, **frustration with the (non-)participatory approaches of the government** can be seen as one of the main motivations for the development of the Parallel Report. The Report can be described as a success, as it is regularly referred to as being *the* voice of civil society and the disability sector, e.g. in scientific papers or in the second Parallel Report that was published by the MS in 2015. Several interviewed persons, including those who work at the BMAS, referred to the Parallel Reports as a good example of civil society's participation. They actually applaud the efforts even if they do not agree with the conclusions reached in the Report.

2.5. Federal Act on Participation

German lawmakers recognized that persons with disabilities are often excluded from full and equal participation in society. The **current welfare system** is viewed as **patronizing**, as there is a lack of self-determined selection of benefits. Persons with disabilities currently receive benefits based on a welfare system model. The aim of the federal government was to develop and improve the support system towards a modern system, embracing the CRPD's ideas and principles. The new regulations should **shift from the current paternalistic approach**, where various benefits are granted to the individual. The proposed new model features a system, where the **person's actual needs and decisions determine the support** they can receive. Accordingly, the German State Report states: "Persons with disabilities have long ceased being mere objects on which the State imposes its will and to which it provides welfare. The realization of a dignified, self-determined life in an inclusive society is the goal of modern policy on persons with disabilities in Germany, and hence corresponds to the core of the Convention."[260] The BMAS set up an **interdisciplinary working group** to

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[259] *BRK-Allianz* (2013) 9.

[260] *Germany* (2011) point 2.

develop this new system, which concluded their work in 2015. A final report describing the progress of the working group was released in April 2015.[261]

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[261] *BMAS* (2015) 9ff.

2.5.1. Empirical studies and methods

The development of the proposed Federal Act on Participation is supposed to follow the principle of self-advocacy of persons with disabilities "*nothing about us without us*". Even very recent legislative processes did not embrace this principle in a similar way. The latest amendment to the guardianship laws that was passed by German parliament in 2013,[262] was preceded by an interdisciplinary working group. This working group held 11 sessions. Only at one single meeting at a very late stage of the process, persons with disabilities were invited to share their lived experience. At another session, representatives of several disability organizations were invited.[263] Even though this is far from a perfect participatory approach, it marks an improvement in this regard compared to earlier legislative processes.

Contrary to the aforementioned guardianship law reform, persons with disabilities and their representative organizations as well as the other actors affected by the intended new system were **included from the very beginning** in the development of the Federal Act on Participation. Accordingly, the BMAS established a working group on the topic, which was carried out between July 2014 and April 2015. The organization of this working group was a suitable setting to carry out a **questionnaire survey** with questions largely following the surveys carried out in connection to the working groups, accompanying the legislative process towards a new regulation of legal guardianship organized by the Austrian BMJ. Contrary to the research conducted in Austria, the research in Germany included only one set of questionnaires that was sent out to all participants of the working group, **after the working group process was concluded**.

The survey was made possible by the BMAS, which provided the minutes of the meetings including the contact information of the participants. Addressees of the questionnaire were all participants of the working group. Each session encompassed 40 seats, 10 of which were reserved for organizations representing persons with disabilities. A total of **141 persons** participated in the working group at one time or another. These 141 persons were contacted via e-mail, informed about the research project and invited to fill in a short online questionnaire via a link provided. The addressees had the opportunity to work with an easy-read version. However, this possibility was not used by any of the respondents. The invitations

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[262] Federal Gazette I 2013 No 53.

[263] See the final report of the working group, which can be found in *Coester-Waltjen/Lipp/ Schumann/Veit* (2013) 95.

to participate were sent out at end of July 2015 and a reminder was sent out in August. After six weeks the online survey was closed.

Additional results are provided by the interviews in which some persons referred to the working group sessions repeatedly. Some of them were directly involved in the process and participated in the working group.

2.5.2. Results

Altogether 13 completed questionnaires have been received. Considering the number of 141 invitations, this is a rather small portion, even though it can be assumed that some invitations did not reach the addressees. Some e-mails actually triggered error-messages. The outcomes of the survey cannot be considered representative for all participants in the working group. They can, however, provide impressions of the perceptions of the efforts to include the people who are the central target groups for the reforms at the developmental stages. Additionally, some suggestions for improvements can be deducted from the outcomes.

Six of the respondents can be considered representatives of public authorities concerned with the issues at hand. They represented Federal Ministries, Ministries of provinces and authorities of the welfare system. Three of the respondents represented socio-political stakeholders, one of them close to the target group of persons with disabilities. The remaining four were representatives of the ten institutions nominated by the German Disability Council (DBR) to participate in the work group.

Besides the question about the organizational affiliation of the respondents, the questionnaire encompassed seven questions. Six of them asked for the contentedness with respect to the overall structure, the time structure, the inclusion and representation of persons with disabilities, the sufficiency and quality of the information material provided, the comprehensibleness of the information material provided and the efforts to support the active participation of all participants, particularly persons with disabilities. The options to answer were “yes” or “no”. Only in the case of negative answers the respondents were asked to provide explanations. The final question asked for recommendations to improve participatory developments in the future and for other general comments.

The **overall** results show a quite **favourable picture**, expressing very much contentedness with the efforts to include persons with disabilities and their views and needs respectively into the work and the deliberations of the working group. The vast majority of the responses on all questions asking for dichotomous responses were positive. None of the questions was answered negatively by more than three of the 13 respondents. Nevertheless, a detailed look at the responses reveals that respondents see room for improvement.

Two negative responses were collected on the question whether the inclusion and the participation of persons with disabilities worked well. On the one hand, it was stated that persons **with mental illnesses** were **not included adequately**. On the other hand, a response referred to a lack of time for the organizations representing persons with disabilities in the working group to sufficiently include and involve their sister organizations at the stages of preparation. The latter problem was also mentioned twice in connection with other questions. Thereby the problem of **insufficient time for preparation and preparatory discussions** appears to be one of the issues that come up repeatedly. In fact, there was another response stressing a time problem, however from a slightly different perspective. The only negative response on the question concerning the overall and the time structure of the work group pointed at too much of a time pressure for volunteers representing groups of interest.

The other topic producing some critical answers concerns the information materials provided by the Ministry. Three of thirteen responses questioned the comprehensibleness of the information material for all participants, in particular persons with disabilities. This was pointed out as one of the biggest challenges. The legal language, the complexity of the possible facts of cases and the need for abstraction make it quite difficult to provide information material easy to understand. Two of the respondents expressed some dissatisfaction with the quality of the information provided before the meetings. Too much material sent out too late was the central critique of one respondent, while the other one expressed dissatisfaction with respect to a lack of information concerning the financial implications of the proposed ideas of the working group.

Two negative responses were to be counted on the question about the efforts to support and encourage the active participation of all participants, particularly persons with disabilities. The one respondent, who already had stated that people with mental illnesses had seemingly not been included adequately, repeated this point, especially highlighting his concern and asking for more support to include this particular group. The other one pointed out that there was no funding available for the needed preparatory meetings of the organizations representing persons with disabilities, especially with the organizations not directly participating in the working group. In the context of the recommendations for the future, this respondent explained that there is a **need for funding for the organizations** to be able to adequately represent their membership. Not least because of this, there would be a need for professionals to disburden the volunteers. Another respondent shared this view in his/her recommendation for the future. While the participation of persons with disabilities and their organizations was perceived to have worked very well by this respondent, he/she recognized obstacles for effective participation due to a lack of funding for the participatory efforts. None of the respondents expressed any dissatisfaction with the representation of persons with disabilities in the work group, indicating that their representatives worked well.

The final question, asking for suggestions with respect to improvement for future participatory procedures and for other comments, was answered by nine respondents. Partially this space was used to repeat comments stated before. Three statements emphasized the quality of this kind of participatory procedure to improve mutual understanding between officials and civil society. Besides the already mentioned demands for an increase in funding, four respondents indicated some limits to the participatory approach. The overall message of these responses is that participants should be **made aware of limitations of the process at the beginning** in order to **prevent unrealistic expectations** by participants, which cannot be fulfilled. In the end, a balance between the interests of the general society and of interests of persons with disabilities will have to be considered. The whole political process will be crucial to the outcome as well as financial limits. Therefore, the aims and the possibilities of the participatory approach and of the working group respectively have to be formulated and expressed clearly beforehand.

The perceptions and views expressed in the questionnaire are at least partially coined by the role the respective respondents had in the working group and which “side” they represented there: representatives of the public authorities generally expressed satisfaction with the process, whereas representatives of the institutions nominated by the DBR provided a more critical voice. While still expressing contentedness with the participatory approach in general, they did state some suggestions and wishes for improvements such as funding for their participatory work, more time to prepare and to include their brother and sister organizations as well as additional efforts to provide information material comprehensible for everybody.

The overall results can be summarized as follows. Most of them are in line with the assessments made in the report published by the MS in 2015:[264]

- There is **general appreciation** of the participatory approach, which should be continued and extended.
- **Clear and realistic goals** of the participatory approach and of the work group have to be formulated and communicated to **avoid expectations that likely will or cannot be met**.
- Especially the representatives of the institutions nominated by the DBR indicated some possibilities for improvement.
- Some of the organizations representing persons with disabilities stress a need for **additional funding** to be able to effectively realize the participatory approach.
- The time structure of the working group has to consider the time needed by the organizations representing persons with disabilities to **adequately prepare** for the meetings and to include their sister organizations. **Information materials** for the meetings have to be sent out in time to allow sufficient preparations.
- **Comprehensible information** material is essential, especially in participatory processes involving civil society representatives.

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[264] *Monitoring-Stelle* (2015) 10.

2.6. Participative monitoring – “Civil society consultations“

As mentioned above, the MS holds **civil society consultations** in Berlin **three times annually** in order to fulfil the requirement of Art 33 (3) to involve civil society in general and organizations in the disability sector in particular.

The MS’s website provides detailed facts on the procedures of these consultations. Additionally, a member of the MS agreed to participate in our research and we were able to conduct a telephone interview. This talk provided very specific information on the MS’s approach in terms of involving civil society.

The consultations started in 2009 and the number of involved organizations[265] has been increasing ever since. An important question is, of course, if there are any **barriers for organizations to participate** in the consultations. The website states: “In principle, the Civil Society Consultations are open to any civil society organization. All that is required is an interest in working resolutely for implementation of the UNCRPD and the desire to exchange experiences relating to the rights of people with disabilities with the National CRPD Monitoring Body and other organizations. Organizations of all sizes take part in the consultations, including self-help organizations and groups representing the interests of both service providers and family members. Although they are open in format, the consultations are not public events. Participation is by invitation only and no organization can be represented by more than one person. Those wishing to find out more about the Civil Society Consultations should contact the National CRPD Monitoring Body […]. We would be happy to hear of your interest. We generally request a **personal meeting with the head** of the National CRPD Monitoring Body before issuing an invitation however. Once you have been added to the list of invitees, you will receive invitations to and the minutes of the consultations on a regular basis, as well as other information, including press releases, notes of upcoming events and statements issued by the National CRPD Monitoring Body.”[266]

According to some interviewees from the disability sector, the fact that all consultations are held in Berlin might cause some issues for smaller organizations outside of Berlin. It may be challenging for these organizations to participate in the

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[265] See a list at http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/civil-society-consultations/ (Feb. 2, 2016).

[266] http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/civil-society-consultations (Feb. 2, 2016).

consultations on a regular basis, as they usually have limited resources and maybe cannot afford the travelling expenses.

As of late 2015, around sixty organizations from all over Germany have sent representatives to the consultations. Each organization is represented by one person, so there is no right for groups with high membership figures to send more representatives. Various types of organizations are regularly involved in the consultations, including powerful service-providing and self-advocacy groups.[267]

Even though the actual deliberations, discussions and results of the consultations are not publicly available, the MS publishes agendas for such events on their website. These are detailed and updated regularly. Therefore, outsiders are able to get a quick overview over current discussions even if they are not part of the consultations.[268]

All in all, the consultations seem like a **good format for regular exchange** between the MS and organizations in the disability sector. The modus operandi guarantees that various issues are put on the agenda and that aside from financial limitations there are **low barriers for different organizations to join** the consultations. Therefore, the consultations provide a comprehensive framework for civil society's regular involvement in the monitoring system.

The fact that **all consultations are held in Berlin** may be one point of **criticism** as it is (financially) challenging for organizations from southern provinces (e.g. Bavaria) to attend the sessions. As described above, the Austrian federal MA adopted a model to alternate sessions between the nation's capital and a capital of one province. This model is worth considering by the German MS as well, as Germany is a much larger country than Austria and travelling expenses seem to be a crucial issue for organizations.

2.7. Criticism

Several points of criticism came up during the research in our interviews and questionnaires. The main themes of critical remarks will be described and summarized in this section.

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[267] A list of involved organizations can be found at http://www.institut-fuer-menschenrechte.de/en/crpd-monitoring-body/civil-society-consultations/ (Feb. 2, 2016).

[268] http://www.institut-fuer-menschenrechte.de/monitoring-stelle-un-brk/verbaendekonsultationen/ (Feb. 2, 2016).

Similar to the situation in Austria, the **federal structure** of Germany seemingly causes difficulties for effective implementation of CRPD rights to some extent. There are no **comprehensive guidelines on involving disabled persons** in these processes on either federal or provincial levels, which is critically pointed out in the Parallel Report to the UN[269] and was also mentioned in scientific papers.[270] This observation was confirmed by the UN Committee in its Concluding Observations following Germany's first State Report: "The Committee recommends that the State party develop frameworks for the inclusive, comprehensive and transparent participation of organizations representing persons with disabilities […] regarding the adoption of legislation, policies and programmes for the implementation and monitoring of the Convention. It also recommends that the State party provide resources to facilitate the participation of such organizations, especially smaller self-advocacy organizations."[271] Two interviewed persons mentioned that there are different levels of awareness and willingness to be open for participation. While the federal BMAS is apparently trying to design the processes in compliance with the CRPD, other Ministries have so far failed to do so.

Several interviewees and even representatives of the BMAS called for a new approach following the principle of **disability mainstreaming**. Disability issues should and must be under discussion at all Ministries and not only at the BMAS. These participants of our research think that disabled persons are often viewed as merely objects of state welfare. Support provided by a state welfare system is only one small aspect of disability politics. Legislative processes and policy-making, that affect the lives of persons with disabilities, are conducted by all Ministries, not only the BMAS.

The latter issue mentioned in the Concluding Observations refers to the **lack of resources provided for organizations** in the disability sector. This is also mentioned in the MS's Parallel Report: "Adopting an empowerment approach, self-advocacy organisations, particularly those of people in especially vulnerable situations, such as institutions, should be strengthened and appropriately equipped."[272] As the apparent lack of resources was also a crucial issue raised in our questionnaire survey, it can be viewed as a general issue. Officials have yet to realize that effective participation can provide valuable expertise in legislative processes. In order to enable this kind of effective participation, appropriate financial support

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[269] See *BRK-Allianz* (2013) 17; see also *Monitoring-Stelle* (2015) 12.

[270] *Lachwitz* (2013) 99.

[271] *Committee on the Rights of Persons with Disabilities* (2015) point 10.

[272] *Monitoring-Stelle* (2015) 10.

for DPOs is needed. Most relevant processes last at least several months and include a number of meetings. This results in costs that are hard to bear, especially for smaller organizations.

Similar to other countries, **representation** is an issue in Germany as well. Big welfare organizations (such as *Lebenshilfe*[273]) are often called upon by lawmakers to participate in working groups, or submit statements to drafts of acts, and represent the "disability sector". Self-advocacy organizations and other DPOs question these organizations' mandate to act and speak on behalf of all disabled persons.

3. Summary

- The **BMAS** serves as the **focal point** under Art 33 (1).
- The **Commissioner of the Federal Government for Matters relating to Disabled Persons** (*Bundesbehindertenbeauftragter*) is responsible for the **overall coordination** of government policies and practices regarding CRPD implementation (Art 33 [1]).
- The **MS** was set up at the German Institute for Human Rights and serves as the **independent mechanism to monitor the implementation** of the CRPD in Germany (Art 33 [2]).
- Germany's disability sector features a broad variety of organizations. These groups have founded **alliances and associations** over recent years in order to have a stronger and louder voice in disability politics.
- There are **no comprehensive guidelines** for government departments and agencies on how to involve persons with disabilities in legislative and other processes. Thus, there are different practices on federal and provincial levels.
- A **Parallel Report** was published by the BRK-Allianz. This paper has proven to be a loud voice of the disability sector and has been taken seriously by most relevant stakeholders.
- An **interdisciplinary working group** was set up by the BMAS to work on a reform to improve the welfare system for persons with disabilities

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[273] https://www.lebenshilfe.de/de/index.php (3.3.2016).

