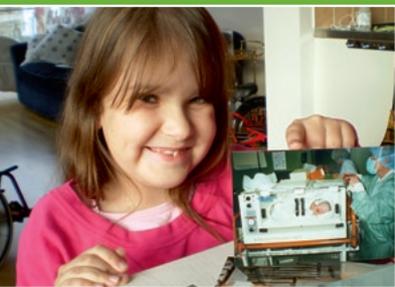




International Federation for Spina Bifida and Hydrocephalus

Position Paper on the Groningen Protocol

Disability Stereotypes, International Human Rights and
Infanticide



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Doctors and lawyers in the Netherlands have developed the Groningen Protocol to regulate and justify recommendations that hasten the death of newborns with severe impairments. The Protocol is based on a review of treatment decisions that lead to the deaths of more than twenty Dutch infants born with Spina Bifida.¹ Other doctors make similar decisions but the Groningen Protocol most clearly expounds a practice where parents are counseled that their babies' impairments will result in a life not worth living, and should die. Stereotypes about the lives of people with disabilities drive these recommendations. These practices are perhaps the most serious instances of disability discrimination.

This paper reviews the Groningen Protocol according to human rights principles. Civil, criminal law and child abuse approaches, are not analyzed.² This paper is about cases where with continued care, an infant is expected to live indefinitely, not instances where death is imminent.

The paper examines the key factor for the Groningen Protocol and similar decision-making - the anticipated "quality of life" for an infant with impairments - and exposes two major problems. First, the Protocol directs doctors to discriminate in their counseling based on the infant's disability. Second, predictions of a poor quality of life, a problematic concept to start with, are often not based on acceptable evidence but are rather a result of implicit stereotyping. This results in discrimination against and death of disabled newborns.

The analysis starts with the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities and also reviews The Charter of Fundamental Rights of the European Union, European Convention for the Protection of Human Rights & Fundamental Freedoms and Europe's Amsterdam Treaty, Article 13 and the Proposed European Commission Directive. The paper analyzes other international standards including the Universal Declaration of Human Rights and the Convention on the Rights of the Child.

These international human rights laws do not set up enforcement schemes for individuals, but are aimed at having all States find ways to enforce the standards within their borders. The paper's conclusions are, therefore, directed to States, which should take the lead in establishing nondiscriminatory standards of local medical practice.

A Note to Families: I believe that an ethical decision can be made to end all but palliative treatment for an infant who is on the edge of life and death, who will live briefly only with the most extreme interventions or will have no consciousness. This should be left in the hands of informed parents who are given not only the most current medical perspective, but also full information about the real lives of people with severe impairments. It may be the hardest thing they do in their lives, whatever their decision. The human rights approach should not be used to second-guess their decisions. I advocate public policies that make certain families are not pushed by systemic stereotypes about people with disabilities when making these decisions.



The Groningen Protocol was developed to regularize treatment decisions for newborns with severe impairments. The Protocol holds that it is medically and legally proper to take 'life ending measures' - to withhold or withdraw treatment or even to give drugs to hasten the death of an infant, in these circumstances:

First, there are infants with no chance of survival. This group consists of infants who will die soon after birth, despite optimal care with the most current methods available locally. These infants have severe underlying disease, such as lung and kidney hypoplasia.³

Infants in the second group have a very poor prognosis and are dependent on intensive care. These patients may survive after a period of intensive treatment, but expectations regarding their future condition are very grim. They are infants with severe brain abnormalities or extensive organ damage caused by extreme hypoxemia. When these infants can survive beyond the period of intensive care, they have an extremely poor prognosis and a poor quality of life.

Finally, there are infants with a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering. Although it is difficult to define in the abstract, this group includes patients who are not dependent on intensive medical treatment but for whom a very poor quality of life, associated with sustained suffering, is predicted. For example, a child with the most serious form of Spina Bifida will have an extremely poor quality of life, even after many operations. This group also includes infants who have survived thanks to intensive care but for whom it becomes clear after intensive treatment has been completed that the quality of life will be very poor and for whom there is no hope of improvement.⁴

The Groningen Protocol has been accepted as a standard of practice by the Dutch Paediatrics Association.⁵ A report to the Netherlands' House of Representatives by State Secretary for Health, Welfare and Sport and the Minister of Justice showed the Dutch government's support of the Protocol. The report endorsed 'due care criteria a doctor would need to meet to avoid prosecution for terminating the life of a seriously ill newborn child.'⁶ When it established an 'experts committee' to assist legal review of such cases, the government said that infant deaths that followed the decision to end or withhold treatment are not subject to review, only deaths after 'active measures.'

It is not only Dutch children with Spina Bifida who are at risk for dying through application of the Groningen Protocol but many others, including premature babies, infants with Down Syndrome and other infants born with significant problems. The Wyatt case in Great Britain shows that doctors there seek to avoid treatment over parental objections if they think the treatment results in the child's suffering with 'no commensurate benefit' because of disability.⁷ A 2006 article in the journal Pediatrics reports that at a Portland, Oregon hospital one-third of neonatal intensive care unit staff would counsel do not resuscitate for 24-25 week gestation infants, up to 68% of whom would be expected to live, if resuscitated. This is justified because 25-30% of the survivors would be expected to have severe and 20-30%, moderate disabilities. Between 40 and 55% of survivors would be predicted to have minor or no disabilities.⁸ In Belgium, doctors reported seventeen instances in one year where they gave drugs to kill severely impaired babies.⁹

In 1989, the US Civil Rights Commission issued a report, Medical Discrimination against Children with Disabilities, which includes a long review of medical literature and other evidence of neonatal practices. It concluded that the practice of withholding treatment from viable infants with impairments was common.¹⁰

Ethics, Policy Debates and the Groningen Protocol

Ethical considerations relating to quality of life arguments are critically important in developing public policy and private practices in this field but are not fully explored here. Proponents of the practice believe that they are justified by their concern to avoid unbearable suffering and worthless lives and a conclusion that it is ethical to decide for another that 'death would be more humane than continued life.'¹¹

Justifications for such practices were criticized as early as a 1975 Stanford Law Review article and found wanting.¹² Pierre Mertens, President of the International Federation for Spina Bifida and Hydrocephalus (IF) has written on the moral dimensions of this practice.¹³ Martha Field, writing in the Harvard Women's Law Journal in 1993 identified a range of serious problems with killing the handicapped after birth.¹⁴ Field viewed the practice as disability discrimination and a form of eugenics.¹⁵ She asked: Where is the line drawn among babies predicted to be to some degree undesirable - and on what principle? For how long should the option be given to the parents? What if adoptive parents present themselves?¹⁶ Philosopher Peter Singer, however, writes from a utilitarian perspective that sees infants as replaceable and lives' value as measurable. He writes: 'Killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all.'¹⁷ A recent article criticizes the Groningen Protocol and Singer's support for it for turning away from the social norm of punishing unjustified homicide (e.g. when not in self-defense) and for adopting a twisted victim-centric ethos that absolves killing because of the unique characteristics of the victim.¹⁸

Organizations representing people with impairments, including The International Federation for Spina Bifida and Hydrocephalus (IF) oppose the Protocol. IF and its allies in the European Disability Forum have adopted a resolution stating in part:

1. All infants with impairments have the right to live and to benefit from all treatments which can improve their quality of life or prevent further impairment. Active termination of life of infants with impairments should not be permitted on the basis of their expected quality of life;
2. A disability should never be an argument not to provide available life-saving and life-improving treatment;
3. Pain and suffering of the infant must not serve as justification for active termination of life. Instead, alleviation of that pain and suffering must be sought as the primary solution;
5. Societal assumptions about the quality of life of people with disabilities or social provision cost factors should not justify active termination of life on the ground of disability in violation of internationally accepted human rights principles...;
7. Counselling for parents should be supportive, focusing on all aspects of life for a child with impairments. Parents should be informed about all recent scientific advances that have improved considerably the quality of life of people with impairments, and about legislative initiatives, including non-discrimination and human rights legislation, which offer more legal protection to disabled people and their families. They should also receive information and access to care and support opportunities, which may help the optimal development of the child;
8. Any explicit or implicit bias, practice or procedure in counselling that devalues the worth of the life of people with impairments is a form of discrimination and is a violation of universal human rights principles...;
9. Every form of discrimination against disabled people should be outlawed including in any legislation on active termination of life of infants with impairments;¹⁹

The Groningen Protocol has also been questioned in the Netherlands. In 2007, the Health Council of the Netherlands' Centre for Ethics and Health urged reexamination of key medical assumptions underlying of the Protocol and the government policy. The Centre questioned whether reliable predictions of suffering and quality of life can be accurately made.²⁰

The IF and EDF resolutions and parents' in the cases of Wyatt in the UK and Johnson in the US raised human rights standards as a basis for opposing 'no treatment' decisions for disabled newborns.²¹ Their demand for an end to discrimination in neonatal services is treated in detail in this paper.

