



Legal protection of adults, guardianship, and court-appointed legal representation (Betreuung) from a perspective of human rights and disability

Prof. Dr. Theresia Degener, Germany; Translation from German: Ekpenyong Ani

I want to thank the hosts of the 4th World Congress for inviting me and I gladly accepted the invitation.

1. Introduction

In many respects, the 2006 UN Convention on the Rights of Persons with Disabilities represents an advancement of the international protection of human rights. For one, the UN CRPD is one of the sources of modern international law which has introduced national monitoring as a new instrument for implementing and monitoring human rights. Secondly, the EU as a regional organization was able to accede to a human rights convention for the first time and has been a member of the UN CRPD since 2010. As a third example let me mention the conflation of development cooperation and human rights policy which has found its expression in the UN CRPD as in no other core human rights instrument of the United Nations. The list of innovations that were adopted with the UN CRPD could be extended. It is not surprising that the UN CRPD has an impact on international and national law or rather poses new reform challenges. After all, looking ahead, envisioning the future, is the ratio legis of any human rights convention. If there is no need for change, there is no need for a new human rights covenant.

Human rights are the normative response to collective experiences of injustice. In order to overcome collective experiences of injustice, values and norms are needed that transcend what is already in place, subjective rights are needed that enable those that have been abused to defend their human dignity as persons. Human rights instruments always serve social transformation. They always premise a transformation in social attitudes and are intended to initiate further changes. This becomes apparent in the history of international human rights in the United Nations. For instance the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) was developed through the process of decolonization in the 1960s and advanced the interrogation of racism all over the world. With the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the international women's movement introduced the issue of gender equality into international and national politics. The Convention on the Rights of the Child (CRC) challenged outdated concepts of parental authority and children's legal incapacity. Especially the human rights conventions adopted at the end of the 20th century became increasingly specific in focusing on individual groups of people. In international law this process is termed the pluralization or personification of human rights. This is based on the realization that the mothers and fathers of the 1948 Universal Declaration of Human Rights only had a very one-dimensional idea of the individual as a legal entity. You could also say, the prototype of a legal entity was a white, healthy, European man. The circumstances of people of color, people of different ethnical backgrounds, of women, of children, were not part of the concept. Human rights were Eurocentric men's rights. Only the different social movements changed this concept of human rights.



4. Weltkongress Betreuungsrecht 4th World Congress on Adult Guardianship 14.–17.09.2016



With the UN Convention on the Rights of Persons with Disabilities the disability rights movement fought for and attained a place at the table of human rights. This has led disability issues out of the one-way street of care and charity. The UN Convention on the Rights of Persons with Disabilities is to replace the medical model of disability by the human rights model of disability. Underlying this is more than a critique of medicine or therapy and rehabilitation. Besides criticizing the medical model of disability as a one-dimensional, essentialist reduction of disability to a deficient state of health, the human rights model of disability is aimed at a new understanding of fundamental concepts such as discrimination, autonomy, and solidarity.

The definition of discrimination within international law is expanded by the UN Convention on the Rights of Persons with Disabilities. Not only any distinction, exclusion or limitation because of disability aimed at or resulting in a violation or obstruction of human rights is regarded as discrimination. Also the so-called “denial of reasonable accommodation” is considered to be discrimination due to disability. This refers to the refusal to eliminate barriers, be they of physical or communicative nature. For instance, access that is only possible via stairs, information only available in normal print or spoken language, or in a language difficult to understand. For example the fact that there are no sign language interpreters at this conference means that deaf people are excluded. The circumstance that no speech-to-text interpreters have been deployed creates barriers for those people that depend on following the discussion by reading in order to understand. The same applies to a translation into Easy to Read- language. Codifying the denial of reasonable accommodation as a new form of discrimination means having a concept of equality that focuses on the needs of all people as equally important needs, taking them into consideration when allocating resources in the process of planning.