(Federal Act on Participation). This process was viewed positively by all sides.

- The MS holds **civil society consultations** three times a year. A broad variety of organizations participates in these events on a regular basis.
- Major issues in Germany include **funding for civil society organizations** in order to enable effective participation and **representation of disabled persons by welfare organizations** whose mandate to speak on behalf of them is questioned.

F. New Zealand

NZ signed the CRPD in March 2007 and ratified it in September 2008 but has yet to sign and ratify the OP.[274] According to recent government reports, the domestic treaty examination process for the OP has already started.[275] Various government agencies and non-government organizations have started working together over the past years, especially since NZ signed and ratified the CRPD, to ensure effective implementation and monitoring of the Convention's implementation.

The following sections describe the most important government institutions and non-government players in NZ's disability politics and depict disabled persons' involvement in political processes over the past years. This includes a summary of findings of the empirical studies undertaken primarily in March 2015 and February 2016 in Wellington and Auckland. It was attempted to include most of the key actors in the sector to get a broad overview on their roles.

1. Framework of organizations in the field of disability politics

1.1. Government agencies

The NZ government took a systematic approach and created an **institutional framework** with specific government[276] agencies to promote and improve the involvement of civil society in the field of disability politics, especially in the process of implementing the CRPD and the monitoring of this implementation. The following section names and briefly describes the role of the most important government entities in this sector.

The **Office for Disability Issues (ODI)** was designated as the focal point for implementation issues (Art 33 [1] CRPD) in 2009.[277] In fact, the ODI had already been established in 2002 and played an important role in NZ's disability politics for some years before the CRPD's ratification.[278] The ODI's work is underpinned by the CPRD as well as the National Disability Strategy (NDS).[279] The Office is

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[274] https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en (Feb. 2, 2016).

[275] *New Zealand Government* (2015) 2.

[276] As there are no federal states in NZ, the term government in this section always refers to the federal government of NZ.

[277] See *New Zealand* (2011) point 267.

[278] See http://www.odi.govt.nz/about-us/office-history.html (Feb. 2, 2016) for a brief history of the ODI.

[279] *Flynn* (2011) 165; http://www.odi.govt.nz/about-us/index.html (Feb. 2, 2016).

located within the Ministry of Social Development (MSD) but it reports directly to the Minister for Disability Issues. The ODI's key roles are the following:

- "supporting the Minister for Disability Issues;
- providing advice on disability issues;
- maintaining an overview of, and contributing a disability perspective to, policy development by other agencies;
- meeting formal international obligations in relation to disability issues;
- promoting, monitoring and reporting on the progress of the New Zealand Disability Strategy within government and the wider community;
- ensuring the disability sector has a voice within government by building strong government – disability sector relationships to enhance understanding of sector perspectives, issues and concerns (including around emerging issues)."[280]

This list shows that the ODI is not in any way responsible for the implementation of the NDS or the CRPD in NZ. Its role is limited to raising issues, providing advice, coordinating government action and building relationships between government agencies and the disability sector.

The ODI is supported by a consultative forum of persons with disabilities and their families, called **Disability Advisory Council**. This Council merely has an advisory role in keeping the ODI informed on current issues and the implementation status of the NDS.[281]

The **Minister for Disability Issues** is a minister outside of cabinet. The ODI's website describes the role of the Minister as follows:

"The role of the Minister is to advocate disability issues and to establish and report on the New Zealand Disability Strategy. Legislation set out specific duties for the Minister (New Zealand Public Health and Disability Act 2000, Part 2: Responsibilities of Minister, Section 8: Health and Disability Strategies). This focuses on the preparation of a strategy for disability support services, the New Zealand Disability Strategy. This provides the framework for the Government's

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[280] http://www.odi.govt.nz/about-us/index.html (Feb. 2, 2016).

[281] http://www.odi.govt.nz/nzds/disability-advisory-council/index.html (Feb. 2, 2016).

overall direction for the disability sector and for improving disability support services. The legislation empowers the Minister to amend or replace that strategy at any time. It also requires the Minister to:

- consult any organisations and individuals that the Minister considers appropriate, before determining the New Zealand disability strategy;
- report each year on progress in implementing the strategy; and
- make publicly available, and present to the House of Representatives, a copy of the strategy, or any amendment of it or replacement to it, and to report as soon as practicable after its determination or completion."[282]

Therefore, the Minister's main assignments are the development and implementation of a disability strategy and reporting the progress to parliament. With regard to the issues discussed in this report, it is particularly interesting that the Minister is **required to consult with any organizations and individuals** who are considered "appropriate" in the process of developing the strategy.

Another important governmental institution regarding disability politics is the **Ministerial Committee on Disability Issues** which was established in 2009 for the purpose of providing "visible leadership and accountability for implementing the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities, and setting a coherent direction for disability issues across government."[283] The Ministerial Committee serves as the **national coordination mechanism** under Art 33 (1).[284]

The role, function and membership of the Ministerial Committee on Disability Issues are described in its Terms of Reference, which were adopted by the government in 2009. It states that the "purpose of the Ministerial Committee is to act collectively to provide a coherent overall direction for disability issues across government. It will do this by providing leadership and improving decision-making and accountability." Key objectives of the Ministerial Committee are to ensure that government agencies are achieving **progress in the implementation of the CRPD as well as the NDS**. The Terms of Reference very vaguely touch on the involvement of the disability community in the work of the Committee: "The

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[282] http://www.odi.govt.nz/about-us/minister.html (Feb. 2, 2016).

[283] http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/index.html (Feb. 2, 2016); *Convention Coalition* (2014) 11.

[284] *New Zealand* (2011) point 267f.

Ministerial Committee on Disability Issues will determine its own administrative support arrangements and **will consult with the disability community in ways that it believes is most appropriate for the issues that arise**."[285] The Ministerial Committee on Disability Issues is chaired by the Minister for Disability Issues and comprises eight "core ministers"[286] with the chair having the power to invite other ministers to meetings.

Ministers are supported by the **Chief Executives' Group on Disability Issues**, which is tasked to lead and coordinate government agencies' implementation of the Ministerial Committee's priorities on disability issues.[287] The Ministerial Committee reports to the government cabinet, which ultimately makes the final decision on government policy.

The **Human Rights Commission (HRC)** is an independent statutory body under the Human Rights Act 1993. According to the Act, the HRC's primary functions are:

- to advocate and promote respect for, and an understanding and appreciation of human rights in New Zealand's society and
- to encourage the maintenance and development of harmonious relations between individuals and among the diverse groups in New Zealand's society.[288]

Under these regulations, disability rights are an important issue in the HRC's work. Furthermore, the HRC plays a major role in NZ's mechanism of monitoring the CRPD under Art 33, as it is one of the three "pillars" of the Independent Monitoring Mechanism (IMM) along with the Office of the Ombudsman and the Convention Coalition. The IMM, which technically is also an entity set up by the government, will be described in a separate section of this report.

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[285] http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/terms-of-reference.html (Feb. 2, 2016).

[286] These are: Minister for Tertiary Education, Skills and Employment, Minister of Health, Minister of Justice, Minister for ACC (Accident Compensation Corporation), Minister of Education, Minister for Social Development, Minister of Housing, Minister for Senior Citizens, Associate Minister of Transport.

[287] http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/index.html (Feb. 2, 2016).

[288] Section 5 para 1 Human Rights Act 1993; see *NZ Human Rights Commission* (2014) 2.

1.2. Organizations in the disability sector

As most other countries, NZ features a broad variety of organizations in the disability sector. These are government contracted service providers as well as consumer organizations that do not receive any government funding. Some of these organizations are merely local groups; others act nationwide and have several regional branches.

A **key distinction** is made **between DPOs and other organizations** in the sector (especially those providing services). This is **crucial for the principles of engagement** between the government and organizations in the disability sector, as the understanding of the term "representative organizations" in Art 4 (3) and 33 (3) is that it relates primarily to DPOs.

An organization has to fulfil a set of attributes to be recognized as a DPO in NZ. DPOs are organizations that fulfil the following requirements:

- "a **national** structure and focus;
- organizational goals and objectives that **reflect the CRPD**;
- are **governed by a majority of disabled people**;
- the **majority of members are disabled**;
- a **mandate** or authority to speak on behalf of its members;
- **engage with its members**, including by sharing information."[289]

The DAP, which was published by the ODI in early 2014, describes the attributes of DPOs slightly differently than the Convention Coalition. It defines DPOs as organizations that:

- are **governed and led by disabled people**,
- focus on **representing the lived experience** of disability in one or more impairment areas,
- have **members** who are **disabled people**.[290]

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[289] *Convention Coalition* (2014) 7.

[290] *ODI* (2014) 2.

In conclusion, the main difference between DPOs and other organizations in the disability sector is that the latter ones mainly provide services and/or are not necessarily driven or led by disabled persons.[291]

Some of NZ's major DPOs formed an alliance several years ago. This alliance is called "Convention Coalition" and is an important player in NZ's disability politics in general and the monitoring mechanism in particular.

1.3. The Independent Monitoring Mechanism (IMM)

Contrary to other countries (e.g. Germany, Austria), where a single institution is tasked with fulfilling the duties of monitoring, NZ chose to establish a **mechanism consisting of three different bodies**. The mechanism also directly involves NZ's major DPOs into the monitoring duties. It was set up by the government in October 2011.[292] The HRC published a pamphlet on their website, briefly describing all parties involved:[293]

- *HRC*: The HRC is an independent statutory body under the Human Rights Act 1993. Its main objectives were already described above.
- *Office of the Ombudsman*: The Ombudsman only reports to parliament (and not to the government or specific Ministers), which makes this institution independent from the executive branch. It handles complaints and investigates the conduct of state sector agencies and considers whether the agency has acted reasonably and fairly. The Ombudsmen provide advice, guidance and training to these agencies as well.[294]
- *New Zealand Convention Coalition Monitoring Group* (**Convention Coalition**) which consisted of six organizations at the beginning[295] and now consists of eight DPOs: Blind Citizens NZ, Balance NZ, Deaf Aotearoa NZ, Deafblind (NZ) Incorporated, Disabled Persons Assembly NZ (DPA), Ngā Hau e Whā, Ngāti Kāpo o Aotearoa Inc. and People First NZ Inc. There is a provision that guarantees that additional DPOs –

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[291] See *Convention Coalition* (2014) 7; *Office for Disability Issues* (2014) 2.
[292] *Independent Monitoring Mechanism* (2013) 1.
[293] See https://www.hrc.co.nz/files/4514/2357/0094/Making-disability-rights-real-A4.pdf (Feb. 2, 2016).
[294] http://www.ombudsman.parliament.nz/what-we-do (Feb. 2, 2016).
[295] https://www.hrc.co.nz/files/4514/2357/0094/Making-disability-rights-real-A4.pdf (Feb. 2, 2016).

> given they fulfil the attributes described above – can join the coalition anytime.[296]

All parties agreed upon **Terms of Reference**, which describe the purpose and role of the mechanism within NZ's disability politics and the scope of their work. The modus operandi of the IMM is also laid out in detail in this document: this includes descriptions of the "quarterly strategic meetings" and general explanations of decision-making processes within the mechanism. The Terms of Reference reaffirm that **all parties of the IMM work and decide on an equal basis** with each other and none of the three pillars holds a leading role.

The IMM regularly publishes reports on the status of the CRPD's implementation in NZ. The first report was released in 2012 and tried to draw a basic picture of the current status of disability rights in NZ.[297] The **second and most recent report** was published in June 2014 under the title **"Making disability rights real"**. It provides detailed information and recommendations regarding the current and future status of the CRPD's implementation in NZ.

Aside from the official IMM report, the Convention Coalition released a separate paper in 2014, commonly known as the **"Shadow Report"**. The Shadow Report was led by the seven DPOs, which were included in the IMM at the time. However, before the Report's release a so-called "consultation draft" was shared widely throughout the disability sector to gain insight and feedback from disabled persons, who are not affiliated with the DPOs or the IMM. However, the paper does not give any more information on the key issues raised in these submissions and in which way they were incorporated in the final version of the Report. It simply states that the feedback was included and the governing bodies of the DPOs signed it off. Therefore, the Shadow Report stresses to present the collective voices of disabled persons, as mandated through their representative organizations.[298]

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[296] *Independent Monitoring Mechanism* (2013) 1.

[297] *Independent Monitoring Mechanism* (2014) 8.

[298] *Convention Coalition* (2014) 8.

2. Involvement of persons with disabilities

2.1. National Disability Strategy and Disability Action Plan 2014-2018 (DAP)

The NDS has been the major government paper in NZ's disability politics. It was created in 2000-2001 by the Ministry of Health in **consultation with the "disability sector"**.[299] There was a consultation process where organizations could hand in submissions.[300] Since 2002, annual progress reports on the implementation status of the NDS have been published.[301] The NDS' purpose is to **guide the policy development and services of all government departments** and it aims to **change NZ from a disabling to an enabling society** – a goal that is achieved, when "individuals who have experienced disability reach and can sustain their optimum level of participation within their community."[302] When the NDS repeatedly refers to participation, it means participation in the broadest sense as an important aspect of an inclusive society, and not exclusively political participation.

When referring to the NDS, the **Shadow Report** criticizes that **NZ has been good at "defining aspirational goals" but lacks implementation**. It comes to the conclusion that "official policies often differ from actual practice."[303]

In early 2016, a process to **revise the original NDS** from 2001 started. The Minister for Disability Issues appointed an **advisory group** that is currently working on the revision. This group comprises "individuals with lived experience of disability and expertise, representatives from Disabled People's Organisations and government agencies, and stakeholders from a variety of sectors in the community".[304] Detailed information on composition, membership and areas of work of this "Reference Group" is available online on the ODI's website.[305] The main purpose of the group's instalment is to include relevant players from the disability sector in the revision process from the very beginning.

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[299] *Milner/Kelly* (2009) 48.

[300] *Flynn* (2011) 163; see the discussion paper originally sent out: *Minister for Disability Issues* (2001) 23ff, where the options of sending submissions or participating in workshops are described.

[301] See http://www.odi.govt.nz/resources/publications/new-zealand-disability-strategy.html (Feb. 2, 2016) for all important documents regarding the development and history of the NDS. Summaries of the papers submitted by various organizations of the disability sector can also be found there; *Flynn* (2011) 166f.

[302] *Minister for Disability Issues* (2001) 5; see also *Flynn* (2011) 161f.

[303] *Convention Coalition* (2014) 10.

[304] http://www.odi.govt.nz/nzds/2016-revision/index.html (Mar. 3, 2016).

[305] http://www.odi.govt.nz/nzds/2016-revision/reference-group/index.html (Mar. 3, 2016).

The **DAP** is **based on the NDS**. It was approved by the Ministerial Committee on Disability Issues in April 2014 and is available online.[306] It is the fourth such plan since 2010, but for the first time, DPOs have been strategically involved in the development right from the beginning.[307] The **DAP sets strategic priorities to advance implementation** of the CRPD and the NDS from 2014 to 2018 "to provide consistency and certainty in the areas that Ministers expect to be progressed."[308]

The **involvement of persons with disabilities** – mainly through DPOs – in the development and implementation of the DAP is the **paramount principle of the plan**. Throughout the introduction to the document, the cooperation between government agencies and DPOs is highlighted several times.

Aside from the introduction, the DAP consists of two main sections: The first segment is headlined **"We worked with DPOs to develop the new plan"** and describes the approach of NZ's government in the evolutionary process of the DAP. The Chief Executives' Group on Disability Issues met with members of all three IMM parties in July 2013 to discuss the status quo in disability policy development. As a conclusion of the meeting, the Chief Executives' Group decided to "take a more inclusive and collaborative approach" in the development of the DAP and directed government agencies to closely involve DPOs from the start.[309]

The DAP's understanding of Art 4 (3) seems to be that **disabled persons should be involved** in the process of implementing the CRPD **primarily via DPOs**. Nevertheless, the DAP does not rule out the involvement of other organizations within the disability sector and explicitly states: "The obligation to involve DPOs does not exclude any other organization from being involved based on their expertise, so long as DPOs always have the opportunity to participate. This obligation acknowledges the long history of exclusion and invisibility of disabled people from government policy development and other matters impacting on them."[310] Therefore, the participation of disabled persons via DPOs is guaranteed in any case and in addition to that, other organizations may be involved based on their specific expertise in the specific matters at hand.