Part III



The Groningen Protocol and the International Convention on the Rights of Persons with Disabilities: Medical Discrimination

A. Key Provisions of the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (Convention on the Rights of Persons with Disabilities)²²

This Convention, now being adopted by nations around the world, is intended to create a universal understanding of and approach to disability rights.²³ The Convention is directed to States, not to individuals or organizations. It obligates States to adopt and enforce non-discrimination policies and to promote the rights and interests of people with disabilities. The Convention's principles and specifications that govern an approach to neonatal treatment of those facing severe disabilities are both general and specific.

Principles set out in Article 3 include:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity; and
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Among provisions of the Convention relating to treatment of severely impaired newborns are:

[E]very human being has the inherent right to life and ... all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others. (Article 10.)

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others. (Article 17.)

[P]ersons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. (Article 25.)

Paragraph (b) of Article 25 obligates States to:

Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children....

Most directly applicable is paragraph (f) of Article 25, which demands that States:

Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

This reinforces the demand set out in paragraph (d) of the same article which will have States:

Require health professionals to provide care of the same quality to persons with disabilities as to others....

The Convention on the Rights of Persons with Disabilities (CRPD) pledges States 'to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;' and 'to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise...' Articles 4 (b) and (d).

The overall approach of the CRPD is to protect the most basic interests of persons with disabilities, including life, to stop discrimination and to encourage a wide range of efforts to maximize their human potential.

B. Discrimination Prohibited By the Convention on the Rights of Persons with Disabilities

The Convention's Article 5 provides for equal protection of the law and non-discrimination:

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

The Convention requires reasonable accommodations consisting of: 'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.' Article 2.

Three forms of discrimination are addressed. Discrimination is defined as:

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination... Article 2.

Article 25 (f) of the Convention expressly bars direct discrimination including the 'discriminatory denial of health care or health services ... on the basis of disability.' It also holds that failure to make reasonable accommodations necessary for a disabled person when needed to promote equality and eliminate discrimination is a second form of discrimination. Articles 2 and 5 (3).

The third is indirect or disparate impact discrimination, such as a rule that every visitor to a neonatal intensive care unit must first don clean-room gear, without assistance. That rule is neutral but will have

a predictably negative impact on a group of disabled persons – those who have paralysis of their hands and arms. Without strong justification for the rule, legitimate goals that cannot be met with less-impacting means, it is illegal discrimination on the basis of disability. This kind of discrimination claim is not explicit in the Convention but must be recognized in order to address practices that have 'the effect of impairing...exercise...of all human rights...' as required by Article 2, as well as to effectuate Article 5's requirement for 'equal and effective legal protection against discrimination on all grounds.'

The Convention sets as one of its purposes 'to combat stereotypes, prejudices and harmful practices...' Article 8(1)(b). Actions that are based on stereotypes are illegal discrimination under Article 2. As the US Supreme Court explained in a disability rights case:

Underlying much discrimination law is the notion that animus can lead to false and unjustified stereotypes, and vice versa. Of course, the line between animus and stereotype is often indistinct, and it is not always necessary to distinguish between them.²⁴

C. Infants' Rights and Proxy Decisions

Article 7 of the CRPD, 'Children with Disabilities', requires parties 'to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.' Paragraph 2 states: '[I]n all actions concerning children with disabilities, the best interests of the child shall be a primary.' Principled arguments can be made that a child's best interests may be to limit treatment to comfort care in the end-of-life situation, despite the likelihood that this will lead to a quicker death. Whether it is doctors or parents and courts that are responsible to determine best interests, is the controversy addressed throughout this paper.

The Convention in Article 12 requires recognition of both these persons' right of individuality and their legal capacity under States' laws. This recognition is not restricted to adults. Infants cannot themselves exercise any rights and are dependent on others to assert them. The Convention endorses guardianship arrangements for substitute decision-making for infants, so long as the measures:

are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests. Article 12, paragraph 4.

Normal proxy decision-making for medical issues by parents of infants is unlikely to be problematic. Parents regularly exercise this authority, but almost never with any examination by independent authority or judicial body. Parental guardianship related to medical care is a matter of natural law, constitutional interpretation²⁵ or is recognized by statute. It is rarely reviewed by outside authorities.

The Convention assumes that informed and active parents are the primary guardians of the infant's interests.²⁶ Child neglect laws should be sufficient to address medically dangerous decisions of parents and could provide the kind of independent review envisioned by Article 12 of the CRPD. The Convention's approach to the problem of potential parental prejudice towards children with impairments says that States should work through education and provisions of support to change behavior that reflects customs and practices that harm disabled children.²⁷ The Convention does not support the use of anti-discrimination laws against parents.

However, the participation of third parties – medical providers – in making and in carrying out these medical decisions – should take into account the child's human rights set out by the CRPD.

D. Counseling and Consent at the End of Life

The Convention does not attempt to define the beginning or end of life. States that allow medical personnel to stop medical care at any time before the very end of life, however defined, might be charged by some with violating Articles 10, 17 and 25 of the CRPD. That is unlikely to be widely accepted. A competent person's right to make end-of-life choices, and to not have interference with that decision, has been accepted in some nations to be consistent with the right to life principle.²⁸ The right of a person to make end-of-life medical decisions can be justified by Article 3's reference to autonomy and freedom to make personal choices and the informed consent perspective set out in the health care Article, 25(d). When a person has chosen to stop medical treatment that prolongs the process of death, there is no 'discriminatory denial of health care' nor 'interference with attaining the highest level of health', because the person has exercised her own rights of integrity, decided that the death process need not be prolonged.

This is not an infant's option. The Convention's Article 12(4) recognizes the role of substitute decision-makers for incompetents and calls for oversight. For infants there are circumstances where treatment is futile and may only briefly prolong life – the patient is both disabled and has essentially no chance of survival.²⁹ Counseling parents to halt or forgo treatment for these babies, would not be disability discrimination if based on a belief that the life is likely to be very short and thus no benefit will be gained from treatment. This is because the medical counseling would be based on a factor other than the child's disability status. The first category of the Groningen Protocol, see page 5, relates to such infants who have no chance to survive and counseling to stop treatment of those babies does not violate nondiscrimination principles.

In the UK's Wyatt case, judicial approval of a hospital's plan to forgo ventilation in case of an infection was based on an extension of this reasoning – it is in the child's best interests to have an easy, as opposed to a difficult death. Judge Hedley wrote in his 5th opinion denying Charlotte's parents' plea for treatment: 'no sensible view of life is complete without a view of how it ends and the aspiration for a good death is one which is deep within the human psyche.'³⁰ The appellate court rejected a view that withholding treatment was permissible only when life was thought to be intolerable and it directed use of a best interests balancing test for future decisions.³¹ In the Wyatt case, the doctors' recommendation for no treatment turned out not to be an end of life decision because she has lived for years, as opposed to a few weeks or months.³²

The law in Great Britain and the European Convention on Human Rights afford no right of a competent disabled adult with an intolerably poor and suffering life to obtain legal authorization for help with suicide, despite recognition of her personal autonomy and personal integrity.³³ It is anomalous that in the U.K. an infant with disabilities may die through deliberate medical actions because others decide her life is worthless, but that if she were to survive for twenty years and come to her own decision that her life should end, she might have no right to get the same 'assistance'.

E. Analysis of the Groningen Protocol under the International Convention on the Rights of Persons with Disabilities

In the analysis that follows, counseling by medical staff using the Groningen Protocol or similar practices is examined as a matter of direct discrimination. To establish a case of direct disability discrimination, a complainant must show that a person with a disability is treated unfavorably by a party subject to the law in providing covered services, because of the person's disability.

The following confirms that severely disabled infants are protected by the Convention and that counseling in the course of neonatal medical services is covered by anti-discrimination principles. It is in that counseling that stereotyped attitudes towards people with disabilities leads to overt discrimination against some babies.