The UN Convention on the Rights of Persons with Disabilities also changes the concept of autonomy. Autonomy no longer means freedom only for certain people who are part of the mainstream. In the sense of the Convention on the Rights of Persons with Disabilities autonomy not only means the right to be left alone in order to enjoy private freedom independently and autarchically. In the sense of the Convention on the Rights of Persons with Disabilities autonomy above all means the freedom to make one’s own decisions, even if I should need support in the process. Autonomy in the sense of the Convention on the Rights of Persons with Disabilities is no longer foreclosed or limited when I don’t fulfill a certain criterion of reason or health. Autonomy in the sense of the human rights model of disability means recognizing and respecting decisions and ways of behavior that do not necessarily conform to the norm. Actually this concept of autonomy is not exactly new. After all, feminist theory has long uncovered that the idea of the self-sufficient person making decisions in complete isolation is an illusion. No one makes important decisions alone and without support. Whether we want to get married, buy a house, have children or not, prepare a goose or fish for Christmas, whether we apply for this job or the other, whether we make use of this medical therapy or another – always and everywhere will we consult with people from our social networks, that is, we draw on support and help. The human rights model prohibits the limitation or even denial of the right to autonomy based on disability. The human rights model of disability is based on the knowledge that human rights are acknowledged qua birth, qua being human, and can never be revoked. Therefore it is a basic error to assume that a disability or a chronic illness could limit the capacity for human rights.

The concept of solidarity is also shaped by the UN Convention on the Rights of Persons with Disabilities. Social rights such as education, social security, work, participation in the community, can no

Organisationskomitee
organizing committee

Prof. Dr. Dagmar Brosey
Vizepräsidentin · vice-president

www.wcag2016.de

Prof. Dr. Volker Lipp
Präsident · president

Karl-Heinz Zander
Geschäftsführer · secretary

orga@wcag2016.de

c/o
Betreuungsgerichtstag e.V.
Kurt-Schumacher-Platz 9
D-44787 Bochum
Deutschland · Germany

Bankverbindung
bank account

Bank für Sozialwirtschaft Köln
BIC: BFSWDE33XXX
IBAN:
DE73 3702 0500 0008 2767 01



longer be subject to a certain functional capacity. As human rights they must be conceded to every human being qua being human. They are human rights, not charity. Although as human rights that are to be progressively implemented they are dependent on the existence of sufficient resources, they are part of what we call the internationally recognized catalogue of human rights. A person who is granted social rights does not lose their personal status because of this. He/she must not pay the price of being relegated to so-called parallel or special worlds for being granted social rights. Above all, a person asserting social rights must not lose their civil rights and liberties. However, this is the case in many countries. Disability policy in many states is shaped by a high degree of incapacitating care and isolation in institutions that are presented as protective spaces although they actually represent a threat to human rights. In most countries, disability policy still means receiving social welfare at the cost of disenfranchisement, at the cost of being relegated to special worlds, or even at the cost of forced medical treatment. Die UN Convention on the Rights of Persons with Disabilities counters this with a concept of solidarity based on both equality and on freedom. Implementing this requires a considerable change of mindset especially with service providers in disability services.

2. The right to recognition as a person as a human right

The right to recognition as a person is already included in the Universal Declaration of Human Rights (1948). The International Covenant on Civil and Political Rights – ICCPR (1966) and the Convention on the Elimination of All Forms of Discrimination against Women – CEDAW (1979) also include the right to equal recognition as a person as a human right. In the ICCPR the human right to recognition as a person applies everywhere and cannot be rescinded – not even in a state of emergency. CEDAW was the model for Article 12 in the UN CRPD, which not only certified human rights also for persons with disabilities but in addition innovates and develops these further. As it is, the UN CRPD made it unmistakably clear for the first time that the right to recognition as a person before the law not only includes legal capacity but also the capacity to act. Not all legal systems have this distinction, but those that do have it, make a distinction between the capacity to have rights and the capacity to exercise rights. This second component, the capacity for legally binding actions was and still is denied certain groups in the past and present: slaves, women, persons with a different or no nationality, and, of course, persons with disabilities.

Article 12, sections 1 and 2 UN CRPD unmistakably state that all persons with disabilities must be recognized as persons with legal capacity. Legal capacity is therefore an essential part of this human right. The right to be recognized as a legal person is one of the basic human rights, in the spirit of Hannah Arendt, who coined the expression “the right to have rights”. Only someone recognized as a legal person may resort to the complete catalogue of human rights. Therefore these first two sections of Article 12 represent the aspect of freedom of the right to recognition as a person before the law.

