

CROSSROADS: WHERE MEDICINE AND THE HUMANITIES MEET

The Morality of Having Children with Disabilities

A Different Perspective on Happiness and Quality of Life

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INTRODUCTION

With the advent of new predictive medical technologies, such as genetic screening, our ability to foresee, identify and correct genetic and birth disorders has gained new ground. There are four types of screening programmes currently available: newborn screening, where treatable disorders are identified early in order to improve the prospects of the affected child; carrier screening, to identify if a healthy individual is asymptomatic for a genetic disorder and the chances of passing on the recessive gene to future offspring; prenatal screening, to detect malformations or genetic defects in the foetus (e.g. Down's syndrome); and susceptibility screening, which reveals an individual's genetic predisposition to particular diseases, such as heart disease and Alzheimer's dementia (1). These medical advances raise important ethical issues concerning the limits of their use and the resulting social and moral consequences. This is evident in the case of carrier screening, where a couple finds out that they are both carriers of an autosomal recessive disorder and are faced with a major dilemma: is it morally wrong for them to have children given the risk of transmitting a hereditary disease? Similarly, when prenatal screening reveals a defect in the foetus, is it morally wrong for the parents to carry the pregnancy to term?

If we are to answer in the affirmative, it is imperative that we consider what factors make it unethical to have a child that might be born with a disorder. People who believe couples in such a situation have a moral duty not to conceive of or give birth to a child are often motivated by the common desire to avoid unhappiness or low quality of life, which they believe will almost certainly afflict a child born with a birth defect. The

present paper will argue that this view is flawed and that it is based on social prejudices rather than sound biomedical ethics. The focus will be on the issues of happiness and quality of life among people with disabilities, where the word disability will be used here to refer to a physical or mental handicap resulting from a genetic or birth disorder.

DISABILITY AND SOCIETY

The characterization of what constitutes a disability varies largely from one culture to another, and the same condition can be seen in one country as a curse and in another as a blessing. For example, some cultures in Southeast Asia, rather than viewing a person with blindness as disabled, perceive the latter as "one who possesses a certain valued insight" (2); in the Tswana culture, children born with disabilities are named "gifts from God" (3). A disability is then not a harm a priori, but rather a condition differing from the norms and standards set by a certain society. To further illustrate, if a person with a genetic disease causing abnormally short legs lived in a society where small legs were highly valued and considered a mark of beauty, then surely this person would not be viewed as disabled. Similarly, if a society had in place all the services and resources necessary for people with short legs to live at the same level of ease and comfort as anyone else, then such people would not be seen as "harmed" by their condition. A disability is thus a subjective concept that depends to a great extent on the existence or absence of technological, legal, cultural and attitudinal barriers within the environment of a disabled individual.

Deborah Kaplan, the Executive Director of the World Institute on Disability, remarks that "until children with a disability could go to their local schools and obtain the services needed to benefit fully from an education, it was easier to assume that the disability was the cause of

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the lack of educational equality in these children's lives" (4). Likewise, it was generally understood that people in wheelchairs were severely limited and "confined" until assistive technology, accessible environments, lightweight sports wheelchairs and adequate social services became widely available. As shown by Kaplan, the emergence of better services provided to the disabled as well as the more tolerant attitudes that society has adopted towards these individuals in the past decades have allowed both the disabled and the able-bodied populations to gain new, more positive perspectives of the lives of people with disabilities.

QUALITY OF LIFE

The majority of arguments against procreation with high reproductive risks to the offspring involve the concept of "quality of life". It is a generally accepted notion that everyone is entitled to a high quality of life, generally including such values as happiness, fruitful relationships, freedoms and rights, fulfilment of dreams and desires. When conditions such as poverty, civil war or disability at birth threaten to diminish the quality of life of a couple's future children, some might argue that there is a moral duty on the parents' part not to reproduce; or if a child has already been conceived, not to carry it to term (i.e. through abortion).