1. Severely Disabled Infants are Protected by the CRPD

The Convention's own terms set out that these infants are covered. Children's rights are given a special section in the Convention. Article 7. Infants subject to the Groningen Protocol are without doubt disabled as they have 'long-term physical, mental, intellectual or sensory impairments which ... hinder their full and effective participation in society on an equal basis with others.' Article 1. Arguments that infants with disabilities should not be recognized as persons are addressed on page 16.

2. Medical Staff and Institutions' Provision of Neonatal Services Are Covered by the CRPD

The application of national laws implementing the provisions of the Convention to practices of medical staff and institutions using the Groningen Protocol is required by the Convention. In order to implement the Convention's ban on discriminatory denial of health care, Article 25 in paragraphs (d) and (f), States must apply non-discrimination standards to medical practices.

In medical services, there is a series of actions between provider and patient. The patient comes to the attention of the doctor. The doctor gets permission to examine. She then examines the patient to diagnose and to develop a course of treatment. At stages in the relationship, the doctor counsels the patient, in these cases through the infant's parents.

a. Acceptance for Care and Assessment

It is unlikely, but possible, that providers may refuse to provide any care to a severely disabled newborn. Article 25(d) of the Convention requires equality of treatment and bans, in paragraph (f), 'discriminatory denial of health care or health services or food and fluids on the basis of disability.' Refusal to treat because of disability violates many of the Convention's basic premises.³⁴ This does not mean that all doctors are required to treat any patient in any circumstances.³⁵

It would also be discrimination to accept for treatment only those children who have minor or moderate disabilities. Article 4 of the CRPD directs States to forbid 'discrimination of any kind' on the basis of disability. The Convention's goals of protection of life and liberty, privacy, social integration and habilitation for all disabled persons would be perversely skewed if laws permitted only the 'deserving disabled', or those whose cases are less difficult, to benefit from equal treatment and equal access to medical care. In the US, discrimination based on severity of disability has been held to violate the ADA.³⁶ Suggestions that the most extremely disabling and fatal conditions are a justification for giving some fetuses less protection under abortion funding restrictions have been rejected in the US³⁷ In the UK, a proposal that a less-developed conjoined twin should not be treated as a person was rejected.³⁸ To combat stereotyping of people with disabilities, to eliminate their institutionalization and to strike at the full range of discrimination, the CRPD should likewise be interpreted to forbid discrimination based on the severity of disability.

b. Counseling and Obtaining Consent for Treatment Plans

The counseling stage of doctor-patient relationships is critical. These services, as surely as provision of drugs or specialist referrals, must be delivered without discrimination.

No-one will think that the parents of a child of Caribbean heritage should be given different information or options than the parents of a Swiss child. Presumably no professional will restrict counseling for various treatment options based on the infant's gender. A doctor who differentiates his counseling and treatment recommendations based solely on an adult's disability would be subject to legal action in States that comply with the Convention.

3. Groningen Protocol: How Stereotypes Determine Life or Death for Viable Infants

The Groningen Protocol guides medical counseling services for disabled Dutch infants and when the Netherlands adopts the Convention, those services will be subject to the Convention. The Protocol recommends ending treatment and taking active life-ending measures when the infants may 'survive beyond the period of intensive care, [but] they have an extremely poor prognosis and a poor quality of life.'³⁹ It also supports ending the lives of 'infants who have survived thanks to intensive care but for whom it becomes clear after intensive treatment has been completed that the quality of life will be very poor and for whom there is no hope of improvement.'⁴⁰

There are two ways in which discrimination occurs. First, the Protocol's quality of life assessment actually uses disability status as a deciding factor for whether or not a baby should live or die. Second, the quality of life assessment is error-ridden and reflects negative stereotypes about the value of life with disabilities.

a. The Groningen Protocol Specifies Direct Discrimination Based on Disability

The Groningen Protocol sets out factors which, if one or more are expected to be severe, will predict a quality of life that is worse than death and justify medical actions to terminate the infant's life:

- functional disability,
- pain, discomfort,
- poor prognosis, and hopelessness,
- lack of self-sufficiency,
- inability to communicate,
- hospital dependency and
- long life expectancy.⁴¹

These factors are explicit or implicit predictions of the infant's disability. The phrase 'functional disability' states it very directly. The factors 'lack of self-sufficiency' and 'hospital dependency' are descriptors of functional disability. 'Inability to communicate' is a form of disability. Pain and discomfort are symptoms that may have the effect of restricting activities. The 'poor prognosis, and hopelessness' factors are cumulative judgments rather than separate analytical items. Long life expectancy is included because of the duration of disability and suffering.

It is only because of their predicted disabled condition that 'no treatment' or 'active life-ending measures' recommendations are made. Parents whose 'normal' baby needs temporary help breathing would surely be counseled to approve ventilation, but not parents of a baby with severe disabilities. Nor is a purportedly benign motive a defense. This is not a form of 'positive action' or positive discrimination endorsed by the Convention by which past and current deficits in treatment or capacity are made up for by compensatory practices.⁴²

When negative medical recommendations are based on an explicit assessment of the infant's projected disability, she has been directly discriminated against, in violation of the principles established in Article 5(2) of the Convention. Even if we set aside this direct discrimination, which lies at the very core of the Groningen Protocol's decision-making process, it remains objectionable. That is because it lacks foundation in either medicine or in disabled people's lives, it fails to guard against conflicts of interest and it invites stereotypes to determine these life and death matters.

b. Quality of Life Considerations - Stereotypes and Guesses

Quality of life predictions involve a value judgment that invites stereotyping by medical and lay persons. The Protocol states a value judgment that persons with severe disabilities have a poor quality of life – often so poor that others are entitled to decide that they should die.

The statement that '...a child with the most serious form of Spina Bifida will have an extremely poor quality of life...'⁴³ is untrue when applied to all children with severe Spina Bifida. A statement or belief which assigns to all persons in a group an attribute true of some members of their group is a stereotype. The quoted statement is a stereotypical assessment concerning people with impairments and reflects a discriminatory attitude towards people with disabilities. Actions, including treatment recommendations that are based on such stereotypes are tainted by discrimination. Errant medical predictions, e.g., a prediction of full rather than partial paralysis, are not discrimination – it is the judgment that life with paralysis is of inherently low quality and worthless that is based on stereotypes. That value judgment may lead to a discriminatory recommendation to end treatment or even to inject a medication to stop the baby's heart.

The Groningen Protocol and its counterparts, such as the Oregon perinatal counseling guidelines, create situations where the 'physician's decision (is) discriminatory on its face, because it rest(s) on stereotypes of the disabled rather than an individualized inquiry into the patient's condition...'⁴⁴ Refusing to counsel for life sustaining-treatment because of perceived negative quality of life predictions is disability discrimination. The error in these practices is compounded by fundamental flaws in quality of life predictions.

1. Can Medicine Predict Quality of Life Without Stereotyping?

Quality of life is neither susceptible to a single definition nor to reliable prediction.

In recent years, an increasing number of studies on the quality of life of adults and children have been published, mostly describing outcomes of various medical conditions. Yet, despite the wide interest, there is no universal consensus even on the very definition of what constitutes quality of life, particularly for children.⁴⁵

The Groningen Protocol is controversial among doctors, in part because of the quality of life or suffering assessment. One wrote:

neonatal euthanasia cannot be supported, primarily because physicians and parents can never accurately assess the suffering of children.... without the testament of the patient herself as to the nature and magnitude of her suffering, physicians can never accurately weigh the benefits and burdens of a child's life, and therefore any such system would condemn to death some children whose suffering is not unbearable.⁴⁶

Furthermore, the concept of "suffering" is not rigorously defined and cannot be reliably predicted. Dr. R. de Jong reviewed the evidence and concluded that infants with Spina Bifida did not necessarily suffer pain and that while children and adults with Spina Bifida suffer from pain and discomfort related to their conditions, they do not experience unbearable and hopeless suffering, as believed by the authors of the Protocol.⁴⁷

De Jong questions the use of the term suffering at all for this purpose and also relates studies showing the falsity of the Groningen Protocol's authors' highly negative predictions about children with severe Spina Bifida (or other severe disabilities).⁴⁸

