

The Israeli children who are suing for being born

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Wrongfully alive? (Image: [Stretch/Iconica/Getty](#))

ISRAELI children with birth defects are increasingly suing the medical authorities for ever allowing them to be born. The rise in such "wrongful life" lawsuits, which the medical profession estimates at 600 since the first case in 1987, has prompted an investigation by the Israeli government.

According to medical ethicists contacted by *New Scientist*, these cases raise serious ethical questions – not least concerning the value of the lives of disabled people – and raise fears that medical professionals may become overly cautious in their interpretations of diagnostic tests, resulting in terminations of healthy pregnancies. One ethicist also claims that lawyers looking to drum up business are trawling communities with high rates of inbreeding and genetic disease.

"Wrongful birth" cases, in which parents seek compensation for the costs of raising a disabled child, are well documented. Last month, a couple in California won \$4.5 million in damages after doctors and sonographers failed to pick up that their son, now aged 3, had no legs and only one arm.

"I find it very difficult to understand how parents can go on the witness stand and tell their children 'it would have better for you not to have been born'," says [Rabbi Avraham Steinberg](#), a medical ethicist from the Hebrew University-Hadassah Medical School in Jerusalem. "What are the psychological effects on the children?"

The trend in Israel is now for the children themselves to sue for wrongful life, which generally carries a bigger award designed to compensate for a lifetime of suffering. Steinberg sits on the Matza committee – named after the judge chairing it – set up by the government to investigate the issue. He has also been an expert witness in such cases.

One of the first successful wrongful life cases was brought before the California Court of Appeal in 1980, when a child sued for damages for being born with a neurodegenerative condition called [Tay-Sachs disease](#). In Israel the rate of lawsuits has been rising since a legal precedent was set there in

1987, whereas wrongful life litigation is not accepted in many other countries, including the UK and all but four US states.

The problem is exacerbated in Israel by a very strong pro-science, pro-genetic testing culture. "There is an entire system fuelled by money and the quest for the perfect baby," says [Carmel Shalev](#), a human rights lawyer and bioethicist at the University of Haifa in Israel. "Everyone buys in to it – parents, doctors and labs. Parents want healthy babies, doctors encourage them to get tested, and some genetic tests are being marketed too early. Genetic testing has enormous benefits but it is overused and misused."

The popularity of these tests is in part due to the fact that genetic disorders such as Down's syndrome, deafness and cystic fibrosis are prevalent in Israel because of high rates of consanguineous marriage– unions between second cousins or closer relatives. Many settlements were founded only a few generations ago by a handful of people, and marriage within villages means that couples end up effectively marrying within their extended family (see "[Risky relationships](#)").

Since we all carry a smattering of defective genes, marrying a blood relative increases the risk of autosomal recessive disorders, in which two healthy partners – each carrying a single faulty copy – produce a child who inherits the double whammy of two defective copies.

A common example within ultra-orthodox Jewish communities is Tay-Sachs disease, which manifests itself in people carrying both faulty copies of the gene. If both parents carry a single copy, children have a 1-in-4 chance of having the disease.

Couples at high risk have the option of being screened before making the decision to marry or try for children. In Israel, in particular, a wide range of prenatal testing is offered by the state. Private genetic testing is also extremely popular with Israeli couples, and it is permissible there to terminate viable pregnancies due to health reasons, with permission from an abortion committee. Asaf Posner, a prominent medical malpractice lawyer in Jerusalem, says he has dealt with families who, despite being very religious, had been given special dispensation by religious elders to abort a fetus suspected of having cystic fibrosis – a decision which would almost certainly have been approved by the committee.

In the past five years, Posner has won wrongful life cases on behalf of children with cystic fibrosis and spina bifida, and says typical payouts are in the region of 4.5 million shekels (£775,000). He reckons a forthcoming ruling on a fragile – X syndrome case could potentially bring in 10 million shekels (£1.7 million).

Following a handful of wrongful life lawsuits in the past year, the [Israel Society of Obstetrics and Gynecology](#) advised the country's Supreme Court that not every undetected birth defect should be the basis of a malpractice suit. Extreme learning difficulties or around-the-clock assistance with basic tasks such as eating and going to the toilet, for example, should not be equated with milder impairments such as missing fingers.

Without such distinctions, clinicians and sonographers who fear being sued over the birth of a disabled or diseased baby might become over – cautious in their risk assessments, leading couples to

abort healthy fetuses. "Physicians are increasingly practising defensive medicine, and doing a lot of testing," Steinberg says. "But more testing means more false positives – and that means more abortions, because geneticists don't always know if results indicating the possibility of chromosomal abnormalities are meaningful. I'd like to see a study of aborted fetuses to see how many are diseased." The Matza committee will submit its findings in the next few months.

Speaking at a genetics conference in Jerusalem last month, organised by the [Anglo-Israel Association](#) charity, Steinberg also voiced concerns that some lawyers are seeking to exploit the high rates of genetic defects in some communities by trawling them for cases. "To go to these villages and look around for people willing to file a claim that it would have been better not to be born is going too far," he said.

Posner, who also sits on the Matza committee, reckons only a small number of cases exist as a result of rogue lawyers targeting villages with high rates of inbreeding. He says most of his own clients are Jewish couples who feel they have been let down by the medical profession following genetic testing.

"Doctors gain a tremendous amount of money from prospective parents paying for private tests, such as ultrasound," Posner says. "They shouldn't complain when, if they are negligent, someone comes after them. Without criticism, the medical profession would become corrupt."

Risky relationships

Israel is home to a diverse population of traditional communities with high rates of consanguineous marriage (between second cousins or closer relatives). Among Muslims and Druze, it accounts for around 40 per cent of marriages, among the Bedouin 67 per cent, and among Christians about 20 per cent.

But Israel is not alone: consanguinity is common in the Middle East, India and North Africa. According to [Joel Zlotogora](#) of Israel's Ministry of Health, kinship marriage also carries advantages: it strengthens social ties and lowers rates of domestic violence and family breakdown.

Zlotogora, who has documented Bedouin villages with genetic conditions caused by inbreeding, told the Anglo-Israel Association: "Our message is not 'Don't marry your cousin' but 'Marry your cousin and know the risk'." The ministry offers genetic screening and testing for at-risk communities.

That sentiment is shared by [Dian Donnai](#), a geneticist at the University of Manchester, UK, who has worked with the UK's Pakistani Muslim community, where 55 per cent of marriages are between first cousins. "We are not there to influence people," Donnai says. "We give people the genetic information they need in order to make the right reproductive choices for them," she says.

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