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ÉVA STEINBACH[*] – ÁKOS HEGEDŰS[**]

Life is a value – the situation of and opportunities for people with Down syndrome[***]

ABSTRACT: We consider life as a fundamental value and treat it as an axiom. Nevertheless, this critically important right is frequently attacked. The most dangerous of these attacks occur when we pass judgement on difficult issues without sufficient caution. This can determine when and where life can have opportunities, especially when it is fragile and small. The Fundamental Law of Hungary begins its enumeration of fundamental rights with the statement that 'human dignity shall be inviolable'. It then goes on to say that 'every human being shall have the right to life and human dignity; the life of the foetus shall be protected from the moment of conception'. It is clear from this wording that the law recognises the beginning of life at live birth but also protects the foetus from conception as part of the process leading to life. Unfortunately, this protection is not without discrimination. Families encountering Down syndrome face numerous challenges from the moment of diagnosis. It is apparent from judicial practice that some form of assistance is sought to be provided to families in difficult situations. The question is how effective this assistance is and how it affects the families and the attitude of health care providers. The aim of this study is to raise the issues that counteract life as a value, taking into account the perspectives of the very lovable individuals with Down syndrome.

KEYWORDS: Down syndrome, right to self-determination, foetal life, protection of life, compensations, screening tests.

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[*] Head of the Down nanny service, Down Foundation, Hungary, steinbach.eva@downalapitvany.hu.

[**] Judge, Eger District Court, Hungary, https://orcid.org/0000-0002-7583-3571, drhegedusa@birosag.hu.

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> Yet you brought me out of the womb;
> you made me trust in you, even at my mother's
> breast. From birth I was cast on you;
> from my mother's womb you have been my God.[1]

1. Introduction[****]

There are certain premises that largely determine our worldview. There are choices that can be logically deduced from these premises, but when searching for their underlying rationale, we run out of the foundations for the logical structure we built our reasoning on. The impact of value pluralism is so acute in today's world that there is little common ground and few slogans that people can unite behind. The beginning and end of life, however simple it may seem, has been a subject of constant debate. The Fundamental Law of Hungary (Hungarian Constitution) begins its catalogue of fundamental rights by stating that 'human dignity shall be inviolable'. It then goes on to say that 'every human being shall have the right to life and human dignity; the life of the foetus shall be protected from the moment of conception'.[2] It is clear from the wording that the law recognises the beginning of life from the moment of live birth but protects the foetus starting from conception as the process leading to life. Unfortunately, it does not do so without discrimination. It articulates the right to human dignity as the basis of human existence, together with the right to life, and recognises the right to life and human dignity of all human beings. In the same sentence as human life, but separate from it, it mentions foetal life, which is protected from the moment of conception. Within the framework of its objective duty to protect institutions, the Hungarian State must protect newly created human life in its process of conception.

2. Analysis from the perspective of fundamental rights

It is difficult to answer the very first question that arises in this context, namely: when does human life begin? The Explanatory Memorandum of the Fundamental Law clarifies the scope of legal protection of the life, as it is conceptualised and recognised under the current Hungarian legislation.

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[1] Psalm 22:9–10.

[****] The manuscript is translated by Dr. Petra Lea Láncos, Professor, vice dean for international relations, Pázmány Peter Catholic University, Department for EU law.

[2] The Fundamental Law of Hungary (Hungarian constitution), Article II.

Already at this point however, a normative gap arises, since a significant part of society does not consider human life to begin only from the moment of live birth. In its earlier decisions, the Constitutional Court consistently refused to decide whether a foetus is a human being.[3] It referred the issue back to the legislator. At the same time, it stressed that, should the legislator decide that the foetus is not a human, the regulation of abortion must nevertheless take account of the State's objective duty to protect life. The legislator must therefore strike a balance between the State's duty to protect the life of the foetus and the mother's right to self-determination.[4] The Fundamental Law attempts to reconcile the protection of life and the right to self-determination, which is why the protection of foetal life, which is not human life and can be limited, appears separately alongside the main values of life and human dignity.