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[306] http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan/2014-2018/index.html (Feb. 2, 2016).

[307] *Convention Coalition* (2014) 11.

[308] *Office for Disability Issues* (2014) 1.

[309] *Office for Disability Issues* (2014) 2.

[310] *Office for Disability Issues* (2014) 3.

At a very early stage of developing the DAP, the Chief Executives' Group on Disability Issues agreed on fundamental principles – the **"New principles of engagement"** – to guarantee a practice of involvement of disabled persons in line with NZ's interpretation of Art 4 (3). These principles have already been discussed in a previous section of this report.

They have already been put into practice in the development process of the DAP. The document itself calls it a **"collaborative, codesign process"** that allowed DPOs to be involved in setting priorities together with government agencies in the development stage of the DAP. By involving persons with disabilities following the principles listed above, the DAP hopes to ensure that the **lived experience of all people involved is reflected in the work being done.**[311] Thus, contrary to other countries, such as Austria, Germany or Australia, NZ managed to establish comprehensive guidelines concerning the participation of disabled persons in political processes.

The second section of the DAP contains the actual actions that are planned for the years 2014 to 2018 and highlights the fundamental principles of the CRPD, such as non-discrimination and equality, personal safety, self-determination and so on. The importance of the involvement of disabled persons is mentioned and highlighted several times in this section as well.[312]

2.2. Empirical studies

2.2.1. Methods and participants

A total of **14 interviews** were conducted with representatives of important stakeholders in the disability sector of NZ. Ten of these interviews took place in Wellington in March 2015 at the respective organizations' offices or other venues in Wellington. One interview was conducted via videoconference (from Austria to NZ) in April 2015. Three additional interviews were conducted in February 2016 in Auckland and Wellington. The idea was to collect a **broad variety of opinions** from the whole range of government and non-government organizations. Therefore, only one interview per organization was conducted, so it was possible to include a maximum number of parties in our research. Two of the interviews also included videoconferences with persons from other parts of NZ.

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[311] *Office for Disability Issues* (2014) 3.

[312] *Office for Disability Issues* (2014) 4ff.

Guidelines with bullet points were sent to the interviewees in advance in order to allow them to prepare for the meetings. Thus, the interviews were semi-structured. Two different sets of interview guidelines were used, one for the interviewees on the "government side", and one for those on the "non-government side". These guidelines are included in the appendix of this report.

The interviews were conducted by two researchers, recorded and transcribed shortly afterwards. The average duration of an interview was around 58 minutes (durations between 42 minutes and 73 minutes). The data gathered during the interviews was evaluated by establishing categories in order to identify significant themes, such as "problems regarding representation within the disability sector" or "issues caused by the fact that DPOs accept government funding". Relevant categories were established *after* the interviews were conducted; therefore the risk of imposing "preconceived categories or theories on the data"[313] was reduced.

A total of five interviews were conducted with (former) representatives of various government entities:

- two senior representatives of the ODI were interviewed,
- two senior officials at the HRC were interviewed,
- two advisors at the Office of the Ombudsmen were interviewed in March 2015,
- two advisors at the Office of the Ombudsmen were interviewed in February 2016,
- a former ODI director was interviewed.

A total of nine interviews were conducted with representatives from NZ's major DPOs and other non-government organizations in the disability sector. As DPOs play the key role in the involvement in different processes, a slight focus was put on this type of organizations:

- four interviews were conducted with representatives of NZ's major DPOs,
- three interviewees represented other organizations in the disability sector which are not categorized as DPOs.

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[313] *Moriartity/Dew* (2011) 688.

Most interviewees are (former) senior representatives on a national level or advisors in their respective organizations. As shown in the list above, representatives of most of the key organizations in the wider sector of disability politics in NZ were involved in the research. This includes the most important members of NZ's IMM (HRC, Office of the Ombudsman and several member organizations of the Convention Coalition).

The aim of most questions was to point out ongoing difficulties and challenges on the path of fully implementing and monitoring the CRPD with a special focus on the involvement of persons with disabilities in these processes.

2.2.2. Key findings

2.2.2.1. Status of CRPD implementation – need for action?

There is general consent between all interviewed persons that **NZ still has a long way to go** until the goal of full CRPD implementation is accomplished. There are still some areas of domestic law that are thought to be in breach of the Convention and a lot of work has to be done in order to achieve the goal of an inclusive society in all fields. Some experts argue that **legislation is not the issue at all, but implementation and how the law is put into practice**. They think that full implementation can be achieved without actual legislative change but with a different interpretation and application of the existing laws. *Suzy*, a former representative of an organization in the disability sector, said:

"I cannot think of a single piece of legislation that stops us from achieving what we want to. […] I don't think legislation is the issue but I think implementation is."

One main issue however seems to be legislation around legal and mental capacity as well as supported decision making, e.g. in the **Mental Health (Compulsory Assessment and Treatment) Act 1992**, the **Protection of Personal and Property Rights Act 1988** and the **Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003**, which according to interview partners, all seem to be questionable in the light of **Art 12** and its guarantee of equal recognition before the law. The domestic legal documents protecting human rights are affected as well: the **NZ Bill of Rights Act 1990** and the **Human Rights Act 1993**.

One overarching principle of the CRPD is **reasonable accommodation**. In NZ there is apparently still work to be done in that regard in various areas such as **social security and health**, **employment, education** and **(public) transport**. *Rick*, a long-time DPO representative said:

"We have issues with the Bill of Rights around reasonable accommodation. […] We need to understand what the new rights-based approach means for disabled people: What does it mean in education, in justice, in health, in buildings and so on. I think we need to understand this human-rights approach and we need to understand reasonable accommodation and what that means all across the sector."

Another crucial issue that was mentioned by several participants is accessibility of information (especially government documents), as it is of massive importance to enable DPOs and other organizations to effectively participate in policy-making. Oftentimes, when DPOs are invited to participate in working groups, information materials are sent out by the government on very short notice. This leads to difficulties in terms of sufficient preparation for meetings.

2.2.2.2. Involvement of persons with disabilities via DPOs

When the CRPD was ratified by NZ there was a process of **determining which areas of the domestic law were inconsistent** with the Convention. Several organizations mentioned that "disabled persons" were involved in that process, however nobody mentioned who exactly was involved and in what way.

All persons who were interviewed confirmed that there are currently **no legislative processes** in NZ touching on areas that affect persons with disabilities. Nevertheless, there are other processes such as developing plans and strategies in which persons with disabilities are involved. The government drew up guidelines to ensure comprehensive and consistent involvement that is in line with Art 4 (3). Disabled persons' involvement in the **monitoring system** seems to be **working fairly well**.

From the DPOs' point of view, NZ government understands the term "representative organizations" in Art 4 (3) as a term, which **primarily refers to DPOs**. This reflects the principles of engagement which are specified in the DAP. The model of primarily involving DPOs as representatives of disabled persons into processes like policy-making and monitoring the Convention's implementation, in general, is **viewed positively**.

However, some voices claim that the **CRPD's inclusive paradigm** requires the **involvement of all relevant parties** in the disability sector such as service providers or family and consumer organizations. They argue that all parties should be sitting around the table to begin with and the principle of primarily including DPOs should not lead to the exclusion of other organizations. For example, board members of major service providing and family organizations **question their non-involvement in the development of the DAP**, because the outcome affects them as well as DPOs. *Frank*, a representative of a service providing organization said:

"The Convention is inclusive by nature and it wants all the voices around the table. […] What happened in NZ was that the monitoring group [the Convention Coalition] was set up; but I think there are other people outside that group that need to be part of these conversations as well."

Government representatives take a similar stance on this issue while reaffirming the principle of primarily involving DPOs, as *Max*, a member of the ODI, confirmed:

"DPOs are the smallest and poorest organizations in the disability community. The service providers have a lot of money but the DPOs say that it is now time for them to sit around the table. Art 4 (3) and 33 (3) do not exclude any voices, they just say that it is time that more DPOs should join the table."

One organization representative mentioned **difficulties for regional branches** of key organizations to participate, if they are not located around the major cities such as Wellington or Auckland. They would often like to take more critical stances on certain matters but are overruled by compromises made by their representatives in nationwide meetings with the government or other organizations.

This aspect somehow relates to the findings of a study cited by *Mladenov*, which identifies that sometimes "professionalization and institutionalization alienates NGOs from their social base".[314] On the one hand, institutional unification of several DPOs in NZ strengthens their negotiating power towards the government. On the other hand, it might also lead to a more centralized decision-making process within these organizations. Alienation from regional branches, and as a result from the very people whose interests they are supposed to represent, is a possible effect of several DPOs forming a union. However, our research did not show at all that a transition like this is currently underway in NZ's DPO sector.

The ways in which DPOs are involved in processes of policy-making vary strongly, depending on the government department responsible. There are **working groups** and possibilities to **submit written statements** to ongoing processes. A crucial development in recent years has been that DPOs now have the opportuni-

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[314] *Mladenov* (2009) 34.

ty to **participate at very early stages of policy-making processes ("initial discussions")**. They sit at the table from the beginning whereas before the DAP was established they were only able to have their say at the end of these processes (comment on already "finished products").

Critics however say that the processes are generally **not very transparent** and it is often the case that a person or organization, who contributes to a process, does not know if or how their submission was reflected in the outcome of the process. It has often been criticized that the government entity, which is responsible for the respective process, usually keeps the right to make the ultimate decision on the matter at hand. Thus, there seems to be **no real co-decision process** with the government and DPOs as equal partners yet. *Rick*, a senior DPO representative said:

"I think government officials are really trying to work it out, some of course better than others. Some of them are really engaging [with the DPOs] but I don't know if they are really getting what 'partnership' means because at the end of the day they will make the ultimate decision."

DPOs are hoping to move forward to the **next step**, which they describe as **"real partnership work"** where the perimeters are not set by the government and the DPOs do not have to depend on the government "opening the door" for them. They wish for public forums to gather feedback. There would then be a solid foundation to start doing a process together with the government. While the government is trying to include DPOs as closely and regularly as possible, there is still an imbalance of resources between the government and the organizations they are trying to include. This massive discrepancy of resources leads to an **imbalance of power**. *Rick*, again speaking on behalf of his DPO, noted:

"I believe that government is genuinely interested and keen and wants to do the right thing. A problem is the imbalance of power because government has all the resources and we have none. This has a big impact."

Before the DAP and the Convention Coalition, the government tended to **involve rather non-critical organizations**, which has changed in recent years. However, some DPO members have the feeling that the government is still very selective about which organizations they will engage with. *Chris*, a DPO representative, stated:

"The problem is that they would handpick the ones [organizations] they would engage with. They would rather pick someone that would give them the answers they were looking for – the least line of resistance."

However, other DPOs have noticed recent improvements in that regard since the CRPD was ratified and especially since the Convention Coalition was established. *Ann*, a senior DPO representative, said:

"Before the network [the Convention Coalition] was formalized, it was more like 'if they knew you would say the right thing, you would be contacted'. In recent years government was asking different people until they heard what they wanted to hear, but that is slowly going away."

2.2.2.3. Government funding for DPOs

Government funding for **DPOs** and other organizations is a crucial matter, as these organizations are **usually underfunded**. Government money enables these organizations to participate more effectively. *Jim*, a DPO representative, said:

"All in all, it is quite money and time consuming to have your say but I think that's what we're all about."

Funding and resources in general are a major issue for DPOs. Several interviewed DPO representatives emphasized that the government has yet to realize that **participation at all stages** can benefit the outcome and increase the quality of policy.

The government is **funding the Convention Coalition** for monitoring the implementation of the CRPD. Therefore, there are concerns whether they will still provide a **critical voice** in the future if they accept funding from the government, whose work they are supposed to critically influence and monitor.[315] Several organizations mentioned the possibility of a "fear of being too critical" and, subsequently, not being included in the processes anymore. *Frank*, a representative of a non-DPO organization, said:

"When DPOs form coalitions with government, it restrains them from their ability to monitor and criticize government. [...] You don't bite the hand that feeds you. [...] So my concerns with the arrangements of Art 4 (3) are that it is silencing the DPOs."

Suzy, another representative, stated:

"You cannot be a supercritical and sometimes very political voice and also sit at the table with government – at least not long term."

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[315] See also *Mladenov* (2009) 34.

Another consequence of DPOs accepting government funding might be that the clear **distinction between DPOs and service providing organizations is blurred**, as the acceptance of money usually involves obligations for the DPOs.

However, when asked about the issue of government funding for the IMM, *Max*, a government representative, stated that their independence is not endangered:

"The ODI gives money to the DPOs involved in the IMM and we have a contract that states pretty clearly that we do not control what they say. […] We just enable them to do their work."

Nevertheless, there can be no doubt that government funding for DPOs in combination with the "incorporation of civil participation into established institutional structures"[316] at least bears a certain risk of disempowering the critical voice of the DPOs. It seems to be a balancing act for the government. On the one hand, some kind of financial contributions are absolutely necessary to enable organizations to participate effectively. On the other hand, funding must not influence the organization's work and critical input in political processes.

2.2.2.4. Awareness of government officials and the general public

The level of awareness of government officials regarding the necessity to involve DPOs according to the principles set forth in the DAP **has risen over the past years** since the ratification of the CRPD. The DAP has increased the DPOs' ability to have their say. Since the DAP was signed off, there is a higher level of knowledge and understanding from the government side regarding the importance of lived experience in the process of policy-making. Most organizations' overall impression is that, in general, the government is genuinely interested and keen on involving the DPOs. Some reasons are given for that development: the formation of the Convention Coalition that presents a very vocal and critical voice in NZ's disability politics, NZ's going through the UN examination process with the Concluding Observations[317] being published in October 2014, or the proactive cross-government work of the ODI.

NGOs notice **differences between different government departments** in terms of how seriously they are taking the obligation in Art 4 (3) and to which degree they are showing commitment to the principles of engagement. The Min-

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[316] *Mladenov* (2009) 42, 44.

[317] See http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fNZL %2fCO%2f1&Lang=en (Feb. 2, 2016).

istry of Social Development is often mentioned as the prime example for best practice. The fact that this Ministry houses the ODI might be a possible explanation for that.

According to some statements, not all Ministries obey the principles of engagement and do not necessarily make a clear distinction between DPOs and service providing organizations. They consider it sufficient to involve “someone from the disability sector”.

Even though the principles of engagement are specified in the DAP – an official government document – they are **not legally enforceable** and government agencies are not penalized and do not face other consequences in case of breach. Some organizations hope for the principles to become an enforceable requirement written down in an act that actually requires all government departments and agencies to obey the principles. *Frank*, a civil society organization representative, worries that the principles of engagement specified in the DAP are still perceived as some sort of non-mandatory aspect of political processes:

“I think there are problems with the implementation from a government perspective because I don’t know how seriously government is taking their responsibilities. It’s still seen as kind of voluntary even though we have the DAP that’s been developed in consultation with DPOs and the HRC.”

With the formation of the Convention Coalition in 2013, active participation has become more visual to the government and the general public, and, in that regard great progress has been made. The **Convention Coalition**, as an association of the major DPOs, works as an **interface** between government departments and the DPO system. The exact processes however are yet to be developed. Most DPOs see the Convention as the foundation of NZ’s DAP and there is a positive vibe towards the principles of engagement that were agreed upon. This, according to most representatives, leads to a more structured and consistent involvement of DPOs in policy development.

2.2.2.5. Representation issues

A crucial challenge for the DPOs, especially for DPA as a cross-disability organization, is to i**nclude the whole disabled persons’ community as broadly as possible**, and collect their voices, and then take it to the government. A priority for the DPOs is to **build up capacities** that disabled persons all over the country can easily contact. This is a necessity in order to enable these persons to effectively engage with the (local) government.

The Convention Coalition sees itself as a broad network representing a wide variety of disabled persons, but representatives admit that the **spectrum of disabilities is not fully represented** in the network as it is. *Ann*, a DPO representative, said:

"It's also a problem that we [the DPOs] haven't sorted out our common values and interests yet. We are also just starting to learn the principle of representation: at first it is difficult to trust someone who has to represent you somewhere else."

