Editorial

‘Wrongful life’ claims

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A child with a genetic defect should be legally entitled to sue a genetic counsellor for “wrongful life” in cases where, but for the counsellor’s negligence to the child’s parents the child would not have been born at all, argues Professor Amos Shapira in this issue of the journal.¹ Professor Shapira, an eminent Israeli academic lawyer, argues that: such legal provision is just and fair in requiring negligent health professionals to compensate the victims of their negligence; beneficial to the handicapped child’s welfare; spreads the load of paying for this through professional malpractice insurance premiums; helps to maintain high professional standards among genetic counsellors and thus reduces the incidence of unwanted genetic disorder in the community; is logically defensible despite claims to the contrary; and can escape slippery slope concerns. His impressive case none the less leaves some doubts. In particular, while few would disagree with Professor Shapira’s general claims (a) that a “wrong-doer should not be allowed to escape liability towards the victim of his or her own malpractice”; and (b) that such wrong-doing can in principle occur before a child is born or even conceived, is it accurate to say that a child born with a disabling genetic defect as a result of negligent genetic counselling to the child’s parents is properly described as a “victim” of the genetic counsellor’s negligence?

The counterclaim is that the negligent genetic counsellor is - at least in very many cases - the child’s saviour, for it is only because of his or her negligence that the child exists at all. Unless that genetically impaired existence is so awful that, *from the child’s point of view* it would be better not to exist at all then it is wrong to call the child the victim of the genetic counsellor’s negligence. Instead, for all cases where *from the child’s point of view* its existence even with its genetic disabilities is preferable to non-existence, the child is a beneficiary rather than a victim of that advice, and the child has no ethical basis for a claim against the genetic counsellor (though of course the parents certainly do). To be a victim one must be

harmed or wronged or damaged or be otherwise disadvantaged as a result of the activities - or lack of them - of those whose victim one is. The parents are undoubtedly victims if they have been harmed or otherwise wronged or disadvantaged by the genetic counsellor’s negligence, and they have a legal remedy, known as a “wrongful birth” suit, against the counsellor for compensation. But in what way can the handicapped child be said to have been harmed, wronged or otherwise disadvantaged by, and thus a victim of, the genetic counsellor’s negligence?

The obvious response is that the child would not have existed with the grievous genetic disabilities that it has if the genetic counsellor had done his or her job properly. But to be harmed or wronged or disadvantaged by a person’s actions one has to be in a worse situation than one would otherwise have been in, had it not been for that person’s action. Can one properly say - does it make sense to say, and if so can it ever be true to say - that a person is in a worse situation than if the person did not exist? If it does not make sense even to state it - if such a statement is incoherent - then a law which depends on the making of such statements is itself incoherent. To avoid rash assertions or lengthy argument let us simply assume, along with the judges whose logic is questioned by Professor Shapira, that the logic of counterfactuals does indeed make it possible to assert coherently that a person can be currently worse off than he would have been had he not existed - or worse off than if he ceased to exist. And thus let us accept that the judges referred to by Professor Shapira were making entirely coherent claims when they compared non-existence to defective existence. Such an assumption would also be necessary to make it coherent for a patient dying in great pain from irremediable disease to believe and claim that death and a consequent state of non-existence is better from his point of view than to continue his current existence.

But even if we assume that such claims are coherent it does not of course follow that they are true. What is true is that none of us has ever expe-

rienced non-existence and so we can't make a direct comparison between our experiences of existence and non-existence. Some of us believe we can get close enough by extrapolating our subjective lack of experience in dreamless sleep - or other states of unconsciousness - backwards in time to represent the state of our non-existence before we came into being and forwards into perpetuity to represent our state of non-existence after we cease to exist when we die. It seems likely however, that people will vary in their conceptions - if they have them - and their evaluations - if they have them - of non-existence, whether before or after their current existence.

Where does this lead in relation to the problem of "wrongful life" claims? Well on one conception of existence and non-existence, and of their relative value, existence as a person - or even simply as a sentient being with experience of the world - is generally preferable to non-existence, even in circumstances that others might pity. On such a conception the idea that others might decide (or might have decided) on one's behalf that one's existence would have been - or is - worse than non-existence (because, for example of disability, or social problems, or medical diagnosis, or a poor family environment) and then take or have taken action to prevent or end one's existence, is utterly obnoxious. On another conception and evaluation, it does not much matter what others do about one's existence before it's actually happened, but it matters a lot once one has come into existence (here ignoring the contentious question of when it is that a person comes into existence).

Many of us are glad that our parents did not make the decision to abort us, or contraceives us. That, it seems, is a common view, even amongst people suffering from severe disabilities, and amongst people living in poor social and or family circumstances. Of course some of us can also see that had our parents done so there would have been no "us" to care, but none the less *from their own point of view, having come into existence*, many people, even in very poor circumstances are glad that they have come into existence.

From such perspectives it makes sense to argue that when prospective parents make decisions to abort or contraceives they are quite likely to be acting against the interests of the child that would otherwise have come into existence. Indeed, only where the potential children would very probably have such an awful life that it would clearly be

better for them, seen from their own hypothetical perspective, never to have existed, can parents who decide to abort or contraceives be properly said to be acting in the interests of their potential child. Similarly anyone, including a genetic counsellor, who helps such parents to decide to contraceives or abort is in many cases acting against the interests of the potential child, as seen from the child's hypothetical perspective.

This is in no way to argue that contraception and abortion are wrong when they are done against, or not in, the interests of the potential child. On the contrary potential parents may have good moral reasons of their own, as seen from their own perspective, for not bringing another child into existence. But they would generally be mistaken if they thought that it was in the interests of the child for them to decide that the child should not exist.

If these arguments are valid, then it would seem to be only in those cases where genetic diseases can be reliably predicted to produce near universal agreement that life with the disease is worse than non-existence that a child born with such a disease would have an ethically valid claim for wrongful life against a negligent genetic counsellor. This position would be consistent with that of the first two judges cited by Professor Shapira.

However, there remains one of the "slippery slope" problems, addressed but rejected by Professor Shapira as "speculative and highly irrelevant", notably that such a child would have an equally valid claim against his or her mother if she had continued a pregnancy knowing that the baby-to-be would have the genetic disease concerned, and having some way of preventing that birth that she would find morally acceptable. This seems to be a "logical slippery slope" that can't be avoided, but which has all the adverse public policy implications alluded to by Professor Shapira. In which case, given the few cases where which a wrongful life suit against a negligent genetic counsellor would be morally justified, and given the adverse public policy implications of permitting such suits, it might be preferable to avoid wrongful life claims altogether, relying instead on wrongful birth claims to achieve at least some of the benefits thus foregone.

References

- 1 Shapira A. "Wrongful life" lawsuits for faulty genetic counselling: should the impaired newborn be entitled to sue? *Journal of Medical Ethics* 1998;24: 369-75.