From amongst the benefits of the change of the political system, we consider it to be a value that now, the fundamental rights of citizens must be regulated by statute, not merely decrees. The Act on the Protection of Foetal Life sought to change the view that there is a right to abortion.[5] The Act declares that foetal life, which begins at conception, deserves respect and protection, to be achieved primarily through an enhanced care for a woman expecting a child.[6] To ensure the healthy development of the foetus, the Act guarantees free prenatal care to all Hungarian citizens permanently residing in Hungary, their spouses, and foreign citizens with a valid permanent residence permit, regardless of their insurance status. The Act further aims to ensure the healthy development of the foetus by introducing a maternity allowance that is meant to improve the living conditions of expecting mothers. The basic principle underlying the legislation, which entered into force on 1 January 1993, is that the number of abortions does not depend on the rules governing its conditions, and it directly affects the number of births, the frequency of abortions being primarily a matter of values and culture. In this case, however, the development of values and culture is essential, and civil society organisations have a major role to play in this

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[3] Constitutional Court Decision No. 64/1991 (XII. 17.) AB; Constitutional Court Decision No. 48/1998 (XI. 23.) AB.

[4] Office of the Commissioner for Fundamental Rights of Hungary - On the rules of artificial abortion and the protection of foetal life, [Online]. Available at: https://www.ajbh.hu/-/a-muvi-terhesseg-megszakitas-szabalyairol-es-a-magzati-elet-vedelmerol (Accessed: 25 November 2024).

[5] Act LXXIX of 1992 on the protection of foetal life.

[6] According to the reasoning of the proponents of the legislative proposals.

process. In the absence of their reinforcement and support, legislation may become dysfunctional.

In view of the change in approach, the Act on the Protection of Foetal Life first lists the means and methods of support for, and protection of, life, and only then does it go on to cover abortion. In setting out the statutory conditions for abortion, the Act stipulates that pregnancy can only be terminated in the event of a threat to, or serious crisis for, the pregnant woman. The Act defines ‘serious crisis’ as a situation that causes physical or psychological distress or social ruin. However, the pregnant woman may substantiate the prevalence of this serious crisis by merely signing a declaration. The Act on the Protection of Foetal Life defines the cases of, and time limits for, the termination of pregnancy based on the degree of threat and the period of the pregnancy. The second abortion decision of the Constitutional Court makes it clear that abortion is outlawed in the case of a minor malformation of the foetus. Article 6 of the Act on the Protection of Foetal Life may only be interpreted in conjunction with the provisions of its Article 12. The more serious the threat, the later the pregnancy may be lawfully terminated. In essence, the Act on the Protection of Foetal Life merely details health indications for abortion while refraining from elaborating on the substance of those crisis situations that may adversely affect the healthy development of the foetus, thus emphasising that abortion cannot be considered a subjective right linked to a specific life situation. The fact that the legislator refrained from including such a taxonomy suggests that there are no social situations in which childbearing is discouraged, nor is there a number of children that is considered desirable from the perspective of social policy. Pregnancies may be terminated up to the 12th week of pregnancy for reasons that seriously threaten the health of the pregnant woman, in the event of a medically probable serious disability or other impairment of the foetus, in the event of a serious crisis of the pregnant woman, or in case the pregnancy is the result of a criminal offence. A legal incapacity of the mother or a delay in recognising the pregnancy postpone the time limit available for termination until the 18th week.

3. Screening tests

Down syndrome is considered a severe disability, but among people with Down Syndrome, severe intellectual disabilities are less common, with the majority of Down syndrome patients exhibiting a mild-to-moderate intellectual disability; yet these foetuses are subjects to the later time limits available for abortion. Diagnostics are generally not reliable predictors of the extent of Down syndrome-related health impairments, so the time limit for termination of the pregnancy falls at a time when it is still merely likely that Down syndrome is present in the foetus. Hungarian law allows for the termination up to the 20th week of the pregnancy – or 24 weeks in case the diagnostic procedure is delayed – if the probability of genetic, teratological harm to the foetus reaches 50%. In case the foetus suffers from an abnormality incompatible with postnatal life, the pregnancy may be terminated regardless of its term, a condition that is again of particular concern for foetuses with Down syndrome. Down syndrome is associated with other developmental disorders in 40–60% of cases. The most common congenital abnormalities in cardiac development with Down syndrome are atrioventricular septal defects and tetralogy of Fallot. Cardiac malformations are now remediable in most cases with surgery, but they can easily be deemed disorders incompatible with postnatal life. Before 1990, such surgeries were only performed in exceptional cases.[7] People with Down syndrome are therefore more vulnerable to stigmatisation before they are born than are people with any other developmental disorder or disability.[8]

Genetic screening tests can detect other developmental disorders, such as spina bifida or Edwards syndrome, but they are primarily used to screen for Down syndrome. Foetuses with Down syndrome are at the greatest risk of having decisions made about their life in the absence of comprehensive information. Down syndrome is considered the most common of genetic disorders, accounting for one in 700 pregnancies, but the number is not as high among people with disabilities. This suggests that a large proportion of screenings results in abortion. In Hungary, 1,747 babies were born with Down syndrome between 2001 and 2010; they were not identified during pregnancy due to lack of foetal screening. In this country, it is extremely rare for a mother to give birth to a child with Down syndrome after receiving the foetal diagnosis.