Article 12, section 3 UN CRPD introduces another innovation into international law, the concept of supported legal capacity. It reads: »States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.« What is meant by this are two important core elements of the human rights model of disability: first, disability and autonomy are not a contradiction. Even when someone needs support due to a disability, they retain the right to act autonomously. Second, the right to recognition as a person before the law is also a right of equality. Persons with disabilities who require support for legally relevant actions

Organisationskomitee
organizing committee

Prof. Dr. Dagmar Brosey
Vizepräsidentin · vice-president

www.wcag2016.de

Prof. Dr. Volker Lipp
Präsident · president

Karl-Heinz Zander
Geschäftsführer · secretary

orga@wcag2016.de

c/o
Betreuungsgerichtstag e.V.
Kurt-Schumacher-Platz 9
D-44787 Bochum
Deutschland · Germany

Bankverbindung
bank account

Bank für Sozialwirtschaft Köln
BIC: BFSWDE33XXX
IBAN:
DE73 3702 0500 0008 2767 01



4. Weltkongress Betreuungsrecht 4th World Congress on Adult Guardianship 14.–17.09.2016



have the same right as non-disabled persons to make their own personal decisions. To lead a life according to their own conceptions. This clearly implies a rejection of the legal instrument of incapacity to consent and/or legal incapacity. These legal constructs served and serve to deny persons with disabilities all over the world the right to legal subjectivity and/or limit them in exercising it, especially when they are cognitively or psycho-socially impaired. In most cases the dichotomy between free and unfree will in the context of disability is fiction. This does not mean to say persons with disabilities may not at times come to be in a state of lack of willpower, of mental incapacity or legal incapacity. All people experience these conditions in life: for instance as an infant, in a state of unconsciousness or in a coma, while sleeping, possibly due to the consumption of alcohol or drugs. But even though no one is permanently awake, cognitively at their best, sane, therefore invulnerable, the human right to recognition as a person is denied only certain persons, or respectively granted them under limitations. Today these include children, women in certain legal cultures, and almost everywhere persons with disabilities. By attesting some persons with disabilities an unfree will based on their health impairment, they are simultaneously diverted to another legal track. Public assistance is granted by adult guardianship or legal representation (Betreuung), by commitment to special institutions and/or by forced medical treatment based on mental health laws or other special laws.

Non-disabled persons would however never accept heteronomous legal representation, isolation, institutionalization and forced medical treatment as forms of assistance. Their need for protection is met on the first legal track, for instance by consumer protection laws, by emergency laws, by social security, by human rights protection. Above this all hovers autonomy as an element of human dignity, which on the surface is universally recognized, but effectively only awarded those that fulfill a minimum of mainstream normality. Secretly there is a reservation of non-disability for human rights to be fully recognized. In Disability Studies the ideology this type of discrimination is rooted in is called “ableism”. Ableism can be compared to racism or sexism, so it is comparable to other forms of discrimination that are based on an ideology of dominance. Ableism is used to degrade persons with disabilities. Their lives appear to be less valuable due to suffering; incompetence is ascribed to them, as well as other differences, which make the denial of an equal enjoyment of human rights seem legitimate. Ableism can turn into hostility towards the disabled, although it is also quite possible that ableism comes along under the guise of care. In any case, ableism always goes hand in hand with the notion that non-disabled persons know exactly what is good for persons with disabilities. As an expression of dominant culture, ableism means the dominance of non-disabled persons over persons with disabilities.

Ableism is compatible with the medical model of disability. In the medical model, legal capacity and the mental ability to make “reasonable” decisions are mixed together. However, this refers to two different legal concepts. In our first General Comment on Article 12 UN CRPD we pointed this out. I quote: »Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (...) and to exercise those rights and duties (...).It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. (...)The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts,

Organisationskomitee
organizing committee

Prof. Dr. Dagmar Brosey
Vizepräsidentin · vice-president

www.wcag2016.de

Prof. Dr. Volker Lipp
Präsident · president

Karl-Heinz Zander
Geschäftsführer · secretary

orga@wcag2016.de

c/o
Betreuungsgerichtstag e.V.
Kurt-Schumacher-Platz 9
D-44787 Bochum
Deutschland · Germany

Bankverbindung
bank account

Bank für Sozialwirtschaft Köln
BIC: BFSWDE33XXX
IBAN:
DE73 3702 0500 0008 2767 01



4. Weltkongress Betreuungsrecht 4th World Congress on Adult Guardianship 14.–17.09.2016



as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.« The incapacity approach is also compatible with the medical model. However, the human rights model of disability rejects ableism. Since the human rights model of disability, was codified with the UN CRPD, the capacity approach applies in the context of disability.