In a study cited by the Health Council of the Netherlands, for half of a group of Spina Bifida patients there was a large discrepancy between the negative medical prognosis made during the patients' infancy and the degree of disability described by parents after a four to eighteen year period.⁴⁹

2. Quality Judged By Those Who Live It

Quality of life can best be assessed by persons who are living or are intimately bound up with the life of the person with a disability. (Ethicists properly question whether any person can, especially without an intimate understanding of the other person, ever make a valid judgment on quality of life.⁵⁰) In fact, the self-assessed quality of life of people with disabilities is often equal that of people without disabilities,

despite the serious challenges posed by conditions such as Spina Bifida.. One study concludes that Spina Bifida is not a very important determinant of life satisfaction.⁵¹

Patients' self-assessments always seem to exceed the quality predicted for them. In a US study, the authors stated: 'We conclude that pediatricians overestimate the negative effects while also underestimating the positive effects of the disability (Spina Bifida) on the family.'⁵² A study of Spina Bifida patients showed that teens with lower levels of physical problems felt higher degrees of psychological distress, contrary to the expectations of investigators.⁵³

In a study of young adults who had been extremely low birth-weight (ELBW) infants, Canadian authors were surprised to find:

The positive valuation of (health-related quality of life) by a significant majority of ELBW respondents is in accord with their successful transition to adulthood, in terms of educational status, employment, living independently, marrying, and having a family. Concerns that formerly preterm subjects would experience diminished quality of social engagement, interpersonal competence, and life satisfaction also were not borne out in our study.⁵⁴

At the First World Congress on Spina Bifida Research and Care, Melissa Bellin reported on psychological status of young adults with Spina Bifida. The incidence of psychological distress was higher than in the population at large, but the likelihood of reduced distress correlated with having a positive attitude towards Spina Bifida and having positive family functioning.⁵⁵ Another report says that families with a child with Spina Bifida are less affected than families who have a child with epilepsy or asthma.⁵⁶

3. Environment and Social Context Are Critical

If it is possible to meaningfully discuss quality of life, it must be placed in context. To what extent are life differences based on the disabling impairments or on external factors? As the CRPD emphasizes in paragraph (e) of the preamble:

disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others....

The social responses to impairments are critical to making life as good as possible for persons with severe disabilities. According to a study by Grayson Holmbeck: '...families of youth with Spina Bifida are not as responsive to the developmental changes of adolescence as are comparison families.' These findings are significant for the impact of social environment; not only did parents of children with Spina Bifida respond less effectively to developmental changes, but lower socio-economic status families did worse - and boys and girls experienced different kinds of distress.⁵⁷

According to Dr. Sandler at the University of North Carolina, repeated studies show that:

employability and independence are not determined by... IQ score or the level of Spina Bifida. Among the most powerful influences on these long-term outcomes is the individual's sense of self.⁵⁸

While there may be a good chance of predicting the degree of paralysis of a person's legs, successfully predicting the future social environment and a person's degree of self-awareness, confidence and other influential factors, is impossible.

Examination of the social and environmental factors through another lens casts further doubt on using predicted suffering as a basis for life or death decisions. An infant born with Hydrocephalus in Canada, with its extensive social support system, will have a very different (better?) life than will an infant with Hydrocephalus in Kenya. Should the more negative prospects for children in less developed areas be

used to justify counseling to take active measures to end the lives of Kenyan newborns? Could it not be objectively predicted that girls will suffer more than boys, in some places? Should such factors be included in quality of life equations?

Unfortunately, this occurred in the "first world." From 1977 to 1982 the Children's Hospital of Oklahoma developed a quality of life formula for babies with Spina Bifida which took into account the socioeconomic status of the baby's family to determine how to advise parents about life-saving procedures. Better-off families were provided a realistic and optimistic picture of the child's potential and were offered medical interventions, while poor families were given a pessimistic picture and no treatment.⁵⁹

4. Third Party Considerations May Intrude

The quality of life factor discussion occurs when parents are burdened with tremendous pain, uncertainty and dependency.⁶⁰ Their judgments are naturally and properly concerned with the best interests of their newborn but also with the interests of their family. The doctor will naturally respond to the family's distress and may seek to give parents counsel that seems to meet their needs and unwittingly fall into a trap in attempting to serve both the needs of the infant-patient and the parent-family.

An extraordinary example of this is reported by authors of the Groningen Protocol in their Pediatrics article. This concerns administration of neuromuscular blocking drugs after removal of a respirator because of the discomfort experienced by parents (and others) when they witnessed the infant gasping for breath.⁶¹ This kills the baby and may, before death, obscure other symptoms of infant discomfort or distress, thus adding to her potential suffering. The deadly treatment was only given to serve others - and not at all to serve the medical needs of the child - a chilling example of how the very life of a child can be taken in order to provide fleeting relief to others.

When third-party considerations intrude into the decisions about the life of a disabled infant, a violation of Article 12(4) of the Convention has occurred, since substitute decisions are required to be: 'free of conflict of interest and undue influence ... proportional and tailored to the person's circumstances...'

We see that the Groningen Protocol explicitly directs doctors to discriminate in treatment recommendations on the basis of expected disability. Studies show the inaccuracy of quality of life assessments and the openings they create for stereotyping. Even if doctors could predict the long term medical or quality of life outcomes for newborns with 100% accuracy, the resulting negative value judgment inherent in a 'allow or help the baby to die' recommendation, itself reflects a prejudice against those who have severe disabilities.

c. Defenses and Objections to Legal Review

1. National Reservations

International human rights instruments permit signatories to issue declarations by which they reserve for national decision-making issues that might otherwise be covered by the CRPD. For example, the Netherlands' declaration says: 'The Kingdom of the Netherlands acknowledges that unborn human life is worthy of protection. The Kingdom interprets the scope of Article 10 to the effect that such protection - and thereby the term 'human being' - is a matter for national legislation.'⁶²

Such reservations will limit the impact of formal proceedings because ratification subject to reservations, by the CRPD's terms, limits enforcement. A closely related feature found in legal standards set in the European Union, is the reservation of certain issues for national competencies.⁶³ In the health area, standards for allowance of different healing practices may vary between Poland and Ireland. It is possible that on issues such as euthanasia, abortion and treatment of very ill newborns, national competencies will be asserted to avoid international scrutiny. While this may become a factor, the principles addressed here may still be raised in public debate, if not formal proceedings.

2. Not A Person

Conceptually related to the Netherlands' reservation as to the meaning of the term human being is the argument that newborns with severe impairments are not persons entitled to the same ethical and legal status as mentally competent adults.⁶⁴ Such arguments have been made in ethical debates but with little success in law⁶⁵. In *Vo v. France*, the European Court of Human Rights refused to accord independent legal status to the fetus on the facts of that case but did not rule out the possibility that in some circumstances even a viable fetus may have legal status.⁶⁶ A child who is not stillborn should pass that threshold. US law now clearly defines any fetus who is born alive at any stage of development as a person, human being, child, and individual.⁶⁷

The CRPD relates to the rights of persons with disabilities and classification of a newborn as a being other than a person would bar its application. However the definition in Article 1 of the Convention: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments...' does not exclude anyone with severe disabilities, such as those with IQs under 40. Using a term other than person, Article 10 of the CRPD affirms that 'every human being has the inherent right to life...'. All newborns have cognitive limitations, so are none are entitled to recognition of personhood? The CRPD extends its protections to children in Article 7, and sets no lowest age or cognitive limit for recognition of childhood. Unless a state establishes that infants or other homo sapiens with low cognitive capacity are some form of life other than children or persons, it seems unlikely that some ethicists' arguments about limited sentience leading to limited personhood and rights will provide a significant defense to claims considered here.

3. Medical Judgment, Not Discrimination

The third major challenge is the possible reluctance by legal institutions to challenge medical judgments using human rights standards. The outcomes in litigation touching on these issues in the US illustrate the careful lines that must be observed to have human rights standards brought to bear on medical practices.

In *Bowen v. A.H.A.*, The US Supreme Court threw out an attempt, using nondiscrimination rules, to implement oversight of neonatal treatment decisions. The opinion cast doubt on whether Congress intended that Section 504's ban on discrimination in federally funded programs authorized investigating discrimination in treatment of infants with severe impairments.⁶⁸ The decision primarily faulted a failure to build a convincing record of facts and logic to support the regulations, especially in having failed to identify any cases where doctors had refused to treat despite the request of parents for medical care. (Without consent, doctors are generally barred from treating a patient and, it was held, could not discriminate in treatment if treatment was barred by parents.)