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[7] Origo.hu - Vannak már Down-kóros öregemberek, [Online]. Available at: https://www.origo.hu/egeszseg/terhesseg/20121009-a-leggyakoribb-tevhitek-a-downkorosokkal-szemben.html (Accessed: 25 November 2024) (not only based on public discourse). Döme, 2021, p. 197.

[8] NPHC, 2022.

Table 1 *Recognition of Down syndrome in Hungary 2015–2020.*[9]

Year	**Number of cases**	**Incidence (‰)**	**Live birth**	**Live birth %**	**Prenatally diagnosed interrupted**	**Child-birth, prenatally diagnosed, retained**	**Prenatal recognition ratio %**
2015	159	1.47	78	49	77	3	50.97
2016	197	1.79	68	35	124	2	63.96
2017	199	1.84	99	36	128	0	64.32
2018	237	2.24	88	37	142	1	61.60
2019	312	2.95	96	30.77	204	7	67.63
2020	240	2.23	54	22.5	177	6	76.25

Although the quality of life of people with Down syndrome is improving, no significant improvement has been made in their chances of being born.[10] The birth chance of people with Down syndrome dropped from 49% to 22.5% between 2015 and 2020.

Since the risk of having a child with Down syndrome strongly correlates with maternal age, screening is recommended or is mandatory based on the mother's age.

Table 2 *Down syndrome risk correlation.*

[11]**Mother's age (year)**	25	30	35	40	45	50
Down syndrome risk per birth	1:1350	1:940	1:350	1:85	1:35	1:25

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[9] NPHC, 2022.

[10] A VRONY története, [Online]. Available at: http://www.gyermekalapellatas.hu/vrony/a_vrony_tortenete/a_vrony_tortenete.html (Accessed: 25 November 2024).

[11] Mi az a Down-szindróma? [Online]. Available at: https://u-szeged.hu/szakk/obgyn/down-szindroma-szurese/mi-down-szindroma (Accessed: 25 November 2024).

A definite diagnosis (about 99.5%) can only be made by chromosomal testing of the foetus, but the risk of miscarriage associated with invasive tests (chorionic villus sampling and amniocentesis) is 1–2%. Testing options for Down syndrome that do not carry a risk of miscarriage include ultrasound, biochemical tests on maternal blood, and laboratory methods based on the detection of cell-free foetal DNA. These methods are not diagnostic in nature but they can be used with a relatively high degree of certainty to infer the likelihood of the presence of Down syndrome.[12] The screening method currently considered to be the most effective is the integrated test, which is self-paid. It involves an ultrasound scan around the 12th week of pregnancy and PAPP-A determination from maternal blood. Later, around the 16th week of pregnancy, the maternal blood markers AFP, hCG, free oestriol, and inhibin-A are determined. Testing options for Down syndrome that do not carry a risk of miscarriage include ultrasound scans, biochemical tests of maternal blood and laboratory methods based on the detection of cell-free foetal DNA (so-called NIPT tests).[13]

Table 3 *Down syndrome screening.*

Down syndrome screening method[14]	**Maximum accepted risk**	**Detection rate (DR, hit rate)**	**False positive rate (FPR, false positivity)**	**Positive result for Down syndrome (OAPR)**
Combined test	1:250	83%	4.7%	1:25
Quadruple test	1:250	84%	5.7%	1:30
Integrated test	1:150	87%	1.9%	1:10

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[12] Magzati kromoszóma-vizsgálatok (CVS,amniocentézis), [Online]. Available at: https://gendiagnosztika.hu/chorion-boholy-biopszia-cvs-magzatviz-vizsgalat-ac/ (Accessed: 25 November 2024).

[13] Trisomy-tesztek – iGen NIPT szűrések minden igényre, [Online]. Available at: https://gendiagnosztika.hu/trisomy-teszt/?gclid=Cj0KCQjwtZK1BhDuARIsAAy2Vzv50p3ZCwv9jwcxTaCsK8L0qrVhlGBgN6bPJ3zfn51V_ACdhaeQRTsaAtwVEALw_wcB (Accessed: 25 November 2024).