As the examination of state reports so far has shown, across the globe the implementation of Article 12 UN CRPD presents the greatest challenge within the context of implementing the UN CRPD. Although with 166 ratifications universal acceptance is well under way, the just under 50 state reviews reveal that most countries experience great difficulties in implementing Article 12. Many states still have very old-fashioned adult guardianship regulations in their civil law. In some countries, blind or deaf persons are not even allowed to have a bank account. It is not uncommon that we encounter laws that determine that the director of an institution for disabled persons also holds guardianship for the home residents. And even laws for legal representation that are less paternalistic still rely on the principle of substituted decision-making on behalf of the person by legal representation. Furthermore: electoral laws often exclude persons with cognitive or psycho-social impairments from the right to vote. In many countries persons with disabilities are not allowed to marry.

As members of the Committee monitoring the implementation of the UN CRPD, we further observe that especially with regard to Article 12 there is still a lot of uncertainty. Although our settled case-law has by now made it clear that Article 12 calls for a replacement of substitute decision-making regimes by supported decision-making, many do wonder where support ends and where representation begins. Then there is the question whether representation and support are compatible with one another regarding Article 12, sections 3 and 4. And finally, the crucial question: what is to be done when the will of the disabled person concerned is not identifiable or focused on endangerment of self or others? Is an external representation also precluded in such cases? Especially with regard to section 4 of Article 12 there's also the question as to which systems need to be in place to ensure that persons who require support in exercising their legal capacity are protected against abuse and exploitation.

We have tried to give answers to all of these questions in our General Comment No. 1 on Article 12. Although these answers may not always and in every respect offer sufficient detail, the General Comment No. 1 is the standard for the implementation of Article 12. It is based on our collected findings from the concluding remarks on state report reviews, which the Committee on the Rights of Persons with Disabilities is legally legitimized to conduct by the UN CRPD.

Concerning the question whether support and representation are compatible and how they can be demarcated from one another, section 17 of the General Comment reads: »Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Article 12, paragraph 3, does not specify what form the support should take. "Support" is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. (...) «

In the exceptionally rare case that the will of the disabled person concerned is not identifiable, it says in section 21: »Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace

Organisationskomitee
organizing committee

Prof. Dr. Dagmar Brosey
Vizepräsidentin · vice-president

www.wcag2016.de

Prof. Dr. Volker Lipp
Präsident · president

Karl-Heinz Zander
Geschäftsführer · secretary

orga@wcag2016.de

c/o
Betreuungsgerichtstag e.V.
Kurt-Schumacher-Platz 9
D-44787 Bochum
Deutschland · Germany

Bankverbindung
bank account

Bank für Sozialwirtschaft Köln
BIC: BFSWDE33XXX
IBAN:
DE73 3702 0500 0008 2767 01



the “best interests” determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4.«

While the criterion of the person’s best interest – as can be found in most adult guardianship laws and laws on “Betreuung” – corresponds with the medical model of disability, the criterion of the best interpretation of the person’s will and preferences is guided by the human rights model of disability. What is crucial is an earlier or current declaration of will of the person concerned, made with support if necessary. Assessing someone’s will according to criteria of reason or apparently objective criteria is inadmissible. The right to make one’s own decisions also includes the right to take risks and to accept the consequences of mistakes.

As regards the question as to when support ends and substitute decision-making begins, the General Comment No. 1 states: »Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.«¹

Furthermore, nine core elements constituting a system of supported decision-making are listed. In short, these are:

1. Supported decision-making must be available to all, even when there is a high level of support needs.
2. All forms of support in the exercise of legal capacity must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interest.
3. A person’s mode of communication must not be a barrier even where this communication is understood by very few people.
4. Legal recognition of the support person(s) formally chosen by a person must be available and accessible, particularly for people who are isolated. There must be a constitutional mechanism for third parties to monitor the support person.
5. Lack of financial resources must not constitute a barrier to accessing support.
6. Support in decision-making must not be used as justification for limiting other fundamental rights, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, the right to give consent for intimate relationships and medical treatment, and the right to liberty.
7. The person must have the right to refuse and/or terminate support.
8. Safeguards must be set up for all processes relating to legal capacity and support in exercising it, ensuring that the person’s will and preferences are respected at all times.