This case did not charge a medical provider with disability discrimination, so the question of the reach of the law (as opposed to the regulations) was not answered. The plurality opinion suggested that discrimination could happen in decisions about medical care: '504 would be violated only if the hospital failed to report [to the state] medical neglect of a handicapped infant when it would report such neglect of a similarly situated nonhandicapped infant.'⁶⁹

The opinion acknowledged the potential for discriminatory treatment, for example if babies were given blood transfusions despite parental religious objection but babies needing correction of disabling conditions were not treated because of similar parental objection. The opinion did not decide whether those babies were 'similarly situated' or whether hospitals

could legitimately distinguish between the two situations on the basis of the different risks and benefits inhering in certain operations to correct birth defects, on the one hand, and blood transfusions, on the other hand.⁷⁰

But an overt, disability-based difference in actions taken by a US hospital could subject it to liability. Medical decisions have since been reviewed for disability discrimination under both Section 504 and the ADA. The courts are careful to distinguish malpractice claims from discrimination claims. As one court ruled:

... a patient may challenge her doctor's decision to refer her elsewhere by showing the decision to be devoid of any reasonable medical support. This is not to say, however, that the Rehabilitation Act prohibits unreasonable medical decisions as such. Rather, the point of considering a medical decision's reasonableness in this context is to determine whether the decision was unreasonable in a way that reveals it to be discriminatory. ... plaintiff's showing of medical unreasonableness must be framed within some larger theory of disability discrimination. ... a plaintiff may argue that her physician's decision was so unreasonable - in the sense of being arbitrary and capricious - as to imply that it was pretext for some discriminatory motive, such as animus, fear, or "apathetic attitudes." *Alexander v. Choate*, 469 US 287, 296, 105 S.Ct. 712, 83 L.Ed.2d 661 (1985); see, e.g., *Howe v. Hull*, 874 F.Supp. 779, 788-89 (N.D. Ohio 1994) (under ADA, jury could find doctor's diagnosis that plaintiff had extremely rare disorder requiring transfer was pretextual, where patient only had an allergic drug reaction, and doctor did not mention the rare disorder in requesting the transfer but only mentioned plaintiff's HIV-status). Or, instead of arguing pretext, a plaintiff may argue that her physician's decision was discriminatory on its face, because it rested on stereotypes of the disabled rather than an individualized inquiry into the patient's condition-and hence was "unreasonable" in that sense. See, e.g., *Sumes v. Andres*, 938 F.Supp. 9, 11-12 (D.D.C. 1996) (issuing summary judgment against doctor who refused to treat deaf patient on ground that "all deaf people are high risk," without making any inquiry regarding her specific condition).⁷¹

An example of a medical institution's refusal to treat a disabled infant being treated as discrimination was in the US *Baby K* case. While not the basis for judgment on appeal, the lower court decided that the hospital was not allowed to refuse to treat a severely disabled infant despite his extremely poor prognosis. The Court found that to do so would countenance disability discrimination.

[T]he plain language of the ADA does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby without disabilities at the parent's request. The Hospital's reasoning would lead to the denial of medical services to anencephalic babies as a class of disabled individuals. Such discrimination against a vulnerable population class is exactly what the American with Disabilities Act was enacted to prohibit.⁷²

Courts and other tribunals may not be eager to use human rights standards to review the practices of hospitals and doctors. Hence, plaintiffs must focus on evidence that shows stereotype, animus, ignorance or other indications of discrimination. Doing so will allow effective enforcement of the broad no discrimination mandate of the CRPD and implementing laws.

4. No Discrimination if No Comparable Patient

Another potential problem relates to the usual need in discrimination cases to identify a similarly situated person, without a disability, who was treated more favorably in order to win a discrimination case. Justice White's dissent in *Bowen* related this view:

refusing treatment that is called for only because of the handicapping condition cannot constitute discrimination on the basis of handicap since there will be no similarly situated nonhandicapped newborn, i.e., one who needs the same treatment....⁷³

This argument relates to the requirements under section 504 (but not the ADA) that a successful plaintiff be 'otherwise qualified' for treatment and that the treatment decision turned 'solely' on the basis of 'handicap.' Some courts interpret these provisions of section 504 to exclude claims by disabled persons when the medical treatment decisions being litigated were caused by the disability.⁷⁴ It was one reason for the rejection of discrimination claims of lower socioeconomic class families who complained of 'no treatment' recommendations for their infants' Spina Bifida at the University of Oklahoma.⁷⁵

The CRPD contains neither of the limiting terms 'solely' or 'otherwise qualified.' In this, it is closer to Americans with Disabilities Act than to section 504. The Supreme Court rejected the objection of a lack of a non-disabled comparison group in its *Olmstead* decision. The Court ruled that developmentally disabled adults with mental health problems were equally entitled to community-based programming as were those without mental illness, despite the facts that mental illness did make them different and that all of those being considered for the programming were disabled.⁷⁶

Justice Thomas' dissent criticized the ruling: "it looks merely to an individual in isolation, without comparing him to otherwise similarly situated persons..."⁷⁷ The majority rejected this, writing that the ADA sought to strike at the entire spectrum of disparate treatment on the basis of disability in the same manner as laws forbidding sex discrimination in employment.⁷⁸ No non-disabled comparison group was necessary for the analysis under the ADA

While not addressed in *Olmstead*, another answer is that in a case of overt discrimination, e.g. a written policy establishing different treatment based on protected class status, there is no need to do comparative analysis; the violation is proven by the words and actions that resulted in harm. In *Johnson Controls*, an employment discrimination case, the US Supreme Court held that a company could not bar women from certain jobs because 'the evidence shows "treatment of a person in a manner which but for that person's sex would be different."⁷⁹ In *Olmstead*, the plaintiff was treated in a manner which, but for her mental illness, would have been different, hence she suffered discrimination.

This potential barrier is answered by the CRPD's pledge to 'take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;' and to 'take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise....' Articles 4 (b) and (d). Further, Article 26 provides that States 'shall take effective and appropriate measures ... to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.' Restricting the counseling regarding life-sustaining treatment options for a severely disabled newborn, because of her disabilities, will be seen to stand in the way of attaining "maximum independence, abilities and participation in life."

5. Best Interests

A final defense could be that the overriding principle in all such decisions is the child's 'best interests.' In cases of lasting intolerable suffering, some argue, it is in the infant's best interests that suffering be ended through death. Britain's courts, in the *Wyatt* case⁸⁰ and experts on the Nuffield Council on Bioethics⁸¹ suggest that this is the standard for decisions in these circumstances. Indeed, Article 7(2) of the CRPD highlights 'best interests' as being the 'primary consideration' with respect to children with disabilities. This is an exception that, if not carefully analyzed, threatens to swallow the whole set of non-discrimination principles of the CRPD as applied to children. There are two ways to insure that this does not happen. First is to demonstrate that the CRPD itself establishes standards for deciding the best interests of disabled children. For example, the bar on 'discriminatory denial of health care... on the basis of disability' is a best interest standard that should not be negated by a medical opinion that the child's life will be worthless and too full of suffering. CRPD 25(f). Second is to understand that the best interest standard has evolved as a legal, not a medical, concept. It takes into account conflicting legal obligations, a community's moral and religious views and other standards, including sometimes, medical factors.⁸²

Decisions about children's best interests are reserved to parents, or when parents fail, to the courts. Principles of patient autonomy and informed consent, including when parents act as proxy, give them the burden and power for determining 'best interests.' In no part of the CRPD are physicians given any authority to overrule these powers of autonomy and consent.⁸³ Given the genesis of this standard and its multivariate considerations, it is not appropriate to give medical providers the power to decide that disabilities may be so severe that the 'best interests' of the child is to die. This remains the province of parents or courts and, as argued throughout, the CRPD instead imposes on medical providers duties to avoid discrimination and maximize the life possibilities of children with impairments.

Part IV



European and Other International Human Rights Law & Policy

The International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities is the most comprehensive existing standard for international disability discrimination analysis. European and other international instruments provide additional sources for the conclusion that the Groningen Protocol and similar practices violate human rights standards.