[14] Wald et al., 2003,

The maximum acceptable risk means that the screening result is considered positive at a higher risk. The detection rate indicates that the method correctly detects Down syndrome foetuses at this rate. A false positive rate indicates that mothers carrying a healthy foetus are as likely to have a positive screening result. Comparing the accuracy and false-positive rates also show that there are very few mothers who keep a foetus despite a positive result in the screening.[15]

4. The first uniformity decision

Screening tests and diagnostics are of particular importance because judicial practice attaches decisive importance to the duty to inform when assessing claims for damages against health care providers. While failure to inform was not a typical ground invoked in the past, it has become a common, even decisive element in malpractice cases over the last decade. Earlier jurisprudence focused primarily on the professionalism and adequacy of medical practice, while current jurisprudence focuses on the verifiability of professional conduct and the importance of the right to self-determination. The reason for this shift lay clearly in the problems surrounding the burden of proof, yet it entails is a disturbing move towards formalism. One significant milestone in the obligation to provide information is the civil law uniformity decision no. 1/2008, which states that

> a child born with a disability resulting from a genetic or teratological defect cannot, in its own right, claim compensation from a health care provider under civil law for the fact that, as a result of the failure to provide medical information or incorrect medical information during prenatal care, the mother was unable to exercise her statutory right to terminate the pregnancy.

Indeed, the Supreme Court, in its Pf.IV chamber, wished to depart from the case law enshrined in several decisions of its Pf.III chamber, according to which, in such cases, the child could bring a claim for damages in her own right against the health care provider. Where the chance for the termination of pregnancy is lost for reasons attributable to the health care provider, the case law is now consistent in recognising the parents’ claim for damages against the institution under the rules of civil liability. According

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[15] NPHC, 2022, especially p. 17.,19. and 23.

to case law, the physician’s unlawful conduct consists in failing to inform the parents that they are likely to have a disabled child, thus depriving them of the right to exercise their right to family planning, to decide whether to have a disabled child or to terminate the pregnancy at an early stage.[16]

> The Act on the Protection of Foetal Life affords parents the opportunity to plan their family and the mother’s right to self-determination is expressed in the fact that she can request the termination of the pregnancy in case the statutory conditions are met. (...) The damage consists in the parents’ life being made more difficult by the existence of a disabled child, the damage being material and non-material, which, monetised, can be passed on to the health institution as a result of the medical negligence.

At this point, it is worth noting Géza Kilényi’s thoughts on the first abortion act.

> The task of secular legislation is to govern the life of society by means of rules of conduct which can be enforced though state coercion. Therefore, secular laws apply to everyone, regardless of denomination. (...) [T]he State must refrain, as far as possible, from coercing its citizens into conduct which would be contrary to their conscientious convictions. It is the inalienable right of every citizen, by virtue of freedom of conscience, to apply to himself a higher moral standard than the State applies to all its citizens, and for this reason not to avail themself of the possibility of an abortion even when the law does not prohibit it.[17]

Thus, on the basis that the legislation provides for the possibility of terminating a pregnancy, the Panel of Uniformity of Law finds that the right of the mother to self-determination and the parents’ right to family planning have been infringed upon when they are prevented from exercising that right by medical negligence or error. However, this does not mean that abortion should be either compulsory or automatic, or that any pressure should be

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[16] Zakariás, 2010.

[17] Constitutional Court Decision No. 64/1991. (XII. 17.) AB.

brought to bear in this context. The Panel of Uniformity of Law points out that in such a case, the proper functioning of the social care system could be the solution. Since in such cases the rules of civil liability cannot apply due to the absence of statutory conditions, the State has a constitutional obligation to maintain a system of institutions that, on the one hand, provides the requisite assistance to the family (the parents) and, on the other, ensures adequate health, educational, and social care and provides allowances directly for those with a disability.

Owing to the judgement referring to ‘life being made more difficult by the existence of a disabled child’, the case law has moved toward awarding the full costs of raising the child in determining the damages. This gave rise to damages awards in the tens of millions of euros. Due to the higher stakes, health care providers started paying more attention to preventing lawsuits, exhausting the full remedy process in cases brought before the courts, and exploiting all means of legal defence. This did not necessarily equate to an increase in the quality of health services, but it certainly meant increased activity of the defendant’s lawyers. Meanwhile, the well-founded civil law uniformity decision No. 1/2008 has, so to speak, taken away the child’s right to compensation, as it is difficult to justify filing a lawsuit for having been born. However, the damages awards for families have not declined; quite the contrary. The resilience of society may be measured in terms of damages awards, in particular, when it comes to health care provider defendants who are already in a precarious financial situation. Privately funded institutions have always found it easier to evade liability, providing information to prospective parents on the margin of error of screening tests, shielding themselves from claims. The increased damages awards for families inevitably bring to mind Jerome Frank’s ideas that the psychological mechanism of forming a judgement does not follow the rules of logic and is therefore not a logical process.[18] Rather, a preliminary decision is made by the judge, who then looks for facts and rules to support it. Should this fail to yield the desired result, the judge then moves on to render another hypothetical judgement influenced by impressions, memories, and personal values.[19] Thus, further guidance from the Supreme Court became necessary on the amount of damages awarded. These cases involved strong emotional elements, and an allowance for divergent case-law would have been a clear indication of judicial uncertainty.