Nearly all the major DPOs admitted to the fact that **representation within the disability sector is a key issue** in the ongoing process of involvement and they all see the problems of smaller organizations being left out. One representative of a non-DPO service providing organization (who is non-disabled himself) described an awkward and peculiar situation when he was invited to a working group by a Ministry and it was made clear to him that he was supposed to be representing the whole disabled persons' community there.

The government side is also aware of this issue, as *Max*, an ODI member specified:

"The seven DPOs involved [in the IMM] are not fairly representative of the whole disability community. Especially, there is an absence of cultural diversity. […] Minorities from the Pacific Islands or Asia are not represented at all. The group also lacks a strong older people's voice, which is a problem because over half of disabled New Zealanders are over 65 years old."

The Māori DPO involved in the Convention Coalition says that they have a clear mandate to represent only blind Māori. Even though they have members with many different types of disabilities, they refuse to represent the whole Māori community within the Convention Coalition. Even representatives from non-Māori DPOs acknowledge the fact that disabled Māori are not adequately represented within the Convention Coalition.

An organization has to be led by disabled persons in order to be recognized as a DPO (according to the set of attributes). However, some senior DPO representatives themselves come to the conclusion that **most DPOs are actually led and represented to the outside by non-disabled persons** even though the majority of people on their boards are disabled. *Rick*, speaking on behalf of his DPO, argues that there is no real *"disability drive"* in policy-making processes and it does not *"[…] feel like the vision and so on comes from disabled people at all. It all feels a bit controlled and restrained […]".*

Even if there is a disabled person representing DPOs at meetings, it often happens that the **non-disabled persons, who are supposed to be there merely for support do most of the talking**. One DPO representative stressed that there is a need for more **initiative from disabled persons themselves**. However, in order to achieve that, it is necessary to strengthen their self-confidence first.

2.2.2.6. Difficulties of working together within the IMM

The **Convention Coalition**, as a network of NZ's major DPOs, is viewed as a great opportunity because it allows these organizations to have a **powerful unified and collective voice** towards the government and the public. However, the very recent formation of the coalition also presents some challenges for the organizations involved. Most of them have been advocating the rights of their specific group of members (specifically for their type of disability) and pursuing their own interests and goals for years and now they have to **start working together** towards the common goal – full implementation of the CRPD.

On the one hand, the various organizations are trying to **preserve their own identity**, which is crucial, especially for the organizations of the indigenous people. On the other hand, they are glad to be working together and to be able to **learn from and about other organizations**. Looking forward, they are trying to work together more efficiently while pursuing their own interests, and preserving their uniqueness as well.

There still seems to be a certain level of **mistrust between the organizations**, probably also caused by representation issues within the respective organizations (e.g. between regional branches). Their common values and interests have still not been figured out.

The variety of organizations within the Convention Coalition causes an important question regarding the outside appearance: **Do they want to present a unified voice and brush over their different views or do they present the full range of views to the outside?** The latter approach could complicate relationships with the government as it quite possibly decreases workability if a variety of opinions has to be sorted out first.

2.2.2.7. Māori as the indigenous people of NZ

Representatives of indigenous organizations consider it a key problem of the CRPD that it only focuses on the rights of the individual person but **does not sufficiently recognize differences of culture or ethnicity**. In Māori culture, **family and whānau**[318] play a very significant role in everyday life; therefore, they should also be included in policy-making and monitoring processes. Certain disadvantages for Māori people are also pointed out in the Concluding Observations after NZ's first State Report in 2014.[319]

Especially for Māori people, there is a lack of knowledge about rights and the Convention. In their language, there are no words for e.g. deaf or blind; they have a **different understanding of disability**.

For more than five years, until October 2014, the Minister for Disability Issues was a member of the Māori party. She brought in a certain expertise in the broader area of discrimination, being a member of a minority that has struggled with equal recognition and faced discrimination for many years.[320]

3. Summary

- The **ODI** serves as the **focal point** under Art 33 (1).
- The **Ministerial Committee on Disability Issues**, chaired by the Minister for Disability Issues, is responsible for **overall coordination** of government policies and practices regarding CRPD implementation (Art 33 [1]).
- The **IMM** was set up as the independent mechanism to **monitor the implementation** of the CRPD in NZ (Art 33 [2]). It consists of three parties: the **HRC**, the **Office of the Ombudsman** and the **Convention Coalition**. The latter one currently comprises eight major DPOs.
- NZ's understanding of the term **"representative organizations"** of disabled persons is that it **refers primarily to DPOs**. There are certain

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[318] This term means "extended family" which may include caretakers, neighbors or other people playing an important role in everyday life, see https://en.wikipedia.org/wiki/Wh%C4%81nau (Feb. 2, 2016).

[319] *Committee on the Rights of Persons with Disabilities* (2013) points 17, 43, 53, 55, 75.

[320] See *Moriarity/Dew* (2011) 684.

attributes an organization has to meet in order to be recognized as a DPO.

- Therefore, some of NZ's major DPOs are directly involved in the monitoring mechanism.
- There are **currently no legislative processes** touching on disability issues underway.
- The recent release of the DAP including its **principles of engagement** and the formation of the Convention Coalition are two of the crucial developments, if not the key developments in recent years.
- On the one hand, **government funding for DPOs** is viewed positively, as it enables participation of these organizations in a more effective way. On the other hand, some experts fear that organizations may lose their critical voice if they get too close to the government.
- Several representatives of DPOs highlighted that **cooperation between different organizations** is one of the major challenges. There is general awareness that representation is a key issue within the disability sector and the DPO system.
- **Officials' awareness** of the importance and benefits of participation is generally **improving**. However, there are huge differences between government departments.

G. Australia

Australia signed the CRPD on 30 March 2007 and ratified it on 17 July 2008. The Convention came into force on 16 August 2008. Australia also became a State Party to the OP in September 2009. In its initial State Report to the UN, the federal government states that the country, including the State and Territory governments, is fully committed to ensure that the Convention is going to be fully and effectively implemented in all parts of Australia. The country's size as well as the federal structure is highlighted several times in the State Report. State and Territory governments are responsible for many government activities regarding CRPD implementation.[321] The COAG (Council of Australian Governments) is an entity including representatives of the federal government, the State and Territory governments and the local governments. It plays an important role in coordinating government work on all levels.

If Australia becomes a States Party to an international treaty such as the CRPD, legislative implementation is necessary. Otherwise the treaty's provisions are not directly applicable in Australia.[322] The Australian National Disability Strategy 2010-2020 sets out a strategic plan for the country's disability politics.[323] The development of this strategy was preceded by an extensive consultation process. Results of this consultative approach were published in the so-called "Shut Out" Report.[324]

The following explanations shall give an overview over Australia's institutional arrangements in disability politics and participatory processes in recent years. The research is focused on federal issues. Australia developed and worked out a number of plans and strategies on both federal and state level to implement the Convention and to ensure participatory approaches are taken.

1. Institutional framework

1.1. Focal points, coordination mechanism (Art 33 [1])

The Australian federal government appointed the Attorney-General's Department (AGD) and the Department of Family, Housing, Community-Service and

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[321] *Australia* (2012) points 2, 5.

[322] *Australia* (2011) point 40.

[323] *Commonwealth of Australia* (2011) 8.

[324] *Commonwealth of Australia* (2009) 1ff.

Indigenous Affairs (FaHCSIA) to serve as joint focal points under Art 33 (1). These two agencies work together and coordinate Australia’s reports to the UN Committee.[325] As a result of an administrative rearrangement, the FaHCSIA was terminated in 2013 and most of its responsibilities were transferred to the Department of Social Services (DSS).

The AGD is mandated to establish programs and policies to perpetuate and evolve Australia’s law and justice framework and to empower national security and emergency management. It also offers legal service (legal advice and representation) through the Australian Government Solicitor to the Commonwealth.[326] Basically, the AGD’s portfolio of responsibilities comprises the promotion of the implementation of government’s human rights policy agenda. The department supports and provides information to the Attorney-General as First Law Officer. He provides policy advice to the government and administration in human rights issues. The scope of functions of the department also includes dealing with international human rights law and treaties, to which Australia is party. Additionally to the human rights administration, the department supervises human rights scrutiny processes and provides support for statements of compatibility. It also represents the Australian government in human rights matters internationally and cooperates with the UN through communication processes and in the treaty body reporting mechanisms.[327]

The DSS lists its field of competence online. In terms of disability, it primarily “helps to support people with disability through programs and services and benefits and payments, and the National Disability Insurance Scheme (NDIS). DSS also helps to support Australians' mental health through programs and community activities. Further support is provided through grants and funding for organisations delivering services for people with disability and people with mental illness.”[328]

Neither the AGD nor the DSS are in power to lead the work of the two collaborating agencies and organizations of civil society. The Australian Shadow Report,

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[325] *Australia* (2012) point 212.

[326] https://www.ag.gov.au/About/Pages/default.aspx (Mar. 25, 2016).

[327] See https://www.ag.gov.au/RightsAndProtections/HumanRights/Pages/default.aspx (Mar. 25, 2016).

[328] https://www.dss.gov.au/disability-and-carers (Mar. 25, 2016).

published in 2012, criticizes the absence of a coordination strategy between the two departments (back then AGD and FaHCSIA).[329]

1.2. Monitoring mechanism (Art 33 [2])

The Australian Human Rights Commission (AHRC) is mandated to monitor the implementation of the Convention within Australia. Under the *Australian Human Rights Act 1986 (Cth)* the AHRC may take the following steps:[330]

Inquire/investigate into actions or practices of the Australian government, which may be inconsistent with the Convention;

- initialize guidelines, which avoid inconsistent acts or practices to the Convention,
- promote the Convention to increase awareness and acceptance for the CRPD's rights,
- observe the legal landscape and filter out which laws should be made or renewed concerning the Convention and report the findings to the Attorney-General,
- report specific actions to the Attorney-General which are needed to fulfil the requirements of the Convention.

The AHRC is a national institution for human rights in Australia fulfilling the requirements of the "Paris Principles". As of April 2016, the AHRC consists of a President and six Commissioners with different areas of responsibility. Up until 2014, there was a full-time Commissioner for disability-related discrimination. This field of work was then added to the portfolio of Commissioner for age-related discrimination due to funding cuts. The fact that there is no dedicated Commissioner for disability-related discrimination issues was criticized by several of our interview partners from the NGO sector.

Australia's Shadow Report criticizes an overall lack of civil society involvement in the monitoring mechanism and calls for an "effective and independent monitor-

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[329] *CRPD Civil Society Report Project Group* (2012) 215.

[330] *Australia* (2012) point 213f.

ing mechanism for progressing both the National Disability Strategy and implementation of the CRPD in Australia."[331]

1.3. Disability sector

The Australian disability sector is highly contested. There are countless federal and regional organizations competing for legitimacy and recognition. *Forrest/French* distinguish between three different "generations" of DPOs when describing the Australian sector:

- *first generation:* these organizations are impairment- or condition-specific;
- *second generation:* they are structured on a cross-disability and cross-population group basis;
- *third generation:* these DPOs are structured according to a particular population group (such as disabled women or indigenous persons with disabilities).[332]

In addition to these DPOs, there are other types of organizations, which also claim representative legitimacy. This includes advocacy and disability rights groups, parent- and family-based organizations or service providing organizations. *Forrest/French* describe that the diversity of the sector in combination with the country's size and low population density in most areas makes it very difficult for DPOs to pursue their interests in a collaborative way. They conclude that this is the main reason why the agenda in Australian disability politics is mainly driven and dominated by (financially stable) service providing and parent-carer organizations.[333]

Over recent years, umbrella organizations and alliances of different groups and organizations have been formed in Australia. A radical change of the Australian DPO system came in late 2014, when the government cut large parts of the DPO's funding and established a new system of "peak bodies". The current system will be described briefly in the following section.

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[331] *CRPD Civil Society Report Project Group* (2012) 34.

[332] *Forrest/French* (2014) 196.

[333] *Forrest/French* (2014) 196.

1.3.1. Australian Federation of Disability Organisations (AFDO)

The Australian Federation of Disability Organisations (AFDO) was founded in 2003. The formation was preceded by years of discussion towards the need for a national cross-disability, cross-population group peak representative body for persons with disabilities.[334] By self-definition, the AFDO "is the national voice representing people with disability in Australia. AFDO and their member organisations are run by and for people with disability, which we believe is imperative to be truly representative of the voice and lived experience of people with disability."[335]

This view is challenged by other voices in the sector. *Forrest/French* describe their observations that the AFDO's mandate to act and speak on behalf of the whole disability sector is challenged. The Federation is sometimes met with suspicion and resentment. It is viewed as established by the government and imposed on the sector to channel disability sector's views through a toothless and government-controlled organization.[336]

Even though the AFDO's role is criticized from different sides, the Australian government utilizes the Federation to channel the views of the sector. The government tasks the AFDO with various responsibilities, such as carrying out community engagement projects or representing the disability sector in policy-making processes. The AFDO also had a prominent role in the process of developing the CRPD and representatives were part of Australia's civil society delegation during the country's examination process in Geneva in 2013.[337]

1.3.2. Australian Cross-Disability Alliance (ACDA)

In December 2014, the Australian government cut the funding of the entire disability sector's representative organizations and established a new disability peaks funding model "representing the interests and views of all people with disability, which will provide advice to the Government on breaking down barriers and improving social and economic participation."[338] The funding cuts for all other or-

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[334] *Forrest/French* (2014) 196.

[335] http://www.afdo.org.au/about-us/ (Mar. 30, 2016).

[336] *Forrest/French* (2014) 197.

[337] *Forrest/French* (2014) 197; http://www.afdo.org.au/our-work/ (Mar. 30, 2016).

[338] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies (Mar. 30, 2016).

ganizations will most likely lead to massive changes in the sector, as some of our interview participants suggested.

Since the new funding system has been put in place, four national, cross-disability organizations form the new **Australian Cross-Disability Alliance** (ACDA), which receives funding from the government for advocacy work.[339] The ACDA views itself as a coalition of DPOs "which are organisations run by and for people with disability."[340] When referring to this new Alliance, all government releases and statements repeatedly emphasize that it is meant to represent all Australian persons with disabilities. The members of the Australian Cross Disability Alliance are:[341]

- *First Peoples Disability Network Australia* (FPDN) is the national peak organization of and for Australia's First Peoples with disability, their families and communities. The organization is governed by First Peoples with lived experience of disability. FPDN proactively engages with communities around Australia and represents Aboriginal and Torres Strait Islander people with disability in Australia and internationally. FPDN follows the human rights framework established by the United Nations Convention on the Rights of Persons with Disability (CRPD), and the UN Declaration on the Rights of Indigenous Peoples.

- *National Ethnic Disability Alliance* (NEDA) is the national peak organization representing the rights and interests of people from non-English speaking background (NESB) with disability, their families and carers throughout Australia. NEDA believes in an inclusive Australia, where cultural diversity and disability rights are valued as essential aspects of an equitable society.

- *People with Disability Australia* (PWDA) is a national disability rights and advocacy, non-profit, non-government organization. They have a cross-disability focus, representing the interests of people with all kinds of disabilities and their membership is made up of people with disability and organizations mainly constituted by people with disability. Their vision is of a socially just, accessible and inclusive community, in which the

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[339] http://crossdisabilityalliance.org.au/about/ (Mar. 30, 2016).
[340] http://crossdisabilityalliance.org.au/about/ (Mar. 30, 2016).
[341] See e.g. http://ymlp.com/zZjD3e (Mar. 30, 2016).

human rights, citizenship, contribution, potential and diversity of all people with disability are respected and celebrated.

- *Women With Disabilities Australia* (WWDA) is the national peak organization for women with all types of disabilities in Australia. WWDA is run by women with disabilities, for women with disabilities. It is the only organization of its kind in Australia and one of only a very small number internationally. WWDA's work is grounded in a human rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. WWDA has affiliate organizations and networks of women with disabilities in most States and Territories, and is internationally recognized for its global leadership in advancing the human rights of women and girls with disabilities.

Children with Disability Australia (CDA) also receives funding from the government. It is the national peak body for children and young people with disability, aged 0-25 years. CDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met. Participants of our research pointed out that CDA is no real DPO because its membership consists of parents and carers. Additionally, the government provides funding for **National Disability Services** to represent service providing organizations.[342]

According to the DSS's website, the government "will work with the six funded disability peak bodies to deliver its commitment to represent all people with disability and disability service providers in the most effective, coordinated and collaborative way."[343] The ACDA views itself as a **nexus between disabled persons, the government and other stakeholders** in the sector.[344]

On their website, the Alliance lists five major goals. They all refer to building networks and further alliances, enhancing cooperation between all stakeholders including the government and building respect for and faith in the Australian DPO sector.[345]

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[342] https://www.nds.org.au/ (Mar. 30, 2016).