A. European Human Rights Standards

1. The Charter of Fundamental Rights of the European Union

The Charter was signed at the end of 2000. Article 2 sets out a general right to life but the beginnings and end of life are not defined.⁸⁴ Relevant to discussion of the Groningen Protocol is Article 3 which establishes the "Right to the integrity of the person":

1. Everyone has the right to respect for his or her physical and mental integrity.
2. In the fields of medicine and biology, the following must be respected in particular:
 - the free and informed consent of the person concerned, according to the procedures laid down by law,
 - the prohibition of eugenic practices, in particular those aiming at the selection of persons...

Medical treatment that results in death negates entirely a person's physical and mental integrity. While the Groningen Protocol does not specify a eugenics purpose, societies operating according to their guidance may move close to a practice of eugenics.

Article 21 of this Charter bans discrimination, including that based on genetic features and disability. As Down syndrome, Spina Bifida and other disabling conditions often have a genetic component, this feature of the Charter would strengthen claims that medical treatment differences based on disability is illegal.

Article 26 references '...the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation...'⁸⁵ The right 'to benefit from medical treatment under the conditions established by national laws and practices' is set out in Article 35.

The specific application of the Charter to the Groningen Protocol is not addressed in detail here.⁸⁶ The similarity between the general principles contained in this agreement and those in the CRPD and other sources should lead to the same outcome.

2. European Convention for the Protection of Human Rights & Fundamental Freedoms (ECHR)

This 1950 Convention has its origins in the Council of Europe, a body with wider membership than the EU. It sets forth a number of familiar principles relevant to the Groningen Protocol.

Section 1, Article 2 affirms all persons general right to life, again without defining parameters. Rights to private and family life and to freedom of thought, conscience and religion are protected by Articles 8 and 9. Discrimination is prohibited by Article 14, but disability is not specified as a ground, though the phrase, "or other status" is interpreted to cover this status.

The specific application of this Convention to the Groningen Protocol or the process for possible review is not addressed in detail here. Again, the similarity between the general principles contained in this agreement and those in the CRPD should lead to the same outcome.

3. The Amsterdam Treaty, Article 13 and Proposed European Commission Directive on Equal Treatment of Persons Irrespective of Religion or Belief, Disability, Age or Sexual Orientation (Proposed Directive).

Laws of the European Union are rooted in its foundational instruments: treaties. Article 13 of the Treaty establishing the European Community (Amsterdam Treaty) states:

Without prejudice to the other provisions of this Treaty and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission and after consulting the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.⁸⁷

The Amsterdam declaration also stated: 'the institutions of the Community shall take account of the needs of persons with a disability.'⁸⁸

In response to Article 13, the European Commission, working to improve the current non-discrimination legal framework, presented on 2 July 2008 a proposal for a Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation.

The proposed Directive, including April 2009 amendments approved by the European Parliament⁸⁹, is consistent with the provisions of CRPD, going beyond it in some features. It provides the measures necessary to enable persons with disabilities to have effective non-discriminatory access to social protection, social advantages, health care, education and access to and supply of goods and services which are available to the public, and in particular cases - reasonable accommodation.

Article 3 defines the scope of the Directive and health care is a covered subject according to paragraph 1(a).

Article 2 states: 'the 'principle of equal treatment' shall mean that there shall be no direct or indirect discrimination...' and defines direct discrimination at paragraph 2(a) as;

where one person, or persons who are or who are assumed to be associated with such a person, is treated less favourably than another is, has been or would be treated in a comparable situation, on... (the basis of disability.)

Indirect discrimination is defined at paragraph 2(b) as:

where an apparently neutral provision, criterion or practice would put persons of ... a particular disability... who are assumed to be associated with such persons, at a particular disadvantage compared with other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary.⁹⁰

The Directive contains a definition of persons with disabilities in Recital 12a:

...those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, whether environmental or attitudinal, may hinder their full and effective participation in society on an equal basis with others.

Recitals 11 and 17 reserve for Member States their competencies in the fields of social protection, including social security and health care, health law, family law and education. By this it is meant that the scope of state provision of health care and the regulation of health care services in terms of licensing, malpractice, etc. are reserved.

The Amsterdam Treaty states at Article 152:

Community action in the field of public health shall fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care. In particular, measures referred to in paragraph 4(a) shall not affect national provisions on the donation or medical use of organs and blood.⁹¹

While health promotion is within EU jurisdiction, the specific organization of healthcare is reserved to States and the field itself is one of indirect effect and subsidiarity. Within nationally defined characteristics, however, healthcare should be provided without discrimination upon adoption of the proposed Directive.

There is limited authorization of age and disability-based criteria set out in Recital 14a:

Differences in treatment on grounds of age and disability may be permitted if they are objectively and reasonably justified by a legitimate aim and the means of achieving that aim are appropriate and necessary ... The promotion of the economic, cultural or social integration of ... persons with disabilities may also be regarded as a legitimate aim. Therefore measures relating to age and disability which set more favourable conditions than are available to others, such as free or reduced tariffs ... are presumed to be compatible with the principle of non-discrimination. (Emphasis added)

However, when the proposal moves to more specifics on this subject, these defenses are narrow in scope and restrictive in application. Article 2 paragraph 6 permits direct age discrimination if properly justified, but does not permit discrimination on the basis of disability as a general matter. Paragraph 7 of Article 2 relates to only to financial services and permits, under strict limits, direct discrimination based on disability, but only if based on actuarial justifications. Therefore there is no basis under the Directive to justify disability-based denial of needed medical care.

This paper asserts that the Groningen Protocol uses consideration of an infant's disability as a key factor in deciding whether the baby will get treatment and live or have treatment ended or fatal drugs administered and die. These infants are disabled under the Directive. The assessment of prospective quality of life is a judgment based the status of the infant's disability and is based on stereotypes that are often inaccurate in individual cases. The principle of equal treatment set out in proposed Article 1 is violated by direct discrimination and is prohibited by Article 2 of the proposed Directive.

The process for adoption of a Directive is complex; some changes are likely.⁹² Adoption of the Directive requires unanimity of twenty seven Member States to be achieved in the Council. But once adopted and effectively implemented, it will be a comprehensive advance for disability and other rights in many public sectors throughout Europe and should, like the CRPD, be enforced to end this form of infanticide.⁹³

B. Other International Standards

1. The Universal Declaration of Human Rights⁹⁴

Adopted by the UN General Assembly in 1948, the Declaration sets 'a common standard of achievement for all peoples and all nations.' Article 3 states: 'Everyone has the right to life, liberty and security of person.' Cruel, inhuman and degrading treatment is barred by Article 5. Article 6 holds: 'Everyone has the recognition everywhere as a person before the law' and Article 7 sets out the goal of each person having equal protection of the law. A right to health and security in the event of disability is set out in Article 25. It is a general statement that has no enforcement mechanisms but its principles align well with those set out for people with disabilities in the Convention on Disabilities.

When an infant will live, even with severe medical conditions, it is difficult to see how the Declaration contains any support for the Protocol. Treatment recommendations to take steps to end a life that is expected to continue, would violate the right to life set out in Article 3, the right to recognition of and equal protection as a person of Articles 5 and 6 as well as the right to health and security in the event of disability, recognized in Article 25.

2. The Convention on the Rights of the Child⁹⁵

This is a twenty year old international Convention that has been adopted by nearly all nations. Article 6 affirmatively states:

1. States Parties recognize that every child has the inherent right to life.
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

Article 2 parts (1) and (2) requires States to protect children without regard to their disability and to protect them from discrimination because of disability.

Article 19 directs that 'States Parties shall take ... measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation ... while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.'

Article 23 is most applicable to the Groningen Protocol.

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care

It continues in paragraph 3 to oblige States to give:

assistance ... designed to ensure that the disabled child has effective access to and receives ... health care services, rehabilitation services... in a manner conducive to the child's achieving the fullest possible ... individual development....

Article 24 provides that States should promote 'the right of the child to the enjoyment of the highest attainable standard of health...'

Medical treatment steps that end a continuing life would likely violate Articles 2 (nondiscrimination based on disability), 3 (best interest), 6 (life), 19 (maltreatment), 23 (health) and 24 (highest attainable health.)

This Convention on the Rights of the Child recognizes that parents play a key role in protecting children's rights. Article 16 establishes rights against "arbitrary or unlawful interference with (a child's) privacy, family..." Article 2 requires States to adopt measures to protect children, but it also emphasizes respect for the rights of parents and families. The importance of the role of parents and extended family is also recognized by Article 5.