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[18] Lábady, 2010, p. 127.

[19] Ackerman, 1974; Szentes, 2011.

5. The second uniformity decision

The next step was uniformity decision no. 2/2022,[20] which stated that

> if the liability of the health care provider for damages can be established because the mother could not exercise her right to terminate the pregnancy due to the fact that the medical information provided during the prenatal care was not provided or was incorrect, the parents may claim compensation for the additional child-rearing costs incurred in connection with the health impairment, but not for the full child-rearing costs.

The decision itself takes account of the fact that neither the Act on the Protection of Foetal Life nor any other legislation defines the concept of genetic or teratological defect, but in practice, the most common defect is Down syndrome, and there are many cases of limb deficiency or defective limbs. According to the Hungarian Catholic Encyclopaedia, teratology (from the Greek terra, “monster”) is the science of human and animal monstrosities.[21] It is worth recalling here that the term ‘mongoloid idiot’, which had been used when referring to persons with Down syndromes, has almost completely disappeared from use for its derogatory nature.

Uniformity decision no. 2/2022 states that a health care provider is exempt from liability for damages if, through no fault of its own, it failed to recognise the developmental disorder and/or failed to inform the expectant mother of the same, or of the possibility of terminating the pregnancy. The right of self-determination of the mother and the right of both parents to family planning, as recognised in case law, are expressly mentioned in the decision. The question, then, in individual cases will be the damages awarded, and the uniformity decision does not determine their amount, merely the basis for calculation. It is only the dissenting opinions that call into question the justification for awarding damages in such cases. Of course, the fact that a significant part of society has a different moral outlook than what is conveyed by the legal framework makes it difficult to evaluate the situation. However, the court can only base its interpretation on

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[20] Curia Uniformity Decision No. 2/2022. JEH (Jpe.III.60.011/2002/15.).

[21] Magyar Katolikus Lexikon – teratológia, [Online]. Available at: https://lexikon.katolikus.hu/T/teratol%C3%B3gia.html (Accessed: 25 November 2024).

what is laid out by the law. Uniform decisions can only be ensured through the setting of legal standards. It is the legislator's responsibility to weigh the different legislative options, taking account of the legal effects and, naturally, social consequences beyond the realm of the law that inevitably arise from the application of the finally enacted rules.[22] However, responsibility cannot be shifted entirely to the legislator in terms of social consequences, since 'the best law is blind – it is the eye of the judge that makes it see'[23], or, in other words, 'the law is a dead letter on the page until the judge breathes life into it through judgements'.[24]

According to the reasoning of the uniformity decision, the pre-injury situation in the family's life was that the parents were planning to have a child and, like all hopeful parents, were expecting a healthy child. By contrast, the child they had planned and accepted was born with a health problem. Thus, the disadvantage they suffered was due to the fact that their lives were made more difficult by the birth of a disabled child. Therefore, the damage is the additional cost of the child's disability besides the voluntarily undertaken cost of the basic upbringing of the child. The difficulty with the argument is that, of course every parent wants a healthy child, but this is rarely the case. Minor or major health problems emerge both immediately after birth and throughout the course of our life. The duty of the health care provider is therefore to inform the person at increased risk and refrain from making decisions for the person using the health service. It would therefore be appropriate to separate the infringement of the right to self-determination from the subsequent consequences.

The health care provider cannot improve the situation of the foetus, only make it worse. The mother is generally not in the position to weigh the circumstances that even doctors can only describe in terms of probabilities. Without involving and informing the pregnant woman, the doctor examining her should not take it upon themselves to weigh the risks of applying an invasive diagnostic intervention against the risk of not detecting Down syndrome in the foetus, but they should not be weighing the risks shouldered by the parents either, nor should they spare them the burden of

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[22] Kilényi G. dissenting opinion attached to Constitutional Court Decision 64/1991. (XII. 17.) AB.

[23] Darák Péter Elnök Úr köszöntője az „Életutak – pályaképek” címmel rendezett konferencián, [Online]. Available at: https://kuria-birosag.hu/sites/default/files/sajto/dp_koszonto-eletutak_0627.pdf (Accessed: 25 November 2024).