[343] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies (Mar. 30, 2016).

[344] http://crossdisabilityalliance.org.au/about/ (Mar. 30, 2016).

[345] http://crossdisabilityalliance.org.au/about/ (Mar. 30, 2016).

2. Involvement of persons with disabilities

2.1. Overview

Australia's States and Territories hold crucial areas of responsibility in terms of legislative power. Therefore, they have a prominent role in legislative and administrative proceedings. This results in a number of different action plans, strategies and other official releases relating to disability issues.

Civil society is involved via consultations on special occasions, such as establishing these strategies, plans or reports. However, the implementation of these as well as the monitoring process often lacks a consistent participatory approach, as our research showed. Generally speaking, Australia as a whole **lacks comprehensive guidelines** on how to fulfil the CRPD's obligations under Art 4 (3) and 33 (3).

2.2. "Shut Out Report" and National Disability Strategy

The development of Australia's National Disability Strategy 2010-2020 (NDS) was preceded by an "extensive consultation" conducted in 2008 and 2009.[346] The results of these consultation processes were published in the report commonly known as the "Shut Out Report".[347] This publication depicts the current situation of disabled Australians and the challenges they have to face in everyday life.[348] It has a very prominent role and is often referred to by various stakeholders.

The Australian government released a discussion paper in 2008 in which the disability community was asked to respond to questions about experiences and challenges faced by persons with disabilities and their families in everyday life. These original questions are included in an appendix to the Shut Out Report.[349] An overwhelming number of Australians used the opportunity to raise their voices. More than 750 submissions were received by the government in response to the discussion paper. More than half of them were responses by individuals; the rest was submitted by organizations.[350]

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[346] *Commonwealth of Australia* (2011) 8.

[347] The official title of the report is "Shut Out: The Experience of People with Disabilities and their Families in Australia".

[348] *Commonwealth of Australia* (2009) 1.

[349] *Commonwealth of Australia* (2009) 64.

[350] The extensive list of submitting organizations is also included in the Shut Out Report, *Commonwealth of Australia* (2009) 65ff.

Consultation meetings were held in all state and territory capitals in October 2008. Additionally, 52 regional and remote area consultations were held between October and December 2008. These were facilitated by the AFDO and targeted specific population groups, such as indigenous Australians. Overall, all consultation meetings were attended by more than 2.500 persons.[351]

The results of all consultations were summarized and published in the Shut Out Report. Overall, they paint a rather negative picture. While persons with disabilities are present as members of Australian society, they do not enjoy full participation yet: "They face discrimination on a regular basis and are excluded from various aspects of everyday life. Many people described their lives as a constant struggle – for support, for resources, for basic necessities, for recognition. Over and over participants made the comment that it should not require such extraordinary effort to live an ordinary life."[352]

The subsequent development of the NDS was based on the findings published in the Shut Out Report in large part. Under the auspices of the COAG, all layers of the government worked together in the process of developing the NDS. The goal of the strategy is "an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens."[353] The NDS is underpinned by the CRPD and will play an important role towards the Convention's implementation between 2010 and 2020.[354]

Regular engagement between all layers of the government and persons with disabilities in the further development, implementation and monitoring is described as an essential part of the NDS.[355] The whole Strategy is underpinned by this principle. Persons' with disabilities views "are central to the design, funding, delivery and evaluation of policies, programs and services which impact on them, with appropriate support and adjustment for participation."[356] The principle of engaging with civil society is highlighted several times in all sections of the Strategy.[357] However, the Shadow Report (see below) criticizes a lack of meaningful en-

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[351] *Commonwealth of Australia* (2009) 76ff.

[352] *Commonwealth of Australia* (2009) 2.

[353] *Commonwealth of Australia* (2011) 8.

[354] *Commonwealth of Australia* (2011) 9.

[355] *Commonwealth of Australia* (2011) 10.

[356] *Commonwealth of Australia* (2011) 23.

[357] See e.g. *Commonwealth of Australia* (2011) 67.

gagement throughout the process of implementing the NDS and describes it as merely "tokenistic consultation and involvement".[358]

2.3. Shadow Report

Australia's Shadow Report was published in 2012 and is headlined "Disability Rights Now". According to the preface, the Report presents the "perspective of people with disability in relation to Australia's compliance with its obligations" under the CRPD. Civil society organizations were heavily involved in the development of the Report.[359] The development of the Report was funded by the government and endorsed by a number of organizations.[360] A Project Group was established to draft the Shadow Report. It comprised representatives of seven leading disability organizations. The ways in which the Project Group engaged with civil society prior to the publication of the Report is described in detail: In late 2009, members of the Project Group travelled to all capital cities of Australia on a "listening tour". Additionally, a website was established in 2009 to encourage civil society to enter submissions.[361]

The Shadow Report offers harsh criticism with regard to disabled persons' involvement in policy making processes on all levels of the country: "Australia has failed to effectively involve people with disability and their organisations at all stages of planning, implementation and monitoring the implementation of the CRPD. This is a critical and underpinning element of compliance with the CRPD and jeopardises all current efforts to respond to human rights breaches and policy gaps in relation to full inclusion of Australians with disability. Australia must establish a robust mechanism and provide adequate resourcing to enable an effective and representative voice for people with disability and their organisations in planning, monitoring and implementation of the CRPD."[362]

Furthermore, the Report calls for the Australian governments to provide adequate resources for persons with disabilities in order for them to be able to exercise their rights under the CRPD effectively.[363] The Shadow Report recommends the establishment of robust engagement mechanisms to ensure effective and

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[358] *Shadow Report Project Group* (2012) 37, 215.
[359] *Shadow Report Project Group* (2012) Preface.
[360] *Shadow Report Project Group* (2012) 2.
[361] *Shadow Report Project Group* (2012) 9.
[362] *Shadow Report Project Group* (2012) 2.
[363] *Shadow Report Project Group* (2012) 11, 37f.

meaningful participation by persons with disabilities. These mechanisms shall be developed in partnership with persons with disabilities and adequate funding has to be provided.[364] Similar recommendations can be found in the Report's section about the monitoring process in Australia.[365]

2.4. Empirical studies

2.4.1. Methods and participants

A total of **twelve interviews** were conducted with representatives of government departments and non-government organizations from the disability sector. Eight of these interviews took place in Sydney and Canberra in March 2015 at the respective organizations' offices. Four additional interviews were conducted in February 2016 in Sydney. The idea was to collect a **broad variety of opinions** from the whole range of government and non-government organizations. One of the interviews also included a videoconference with persons from other parts of Australia participating.

Guidelines with bullet points were sent to the interviewees in advance in order to allow them to prepare for the meetings. Thus, the interviews were semi-structured. Two different sets of interview guidelines were used, one for the interviewees on the "government side", and one for those on the "non-government side". These guidelines are included in the appendix of this report.

A total of seven interviews were conducted with (former) representatives of various **government entities**:

- two senior staff members at the Australian Human Rights Commission,
- one director of service delivery at a trial site of the new National Disability Insurance Scheme (NDIS),
- three members of the Special Council in the legal service branch of the National Disability Insurance Agency (NDIA),
- one assistant public guardian from the NSW Department of Justice,

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[364] *Shadow Report Project Group* (2012) 20.

[365] *Shadow Report Project Group* (2012) 34f, 215f.

- three interviews were conducted with representatives of guardianship agencies in NSW.

Three interviews were conducted with **experts from academia**:

- one interview was conducted with an academic fellow from the University of New South Wales,
- two were conducted with academic fellows from the Western Sydney University.

A total of four interviews were conducted with representatives of different organizations from the **disability sector**:

- two interviews were conducted with three different representatives of a high-profile DPOs (peak bodies) in March 2015 and February 2016,
- in a video-conference, five representatives with different backgrounds were interviewed:
    - one representative of a national peak service provider,
    - one former advisor to the New Zealand Ministry of Health and Disability,
    - one human rights activist and Executive Officer for the NSW Ministerial Advisory Council for People with Disability.
    - one project manager and member of the NSW State Guardianship Tribunal,
    - one member of the “Every Australian Counts” disability rights campaign.
- two members of an independent disability advocacy organization.

The aim of most questions was to point out ongoing difficulties and challenges on the path of fully implementing and monitoring the CRPD with a special focus on the involvement of persons with disabilities in these processes.

Because of the project’s limited time and financial resources and the complexity of Australia’s multi-layered political system, it was not possible to involve all important stakeholders in the research. However, all conducted interviews and thus gathered information provided a reasonable overview over recent developments in the evaluated areas.

2.4.2. Key findings

2.4.2.1. Development of the National Disability Insurance Scheme (NDIS)

The campaign preceding the development of the NDIS was running under the title "Every Australian Counts" (EAC).[366] It was launched in 2011. Recognizing early on that a massive reform had to have bipartisan support in the Australian parliament, activists reached out to advocate accordingly. Including the lived experience of disabled Australians and their families was another important aspect. The campaign also featured different social media channels, e.g. on Facebook or Twitter.

EAC was run by the National Disability and Carer Alliance, a coalition which was formed in 2009.[367] It was led by the NDS, the peak body of service providing organizations, the AFDO, the peak body of advocacy organizations and Carers Australia, the peak body for family carers. The unified alliance by these groups was remarkable because they traditionally were in conflict with each other before.[368]

Thus, the recent development of the new disability support system was carried by an unprecedented coalition of different organizations: "The campaign for a National Disability Insurance Scheme is supported across Australia by an unprecedented, politically bi-partisan and rapidly growing coalition of people with disabilities, their families and carers, disability service providers, advocacy and support organisations, peak bodies and community and welfare organisations. Many organisations in the Australian disability and community sector have publicly endorsed the proposal for an NDIS."[369]

Through EAC, activists tried to give persons with disabilities a louder voice all over Australia. Lobbying and endorsement work on a political level were also done by persons with disabilities themselves to include firsthand experience and

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[366] See *Thill* (2015) 16.

[367] http://disabilitycarealliance.org.au/ (Apr. 19, 2016).

[368] http://www.everyaustraliancounts.com.au/about-ndis/journey-so-far/ (Apr. 19, 2016).

[369] http://www.everyaustraliancounts.com.au/about-ndis/supporters/ (Apr. 19, 2016).

give the campaign credibility and authenticity. Several interviewed persons mentioned that the campaign triggered high public awareness and created political pressure on decision-makers. *Stuart*, who was directly involved in the EAC campaign, remembered:

"We played brutal politics. In local communities, we created an amount of pressure on back bench politicians. […] These were not senior politicians but, in the end, we had a majority in both political parties who supported the NDIS."

The successful campaigning led to legislation that passed the Australian parliament. For the first time, the CRPD is explicitly referred to in a piece of legislation in Australia.[370] Furthermore, the NDIS Act 2013 reaffirms the importance and priority of self-determined decision-making by disabled persons: "People with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives."[371]

Nate, a NDS employee who was strongly involved in the development of the NDIS legislation, said:

"You can see the DNA of the Convention in the legislation which enables the NDIS in Australia."

All interviewed persons viewed the development of the NDIS scheme as a success, overall. The inclusive approach at the developmental stage was highlighted as very positive. There is criticism of the scope of application, as the NDIS is not available to all disabled persons in Australia. As of this time, the NDIS is still at the stage of trial and its full implementation cannot be assessed.

2.4.2.2. Monitoring

The Australian human Rights Commission is meant to be the focus of the monitoring mechanism as an independent organization, and an agenda was created to pass new rights, and to keep the government updated on present issues. The position of the Disability Discrimination Commissioner was curtailed in 2014. Since then this position is half-time and is combined with the position of the Age Discrimination Commissioner. The former full-time Disability Discrimination Com-

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[370] Section 3 (1) lit a of the NDIS Act 2013.

[371] Section 17A (1) of the NDIS Act 2013.

missioner was involved in the preparation of the NDIS reform; he went to New York and Geneva (United Nations). *Kristin* a representative of a DPO said about the former Commissioner: "*He had been there for a long time. He always was a very outspoken man, but they decided to*

ex that. Kind of general trend towards to devaluate the AHRC, basically. It is cost saving measure, they cut the funding to the HRC, and cut his position, and made it part time to Susan Ryan that is fine. But it is a part time position, it does not have anything near the influence, or the resourcing, or the character, his position had. He was really a leader in the disability sector, he pushed, and he was in the media all the time. He said what he meant, was pushing issues, and starting debates. He took the sector along with him. He called out people, when anything was wrong." As a part-time Commissioner, it is not possible to achieve what a full-time Commissioner would have achieved. Another aspect is that the term of the part-time Commissioner will end in July 2016.

Regarding the monitoring function of the Commission, there is no guideline on how the monitoring should be conducted or how people with disabilities should be involved. *Dany* and *Kristin* mentioned the National Disability Strategy system as the only guideline or framework in place. The NDS offers six key areas[372], which serve as framework for the monitoring mechanism.

2.4.2.3. Ongoing processes

In Australia, some CRPD-based processes are ongoing; these processes revolve for example around Art 16 (Freedom from exploitation, violence and abuse), Art 23 (Respect for home and family) and the most famous seems to be Art 12 (Equal recognition before the law). Referring to Art 12, *Kelly*, a member of a disability advocacy organization said,

„*There are some areas we are still struggling credibility to be equal. There is a big challenge around equality, being understood. And in most areas we repeatedly work on and people with disabilities are seen as completely absent or not equal people.*" Compared to former days she mentioned that, "*It was a long travel around to be seen by the community and to be equal people, and to be equal decision-maker, and as leader…One of the thing we all acknowledge is that attitude is the big barrier. There are certainly physical barriers, financial barriers, employment barrier, all of those things, but attitudes are the big ones. If we can come*

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[372] These key areas are: Inclusive and accessible communities, Rights protection, justice and legislation, Economic security, Personal and community support, Learning and skills, Health and wellbeing.

over that barrier, and can be seen as equal people, being part of the community, a lot of other things become much easier. "

Kelly evaluates their function in ongoing processes as followes:

"*We are people, who have a role to play in making change. We know we are needed. This is our biggest challenge and area we have to work on. We use the CRPD as tool to do that, but it is a very challenging area.*" and "*The dominant voice is the voice of complaint*".

2.4.3. Guardianship Law Reform

In Australia guardianship regulations are state- and territory-based. Most of those individual regulations were very old. E.g. ACT received new guardianship legislation. The Guardianship and Management of Property Act 1991 was reprinted on 1 April 2016.[373] The ACT guardianship regulations were no longer compatible with the human rights framework, especially not with the CRPD. Prior to the republication, the Law Reform Commission wrote a paper on equality before the law. This paper was developed in a consultative process. *Kelly* told us enthusiastically,

"*I was on the advisory group on that. It had all sorts of pertinent people, and half of the advisory group were people with disability…We had a couple of other DPOs, national organization, and I was probably the only state based organization, but people wanted me, because I know stuff.*"

2.4.4. Funding issues

2.4.4.1. Disabled Person's Organizations

The funding reform of 2014/2015 impacts almost all organizations in Australia doing advocacy work for persons with disabilities. Over the last decades, there has been a call for the establishment of a new funding model, which is able to represent the realities, experiences and complexities of the lives of persons with disabilities in a better way, and that reflects both the community's and the government's needs on a higher level. The new model should be more logical, trans-

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[373] See https://www.google.at/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwjUjMyRn9LMAhVnAsAKHaR8C_0QFggbMAA&url=http%3A%2F%2Fwww.legislation.act.gov.au%2Fa%2F1991-62%2Fcurrent%2Fpdf%2F1991-62.pdf&usg=AFQjCNFbNaG0vVsz5BODjgScsO-JWl0G2Q&sig2=n5ztUP6WV3ylZq3kXKFJ_g (May 11, 2016).

parent, easier to function and administer, and should reduce duplication and inefficiency. There were several points of criticism of the historical and outdated model: It was argued that there were gaps in representation for all persons with disabilities, there was a lack of shared policy positions due to the lack of a streamlined mechanism through which the sector could speak with a unified voice, an over-reliance on diagnostic-based organizations and limited development and use of a shared evidence-base. The desire of the disability sector was to have representative organizations that are human rights-based and cross-disability-based, and to ensure control of decision-making by persons with disabilities. Moreover, those organizations should recognize the impact of multiple forms of discrimination experienced by women, indigenous peoples, and people from culturally and linguistically diverse backgrounds.[374]

Following those requests and an intensive consultation process between the government and the disability sector, the Australian government presented the new system of funding disability representative organizations in July 2013.[375] It was introduced as a new disability peak funding model, which should provide the best framework to effectively represent the interests and views of persons with disabilities.[376]

Prior to the recent reform, the Australian government funded a total of 13 national peak disability organizations. The program was administered by the DSS. Among the funded organizations were DPOs, run and driven by disabled persons, service providers, hybrid organizations of both, some of them run by family and/or carers of people with disabilities. Most of the organisations were “diagnostic” based groups referring to blind, deaf, hearing impaired, physical disability, etc; some were “population” based groups. This unequal treatment of different disability types was often criticized in Australia. As mentioned, the historic funding model divided the disability community into diagnostic groups, which means problems were located in individual deficits rather than in discriminatory structures, institutions, and attitudes.[377]

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[374] *Australia Cross Disability Alliance* (2015) 2.
[375] *Australia Cross Disability Alliance* (2015) 3.
[376] *Department of Social Services* (2016).
[377] *Australia Cross Disability Alliance* (2015) 3ff.

