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Freedom of research and the right to science: from theory to advocacy

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Although the right to science, which includes both the right of scientists to do research and the right of everyone to benefit from that research, was recognised internationally as early as 1948, it is arguably the least known, discussed and enforced international human right. As a result, its binding normative content is not settled and needs to be better clarified and specified. Progress at the conceptual level has been made in the last few years but we are still far from a full understanding of this right and its normative content, and from having a cohesive and authoritative list of duties that states must abide by to fully realise the right.

In this chapter, we argue that legal and political mobilisation in international forums provides promising paths to further define the normative content of the right to science. Waiting for the theoretical debate on the right to science to settle before seeking its protection would delay its realisation. Mobilisation through advocacy and litigation can provide both a remedy to victims of violations in specific cases and cause the development of a body of opinions and other policy outcomes which can contribute, with authority, to defining the content of the right.

In the first part of this chapter, we map out the recognition of the right to science under international law, both at the global and regional level. We then look at important international developments, and in particular, the work of the United Nations Special Rapporteur on Cultural Rights, and the emergence of an academic debate on the right to science. We then turn to legal and political strategies to mobilise the right to science. By 'legal mobilisation' we mean the use of courts and tribunals (i.e. judicial remedies) to seek vindication of the right to science for violation of this right. We identify international judicial and quasi-judicial institutions that have jurisdiction over violations of this right, and discuss the procedural requirements and some of the challenges claimants face. With regard to 'political mobilisation', we identify venues where human rights advocates, scientific societies and other civil society organisations could push for the realisation of the right to science. At the global level, we identify opportunities

for political mobilisation in connection with the United Nations Human Rights Council's Universal Periodic Review, the State Reporting Procedures and the Special Mandates. Finally, we identify opportunities at the regional level.

Legal recognition of the right to science

The right to science is as old as international human rights. It was recognised first in 1948, in the Universal Declaration of Human Rights, the keystone of the international human rights architecture. Article 27 of the Universal Declaration of Human Rights provides that:

> (1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
> (2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

This right found further recognition in 1966, in the International Covenant on Economic, Social and Cultural Rights (ICESCR), a multilateral treaty adopted by the United Nations General Assembly (in force from 3 January 1976). Under Article 15:

> 1. The States Parties to the present Covenant recognize the right of everyone:
> (a) To take part in cultural life;
> (b) To enjoy the benefits of scientific progress and its applications;
> (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.
> 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science and culture.
> 3. The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research and creative activity.
> 4. The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields.

The combined reading of these two provisions provides the legal foundations of what is now commonly referred to as the 'right to science' (Besson 2015: 404), or, less succinctly, the 'right to enjoy the benefits of scientific and technological progress and its applications'.

Various legal instruments at the regional level also recognise the right to science. In Europe, there is no reference to the right to science either in the European Convention on Human Rights (1950) or in the European

Social Charter (1961; revised 1996), two of the most important human rights treaties in Europe. However, at least as concerns the European Union, this lacuna was filled in 2000 with the adoption of the Charter of Fundamental Rights of the European Union, which provides that scientific research shall be 'free of constraint'.

In the Americas, one can find several relevant provisions in the Charter of the Organization of American States (1948), the most relevant being Articles 17, 30, 34.i, 38, 45, 47 and 51. It is also mentioned in Article XIII of the American Declaration of the Rights and Duties of Man (1948, which provides that '[e]very person has the right . . . to participate in the benefits which result from intellectual progress, especially scientific discoveries'. Finally, it is mentioned in the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights ('Protocol of San Salvador', 1988), which requires states to recognise the right of everyone 'to enjoy the benefits of scientific and technological progress' (art. 14.1.b) and 'extend among themselves the benefits of science and technology by encouraging the exchange and utilisation of scientific and technological knowledge' (art. 38).

In Africa, the Charter of the African Union (1963) identifies scientific and technical cooperation as essential for meeting its goals (art. II (2)), and the Protocol on the Rights of Women in Africa of the African Charter on Human and Peoples' Rights (2003) requires states to take specific measures to promote education and training for women, particularly in the fields of science and technology (art. 12 (2)(b)).