[24] Vavrik, 1910, p. 125., Lábady, 1998, p. 170.

making this decision. On the basis of appropriate information, it is the parents' responsibility to decide whether to accept the proven risk of miscarriage (and the full cost of) invasive testing in case there is an indication that their child may have Down syndrome.[25] The adversity of the situation is that, as explained earlier, mothers who are informed that their foetus has Down syndrome almost always opt for termination of pregnancy, while parents of children with Down syndrome often achieve a good quality of life despite the difficulties.

The person receiving health care has the right to decide, by virtue of their right to self-determination, whether to receive health care and which interventions they consent to or refuse to receive. The fact that a patient gives or denies consent to an intervention in the knowledge of their health condition, the nature of their illness, and the expected course of the disease is ensured by the patient's fundamental right to be informed of their condition at all times. Patients have the right to self-determination based on their right to human dignity, irrespective of the nature of their illness, be it mild or severe, and irrespective of their chances of recovery.[26]

The problem with the duty to inform, however, is that in many cases, it becomes more important than the actual medical activity. The result is that communication skills become the decisive factor in an area where communication is merely of secondary relevance. On the one hand, many people report that they have not been given the correct information when making use of health services, that they have been objectified, or that they could not understand the processes they have been subjected to at all. On the other hand, providing full information takes a lot of energy, and often, it is the essential information that is lost. Parents of children with Down syndrome most often report that the information they received from their health care provider was inadequate. In cases where there is a probability that the foetus has Down syndrome, parents experience very strong pressure to terminate the pregnancy. Where Down syndrome is detected after birth, there is a sense of blame shifting on the part of the health care provider, on the one hand, and an urge to abandon the child, on the other. These processes, which can only be described as unnatural, are largely driven by a fear of liability for damages. Another factor that makes it difficult to provide correct information is that it is almost impossible to draw any conclusions at the foetal stage, but even after birth, about the extent to which Down

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[25] Pécs Regional Court Decision No. Pf.III.20.029/2023/7.

[26] Petkó, 2013.

syndrome will lead to different development of the child. In situations of uncertainty, the health care provider prefers to opt for ‘safe pessimism’.

The Constitutional Court in its Decision No. 64/1991 (XII.17.) AB clearly stated that

> the right to equal dignity, in conjunction with the right to life, ensures that no legal distinction can be made between the value of human lives. The dignity and life of every human being, whatever their physical or mental development or condition, are inviolable.

However, it is in the foetal period that people with Down syndrome are most at risk. They are identified early as a risk through screening. Other health problems and differences in development (e.g. autism) can only be diagnosed much later. A person with Down syndrome is ‘stigmatised’ because of their physical characteristics shortly after birth at the latest. Regardless of their condition, they are surrounded by prejudice. On the positive side, their special education and development can start very early, and their condition can improve significantly. However, special education and development is certainly not something that all families can afford to pay for out of damages awarded. On the one hand, lawsuits are dragged out, and on the other hand, the energy spent on the child is taken away from the parents by the legal battle. Litigation is a battle, but parents instead need support, compassion, and assistance.[27] As a result, the recourse to the courts has the opposite effect than what the real needs of the litigants are. There is a long way to go before we can truly accept life as a value instead of weighing it up in the balance. The following reflections by Dr Éva Vasadi Tersztyánszky, Judge of the Constitutional Court, were written many years ago but still ring true today. The legal protection of life may be expanded in the future (towards a fuller recognition of the rights of the foetus), but any approach that leads to a reduction of the protection of life, formally by reference to the right to self-determination or other rights, but in practice possibly motivated by economic interests, must be firmly opposed. If the legislator were to open the door even a crack towards recognising a

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[27] Döme, 2021, pp. 195-196.

distinction between ‘valuable’ and ‘less valuable’ life, it would lead to unforeseeable consequences.[28]

6. The impact of judicial practice

The evolving judicial practice and, in interaction with it, medical guidelines are moving towards more screening. They are pushing pregnant women towards screening tests that are not meant to cure, but, unfortunately, in the current state of medical science, can offer the primary alternative of killing the foetus.

> Certain segments of specialist medical practice, on the basis of the law aimed at protecting foetal life, also indicate the termination of pregnancy in cases where the diagnosis of a foetal abnormality is unclear or even in doubt for objective reasons, or where the genetic or teratological damage is not serious and the abnormality is no longer medically incompatible with life after childbirth.[29]

The result of a screening test can be reassuring, because a possible negative result may be a relief for parents, while a possible positive result can help them prepare for the birth of a child with an impaired health status or a different development.