2.4.4.2. Funding Process

The DSS, on behalf of the Australian Government, announced a grant funding for national disability peak representation via an open, public tender process. All organisations were called in to apply for governmental funding. The Aim of the new funding model was to shift from a historically-based medical model to a social model of disability. In order to get funded, those organizations have to fulfil a number of requirements. Some of those requirements are for example that the applying organisation has to demonstrate its capacity to work within a human rights framework consistently with regard to the UNCRPD. Moreover they need to show demonstrable evidence of representation on a national level, direct representation of persons with disabilities, clear evidence of effective mechanisms to represent member's views, and to have the ability to develop the evidence base through research, and the ability to represent the disability sector and Government nationally and internationally. Any organization, national or state-based, can apply for funding as long as the organization meets the specific requirements. The new human rights-based model and approach to the structure and funding of national disability peak representation was developed, designed and supported by the Australian Disabled Person's Organisations (DPOs).[378] In March 2015 *Kristin*, a representative of a funded peak organisation, describes the old model as a dysfunctional and outdated model.

At the end of the application period[379], the Australian Cross- Disability Alliance (ACDA) succeeded and got publicly funded. This new cooperation reflects a coherent, logical structure to address human rights issues involving all people with disability in Australia, regardless of their type or diagnoses of impairment. This ensures true and meaningful representation.[380]

Dany a representative of one the remaining five funded peak organisations mentioned that "*In our judgment to be more effective, representing the Convention, there is need to be cross-disability, cross-functioning organisations [….] This has a much better approach, but what is meant though is a number of organisations will be closing their doors closely, which is very sad. But in truth, it had to come to this point eventually. The closing organisations can of course join in ours, if they want.*"

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[378] *Australia Cross Disability Alliance*, Submission (2015) 5f.

[379] June 19, 2014 – July 24, 2014; *Department of Social Services,* Sector Development for Disability Representative Organizations (2015).

[380] *Australia Cross Disability Alliance*, Submission (2015) 6.

The funding cut was announced to the organisations in December 2014, which resulted in profound disappointment. The Department of Social Service's "new way of working" was described as brutal. Among others defunded organisations were also the Australian Federation of Disability Organisations (AFDO) and the National Information Center on Retirement. The defunding process delivered consternation, uncertainty and instability to the disability community and sector.[381]

The defunding of the other eight of thirteen DPOs might be an unpleasant situation, but this new structure provides an innovative, effective possibility to form a bundled and unified voice to governments, to reduce duplication and promote efficiency and effectiveness, to achieve sector development, and to ensure that there are no gaps in the representation of people with disabilities in Australia.[382] One of the five funded DPOs turned out to be not a real DPO[383]. This refers to Children with Disability Australia, an organization, which is run by parents and carers and not by persons with disabilities. However they still get funded.[384]

Under the former funding system, peak organisations received 150.000 AUS$ per year, and under the new system, each of the five representative organisations receive 300.000 AUS$ per year. This is what a representative of a peak organisation told us. With this amount of money, the funded Disability Representative Organisations are able to represent individual and collective interests and represent views on relevant policies and legislations to the Australian Government, and to communicate the government's information to their members and the sector they represent.[385]

The funding compositions are complex. It depends on what kind of function the specific organization is conducting. For instance, we came across one organization, which exercises individual advocacy, delivers individual advocacy services (funded by a Commonwealth Disability Program), and systemic advocacy (funded

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[381] *Morton,* Brutal funding cuts no Christmas cheer for social services bodies in The Australian (2014) http://www.theaustralian.com.au/national-affairs/brutal-funding-cuts-no-christ mas-cheer-for-social-services-bodies/news-story/37f336c3fe24f05ab9081807ae6b639f (Apr. 20, 2016).

[382] *Australia Cross Disability Alliance*, Submission (2015) 7.

[383] In contrast to New Zealand's definition of an DPO there are no such a strict imperative rerequisitions to be a DPO in Australia.

[384] Representative of a DPO.

[385] *Department of Social Services,* Sector Development for Disability Representative Organizations – Feedback summary (2015) 1; see https://www.dss.gov.au/grants/sector-development-for-disability-representative-organisations (Apr. 25, 2016).

by the NSW Government at that moment). *Kristin* the representative of this organisation mentioned additionally that

"*We just become a national peak, we are funded by the Commonwealth to represent the interests of people with disability to the Commonwealth.*"

Within the new funding system there are uncertainties for DPOs, e.g. in NSW funding is provided for one year, and then the DPO has to wait until the last minute, till they find out if their organization will be funded again.

Relating the representative work one DPO has a three-year contract and there is a clause that says, "*It can be terminated, depending on the implementation of the NDIS.*" A representative of a DPO said "*We can lose it anytime*".

So the funding depends on the offered services, functions, roles, duties and responsibilities and also on the level of governments.

2.4.4.3. Defunded DPOs

To refuse funding to organizations, which need the money and often more, meant a deep cut and substantial loss of their capacity to work and handle their tasks properly. The defunded organizations were forced either to close down or to reduce their services or dismantle staff.[386] Those DPOs formed a separate organisation, called Disability Australia, which is not meant to be a "network". They are now dependent on project funding, private funding, or they might get funded on a state level for various issues.

The funding cuts in 2014/2015 and the reorganization of the landscape of the disabled person's organisations had substantial and incisive impacts on the entire disability sector. The defunded DPOs do not have the same access to the government anymore, therefore the left four funded DPOs and Children with Disability have to be their voice and carry their view to the governments. This is a new and challenging job and *Kristin* a representative of a funded DPO said, "T*hey really want to see their views come through. We spend a lot of time to manage all of that. It is not a backward step, it is different.*"

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[386] *Smerdon,* Funding Cuts Closes Disability Orgs (2015) see http://probonoaustralia.com.au/news/2015/01/funding-cuts-closes-disability-orgs/ (Apr. 25 2016).

The changes of the former system had a huge impact on the DPOs' use of their work capacity. There is a contradiction in the fact that DPOs are government-funded but at the same time they have to evaluate the government's work.

Dany, a representative of a funded DPO indicated that

"*We are advocating against the Government, who funds us. This is weird. […] It is an old thing we are funded by the Government, we are criticizing. And if you have a conservative Government like we have now, you have to change your tact significantly.*" *Kristin*, a representative of another funded DPO mentioned, "*We have to do specific things when government asks us. Before we did what we liked. The relationship is different now.*[…] *It prevents us from the work we want to pursue. It really affects our capacity.*"

On the one hand, the new system restricts the organization's tasks; they system supervises and guides the organizations in their daily work. But on the other hand, DPOs gained political power in bundling their capacity to influence the government in topics, the DPOs want them to pursue. The new way of funding DPOs, NGOs and Disability Service Providers presents a more transparent and more structured system, which facilitates governments to get in contact with the organizations. This offers names and organizations to government authorities, who they can consult with.

Kristin mentions that others say that "*the Government's defunding of the other organisations is a breach of the Convention. The Convention says, they have to use Art 33 (3) and Art 4 (3), which say the Convention has to fund these organisations to be the voice to the Government*".

Linda an academic researcher indicates, "*I myself think the Government was not right in cutting 40 per cent of the funding pool, because I don't think the organizations receive enough money to effectively do what they have to, but I do actually agree with the cross-disability approach.*"

The funding reform and specific funding cuts were shocking for the disability sector, but by the time when every organization found its place, the new system seems to move in a good direction and will work effectively for people with disabilities.

2.4.5. National Disability Services

National Disability Services (NDS) is the peak body for non-government disability service organisations in Australia. NDS has its head office in Canberra and offices in every state and territory and represents about 1050 non-government service providers. The NDS members offer thousands of services to people with disability, regardless to the type of disability. The National Disability Services (NDS) traces its roots back to 1945 and was relaunched in 2007. These comprise support for people with disabilities in employment or access to employment and also care types of services.[387]

Nate described the role of the NDS as followes,

"*Our role is to advocate to Government and talk about policies and of a legislative framework, their business environment. This helps them to do what they do. We do a lot of what we call "sector development" […] This kind of representation to Government and sector developments and the other things we have done or the core within the NDS is particularly on the NDIS.*".

Relating to the NDS, the National Disability Agreement (NDA) 2009 regulates the relation of the Australian and States and Territory governments in fields of responsibilities of funding for specialist services for people with disabilities. The NDA shows clear distinguished roles and duties for each level of the government and strives towards the aim of providing enhanced quality of life for people with disabilities, their families and carers, and to improve participation for members of the community equally. In particular, the Agreement shows the responsibilities of the Australian Government to provide income support and employment services for people with disabilities. Moreover, the states and territories are responsible for delivering specialist disability services. These include disability supported accommodation, and community support services such as therapy, early childhood interventions, life skills and case management. These allocations of duties remain the same as stated under the Commonwealth, State and Territory Governments Agreement (CSTDA) 2002 - 2007[388] and remain in place prior to the full rollout of the NDIS.[389]

As a result of the NDA, the Australian and state and territory disability ministers agreed to contribute to a **National Disability Research and Development**

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[387] See https://www.nds.org.au/about (Mar. 2, 2016)

[388] *Buckmaster/Klapdor,* Funding support for people with disability (2010) 2.

[389] *Department of Social Services*, National Disability Agreement (2014) see https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-agreement (Apr. 25, 2016); refer to https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/commonwealth-state-and-territory-disability-agreements/commonwealth-state-territory-disability-agreement-factsheet (Mar. 2, 2016).

Agenda, providing a total of $ 10 million over five years. The program's objective is to gather data, and improve research and development under the NDA.[390]

Regarding the funding reform 2014/2015 *Nate* mentioned further,

"*Funding intermediaries this is what mostly correlates to peoples' outcomes from services. They are not put in place at the moment. The decision-making supports and those things are being cut at the moment. Or consumer advocacy organisations we had around, funding cuts. They looked after specific groups. They are told, you can get together, and there is nothing particular about your group's needs. Weird is, we are putting in place the Scheme, where everything is about people's rights, and things that will help them to get those rights, and services are not in place.*

The new funding system of service providers promises to be preferable, however the interim period is unacceptable for persons in immediate need.

The NDS understands that influence is part of their core products. This is how they achieve positive outcomes for their members and the community.[391] The National Disability Service Limited receives funding of 275.000 AUS$ to represent the service providers that offer services to people with disability.[392]

There is also a huge inequality of funding between Disability service organisations and national DPOs, as *Kelly* mentioned,

"*It was Graeme Innes, who pointed out that carer's organizations are getting out $ 6-10 mil a year from the Federal Government and National DPOs get only one mil, there is a huge gap.*" She additional mentioned that "*Our capacity to change the agenda or to impact on the national discussion is limited, because of that lower level of support.*"

3. Summary

- The Attorney-General's Department (AGD) and the Department of Social Services (DSS) serve as joint focal points under Art 33 (1).
- The Australian Human Rights Commission (AHRC) was mandated to monitor the implementation of the Convention. The NDS serves as a framework for the monitoring process.

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[390] *Department of Social Services*, National Disability Agreement (2014).

[391] *National Disability Services*, Accessible NDS Annual Report 2015 8 see https://www.nds.org.au/about/annual-report (Apr. 25, 2016).

[392] *Department of Social Services,* Sector Development for Disability Representative Organizations (2015).

- The Australian Cross-Disability Alliance (ACDA) was established in 2014 and comprises First Peoples Disability Network Australia (FPDN), National Ethnic Disability Alliance (NEDA), People with Disability Australia (PWDA), and Women With Disabilities Australia (WWDA).
- Australia as a whole lacks comprehensive guidelines on how to fulfil the CRPD's obligations regarding the involvement of persons with disabilities. There are various inclusive plans and strategies for people with disabilities with no enforceable power or enough resources.
- The Australian government funds four DPOs and Children with Disability (ACDA) and National Disability Services (NDS).
- The NDIS was achieved and established through hard work by the National Disability and Carer Alliance and the cooperation of the disability sector. The legislation is seen a huge political achievement.
- Government's recent funding cuts were unexpected to a lot of organizations, but this change in system is viewed positively by some stakeholders.
- The cooperation between government representatives of persons with disabilities is perceived as largely satisfying but there is a lot of room for improvement. The process on the republication of the Guardianship and Management of Property Act 1991 (2016) may be mentioned as a positive instance for a consultative legislative process.

H. Conclusion

- Both Austria and Germany are countries with civil law systems, in which legislative acts are necessary in order to implement the CRPD. New Zealand and Australia have common law systems. Legislation is not necessary in these countries, as the CRPD's regulations can be implemented by interpreting existing statutes and precedents accordingly. Statutory offers better protection of individual rights and a higher degree of legal certainty.

- In none of the countries compared in this project, courts and administrative bodies are able to apply the CRPD directly. In this context, Austria ratified the CRPD with a constitutional reservation (*Erfüllungsvorbehalt*) and in Germany an Act approving the CRPD (*Zustimmungsgesetz*) was enacted. Further legislation is necessary in both these countries to implement the CRPD.

- Austria, Germany and Australia are countries with a federal structure. They have different layers of government, which have their own setup of legislative and administrative bodies. This complicates and delays the CRPD's full implementation.

- Our research showed that, generally, very few persons with mental or cognitive impairments were involved in the observed processes. Persons with different types of impairments are not equally represented; especially older persons and persons with mental impairments tend to be left out.

- In all observed countries, there is a lack of awareness of politicians and the general public regarding the issue of representation of disabled persons. The CRPD is underpinned by the principle of self-representation. Service providing organizations, which may be included in the "disability sector", are not representative organizations of disabled persons. This is especially true in Austria and Germany, where no clear distinction is made between DPOs and other organizations in the sector. Organizations *of* disabled persons (DPOs) are called upon by the CRPD to fulfil the representative role.

- The following chart depicts some of the fundamental differences between organizations of and for persons with disabilities:[393]

Organisations *for* disabled people	Organisations *of* disabled people
Traditional charities, pressure groups	Disability movement, consumer groups
Able-bodied professionals are in power	Disabled people are in power
Access to government funding	Under-resourced, underfunded
Enjoy government support	Lack government support
Representational democracy	Participatory/direct democracy
Service provision, charity	Campaigning and advocacy
Medical model	Social model
Dominant	Subordinate
Conformist or reformist	Radical
Committed to political negotiations, utilising existing power structures	Committed to direct action, utilising tactics outside traditional power structures
Co-opted, inside the system	Independent, outside the system

- Politicians and representatives of public administrative bodies have yet to recognize the **value of participation** of disabled persons and their organizations. The fact, that there are certain barriers for organizations and individuals (such as limited resources) works as a good excuse for why participation had allegedly not worked in the past. Participants in legislative processes, who share their lived experience, can provide fruitful insights and know-how, which will benefit the outcomes of these processes. Persons with disabilities are "eyewitnesses" of ongoing problems and other issues concerning their lives and the lives of other members in their social environment (involving, of course, disabled and non-disabled persons). Therefore, they can provide **firsthand information** and **crucial expertise**. This know-how has to be acknowledged by policy-makers, as it will most likely lead to better results.[394]

- Therefore, participation should be encouraged by at least **reimbursing the expenses** directly related to the participatory process.