This Convention is not self-executing but establishes a Committee on the Rights of the Child to review reports from Convention signatories and to promote studies and recommendations for improvements in children's rights and well-being. Signatories' performance of Convention obligations may be reviewed in the UN Human Rights Commission's system of rotating country reviews.



Conclusion

International human rights instruments set the standards for legal and humane medical treatment recommendations for all people. Giving parents accurate multi-disciplinary information about the medical, social and life prospects of their newborn child in a non-directive and non-judgmental manner will cost little and go far to attaining those goals. Practices, like the Groningen Protocol, that counsel parents that it is best for babies to die because they have severe impairments violate international human rights standards. States adhering to those standards must overturn medical practices that counsel for the death of infants because of stereotyped negative judgments about the worthiness of life with a disability.



References:

- 1** Verhagen, 'The Groningen Protocol - Euthanasia in Severely Ill Newborns', 352 *The New England Journal of Medicine*, 10 March (2005), 959. Spina bifida is one of the most common congenital defects, occurring within the first 25 days of pregnancy. The spine does not close completely and the nervous system is frequently damaged with resulting paralysis. Most will have problems with bowel and bladder control. Other problems also arise. Hydrocephalus arises from the same causes and results in blockage of drainage pathways for fluids around the brain. The fluid accumulates in the brain, causing compression of surrounding tissue. In most cases several surgeries are needed. Good medical care and intensive training for the person and family can prevent many complications and improve the person's life. See: www.ifglobal.org
- 2** For example, the US Child Abuse Prevention and Treatment Act (CAPTA), 42 USC Section 5106G, seeks to mandate treatment in these cases. CAPTA defines child abuse to include:

(6) ... "withholding of medically indicated treatment" [which] means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment -

 - (A) the infant is chronically and irreversibly comatose;
 - (B) the provision of such treatment would -
 - (i) merely prolong dying;
 - (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or
 - (iii) otherwise be futile in terms of the survival of the infant; or
 - (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.
- 3** This paper does not argue that stopping treatment for children in this category is wrong, although a cautionary ethics would doubt the wisdom of taking active measures to end these lives, as opposed to continued palliative care.
- 4** Verhagen, 352 *The New England Journal of Medicine* 10 (2005), 959.
- 5** Human Rights Committee, 'Consideration of Reports Submitted by States Parties under Article 40 of the Covenant', *International Covenant on Civil and Political Rights, Fourth Periodic Report, Netherlands*; (2007), 121 www.netherlandsmission.org/article.asp?articleref=AR00000719EN
- 6** *Ibid.* 151, 154.
- 7** *Wyatt v Portsmouth Hospitals NHS Trust* [2005] EWCA Civ. 1181.
- 8** Kaempf, et al, 'Medical Guidelines For Periviability Pregnancy Counseling and Medical Treatment of Extremely Premature Newborns', 117 *Pediatrics* No. 1, (2006), 24, 25.
- 9** Provoost et al, 'Medical End-of-Life Decisions in Neonates and Infants in Flanders', 365 *The Lancet* 9467 (2005), 1315, 1319.
- 10** US Commission on Civil Rights, *Medical Discrimination against Children with Disabilities*, (1989).
- 11** Verhagen, 352 *The New England Journal of Medicine* 10 (2005), 960.
- 12** Robertson, 'Involuntary Euthanasia of Defective Newborns: A Legal Analysis', 27 *Stan. L. Rev.* 213 (1975), 246.
- 13** Mertens, 'The Echternach Procession in the Ethical Field', *Journal of Medicine and The Person* (2008), 69, 73.
- 14** Field, 'Killing "The Handicapped"—Before and After Birth', 16 *Harvard Women's Law Journal* (1993), 79.
- 15** *Ibid.* 87, 97-101.
- 16** *Ibid.* 90-96.
- 17** Singer, *Practical Ethics*, (Cambridge Univ. Press, 1993), 191.
- 18** MacLeod, 'All For One: A Review Of Victim-Centric Justifications For Criminal Punishment', 13 *Berkeley J. of Cr. Law* 31 (2008), 31, 54-59.
- 19** European Disability Forum, *EDF Resolution on Active Termination of Life of Infants with Impairments and the Right to Live*, (2006). <http://www.ifglobal.org/images/stories/humanrights/edf%20resolution%20right%20to%20live%202006.pdf>
- 20** Health Council of the Netherlands. *Considerations Pertaining to Neonatal Life Termination. Ethics and Health Monitoring Report, 2007/1*. The Hague: Centre for Ethics and Health, 2007, 39-41.
- 21** *Portsmouth NHS v. Derek Wyatt, Charlotte Wyatt by her Guardian (DAFCASS), Southampton NHS Trust* [2004] EWHC 2477 (Fam). The European Convention on Human Rights was said to "add nothing to domestic law." *Johnson by Johnson v. Thompson*, 971 F.2d 1487 (10th Cir.) cert. den. 507 US 910 (1993) The court found discrimination not proven and the then-current disability rights law inapplicable.
- 22** United Nations, *Convention on the Rights of Persons with Disabilities and Optional Protocol*. <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- 23** United Nations Enable, *Declarations and Reservations*, <http://www.un.org/disabilities/default.asp?id=475> As of August, 2009, nations such as Belgium, Burkina Faso and Sweden had ratified both the Convention and its Optional Protocol (necessary for enforcement). The Netherlands and USA have signed but not ratified the Convention. In a signing declaration, the Netherlands made several statements apparently aimed at preserving its policies supporting euthanasia and abortion.
- 24** *Olmstead v. L.C. ex. rel. Zimring*, 527 US 581, 611 (1999).
- 25** *Parham v. J.R.* 442 US 584. (1979). US Supreme Court recognizes parent's rights to consent to medical treatment of teenager, over teen's objections, based in part of Constitutional principles.
- 26** *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, G.A. Res. 61/106, Annex I, U.N. GAOR, 61st Sess., Supp. No. 49, at 65, U.N. Doc. A/61/49 (2006), Art. 23. Paragraph 2, 4-5. <http://www1.umn.edu/humanrts/instree/disability-convention2006.html>
- 27** *Ibid.* Article 8 specifically calls on states to raise awareness, throughout society and including at the family level, to foster respect for the rights and dignity of persons with disabilities.
- 28** Woods, 'The Right to Die with Dignity with the Assistance of a Physician: An Anglo, American and Australian International Perspective', 4 *ILSA Journal of International and Comparative Law* (1998), 817.
- 29** In the US, such cases are narrowly defined in the CAPTA statute, see fn. 2, as situations not involving child abuse or neglect. The CAPTA terminology presents a very conservative approach to the end of life decisions.

- 30 Re: Wyatt [2006] EWHC 319, paragraph 13.
- 31 Re: Wyatt [2005] EWHC 1181, paragraph 76, 87.
- 32 Ibid. A newspaper reported that Charlotte was growing in foster care five years after birth. <http://www.dailymail.co.uk/news/article-1163805/80-lawyers-refused-help-save-Baby-OT-leaving-parents-fend-themselves.html>
- 33 Pretty v. UK [2002] ECHR 427, paragraphs 67-78.
- 34 An alternative approach to regulating admission and assessment is found in a US law, the Emergency Medical Assessment and Active Labor Act. 42 USCA 1395 dd et seq. It requires hospitals to provide assessment and care of any patient who comes in its doors.
- 35 A dermatologist passing through a London clinic would not discriminate by refusing to insert a shunt for a newborn with Hydrocephalus, as this would ask her to perform a service outside of the scope of her professional capacity. See: Bierma et al "We Can't Meet Your Needs": Fair Housing Opens Doors to Housing with Services" 42 Clearinghouse Review 253 (2008). Services outside a standard 'menu' may still be required as a reasonable accommodation, subject to reasonableness and fundamental alteration limits.
- 36 Wood, 'Costs and the Right to Community-Based Treatment', 16 Yale L. & Pol'y Rev. (1998), 501.
- 37 Britell v. US, 372 F.3d 1370, 1383 (Fed. 2004). Plaintiff sought reimbursement from government insurance plan for abortion of fetus with a condition, anencephaly, where key parts of brain do not develop; fewer than 2% born with that condition live longer than a week and none have any consciousness. Plaintiff failed to persuade the court that a fetus with that condition was not a potential human life. 'No reason has been presented, nor do we see one, to explain why consciousness (or extended life span) is the lynchpin of potential human life.'
- 38 Re A (children) [2001] Fam. 147. See Mason JK (2001) Conjoined Twins: A Diagnostic Conundrum Edin L R 5 226.
- 39 Verhagen, 352 The New England Journal of Medicine 10 (2005), 960.
- 40 Ibid.
- 41 Verhagen, , 352 The New England Journal of Medicine 10 (2005), 960 Table 1.
- 42 **International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities**, Article 5(4). <http://www1.umn.edu/humanrts/instree/disability-convention2006.html>
- 43 Verhagen, 352 The New England Journal of Medicine 10 (2005), 960.
- 44 Lesley v. Hee Man Chee, 250 F.3d 47, 55 (1st Cir. 2001).
- 45 Saigal, 'Measurement of Quality of Life of Survivors of Neonatal Intensive Care: Critique and Implications', 32 Seminars in Perinatology 1 (2008), 59, 59-66.
- 46 Kon, 'Neonatal Euthanasia is Unsupportable: The Groningen Protocol Should Be Abandoned', 28 Theoretical Medicine and Bioethics 5 (2007) 453, 453-463.