In the Arab world, the Arab Charter on Human Rights (2004) recognises the right of everyone 'to take part in cultural life and to enjoy the benefits of scientific progress and its application', together with the obligations of states to

> respect the freedom of scientific research and creative activity . . . ensure the protection of moral and material interests resulting from scientific, literary and artistic production . . . enhance cooperation at all levels, with the full participation of intellectuals and inventors and their organisations, in order to develop and implement recreational, cultural, artistic and scientific programmes. (art. 42)

Finally, in South East Asia, the ASEAN Human Rights Declaration (2012) provides that every person has the right, individually or in association with others, to freely take part in cultural life, to enjoy the arts and the benefits of scientific progress and its applications and to benefit from the protection of the moral and material interests resulting from any scientific, literary or appropriate artistic production of which one is the author (art. 32).

International initiatives

Although the right to science has been recognised under international law since 1948, international, regional and national bodies, as well as human

rights activists and scholars, have paid little attention to it. As a result, our understanding of the normative content of the right to science – that is, what exactly are states' obligations – is not entirely settled. However, in the past two decades the right to science has moved to the front and centre of the debate in international forums, and progress towards a more complete understanding of this right has been tangible. Two developments, at the global level, are particularly significant: first the adoption, under the auspices of UNESCO, of the Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications ('Venice Statement', 2009); and, second, the appointment by the Human Rights Council of a Special Rapporteur in the field of Cultural Rights, whose mandate also includes the right to science.

The Venice Statement was the outcome of a 2009 meeting sponsored by UNESCO aiming at 'clarifying the normative content of the right to enjoy the benefits of scientific progress and its applications and generating a discussion among all relevant stakeholders with a view to enhance the implementation of this right'. The Venice Statement makes two significant contributions. The first is to spell out the three duties which states parties to the ICESCR have: the duty to respect, to protect and to fulfil. 'Respecting' means guaranteeing the freedoms which are necessary to do science (e.g. autonomy, freedom of speech, freedom to assemble in professional societies and to collaborate). 'Protecting' means ensuring that science is not done by infringing upon the rights of anybody (e.g. research subjects, vulnerable populations). 'Fulfilling' calls for a variety of strategies including monitoring harms arising from science, enhancing public engagement in decision-making about science and technology, ensuring access to the benefits of scientific progress on a non-discriminatory basis, and developing science curricula at all levels of schooling. Second, the Statement points out that it is also incumbent upon non-governmental actors (e.g. scientific societies, for-profit entities, civil society) to contribute to the realisation of the right to science. The Statement touches upon the issue of the privatisation of science and how it could conflict with the right to science.

The second significant development at the global level is the United Nations Human Rights Council's decision to give a Special Rapporteur a mandate on cultural rights, including the right to science (Resolution 10/23). The first appointee was the Pakistani sociologist Farida Shaheed, and the current one is the Algerian-American law professor Karima Bennoune. In 2011, Farida Shaheed visited several UN members and organised a public consultation in Geneva under the auspices of the Office of the United Nations High Commissioner for Human Rights. Member states' civil society organisations were asked to fill out a questionnaire that the Special Rapporteur later used in her report, entitled 'The right to enjoy the benefits of scientific progress and its applications', released in 2012 (United Nations 2012).

This report is a fundamental contribution to the field as it discusses the right to science from different angles: its normative content, state obligations and its limitations. With regard to the normative content, the report makes

four contributions. First, it connects the right to science to the right to participate freely in the cultural life of the community as recognised by Article 15 of the ICESCR. Article 15 entails the right to contribute to science (as knowledge producers) and enjoy opportunities to participate in decisions about science (as citizens). The report further maintains that the right should be enjoyed free of discrimination. Second, it stresses the importance of freedom of research as a prerequisite of the enjoyment of the right to science. In fact, the ability to 'continuously engage in critical thinking about themselves and the world they inhabit, and . . . the opportunity and wherewithal to interrogate, investigate and contribute new knowledge with ideas, expressions and innovative applications, regardless of frontiers' are prerequisites for implementing both rights (para. 18). Third, it connects the right to science to the concept of human dignity to the extent that the right protects people's 'ability to aspire – namely, to conceive of a better future that is not only desirable but attainable' (para. 20). Aspirations, the Rapporteur notes, 'embody people's conceptions of elements deemed essential for a life with dignity' (para. 20). Fourth, it identifies links to other rights. In some cases, the right to science is enjoyed in conjunction with other rights, such as the right to seek information, to take part in the conduct of public affairs, to self-determination, to development, and to make informed decisions (paras 21–2). The right to science is also a prerequisite for the realisation of other rights, namely the right to food, health, water, housing, education and a clean and healthy environment (para. 23).