- There are calls for comprehensive regulations regarding **compulsory involvement** in legislative and other policy-making processes. In Austria, participants showed gratitude towards the BMJ and praised the design of the guardianship reforming process as unprecedented and posi-

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[393] *Mladenov* (2009) 40.

[394] *Kallehauge* (2009) 207.

tive. This fact shows that Austria still has a long way to go. Involvement of those who are directly affected by legislative work should not be viewed as something extraordinary that is granted by lawmakers in certain cases. It should be an important aspect of *every* legislative process, as it is an important cornerstone of democracy. Actual involvement in the development and amendment of legal regulations right from the beginning should be the rule, not the exception and therefore not something that citizens should be grateful for. What has recently been re-affirmed on an international level by various regulations of the CRPD has yet to be transferred into domestic legislative processes.

- Pieces of legislation, which are an accomplishment of **combined efforts by legislators and civil society**, is viewed as a joint product. This increases the degree of **acceptance** for regulations in civil society.

- A **collegial partnership** of law-makers and experts acting in their own interest provides benefits for both sides. Not only are they able to exchange information but also build a serious foundation of confidence. Their cooperation and a lively open discussion encourage a better understanding for the other party and can benefit future processes.

- Authorities and lawmakers on the government side are responsible for providing clear and transparent guidance, especially for persons with disabilities. **Structures, competences, expectations and limitations** have to be defined in advance in order to prevent unrealistic expectations. Cooperation processes with affected representatives from civil society should be arranged in a **thoughtful, sincere, transparent and well-structured** way. In these processes, disabled persons should have an adequate timeframe and easily c**omprehensible information material** for appropriate preparation. Germany's approach of creating an accessible website before the development process of the "Federal Act on Participation" can be considered an example for best practice. Even though some of the provided documents are not designed accessible, at least all relevant information can be found on this website.

- **Clear structures within the disability sector** and within organizations are important, so that government officials know who to contact for certain matters. New Zealand's clear distinction between DPOs and other organizations is an interesting recent development. Organizations have to fulfil certain attributes to be recognized as a DPO. Even more recently, a new DPO structure was introduced in Australia, which provides a manageable number of cross-disability organizations representing persons with all types of disabilities.

- In general, **financial aspects** play an essential role in the field of representation and advocacy work. Without additional financial resources provided by the government, participation is hardly possible. This is especially true for organizations in the disability sector, as they are usually underfunded.
- However, some organizations' financial dependence from the government raises fundamental issues. Civil society organizations are called upon to provide critical voices. Their independence from the government is important to fulfil this role. *Mladenov's* studies show that the government funding and participation through institutionalization (e.g. advisory councils) bears certain risks, as organizations might lose their ability to critically monitor the work of legislative and administrative bodies.
- As a final conclusion, it can be said that participation and involvement of persons with disabilities in legislative and other policy-making processes requires great empathy on both sides. Lawmakers as well as persons with disabilities and their representative organizations have to show mutual appreciation and acceptance for problems of the opposite side. All participants of our research showed great openness and sincerity in their dealings with disabled persons. The true value of involving persons with disabilities in the process was recognized and praised by all participants. Nevertheless, some officials in their paternalistic attitude still seem unaware of this enrichment. At least in Austria, members of the BMJ have recognized the opportunity to gain experience and deep insights through the input of persons with disabilities in order for our laws to be a bit more equitable.

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Walter Hammerschick
Institut für Rechts- und Kriminalsoziologie
Museumstrasse 5/12, A-1070 Wien
walter.hammerschick@irks.at

Alexander Lamplmayr
A-4030 Linz
A.Lamplmayr@gmail.com

Eva Nachtschatt
D-34125 Kassel, Deutschland
Eva.nachtschatt@gmail.com

Appendix I

A. Guidelines for an interview with a Ministry official (Austria)

Zu Beginn: Was verstehen Sie unter **Teilhabe, Beteiligung, Partizipation**? Oder sehen Sie diese Begriffe differenziert?

<u>Sachwalterrechts(SW)-Reform: Planungsprozess</u>

- Wie sahen Ihre Überlegungen und **Vorbereitungen** im Vorfeld aus?
- Stand der **Fahrplan** des Beteiligungsprozesses von Anfang an in etwa fest oder entwickelte sich dieser erst mit Fortschreiten des Prozesses?
- **Bestanden Vorgaben seitens des BMJ** hinsichtlich der Beteiligung von Menschen mit Behinderungen oder dem Vorgehen hinsichtlich des Ablaufes?
- Kennen Sie den Praxisleitfaden „**Standards der Öffentlichkeitsbeteiligung**“ bzw haben Sie diesen zu Rate gezogen und in Ihre Vorbereitungen einfließen lassen?
- Hatten Sie vor dem Prozess schon eine klare Vorstellung davon, was geändert werden sollte (**Reformbedarf**)?
- Fand in der Vorbereitungsphase ein **Austausch** mit anderen Einrichtungen/Behörden statt? Eventuell auch mit Einrichtungen in anderen Ländern? Deutschland?

<u>SW-Reform: Beteiligungsprozess</u>

- Wie sind Sie hinsichtlich der **Einladungen** an die Teilnehmer vorgegangen (große und kleine AG)?
- Nach welchen **Kriterien** haben Sie die Teilnehmer (Menschen mit Behinderungen bzw deren Vertreterorganisationen) ausgewählt?
- Kamen auch Selbstvertreter oder Behindertenvertreter von sich aus auf Sie zu und baten um Teilnahme?
- **Informationen im Vorfeld** der jeweiligen Sitzungen? Wie sind Sie hinsichtlich der Verbreitung von Informationen vorgegangen? Inhalt und Art (zB Leichte Sprache usw) der Informationen?
- Wie haben Sie sich auf die Sitzungen **vorbereitet**?

SW-Reform: Rückblick

- Wie haben Sie die Beteiligung von Menschen mit Behinderungen UND ihren Vertreterorganisationen wahrgenommen?
- Beteiligung – unterschiedlich je nach Art der Behinderung?
- Gibt es **unterrepräsentierte** Gruppen?
- Inwiefern fanden (finden) die **Ideen/Anregungen der Teilnehmer** Eingang in Ihre legistische Arbeit?

SW-Reform: Erfahrungen

- Wie haben Sie Bereitschaft zur Beteiligung wahrgenommen (aktive oder passiv)?
- Rückblickend, was hat Ihrer Meinung nach gut funktioniert?
- Was können Sie für künftige Beteiligungsprozesse für sich mitnehmen?
- Wird Ihrerseits eine Art Handbuch („Fahrplan“, ähnlich wie der Leitfaden zu den „Standards der Öffentlichkeitsbeteiligung“) für folgende Beteiligungsprozesse geben?
- Was eventuell weniger gut funktioniert?
- Wo sehen Sie Verbesserungsbedarf (möglicherweise auch von Seiten der Beteiligten)?

B. Guidelines for an interview with a person with disability and member of the ÖAR

Wie sehen und bewerten Sie grundsätzlich die Partizipation von behinderten Menschen in politischen Prozessen in Österreich?

Wie sehen Sie den Zusammenhang zur Selbstbestimmt-Leben-Bewegung?

- Entwicklung der Selbstbestimmt-Leben-Bewegung in Österreich?
- Wichtigste organisatorische Player? Vernetzung der Organisationen außerhalb der ÖAR?
- Rolle der ÖAR?

In politischen Prozessen: Repräsentationsprobleme innerhalb des Sektors (organizations *of* disabled persons vs. organizations *for* disabled persons)?

- Selbstvertreter ausreichend eingebunden?
- Unterrepräsentierte Gruppen?

- **Art 4 Abs 3 der UN-BRK sieht bekanntermaßen eine Einbindung betroffener Menschen in den Umsetzungsprozess der Konvention vor. Wird aus Ihrer Sicht dieser Verpflichtung in Österreich ausreichend nachgekommen?**

- Wie beurteilen Sie den *modus operandi* der Einbindung?
- Ablauf der Arbeitsgruppen zum Sachwalterrecht?
- Können Sie (historische) positive Beispiele für eine funktionierende Beteiligung in Österreich nennen?
    - tatsächliche Auswirkungen auf den Gesetzestext?
    - Transparenz/Nachvollziehbarkeit dieser Prozesse?
- Veränderungen in der Beteiligung Betroffener durch die BRK?

Einbindung von Menschen mit Behinderungen bzw der Zivilgesellschaft im Bereich des Monitoring (Art 33 Abs 3 BRK)?

- Wie funktioniert das in den Ausschüssen in den Ländern?
- Rolle der öffentlichen Sitzungen? Eventuell Feedback von „Außenstehenden“? (öffentliche Wahrnehmung?)
- Einfluss behinderter Menschen auf die tatsächliche Arbeit der Ausschüsse?

Information als Voraussetzung für funktionierende Partizipation

Fazit: Insgesamt zur Partizipation behinderter Menschen in Österreich

Appendix II

A. Guidelines for an interview with the head of the German National CRPD Monitoring Body (Germany)

Monitoring: notwendigen, zivilgesellschaftlichen Prozess, der die Einhaltung und Umsetzung der Konvention begleitet und fördert. Erfolgt durch nichtstaatliche Akteure: unabhängige Monitoringstelle (Deutsches Institut für Menschenrechte).

- **Aktuelle Entwicklungen** in Ö, die Vorsitzende des Ö Monitoringausschusses hat ihr Amt ua aus dem Grund der manglenden Unabhängigkeit und wörtlich „*Grund waren strukturelle Defizite der Ausschusskonstruktion bedingt durch unterschiedliche Auffassungen über die Ausrichtung des Ausschusses und diese unter einen Hut zu bringen.", niedergelegt.*" – Ö Finanzierung von Sozialministerium – Wie sehen Sie die Situation der Monitoringstelle?
- konkrete Aufgabenverteilung?
- Konkret Mitarbeiter des D Institutes für Menschenrechte, die nur im Bereich Monitoring arbeiten?
- In D besteht das Monitoring auf Bundesebene und wird durch den UN-Fachausschuss auf internationaler Ebene unterstützt/begleitet. Gibt es diesbezüglich auch Unterstützung auf der **Ebene der Bundesländer**, also gemeint sind eigene Stellen auf Länderebene um deren Kompetenzbereich abzudecken?

<u>Konsultationen:</u>

- 3x jährlich Verbändekonsultationen (Erfahrungs- und Informationsaustausch)
    - Beteiligte: Interesse sich für Umsetzung entschlossen einzusetzen.
- **Große** und **kleine** Organisationen nehmen an der Monitoringtätigkeit teil. Bei den Sitzungen hat jede Organisation, Verein **einen** Vertreter
    - Kommen kleinere Vertreter im Vergleich ausreichend zu Wort? Repräsentation gleichermaßen gewährleistet durch die Zuordnung von jeweils einem Sitz für die beteiligten Vereine?
    - Waren von den anwesenden Repräsentanten auch **Selbstvertreter/innen**? Wenn ja, wie viele?

  - Repräsentationsprobleme: Werden bestimmte Gruppen von Behinderten eher schlechter repräsentiert als andere (Erfahrungen aus den Erhebungen in anderen Ländern) – persönlicher Eindruck?

- Beteiligung bei den nicht-öffentlichen Sitzungen lediglich auf persönliche Einladung?
  - Vorheriges **Gespräch** mit Ihnen….
  - Was wird sozusagen vorausgesetzt oder erwartet von den Vereinen, die sich beteiligen wollen (Auswahlkriterien)? Wie kann man sich diese Gespräche vorstellen? Wie laufen sie ab? Wer ist anwesend?
  - Ihr **persönlicher Eindruck** bezüglich der Einbindung und Beteiligung von Menschen mit Behinderungen in den Prozess des Monitorings (**Unterscheidung** zwischen strukturellen und einzelfallbezogenes Monitoring?) und im Bereich der Gesetzgebung oder politischer Programme (Bsp die Arbeitsgruppe zum Bundesteilhabegesetz)?
  - Persönliche Einschätzung, ob die Beteiligung gut funktioniert?

B. Guidelines for an interview with a member of an organization of persons with disabilities (Germany)

Allen voran, was verstehen sie unter **Teilhabe, Beteiligung, Partizipation**?

Welche Partizipationstheorien/-modelle allgemein werden Ihrem Wissen nach insb in Bezug auf Menschen mit Behinderungen erfolgreich angewendet? Speziell in Bezug auf die Einbeziehung in nationale Gesetzgebungsverfahren?

- Sind Ihnen *best practice*-Beispiele im In- und Ausland bekannt?
- Beispiele aus der Vergangenheit? Positiv und negativ?

Information der Betroffenen als Voraussetzung für funktionierende Partizipation

- Defizite in Deutschland (Leichter Lesen, Gebärdendolmetsch, Braille-Schrift,…)?

- Deutschland: Sind alle erforderlichen Informationen in einer adäquaten Form erhältlich?

- Die Teilhaberechte werden als „hart erkämpfte Rechte“ beschrieben. Wie ist Ihr **persönlicher Eindruck heute gegenüber der UN-BRK und deren Umsetzung: Wird aus Ihrer Sicht der Verpflichtung in Art 4 Abs 3 BRK (**dieser spricht von engen Konsultationen und aktiver Einbeziehung von Betroffenen und ihren Vertreterorgansationen in den Umsetzungsprozess der Konvention**) in Deutschland nachgekommen?**

- *modus operandi* der Beteiligung? Frage der Zuständigkeit, mit wem muss/soll man sprechen?
- Werden Modelle angewandt bzw lassen sich die angewandten Methoden in Modelle verorten?
- Können Sie positive Beispiele für eine funktionierende Beteiligung nennen?
- Einbeziehung, Partizipation in welcher Phase des Verfahrens?
- Auswirkungen auf den Gesetzestext?

Einbindung von Menschen mit Behinderungen bzw der Zivilgesellschaft im Bereich des Monitoring (Art 33 Abs 3 BRK)?

- Einbeziehung der Länder?
- Unabhängigkeit der Monitoring-Stelle?
- Wie sehen Sie die Entwicklung in Deutschland, wo die Unabhängigkeit der Monitoring-Stelle von Ministerien ab 1.1.2016 gesetzlich gewährleistet ist?

- **Repräsentationsthematik bei Menschen mit Behinderungen?**

- **Beteiligung** – unterschiedlich je nach Art und Grad der Behinderung?

Haben Sie Erfahrungen/ Ideen/Vorschläge wie diese unterschiedlichen Bedürfnisse erfüllt werden könnten?

Unstimmigkeiten innerhalb der Behindertenbewegung aufgrund von unterschiedlichen Sichtweisen im Zusammenhang

- Gibt es unterrepräsentierte Gruppen?
- Sind Selbstvertretungsorganisationen ausreichend beteiligt?

Spezifisch hinsichtlich Deutschland:

- Allgemeine Informationen zu den Zielvereinbarungen – **Kriterien** an Verband um ZV verhandeln zu können, Interessen von MmB vertreten.
- Stellung des Behindertenrates?
- **BTHG** – Gedanken
- Wie wird die Organisation, der Ablauf, die Einbeziehung der Veranstaltungen Ihrerseits empfunden?
- Kritik?
- Anregungen?
- Verbesserungsvorschläge?
- Vergleich zu früher – Veränderungen?

Appendix III

A. Guidelines for an interview with senior representatives of the ODI (New Zealand)

- **Can you briefly describe your exact function/occupation and affiliation?**

- **In your opinion, to what extent is the New Zealand Law currently in line with the requirements of the UNCRPD?**
  - In which areas do you see an immediate need for action?
  - In your opinion, where lie the biggest challenges and obstacles for successfully implementing the standards of the UNCRPD into New Zealand law (e.g. lack of awareness, different systems of the Northern or Southern Islands (area of authority, competences), financial issues…)?

- **Have you worked on any legislative processes regarding the national implementation of the UNCRPD into national law?**
  - What were the main issues tackled by these legislative processes?
  - Were people with disabilities or their representative organizations involved in these processes?
  - If so, which organizations were able to participate?
  - If so, how were these organizations selected and contacted?
  - In which way were they able to participate (e.g. written statements in response to drafts, organized workgroups…)
  - Was there any positive or negative feedback given by the people involved regarding the process?