- 47 De Jong, 'Deliberate Termination of Life of Newborns with Spina Bifida, a Critical Reappraisal', 24 Child's Nervous System 1 (2008) 13, 25.
- 48 Ibid.
- 49 Rasmussen et al, 'Nordic Children with Myelomeningocele. Parents' Assessments of the Handicap and Physicians' Classifications of the Disabilities', 82 Acta Paediatrica 3 (1993), 82.
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- 54 Saigal et al, 'Self-Perceived Health-Related Quality of Life of Former Extremely Low Birth Weight Infants at Young Adulthood', 118 Pediatrics 3 (2006), 1140.
- 55 Bellin et al, 'Psychological Health in Transition-Age Individuals with Spina Bifida', <http://medicalconference.spinabifidaassociation.org/atf/cf/%7B10221c89-6b69-45bd-81bf-3194-b0be6fa5%7D/NEUROPSY10.PDF>
- 56 Rauen et al, 'The Impact of Spina Bifida and other Chronic Health Conditions on Families', <http://medicalconference.spinabifidaassociation.org/atf/cf/%7B10221c89-6b69-45bd-81bf-3194-b0be6fa5%7D/NURS08.PDF>
- 57 Holmbeck, 'Psychosocial and Family Functioning In Adolescents with Spina Bifida', <http://medicalconference.spinabifidaassociation.org/atf/cf/%7B10221C89-6B69-45BD-81BF-3194-B0BE6FA5%7D/PsychosocialFamily.pdf>
- 58 A. Sandler, Living with Spina Bifida, (University of North Carolina Press, 1997), 195.
- 59 US Commission on Civil Rights, Medical Discrimination against Children with Disabilities, (1989), 19-21.
- 60 Shaw et al, 'The Relationship Between Acute Stress Disorder and Posttraumatic Stress Disorder in the Neonatal Intensive Care Unit', 50 Psychosomatics 2 (2009) 131. (abstract reviewed only)
- 61 Verhagen et al, 'Physician Medical Decision-making at the End of Life in Newborns: Insight into Implementation at 2 Dutch Centers', 120 Pediatrics 1 (2007), e20.
- 62 United Nations Enable, Declarations and Reservations, <http://www.un.org/disabilities/default.asp?id=475>
- 63 Treaty Establishing the European Community (Nice Consolidated Version). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:12002E152:EN:HTML>

- 64** Fletcher, 'Humanhood: Essays In Biomedical Ethics', (Prometheus Books, 1979), 12. Fletcher argues that persons with IQs less than 40 are not persons. 'Mere biological life, before minimal intelligence is achieved or after it is lost irretrievably, is without personal status.'
- 65** Britell, 372 F.3d 1370, 1383 (refusing to accept argument that severe fetal impairments reduce the legal interest in 'human life.')
- 66** Vo v. France (2005) 10 EHRR 71
- 67** 1 USC.A. § 8.
- 68** Bowen v. American Hospital Assn., 476 US 610, (1986).
- 69** Ibid. Fn. 22.
- 70** Ibid.
- 71** Lesley, 250 F.3d 47. (Transfer of HIV+ patient to hospital with special HIV clinic not discrimination.)
- 72** In Re Baby K, 832 F.Supp. 1022, 1028 (E.D. Va, 1994) aff'd. 16 F.3d 590 (4th Cir. 1994). The appeals court affirmed holding that 42 U.S.C. Section 1395dd(a) Emergency Medical Treatment and Active Labor Act (EMTALA), which prohibits refusal to assess and treat emergency admissions applied to the case and thus it did not decide the ADA and Section 504 issues addressed by the lower court.
- 73** Bowen, 476 US 610, 655.
- 74** United States v. University Hospital, State University of New York at Stony Brook, 729 F.2d 144 (2d Cir.1984).
- 75** Johnson by Johnson, 971 F.2d 1487, 1495.
- 76** Olmstead, 527 US 581, 598.
- 77** Ibid, 624 (Justice Thomas dissent).
- 78** Ibid, 600.
- 79** International Union v. Johnson Controls, 499 US 187, 199-200 (1991).
- 80** Re: Wyatt [2005] EWHC 1181, paragraph 76, 87.
- 81** Critical Care Decisions in Fetal and Neonatal Medicine, Nuffield Council on Bioethics, 2006, p.12-13.
- 82** 'Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations' An NHS Trust v. B [2006] EWHC 507 (Fam). para. 16. (Court agrees with parents and refuses to authorize end of ventilation but does agree that other potential interventions for severely ill child would be wrong.)

- 83** In Glass v. UK, the European Court of Human Rights found British doctors to have violated Article 8 of the Convention on Human Rights and Biomedicine by administering diamorphine (with potentially lethal consequences) over parental objection and without seeking court approval to act in what the doctors believed to have been the child's best interests.
- 84** However the British medical establishment believes that the right to life, set out in Article 2 of the European Convention on Human Rights, is not offended by 'withdrawal of life sustaining treatment in appropriate circumstances....' Royal College of Paediatricians and Child Health (2004) Withholding or Withdrawing Life Sustaining Treatment in Children 2nd Edition (London: RCPCH). European Convention on Human Rights is found at: <http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=005&CM=8&DF=30/10/2009&CL=ENG>
- 85** The European Court of Human Rights determined that a conscious adult with intolerable disabilities has no right, under the European Convention on Human Rights provision guaranteeing personal privacy, to obtain assisted suicide. Pretty v. UK [2002] ECHR 427, paragraphs 67-78. There would be a great inconsistency in forbidding rational adults from seeking medical help to die while permitting medical infanticide, whether sought by parents, doctors or both.
- 86** In Opinion 2/94 Accession by the Community to the ECHR [1996] ECR I-1759, however, the European Court of Justice rejected the proposal that the European Community could fully accede to the ECHR. All the same, the Court does look to the principles established by conventions and treaties like the ECHR to guide interpretation of laws.
- 87** Office for Official Publications of the European Communities, 'Treaty of Amsterdam, Amending the Treaty on European Union, The Treaties Establishing The European Communities and Certain Related Acts, (1997), 26. <http://www.europarl.europa.eu/topics/treaty/pdf/amst-en.pdf>.
- 88** Ibid, 135.
- 89** <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P6-TA-2009-0211&language=EN>
- 90** In this review, we posit a case of direct rather than indirect discrimination. However, the Protocol could not be adequately justified as having either a compelling legitimate aim nor as using appropriate and necessary means, if analyzed as "indirect discrimination."
- 91** Treaty Establishing the European Community (Nice Consolidated Version). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:12002E152:EN:HTML>
- 92** The E.U. may decide there can be no uniform approach to the Groningen Protocol, as has been the case with respect to abortion policies, which are among each nation's reserved "competencies."
- 93** The European Parliament, Legislative Resolution for Equal Treatment between Persons Regardless of Religion, Disability, Age, or Sexual Orientation, (2009). <http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P6-TA-2009-0211&language=EN>
- 94** United Nations, Declaration of Human Rights, (1948). <http://www.un.org/en/documents/udhr/>
- 95** Convention on the Rights of the Child, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force Sept. 2 1990. <http://www1.umn.edu/humanrts/instrree/k2crc.htm>

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Directorate-General Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3



International Federation for Spina Bifida and Hydrocephalus

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