This argument is based on the assumption that choosing not to reproduce or to abort is doing some good to the future child, saving it from pain and harm, or low quality of life. But where do we get the idea that people born with disabilities necessarily have a low quality of life? Is it a self-evident assumption? Has it been documented and proven? Did the people in question tell us so? In actuality, many people with disabilities have testified that the complete opposite is true, and while acknowledging the fact that their condition poses serious challenges, consider their lives of very high quality. Rick Donohue, an example of someone who is genuinely glad to be alive despite suffering from the Joseph family disease (a serious hereditary illness that affects or impairs personality, movements, behaviour and mental functions), said; "You know, if my mom hadn't had me, I wouldn't be here for the life I have had. So there is a good possibility I will have children" (5). Craig Enoch, born with Osteogenesis Imperfecta, a genetic disorder characterised by bones that break easily from little or no cause, requires the use of a wheelchair. Despite the genetic birth defect that has caused him to endure 200 broken bones, he is now District Manager of the Social Security Administration Office in Medina, Ohio and claims to have lived a very fulfilling life (6). Someone better known is Alison Davis, 28 years old, who was born with Myelomeningocele Spina Bifida, a severe

physical disability that leaves her incontinent and bound to a wheelchair. She has written many articles defending the rights of the disabled, in which she claims to have enjoyed a "full and happy life" that has allowed her to obtain a university degree, get married and travel to many countries (7). These accounts are of significance, for if most people with disabilities view their lives as a positive and worthwhile experience, then we must call into question the argument that we would be doing harm to a child by bringing it into existence in the face of potential disability.

HAPPINESS

For a better understanding of the issue at hand, it would be helpful to look at why disabilities are often seen in a negative light by society. If one argues that it is wrong for a couple to conceive or give birth to children with severe disabilities, it is certainly not purely on the basis of the resulting limited physical capacities. For example, if we knew with certainty that a child will be born completely paralysed but will also be absolutely happy, surely we would not qualify the birth of this child as an immoral act on the part of the parents. Therefore there must be a belief that there is considerable negative impact on the psychological or emotional state of the child due to the disability (e.g. profound unhappiness). We must then determine if this belief is well-founded.

Unfortunately, at the present time, the lack of research in this area makes it difficult to arrive at any definite answers. However, a few studies have been carried out with surprising and revelatory results. For example, in one study conducted by Cameron et al., published in the *Journal of Clinical Psychology*, no differences were found between 190 physically disabled persons and 195 able-bodied persons on ratings of life satisfaction, frustration with life and mood (8). In another study by Stensman et al., interviews and tests administered to 133 people with disabilities revealed no significant difference between these severely disabled people (requiring wheelchair use and daily personal assistance) and persons with no disabilities, on measures of quality of life and psychosocial considerations (9). Although more thorough research needs to be carried out in this field (for suggestions of areas which need further investigation, refer to Kaplan 1993), these results are noteworthy, and considered in conjunction with the positive individual accounts given by disabled persons, should lead us to question what is often taken for granted: that a disability is an undesirable condition where suffering and limited capacities override the possibility of happiness and high quality of life.

WE CANNOT SEE ALL ENDS

An intrinsic property of having children is its unpredictability, not only in terms of scientific and medical limitations but also in a broader sense. One set of parents may give birth to a perfectly healthy baby that ends up living a miserable life of depression and social ostracism, while another set may give birth to a disabled child who turns out to be the next Helen Keller, a figure of success and inspiration. How can one compare the worth of lives based on genetic composition or medical condition at birth? How can one be so quick to judge and dismiss the possibility that disabled children could lead successful lives? As Kaplan put it, "[if] we are attempting to protect future human beings from experiencing a terrible quality of life, we had better be sure that there is a relationship between predictable genetic condition and a negative life experience" (10).

Laura M. Purdy, Professor of Philosophy at Wells College, argues that it is our duty to provide each child with a "minimally satisfying life". She claims that some situations would not satisfy this standard, such as the case of parents carrying the defective gene that causes Huntington's Disease, and it would therefore be morally wrong for them to conceive when in full knowledge of the risk of hereditary transmission (11). However, it is not certain that parents whose genetic screening results reveal such a risk will indeed transmit the disease to their child; and if a child is born having inherited the disease, it does not follow that the parents were wrong in conceiving of or giving birth to this child because it does not follow that the child's life will not be worth living. The argument then rests on probability rather than certainty: there is a chance that the child might get the disease, and if the child does, there is a chance that it will be unhappy. Is this chance of unhappiness a sufficient moral argument to deny the parents' right to reproductive autonomy? And who can say that a "normal" child does not have just as great a chance of being unhappy? Can we claim with certainty that the present able-bodied population is happier than the present disabled population? The idea that people with disabilities have a lesser chance of being happy than average people is neither a fact nor a proven reality, but merely a societal prejudice that is often shaken by testimonies of the contrary.