A positive result, however, will necessarily lead to a crisis situation. A mother who decides to give birth may experience a completely different quality of pregnancy from the moment the test results are available.[30] The remaining weeks are spent in a tense, emotionally unbalanced state. This emotional imbalance affects the child’s health and mental and spiritual well-being before and after birth. By contrast, in judicial practice, there are no cases where the mother sues after birth because the screening tests wrongly indicated a positive diagnosis but the mother nevertheless gave birth to a healthy child. The psychological background to these situations is understandable, as the parents are grateful that they have escaped something dire. That is why they do not wish to relive the difficult time caused by the

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[28] Tersztyánszky V. É. concurring opinion attached to Constitutional Court Decision 22/2003. (IV.28.) AB.

[29] Benke, 2022, p. 12.

[30] Navratyil, 2009b, p. 224.

diagnostic error. In this fortunate situation, they choose the path of forgetting and have no desire to litigate. While liability for damages or compensation for infringement of personality rights due to the diagnostic error would clearly be well-founded, such cases will still not be litigated. By contrast, cases involving children born with a health defect due to genetic or teratological damage receive much more publicity. The result is that health care providers are more interested in screening. In terms of the potential for error, minimising the risk becomes the priority. This is a way to screen out foetuses that pose a risk of having a health impairment, thereby threatening the liability of the health care provider. In our opinion, this generally results in a large number of children not being born who are labelled as being at risk in their foetal stage. In addition, in many cases, the fate of children born with health problems is not improved by the amount of compensation that is paid to them.

7. Help or burden?

Judicial practice shows that there is an intention to provide help to families experiencing difficulty. This is also confirmed by the last paragraph of PJE 1/2008, as well as the dissenting opinion attached to uniformity decision no. 2/2022 by Attila Döme, joined by András Kovács. Yet the clearest and most legally defensible position is summarised by the dissenting opinion by Mátyás Parlagi. In his opinion, from a legal dogmatics point of view, only two extreme positions are justifiable. He raises the obligation to compensate and identifies adoption as one of the solutions to the damage incurred. His conclusion may be astonishing, but it is possible to glean a solution from it which the author may not have intended.[31]

Compensation is not an option in cases where the health care provider is only responsible for the failure to detect a genetic or other health impairment. Prolonged litigation only serves to deepen the sense of grievance and does not allow for the process of psychological healing to begin. The mother, parents, and family, who are in a difficult situation in other respects, are faced with another overwhelming challenge: the process of enforcing their claim in court. The situation is often not helped by friends, because one of the most common question is: ‘And they didn’t detect it?’ Many people accept the informed risk of carrying a child with a health impairment, while the health care provider, mainly for fear of having

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[31] Curia Uniformity Decision No. 2/2022. JEH (Jpe.III.60.011/2002/15.).

to pay compensation, pushes the mother towards abortion. Some such women give birth to a ‘healthy’ child and remember the incorrect information about the risk as a cause of foetal distress. There are also many who were ignorant and are now grateful for not having known what lay in store, because living the risk is quite different from imagining it. It is hard and full of struggle, often costly, but also one of life’s great gifts.

Attila Döme’s line of thinking also points to a serious logical flaw in compensation litigation. He emphasises that judicial practice often hears cases in which parental claims are found to be unfounded, such as in the mild cases of Down syndrome, or where there is ‘merely’ an absence of a limb, or perhaps only some degree of impairment, which can even be medically corrected to some extent; in other words, cases in which the parents’ behaviour and personality make it highly probable that they would not have decided to terminate the pregnancy in the knowledge of this harm but they claim that they would have done so in order to improve their family’s financial situation.

It can be seen that, while the violation of the right to self-determination and family planning is cited as the basis for claiming damages, there is a backwards-looking inference.[32] The mother is able to exercise her right to self-determination when she is still necessarily lacking information, with the health care provider avoiding the risk. At this stage, it is not possible to foresee the disadvantages and difficulties that will arise later. The mother’s right to self-determination is violated at that moment, not when she has already given birth and her child’s mild or more serious condition becomes apparent. Her love for the child or the costs incurred are unrelated to the severity of the child’s condition. It is the information received during pregnancy that is considered relevant form the perspective of the right to self-determination. Unfortunately, even this approach is one-sided. No data have been collected on how many unborn children could have been found to have neither genetic nor teratological harm.[33] There are certainly many stories where predictions have been proven wrong, and a mother’s right to self-determination cannot be evaluated on the basis of how her life circumstances have developed after childbirth. If she loved her unborn child and is happy about its subsequent birth, she is not entitled to compensation, but if she honestly believes that she would have preferred to

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[32] Navratyil, 2009a, p. 331; Navratyil, 2019, p. 50.