- **From your point of view, how would you assess the active participation of people with disabilities in the national implementation process of the UNCRPD, as it is outlined in Art 4 para 3?**
  - In your opinion, has New Zealand fulfilled its obligation deriving from Art 4 para 3 UNCRPD ("closely consult with and actively involve people with disabilities") so far?

  - Has the way of participation of people with disabilities changed through the course of implementing the UNCRPD?
  - Has the awareness of government officials regarding the participation of people with disabilities changed throughout the implementation process?
  - In which areas do you see room for improvement concerning the possibilities to participate in legislative processes?
  - Do you have notice of any changes in public perception or media coverage or scientific works pertaining participation of people with disabilities?

- **Have you worked on any other activities aside from legislative processes (e.g. development of action plans…) where people with disabilities were able to participate?**

B. Guidelines for an interview with representatives of DPOs (New Zealand)

- **Have you or your organization been involved in any legislative processes regarding the implementation of the UNCRPD into national law in recent years?**
  - What were the main issues tackled by these legislative processes?
  - In what capacity have you taken part in the process (e.g. expert/consultant, representative of a NGO/DPO…)?
  - In which way were you able to participate (e.g. written statements in response to drafts, organized workgroups by Ministries/governments…)?
  - Can you briefly describe the schedule and organization of the process? How were you/your organization contacted by officials?

- **In your opinion, to what extent is the New Zealand law currently in line with the requirements of the UNCRPD?**
  - In which areas do you see an immediate need for action?
  - In your opinion, where lie the biggest challenges and obstacles for successfully implementing the standards of the UNCRPD into New

  Zealand law (e.g. lack of awareness different systems of the Northern or Southern Islands [area of authority, competences], financial issues…)?

- **From your point of view, how would you assess the active participation of people with disabilities in the national implementation process of the UNCRPD, as it is outlined in Art 4 para 3?**
  - How would you describe your overall impression?
  - In your opinion, has New Zealand fulfilled its obligation deriving from Art 4 para 3 UNCRPD ("closely consult with and actively involve people with disabilities") so far?
  - Do you know, in which way government officials are trying to get in touch with people with disabilities to involve them in legislative processes?
  - Has the way of participation of people with disabilities changed through the course of implementing the UNCRPD?
  - Has the awareness of government officials regarding the participation of people with disabilities changed throughout the implementation process?
  - In which areas do you see room for improvement concerning the possibilities to participate in legislative processes?
  - Have you notices any changes in public perception or media coverage pertaining participation of people with disabilities?

- **Have you or your organization taken part in any other activities aside from legislative processes (e.g. development of action plans…)?**

Appendix IV

A. Guidelines for an interview with an academic researcher (Australia)

- **Can you briefly describe your exact function/occupation and affiliation?**

- **In your opinion, to what extent is the Australian Law currently in line with the requirements of the UNCRPD?**
  - In which areas do you see an immediate need for action?
  - In your opinion, where lie the biggest challenges and obstacles for successfully implementing the standards of the UNCRPD into Australian law (e.g. lack of awareness, different systems in the States and Territories (area of authority, competences), financial issues…)?

- **Have you worked on any legislative processes regarding the national implementation of the UNCRPD into national law?**
  - What were the main issues tackled by these legislative processes?
  - Were people with disabilities or their representative organizations involved in these processes?
  - If so, which organizations were able to participate?
  - If so, how were these organizations selected and contacted?
  - In which way were they able to participate (e.g. written statements in response to drafts, organized workgroups…)
  - Was there any positive or negative feedback given by the people involved regarding the process?

- **From your point of view, how would you assess the active participation of people with disabilities in the national implementation process of the UNCRPD, as it is outlined in Art 4 para 3?**
  - In your opinion, has Australia fulfilled its obligation deriving from Art 4 para 3 UNCRPD ("closely consult with and actively involve people with disabilities") so far?

  - Has the way of participation of people with disabilities changed through the course of implementing the UNCRPD?
  - Has the awareness of government officials regarding the participation of people with disabilities changed throughout the implementation process?
  - In which areas do you see room for improvement concerning the possibilities to participate in legislative processes?
  - Do you have notice of any changes in public perception or media coverage or scientific works pertaining participation of people with disabilities?

- **Have you worked on any other activities aside from legislative processes (e.g. development of action plans…) where people with disabilities were able to participate?**
  - Is there an office or Ministry of some kind for disability issues in Australia?
  - Do you know anything about how the focal point is contacting DPOs and NGOs to work with them?
  - Which laws (concerning disability) are currently being reformed?
  - Independence of monitoring mechanism in Australia?
  - The NGOs wrote the Shadow Report. Are they in any other way involved?
  - Cooperation between DPOs?
  - Was there an official response or reaction to the Shadow Report?

B. Guidelines for an interview with a representative of a DPO (Australia)

- **Have you or your organization been involved in any legislative processes regarding the implementation of the UNCRPD into national law in recent years?**
  - What were the main issues tackled by these legislative processes?
  - In what capacity have you taken part in the process (e.g. expert/consultant, representative of a NGO/DPO…)?

  - In which way were you able to participate (e.g. written statements in response to drafts, organized workgroups by Ministries/ governments…)?
  - Can you briefly describe the schedule and organization of the process? How were you/your organization contacted by officials?

- **In your opinion, to what extent is the Australian law currently in line with the requirements of the UNCRPD?**
  - In which areas do you see an immediate need for action?
  - In your opinion, where lie the biggest challenges and obstacles for successfully implementing the standards of the UNCRPD into Australian law (e.g. lack of awareness, different systems in the States and Territories, financial issues…)?

- **From your point of view, how would you assess the active participation of people with disabilities in the national implementation process of the UNCRPD, as it is outlined in Art 4 para 3?**
  - How would you describe your overall impression?
  - In your opinion, has Australia fulfilled its obligation deriving from Art 4 para 3 UNCRPD ("closely consult with and actively involve people with disabilities") so far?
  - Do you know, in which way government officials are trying to get in touch with people with disabilities to involve them in legislative processes?
  - Has the way of participation of people with disabilities changed through the course of implementing the UNCRPD?
  - Has the awareness of government officials regarding the participation of people with disabilities changed throughout the implementation process?
  - In which areas do you see room for improvement concerning the possibilities to participate in legislative processes?
  - Have you notices any changes in public perception or media coverage pertaining participation of people with disabilities?

- **Have you or your organization taken part in any other activities aside from legislative processes (e.g. development of action plans…)?**

Appendix V

A. Questionnaire (Austria)

Universität Innsbruck
Institut für Zivilrecht

Sehr geehrte Damen und Herren,
wegen der Behinderten-Rechts-Konvention
wird es viele Gesetzes-Änderungen geben.
Die Politiker müssen unbedingt auch
Menschen mit Lernschwierigkeiten
nach ihrer Meinung fragen.
Wir möchten uns das in mehreren Ländern anschauen.
Nämlich in Österreich, Deutschland, Neuseeland und Australien.
Wir wollen Verbesserungen und Änderungen vorschlagen.
Damit das möglich ist,
brauchen wir Ihre Unterstützung!
Sie können uns sehr helfen
wenn Sie den Frage-Bogen ausfüllen.
Der Frage-Bogen ist anonym.
Das heißt Sie brauchen Ihren Namen nicht hinschreiben!

Vielen Dank!

Fragen

1. Ich bin….
   ☐ ein Mann.
   ☐ eine Frau.

2. Wie alt sind Sie?

Ich bin________ Jahre.

3. Wo leben Sie?
☐ Ich lebe in einem **Dorf**.
☐ Ich lebe in einer **Stadt**.

4. In welchem **Bundesland** leben Sie?

____

5. Was sind Sie? **(mehrere Antworten möglich)**
☐ Ich bin **Selbst-Vertreterin** oder **Selbst-Vertreter**.
☐ Ich bin ein **Mensch mit Lernschwierigkeiten**.
☐ Ich bin Vertreterin oder Vertreter einer **Behinderten-Organisation**.
☐ Ich bin Vertreterin oder Vertreter eines **Heimträgers**.
☐ Ich bin Vertreterin oder Vertreter einer **Kranken-Anstalt**.
☐ Ich bin Vertreterin oder Vertreter eines **Sachwalter-Vereins**.
☐ Ich bin **Rechts-Anwältin** oder **Rechts-Anwalt**.
☐ Ich bin **Notarin** oder **Notar**.
☐ Ich bin **Forscherin** oder **Forscher**, zum Beispiel an der Universität.
☐ Ich bin etwas anderes: ______________________________________.

6. Sind Sie bei einer **Organisation** oder einem **Verein**:
☐ Ja.
Wie heißt der Verein? ____________________________________.
☐ Nein.

7. Ich habe…. **(mehrere Antworten möglich)**
☐ eine Sachwalterin oder einen Sachwalter.
☐ eine Angehörigen-Vertretung.
☐ eine sonstige Vertreterin oder einen sonstigen Vertreter.
☐ eine Vorsorge-Vollmacht.
☐ eine Patienten-Verfügung.
☐ Ich habe gar nichts.

8. Heute gab es ein Treffen im Ministerium.
Wir möchten gern wissen,
wie Sie von dem Treffen erfahren haben.

☐ Ich habe **selber** eine Einladung bekommen.
☐ **Mein Verein** hat eine Einladung bekommen.
☐ **Freunde** haben mir von dem Treffen erzählt.
☐ Ich habe anders von dem Treffen erfahren, nämlich:
____
____
____

9. Heute sind einige Menschen mit Lernschwierigkeiten hier.
Sie können über die Gesetzes-Änderungen mitreden.
Finden Sie das wichtig?

☐ Nicht so wichtig.
☐ Schon wichtig.
☐ Sehr wichtig.

10. Warum sind Sie zu dem Treffen heute gekommen?
(mehrere Antworten möglich)

☐ Ich habe selber Ideen und möchte mitreden.
☐ Wenn ich hier bin,
dann zeige ich, dass die Sache wichtig ist.
☐ Ich wollte zuhören,
weil die Menschen hier über wichtige Dinge reden.
☐ Ich wollte mit anderen über das Thema von dem Treffen reden.
☐ Ich habe jemand anderen begleitet.
☐ Ich bin hier, weil ______________________________
____

11. Hat das Treffen Ihre Erwartungen erfüllt?

☐ Ja, ich bin **sehr zufrieden**.
☐ Ja, aber es **könnte** noch **besser sein**.
☐ Nein, ich bin **enttäuscht**.

12. Was soll sich an den Gesetzen ändern?
____
____
____

13. Bei dem Treffen haben viele Menschen geredet.
Haben Sie bei dem Treffen auch etwas gesagt?
<u>(mehrere Antworten möglich)</u>
☐ Ja.
☐ Ich wollte gar nichts sagen.
☐ Jemand anderes hat das gesagt,
was ich sagen wollte.
☐ Nein, es war zu wenig Zeit.
☐ Nein, ich hab mich nicht getraut.

14. Diese Frage brauchen Sie nur ausfüllen,
wenn Sie beim Treffen etwas **gesagt** haben:

Glauben Sie, dass Ihnen die anderen zugehört haben?
☐ Ja.
☐ Nein.

15. Diese Frage brauchen Sie nur ausfüllen,
wenn Sie beim Treffen etwas **gefragt** haben:

Haben Sie eine Antwort auf Ihre Frage bekommen?
☐ Ja.
☐ Nein.

16. Wir haben heute über verschiedene Dinge gesprochen.
Manche Dinge waren sehr schwierig.
War es für Sie zu schwierig?
☐ Ja, es war **alles zu schwierig**.
☐ Ich habe **manche Dinge** nicht verstanden.
☐ Nein, ich habe **alles gut verstanden**.

17. Wir haben heute über verschiedene Dinge gesprochen.
Haben Sie schon **vor dem Treffen** gewusst, worum es geht?
☐ Ja, ich habe **genau** gewusst,
worüber wir sprechen werden.
☐ Ich habe **ungefähr** gewusst,
worüber wir sprechen werden.
☐ Nein, ich habe **nicht** gewusst,
worüber wir sprechen werden.

18. Haben Sie schon **vor dem Treffen** mit Personen vom Ministerium über das Treffen gesprochen?
☐ Nein.
☐ Ja.

Bald wird es wieder so ein Treffen geben wie heute.
Wir möchten wissen,
was beim nächsten Mal besser werden soll.

<u>Kreuzen Sie bitte an:</u>

19. Das Treffen war gut.
☐ Ja. ☐ Nein.

20. Ich brauche mehr Unterstützung bei der Anreise.
☐ Ja. ☐ Nein.

21. Ich brauche einen leichteren Zugang zu den Räumen.
☐ Ja. ☐ Nein.

22. Es soll einen Dolmetscher für Gebärden-Sprache geben.
☐ Ja. ☐ Nein.

23. Es soll Unterlagen in Blinden-Schrift geben.
☐ Ja. ☐ Nein.

24. Die Menschen sollen langsamer sprechen.
☐ Ja. ☐ Nein.

25. Ich brauche Unterstützung, wenn ich beim Treffen etwas sagen will.
☐ Ja. ☐ Nein.

26. Es soll öfter Treffen geben.
☐ Ja. ☐ Nein.

27. Es soll mehrere Pausen beim Treffen geben.
☐ Ja. ☐ Nein.

28. Es sollen beim Treffen kleinere Gruppen gemacht werden.
☐ Ja. ☐ Nein.

29. Ich möchte mehr Informationen **vor** dem Treffen haben.
☐ Ja. ☐ Nein.

30. Das nächste Treffen soll an einem anderen Ort sein.
☐ Ja. ☐ Nein.
Wo soll es sein?______________________________.

31. Menschen mit Lernschwierigkeiten sollen mehr mitreden über die Themen, die beim Treffen besprochen werden.
☐ Ja. ☐ Nein.

32. Haben Sie noch andere Vorschläge,
was man besser machen sollte?

____

____

33. Es wird wahrscheinlich Gesetzes-Änderungen geben.
Darüber haben wir heute bei dem Treffen gesprochen.
Glauben Sie, dass die neuen Gesetze
wegen dem Treffen besser werden?
☐ Ja, sicher.
☐ Nein, das glaube ich nicht.
☐ Ich weiß es nicht.

34. Möchten Sie den Personen vom Ministerium
noch etwas sagen?

____

____

____

Vielen Dank für die Teilnahme!

Wenn Sie mehr Zeit haben wollen,
um den Frage-Bogen zu machen,
können Sie den Fragebogen gerne auch später machen
und bitte bis XXX an uns schicken:

Die Adresse ist:

XXX

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Contact Details

Michael Ganner
Institut für Zivilrecht
Universität Innsbruck
Innrain 52, A-6020 Innsbruck
michael.ganner@uibk.ac.at

Walter Hammerschick
Institut für Rechts- und Kriminalsoziologie
Museumstrasse 5/12, A-1070 Wien
walter.hammerschick@irks.at

Alexander Lamplmayr
A-4030 Linz
A.Lamplmayr@gmail.com

Eva Nachtschatt
D-34125 Kassel, Deutschland
Eva.nachtschatt@gmail.com

Caroline Voithofer
Institut für Zivilrecht
Universität Innsbruck
Innrain 52, A-6020 Innsbruck
caroline.voithofer@uibk.ac.at

Die Reihe „Innsbrucker Beiträge zur Rechtstatsachenforschung“ verfolgt das Ziel, die gesellschaftlichen Grundlagen des Rechts und seine tatsächliche Anwendung darzustellen und zu analysieren. Mit Band 8 wird eine Zusammenschau der Ergebnisse des vom *FWF – Der Wissenschaftsfonds* geförderten Forschungsprojekts „Observing legislative processes: Implementation of the CRPD“ (Austrian Science Fund (FWF): P 26710-G16) geboten. In dem Projekt wurde analysiert, wie Menschen mit Behinderungen in nationale Umsetzungs- und Monitoringprozesse der UN-Behindertenrechtskonvention in Österreich, Deutschland, Australien und Neuseeland eingebunden werden.

The series „Innsbrucker Beiträge zur Rechtstatsachenforschung“ („Innsbruck‘ contributions to empirical legal studies“) aims at analysing the interconnections of law in the books and law in action with a special focus on the functioning of law. Volume 8 presents the results of the research project „Observing legislative processes: Implementation of the CRPD“ which was funded by the *Austrian Science Fund (FWF)*: P 26710-G16. The main focus of the project was the evaluation of the involvement of persons with disabilities in the processes of implementing the CRPD into domestic law and their involvement in the monitoring of these implementation processes within Austria, Germany, Australia and New Zealand.

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