The second part of the report focuses on the normative content and related obligations of states. In this section, the Rapporteur proposes a list of objectives which states must guarantee: access by all without discrimination; freedom of scientific research and opportunities for all to contribute to the scientific enterprise; individual and collective participation in decision-making; and an environment which enables knowledge production and exchange.

The last section of the report discusses the limitations of the right to science. The Rapporteur points out that limitations certainly arise from the very same body of human rights law and, thus, it must promote general welfare and be proportionate to the objective (para. 49). The regulation of research subjects provides an example of a justifiable limitation of the right to science (para. 51). More controversially, the Rapporteur also cites the precautionary principle as an important guide for science and technology policies in the absence of scientific consent such that a certain sense of caution would not cause irreparable harm to the public or the environment (para. 50).[1]

Academic debate

The academic debate has mainly taken place between a handful of scholars whose work primarily focuses on refining the theoretical framework for

thinking about this right and defying its place in human rights law. Schabas (2007) argues that states must respect scientists' freedom to conduct research, build facilities for research, preserve minorities' cultural rights and protect the rights of indigenous peoples. Chapman (2009) identifies three rights: to access the benefits of scientific progress and technology without being discriminated against; to be protected from the harmful effects of science and technology; and to protect individuals' intellectual property. Muller (2010) argues that states must create 'an institutional framework and [adopt] policies and laws in relation to science and technology that enable individuals to freely conduct scientific research, to access the benefits of scientific progress and to be protected against the harmful effects of science and technologies'. After tracing the historical emergence of the right (Shaver 2010), in her later work Shaver (2015) interprets the right to science as a call to frame science as a public good. This implies that 'the supply of scientific knowledge and the development of technology is must not be left entirely – or even primarily – to market forces' (Shaver 2015: 417). Shaver also proposes a 'pragmatic approach' to defining the normative content of the right, which requires being 'responsive to the particular challenges and issues of the time' (2015: 427). Using the treaty interpretation methods described in the Vienna Convention on the Law of Treaties, Donders (2011) argues that the inextricable link between the right to science and the right to health determines the positive and negative obligation of states.

Scholars have also begun investigating what implications for policymakers can be derived from applying the human rights framework to the analysis of those issues. Knoppers et al. (2014) frame their proposal for an international code of conduct enabling global genomic and clinical data sharing for biomedical research with reference to the right to science and the right to the protection of the moral and material interests resulting from scientific productions. Gran et al. (2014: 344) explore children's rights through the lens of the right to science and, after showing that indicators reveal dramatic differences in children's conditions across and within countries, argue that the right to science has the potential to address some of these inequalities by leading to 'improvements in young people's health and well-being, to greater participation in their communities, and to stronger legal protections, among other advances'. Skre and Eide (2013) connect the right to access to open access to scientific knowledge. Harris and Wyndham (2015) urged that data sharing must take into account human rights considerations, arguing that data is both a tool of scientific inquiry, to which access is vital, and a product of science, from which everyone should benefit. Vayena and Tasioulas (2015) propose using the human right to science as a promising, proper framework to develop policies in the area of citizen science.

While academic discourse has primarily developed through scholarship, various initiatives and conferences have looked at the right to science. An important initiative, focusing primarily on the United States, is led by the American Association for the Advancement of Science (AAAS). In 2009,

the AAAS started a programme devoted to mobilising science and scientists to advance human rights. The project has produced important outcomes which include building a database of state reports to the UN on the implementation of the right to science (AAAS 2017a); creating the AAAS Science and Human Rights Coalition; publishing a study (authored by Margaret Weigers Vitullo and Jessica Wyndham (AAAS 2013)) on how scientists in the United States perceive the meaning and application of the right; and the Science and Human Right Report on a monthly basis (AAAS 2017b).