¹ The quote is from a corrected version of the GC no 1, which was discussed and worked on during the 16th session (15th August – 2nd September 2016) of the CRPD Committee. The issuance of the corrigendum in the Official Documentation System (ODS) by UN documentation unit is still pending. (Theresia Degener 25 December 2016)



9. The provision of support should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support.

Implementing these core elements, creating systems of supported decision-making guided by human rights is one of the greatest challenges of our time. Due to the demographic development of our society, but also from a legal perspective, the immediate implementation of Article 12 UN CRPD is a prime duty for all States Parties. After all, the human right to equal recognition as a person before the law is a civil right and the so-called progression proviso in accordance with Article 4, section 2 UN CRPD does not apply. An incremental implementation of Article 12, e.g. by abolishing conventional guardianship laws while simultaneously retaining partial systems of legal representation, or providing only isolated model systems of support would be in breach of the convention. Obviously an immediate implementation of Article 12 UN CRPD also requires an immediate ban of any sort of forced medical treatment for curative or corrective purposes. Modern studies show that forced medical treatment neither serves its medical purpose nor is it compatible with the fundamental principles of the rule of law. Just as violence will always breed more violence, forced medical treatment leads to further abuse. In our guidelines on Article 14 UN CRPD as well as our jurisdiction on Articles 14, 15, 16 and 17, the Committee has clearly and repeatedly expressed its opposition to forced medical treatment. Those that understand Article 12 UN CRPD and the human rights model of disability correctly must consequently call for a ban of forced medical treatment as *jus cogens*, as compelling international law. In reality, and the Committee is aware of this, we still have a long way to go in international law. Apart from this there are divergent views within the different expert committees. However, this is also not unusual in international human rights law. Particularly this field of law is characterized by what legal experts call “living instruments”. Like in no other area of law, international law and in particular international human rights law is a developing field of law. In the beginning, the Committee on the Elimination of Discrimination against Women also had an isolated position with its legal opinions. An analysis of the jurisdiction of expert committees over the past decades reveals that every now and then the committees were inconsistent but also inspired one another and learned from each other. The legal interpretations that will eventually prevail in international human rights law will not least depend on the political, cultural and economic circumstances. Civil society plays a crucial role in the legal discourse. Human rights have to be visionary in order to stimulate change. Social movements such as the women’s or disability rights movement are often the engine for these changes, which then need to be put into practice with expert knowledge and accompanying scientific research. We will not be able to accomplish a paradigm shift towards the human rights model of disability without abolishing special systems, particularly when it comes to special legal systems. A continuous reflection of and the legal focus on exceptional cases (the famous example of the coma patient) will also not bring about the necessary changes in dealing with disabled adults or older persons who are cognitively impaired. In reality, modern laws on legal representation (Betreuung) and mental health – which already include human rights aspects – are hardly put into practice. The reason for this does not only lie in a lack of knowledge of the law. The system will not change until we have closed all the loopholes.

We should not try to solve the problems that arise in the process without involving those concerned. Only when the perspectives of all persons concerned are included in the development of the law will we find adequate answers. This requires human-rights-based participative research, which is still



4. Weltkongress Betreuungsrecht 4th World Congress on Adult Guardianship 14.–17.09.2016



quite underdeveloped in most countries. This particularly applies to the exploration of legal and social issues in the context of cognitive impairment. However, wherever participative research is being pursued, the developments are amazing. For example Eilionóir Flynn from the Centre for Disability Law and Policy at the National University of Ireland in Galway is currently heading a European project on this issue, which includes the active participation of persons who have for decades lived in isolated institutions, who have experienced mental hospitals, who were deprived of their legal capacity due to their cognitive or psycho-social impairment. The project called VOICES (Voices of Individuals: Collectively Exploring Self-Determination) is aimed at legal reforms in the area of legal capacity. The radical approach of VOICES is to have these persons with disabilities form research tandems with legal or social science experts and to develop recommendations for reforms. How would one envisage human rights support in contract law? What would it look like in medical treatment in situations of ethical conflict? How can legal subjectivity be retained in criminal law? The VOICES project is one of the most exciting research projects I have been allowed to participate in so far in my academic career, and I am certain it will yield innovative solutions. I hope the same is true for the numerous projects that will be presented within the context of this fourth World Congress.

Thank you for listening.

Organisationskomitee
organizing committee

Prof. Dr. Dagmar Brosey
Vizepräsidentin · vice-president

www.wcag2016.de

Prof. Dr. Volker Lipp
Präsident · president

Karl-Heinz Zander
Geschäftsführer · secretary

orga@wcag2016.de

c/o
Betreuungsgerichtstag e.V.
Kurt-Schumacher-Platz 9
D-44787 Bochum
Deutschland · Germany

Bankverbindung
bank account

Bank für Sozialwirtschaft Köln
BIC: BFSWDE33XXX
IBAN:
DE73 3702 0500 0008 2767 01