Even if technology could be perfected to the point where screening tests could predict hereditary transmission and birth defects with 100% accuracy (a highly improbable achievement), there is still the second "chance" factor of happiness versus unhappiness that can not be predicted by further technological progress. It may be possible to know without a doubt that a child will be born disabled, but the quality of life

of this child is not a property that can be foreseen and evaluated. The fact that we *cannot see all ends* is a crucial argument against the contention of immoral reproduction.

WHAT ABOUT ANDREW?

Opinions vary as to what parents should do when prenatal screening detects a disorder in their unborn child. Richard M. Hare, a moral philosopher of the twentieth century, maintains that to be taken into account when dealing with parental reproductive decisions is the consideration of a future normal child (arbitrarily named Andrew) whose birth may follow that of an "abnormal child". Supposing that a couple has conceived an "abnormal child" who has little chance of leading a normal life (i.e. without disabilities) and that a hypothetical Andrew, who will be perfectly healthy, may be born later unless his life is "withheld from him" by the birth of the first child (if, for example, the parents only intended on having one child or if raising a disabled child does not allow the time for another child). Hare argues that parents should choose Andrew over his brother (the existing disabled foetus) if all attempts to treat the latter fail (12). In other words, the first child should be aborted for the sake of a future Andrew. Hare does not give the basis for his judgement that Andrew would have a "high[er] prospect of a normal and happy life" and that therefore the parents are morally obliged to give him priority. This line of reasoning is flawed and can be refuted by bringing back the above argument: that quality of life has not been proven to be greater for a "normal" child than for an "abnormal" child. Furthermore, it is illogical and unsound to evaluate bioethical cases taking into account, in addition to the individuals involved, potential inexistent beings that are only of possible and future moral significance.

UNRESOLVED QUESTIONS

Suppose that we adopt the view that I have so far argued against. What happens if it is put into practice? If the results of a couple's genetic screening shows that one or both of them are carriers of a genetic mutation that normally leads to a disability in the offspring, or if prenatal screening reveals a defect in an existing foetus, who decides if their right to having children is overridden by the risk of giving birth to a disabled child? Are there diseases which, from moral considerations, give us more reason to refrain from exercising our right to reproductive autonomy? If so, on which basis do we judge one disease in comparison to another? In the case of genetic disease, how high do the risks of transmission have to be in order to make a case against reproduction? 75%? 30%? 5%?

Furthermore, if bringing to life a disabled child constitutes a condemnable course of action, then does moral duty require all potential child-bearing couples to undergo either genetic screening before engaging in reproductive activities or prenatal screening before giving birth? These unresolved questions, which will inevitably surface if we were to condemn the conception or birth of children with disabilities, show that aside from its doubtful ethical foundations, this stance also poses great difficulties if considered in policy-making and implemented in medical practice.

A FINAL WORD

Purdy is right in saying that "given [the fact] that possible children do not presently exist as actual individuals, they do not have a right to be brought into existence, and hence no one is maltreated by measures to avoid the conception of a possible person" (13). The contention that it is not morally wrong to reproduce despite high risks of disability at birth does not entail a duty to reproduce, but only negates its moral condemnation. In fact, it can be successfully argued that it may be preferable for the parents to choose to refrain from having children in some cases where the disease is rapidly lethal and the risk of transmitting it is very high (e.g. carriers of Tay Sachs), without having a moral duty binding them to this course of action. The fact that preference does not equal moral duty can easily be illustrated: it is *preferable* for people who can donate blood every month to do so, but it is not morally wrong of them if they should refuse. In other words, I am not arguing that it is wrong for parents to refrain from conceiving of a child if there is a chance it will be born disabled, only that it is not wrong for parents who wish to have children *despite* the risk to do so.

If we are to accept the argument against reproduction, which implies that it is better for a child not to exist than to be born disabled, there must be powerful evidence that there is indeed harm done if parents choose to have a child likely to experience a disability. But since there

is no evidence, either based on statistical data, documented research findings or guiding ethical and moral principles, that a disabled child is more at risk of being unhappy than an average child, the argument that it is immoral to have children in such cases must be dismissed.

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