All of these international initiatives and scholarly works are welcome and very promising. However, in spite of all these initiatives and documents, the contours of the 'right to science' remain ill defined. It remains unclear how it should be understood, what rights society, individuals and scientists exactly have, and what the corresponding duties of the states are. To advance the debate, we argue that conceptual clarity can also be achieved via mobilisation of the right, that is to say, use of the judicial and political forums where the right can be invoked.

Mobilising the right to science: realising the right to science through judicial mobilisation

The judicial path entails bringing claims before international judicial and quasi-judicial forums against states whenever the right to science is violated. The most promising forum at the global level is the individual complaints procedure of the Committee on Economic, Social and Cultural Rights (ESCR Committee) (Forman 2016). While still in its infancy (the mechanism was established in 2008 and started operating in 2014), this tool is attractive because the committee's decisions on the right to science are, arguably, authoritative interpretations of the provision of the ICESCR (1966). These decisions will help build the body of law on this matter. The procedure requires individuals or groups of individuals to file a communication (i.e. complaint) with the committee, alleging violations of the ICESCR by a state which has ratified both the committee and the Optional Protocol (2008). Decisions made by the committee are not legally binding but, if the committee finds for the victim, its decision will contain a finding of law as well as recommendations to the state in question on how the violations should be remedied. In addition, the case will remain under consideration until satisfactory measures are taken by the state party.

Mobilisation may also involve judicial and quasi-judicial bodies at the regional level. The Court of Justice of the European Union can hear cases arising from violations of the Charter of the Fundamental Rights of the European Union. A major limitation of this process is that the Court of Justice of the European Union can only hear claims for violations committed by an institution, body, office or agency of the European Union, not by member states. Cases could also be brought in the inter-American human rights system by activating the Inter-American Commission on Human Rights,

and perhaps even the Inter-American Court of Human Rights. Questions of violations of the right to science could be brought before the commission on the basis of the OAS Charter, American Declaration and Protocol of San Salvador. As in the case of the ESCR Committee, decisions of the Inter-American Commission are not binding but help build the body of law. The right to science could also be invoked before the Inter-American Court of Human Rights, a body whose decisions are binding by its interpretations of rights within the American Convention of Human Rights, over which the court has jurisdiction. (While the court's jurisdiction over the Protocol of San Salvador is limited to the right to education and the right to form trade unions, the right to science could be brought up via Article 26 of the American Convention.) Judicial mobilisation in regional bodies could target laws and regulations of states which prohibit or unreasonably restrict the freedom of scientific research, for instance as in the case of bans on research on embryos or with human–animal hybrids.[2] In addition, they could target restrictions to data sharing or access to genetic resources, and measures unreasonably limiting scientists' freedom to communicate research results, to join professional associations, to collaborate with foreign scientists or to travel internationally.[3] Some limitations are in fact acceptable as long as they 'pursue a legitimate aim, [are] compatible with the nature of this right and [are] strictly necessary for the promotion of general welfare in a democratic society' (United Nations 2012: 13, citing Article 4 of the ICESCR 1966).[4] Finally, they could challenge policies excluding marginalised populations, such as indigenous peoples, from public consultations, participation in clinical trials or membership in academia (United Nations 2012: 12).

One indirect avenue to litigate the right to science is through the right to health. The right to health is better established and recognised by more legal instruments than the right to science. A greater number of international adjudicative and quasi-adjudicative bodies can consider cases of violation of this right. Thus, besides the judicial and quasi-judicial forums listed above, the right to health can also be invoked before the European Committee of Social Rights, which reviews the Council of Europe's member states' compliance with the European Social Charter (1961, revised 1996). It should be noted that only NGOs, and only certain kinds of NGOs, and not individuals have standing before the European Committee of Social Rights. Although the European Convention on Human Rights (1950) does not guarantee a right to health, over the years the European Court of Human Rights has been called upon to consider cases having a socio-economic dimension, including health – such as questions relating to medical negligence, health and bioethics, detainees' rights, health and immigration, and health and the environment – while discussing one or more fundamental civil and political rights guaranteed under the Convention. Mobilisation advancing the right to science through the right to health could focus on policies which disregard scientific evidence in setting access to treatment and cures.