[33] Benke, 2022. p. 12.

abort the child, she is entitled to it.[34] What are the social implications of this thinking? What sort of family benefits from the compensation awarded?

The judicial practice ensuing from this legislative environment has also recognised these contradictions, but so far, the Constitutional Court has not taken a position on the issue for formal reasons. A Metropolitan Court judge submitted a petition to the Constitutional Court asking it to declare Article 6(3) of the Act on the Protection of Foetal Life to be unconstitutional and to annul it, as the relevant legislative provision violates Article II and Article 28 of the Fundamental Law.[35] The dissenting opinions attached to the order dismissing the petition[36] show that the problem has been detected, but relevant responses have not yet been found. For example, Béla Pokol did not support the dismissal because the judicial petition referred to a too-broad formulation of the challenged legal provision, which created the possibility of violating the protection of foetal life. Pokol underlined that this must be opposed by the Constitutional Court in order to protect Article II of the Fundamental Law. He wrote that the basis of the challenged provision, the overly broad possibility to terminate a pregnancy, renders the deprivation of foetal life unconstitutional and that the Constitutional Court may counteract this either by annulling the provision, by declaring a constitutional omission, or by foreseeing a constitutional requirement regarding the binding interpretation of the provision guiding its application, pursuant to Article 46(3) of the Constitution. Given that dozens of foetal lives are lost every year as a result of the overly broad formulation of the provisions on the termination of pregnancy, Pokol is of the view that a decision on the merits would have been justified. Balázs Schanda (joined in his dissenting opinion by Ildikó Hörcher Marosi) pointed out that the damages action has a strong constitutional background: how far does the mother's freedom of choice extend, and what obligations does the legislator have to protect foetal life? In his opinion, the legal background governing the termination of pregnancy, in itself a contradictory assessment of teratological harm, serious disability, and other harm, should have been subject to constitutional review. The enormous progress in medical diagnostics and premature infant care that has taken place over the decades since the adoption of the Act on the Protection of Foetal Life should also have considered. The dissenting opinion of judge Marcel Szabó draws

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[34] Hensel, 2005, p. 142

[35] Metropolitan Court Decision No. 8.P.24.175/2017/82.

[36] Constitutional Court Order No. 3112/2021. (IV. 14.) AB.

attention to the fact that currently, in most cases, a child can be viable even at a premature birth following just 24 weeks of gestation. He therefore considered it necessary, in the event of a substantive review, to examine whether a yes-or-no type of diagnostic answer in the case of foetuses that are already viable outside the womb would even be constitutionally acceptable to authorise and conduct a medical intervention to terminate the pregnancy.

8. Summary, solutions

There are several contradictions when it comes to the compensatory approach. Most strikingly, the condition of the child and the costs associated with it fall into the category of prediction. The greater the damage to the child, the more severe his or her condition, the less chance there is for improvement, which may even mean that the costs of raising the child may actually turn out to be lower. Conversely, the costs associated with raising a child with mild Down syndrome (with little information available at the time of screening or genetic testing) can be very high. A lot of money may be spent precisely to enable them to live a full life, to be as self-sufficient as possible, to be a useful member of society. Is it worth it? It is always worth it. But the situation in Hungary is not evolving towards the protection of life.

Torstein distinguishes three methods of dispute resolution: mediation, adjudication and administration. For him, the administrator is concerned with the administration, with state subsidies.[37] In this conflict situation, judicial settlement, like mediation, is ineffective. Rather, it is support and assistance that is necessary and appropriate to resolve the situation.[38] Compensation would be appropriate at most if there were a separate sanction for failure to provide information. It should be acknowledged that the legal consequences are not visible at the time the obligation to inform arises. The breach could therefore be sanctioned separately. From the point of view of the right to self-determination, whether a person lovingly brings up a child with a different development or puts a child in an intolerable situation by placing them in state care or gives them up for adoption is obviously irrelevant. It would be hard to say which decision is more difficult.

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[37] Eckhoff, 1979.

[38] Navratyil, 2023, pp. 67-68.

It would also help if state allowances would be improved to at least reach the level of support foreseen under the legislation. There should not be a constant struggle to secure the minimum result. The best solution would be to strengthen the role of NGOs dealing with problematic situations. The protection of life could be more effective if mothers who find themselves in difficult situations were not merely confronted with medical aspects but also received information on other solutions. They should be able to gain insight into the lives of people who have learnt to smile in spite of their difficulties. The solution is to give more space and acceptance and to increase support and assistance.

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