In fact, patients' right to health includes the right to access treatments and cures which are based on the best possible scientific evidence. Their human rights to health and to science would be violated, for instance, when vaccines that are proven to be both safe and effective are banned. The right to science further requires states to enable downstream use of scientific knowledge and to 'promote the transfer of technologies, practices and procedures to endure the well-being or people' (United Nations 2012: 20). The right is violated when drug or biotech companies are prohibited from developing products applying scientific knowledge.

Cases can also be brought before the African Court on Human and Peoples' Rights, which has jurisdiction over cases involving the interpretation and application of the African Charter on Human and Peoples' Rights (1981), the Protocol and any other relevant human rights instrument ratified by the states concerned.

At the global and regional levels there are several bodies which could be used by scientists, citizens and advocacy groups to challenge violations of the right to science. These 'judicial methods', however, present general challenges besides those discussed above for each procedure. First, cases can be brought only if a state party to the treaty defers to the court's or committee's jurisdiction. Not all states have ratified both the ICESCR and the Additional Protocol, creating an Individual Communications procedure. By September 2016, only twenty-six states parties had ratified both. Likewise, not all countries have ratified regional instruments and/or accepted the jurisdiction of the regional courts. Second, claimants can file a claim with a supranational body only after domestic remedies have been exhausted. This process can take several years, if not decades. Third, claims must concern the violation of the rights of one or more named individuals. Cases cannot be based on general assertions that state members are violating the right to science – for instance, by enacting a law banning certain forms of scientific research. Cases are viable only if the law interferes with the enjoyment of the right to science of a specific victim, and those victims must consent to have their case brought before an international jurisdiction. Fourth, as for any legal proceedings, complaints must be filed within a certain amount of time after the violation has occurred. Otherwise legitimate cases cannot proceed if the time frame for filing them has passed. Finally, legal proceedings in supranational courts and bodies are often slow. This is due to the number of cases brought before these bodies every year and the insufficient resources available to process them expeditiously.

Realising the right to science through political mobilisation

The second path to mobilisation is to exploit the opportunities offered by the political processes of international institutions. There are opportunities for political advocacy at both the global and regional levels. Within the United Nations, under the Universal Periodic Review (UPR), all UN member

states must submit a report every five years to the UN Human Rights Council describing how they have discharged all of their international human rights obligations. The procedure covers all human rights, independently of whether the state in question has ratified any given international human rights treaty. On average, each year forty-two states are reviewed during the sessions of the UPR Working Group, which meets three times a year. Human rights experts and groups are formally recognised as important stakeholders that can submit information, which the Working Group can then use as part of its review. Experts and groups can also make statements at the regular session of the Human Rights Council, when the outcome of the state reviews is considered. Although the UPR is still looking for a precise identity (Cowan and Billaud 2015), the potential for advancing the human rights agenda is substantial. In fact, the UPR intends to provide technical assistance to states and enhance their capacity to effectively deal with human rights challenges. Even more important to the present discussion, the UPR includes a sharing of best human rights practices. With regard to the right to science, the UPR process has the potential to help further define the normative content of the right to science.

A similar mechanism is the reporting procedure of the Covenant on Economic, Social and Cultural Rights. In addition to the judicial process discussed above, the ESCR Committee reviews reports that states parties file periodically to update the committee on the what they have done to implement the Covenant. The committee examines each report, addresses its concerns and makes recommendations to the state party in the form of 'concluding observations'. As part of this process, NGOs can submit 'shadow reports' which bring to the attention of the committee facts which are relevant to their review of state parties. Representatives of accredited organisations can also attend the committee's sessions and make an oral presentation, and organise lunchtime briefings and other informal meetings during the sessions.

A broad range of less formal opportunities to contribute to shaping the human rights agenda and discussion at international bodies is also available to human rights advocates. One such opportunity is engaging the Special Rapporteur in the field of cultural rights in a discussion on the right to science. Organisations and individuals can submit reports and individual communications which point to violations of the right to science. The Rapporteur can then raise the issue with member states. In addition, human rights advocates can participate in UNESCO's discussions involving science, and in particular working groups which focus on different aspects of the right to science.

International organisations at the regional level also offer opportunities for participation in their activities. In these forums, political mobilisation takes both the form of lobbying and direct participation in working groups and debates. In Europe, science and human rights advocates can work with members of the European Parliament and those of the Parliamentary Assembly

of the Council of Europe to facilitate discussions and present policy proposals promoting the right to science.

In the Americas, advocates have the option to work with various institutions. The first is the General Assembly of the Organization of American States, whose meetings are held annually. The Summit of the Americas encourages civil society representatives to participate by providing recommendations on thematic areas to the member states and assisting in the implementation of initiatives in the development of an agenda for the region. Also, the Inter-American Commission on Human Rights has created a Secretariat on Access to Rights and Equity and can establish working groups to focus on various aspects of the right to science.

In Africa, advocates can participate in the periodic reviews of the African Commission on Human Rights and the summits of the African Union. Similar to the reviews conducted by the Committee on Economic, Social and Cultural Rights, the African Union mandates that states parties submit two-yearly reports to the African Commission on Human and Peoples' Rights, describing legislative and other measures they have taken in giving effect to the rights and freedoms recognised and guaranteed by the Charter. Among them is the right to science. To this end, African Union guidelines require states parties to report on the right to science by submitting information on 'laws, administrative regulations, collective agreements and court decisions' relevant to the promotion of the right

> measures taken to ensure the application of scientific progress for the benefit of everyone . . . to promote the diffusion of information on scientific progress [and] to prevent the use of scientific and technical progress for purposes which are contrary to the enjoyment of all human rights [as well as] any restrictions which are placed upon the exercise of this right, with details of the legal provisions prescribing such restrictions. (African Union 1989)

Looking to the future of the right to science

While recognised in 1948 by the Universal Declaration of Human Rights, the right to science was almost forgotten for half a century and, to borrow from Chalmers et al. (2014), it has been 'resuscitated' only recently. As a result, the normative content of this right is not yet sufficiently clear and there is no consensus on states' duties on this right. International initiatives and scholarly work are broadening the boundaries of our understanding of what the right to science entails, and what it takes to fully realise it. All are welcome developments, but we believe that it is also paramount to work on the realisation of this right from the bottom-up, through mobilisation and use of judicial and political tools. Judicial mobilisation has the potential to promote the realisation of the right to science in two ways: by addressing and redressing specific violations of the right and by obtaining formal pronouncements of supranational bodies which contribute to defining the

normative content of the right. Political mobilisation can help states focus their attention on this much-neglected right and create the space for a debate between states and between states and civil society which can promote and advance freedom of scientific research.

Mobilisation certainly faces challenges. We have discussed some procedural and political challenges. These challenges are neither negligible nor insurmountable. To promote mobilisation, it is important for academia, scientific societies and human rights advocacy groups to establish a network aimed at monitoring state actions which may be in violation of the right to science, and to develop expertise for claims based on the right to science to emerge.

Judicial and political mobilisation will not only contribute to our understanding of this right and defining its normative content, but will also ensure that states incorporate this right into their policies and respect it. The hope is that, eventually, the right to science will be fully realised. As the Special Rapporteur argued, this entails living in a world in which national laws and regulations ensure that all humans have freedom to participate to the scientific enterprise, to enjoy the benefits of science, to participate in decisions relating to science and to live in a world which fosters the development and diffusion of scientific knowledge (United Nations 2012: 19–22).

Notes

1 For further discussion of the precautionary principle, see Chapter 14 in this volume.
2 Several states prohibit the derivation of embryonic stem cell lines. According to EuroStemCell (2017), this is the case in Austria, Germany and Italy.
3 For a discussion of the right to science as the freedom to contribute to the scientific enterprise, see United Nations (2012: 12).
4 For a discussion of reasonable limitations to freedom to publish scientific data, see Chapter 6 in this volume.

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