

Who is Normal? - Who is Handicapped?; An Ethical Approach to the Concepts

KİM SAĞLAM? - KİM SAKAT?: KAVRAMLARA ETİK BİR YAKLAŞIM

Şahin AKSOY*

* Harran University Faculty of Medicine, Department of Medical Ethics and History of Medicine, ŞANLIURFA

Summary

Disabled, handicapped, abnormal are concepts used in professional and daily life routinely but paying no attention to their actual meaning. In this article it is tried to explore the conceptual meaning of these terms by taking examples from daily life and medical practice. This study has shown that 'healthy'- 'handicapped' and 'normal'- 'abnormal' are relative terms, that their meaning can vary from person to person and society to society. It is also discussed in the article that the way the handicapped people perceive life is very closely related how they were treated in the society by the 'healthy'. It is also examined how an ideal society and a civilised person should behave in respect to less lucky individuals of the society.

Key Words: Handicapped, Disabled, Normality

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There is some perplexity in the literature, which indicates difficulty in distinguishing between handicap and disability. What are the differences and similarities? There are some other terms that are also used widely and also interchangeably: abnormality, malformation, anomaly and defect. Even if the concepts of impairment, disability or handicap, cannot have an absolute or fixed meaning, it is essential to start from at least a relatively stable meaning for these terms. The World Health Organisation (WHO) defines impairment as: "Any loss or abnormality of psychological, physiological or anatomical structure or function. Impairment is

Yazışma Adresi: Dr.Şahin AKSOY
Harran Üniversitesi Tıp Fakültesi
Deontoloji ve Tıp Tarihi AD
63200 ŞANLIURFA

Özet

Özürlü, sakat, anormal kavramları gerek sosyal gerekse profesyonel hayatta üzerinde çokça düşünülmeden kullanılan kavramlardır. Bu makalede günlük hayattan ve tıp uygulamasında karşılaşılan durumlardan alınan örneklerle bu kavramlar tartışılarak aslında 'sağlam'- 'sakat' ve 'normal'- 'anormal' kavramlarının ne derece göreceli olduğu ortaya konulmaya çalışılmıştır. Ayrıca makalede hayatın 'sakat' insanlar tarafından algılanış biçiminin 'sağlamların onlara karşı olan tavırları ile yakından ilişkili olduğu vurgulanarak, sosyal devletin ve çağdaş insanın toplumdaki daha az şanslı bireylere nasıl davranması gerektiği tartışılmıştır.

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characterised by losses or abnormalities that may be temporary or permanent, and that include the existence or occurrence of an anomaly, or loss in a limb, organ, tissue or other structure of the body, including the systems of mental function". (1) WHO defines disability, in the context of health experience as: "Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Disability is characterised by excesses or deficiencies of customarily expected activity, performance and behaviour, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive". (2) Finally, handicap is defined as: "A disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex and socio-cultural factors) for that individual. It is characterised with a discordance between the individual's

performance or status and the expectations of the individual himself or of the particular group of which he is a member," (3) It is clear from these definitions that these are all unhealthy and unwanted situations no one would like to be in.

All these terms are related in some way to the concept of normality. The word 'normal' is used in many different fields. In medicine, it is very hard to give a clear definition of being 'normal'. Although there may be some shared or general norms, every individual also has his or her own concept of 'normality', and a few examples may be worthwhile to clarify this point.

According to medical science, Congenital Hip Dislocation (CHD) is an abnormality, which should be diagnosed at an early age and treated as soon as possible. In our medical practice, we once had a two-year-old girl patient with an extreme bilateral CHD who was walking like a duck (which is characteristic for this abnormality). When we asked her mother whether her child had had any treatment, she replied: "Why? Is there anything wrong with her? She is quite normal. She walks the way she does just because she is a little overweight."

Let me quote another personal experience. A squint is an eye disorder that requires surgery if it is to be corrected. An eight-year-old girl with a serious squint came to our clinic with her father. Her gaze was directed in a different obviously "cross-eyed" way. Her father said: "My daughter has been completely normal, but over the last year she has had some sight problems. This may be because of the 'slight cast' in her eyes." He entirely rejected surgery because we could not make him accept that his daughter had a medically defined abnormality.

These two anecdotal examples indicate that the perceptions and understandings of the persons involved are very important. These two parents were aware that something was wrong with their children, but they refused to admit as much. As such we could not convince them to let their children undergo treatment.

Consider the notion of 'malformation'. If a little girl with six fingers on one hand, says that she loves her sixth finger very much, how can (or should) we tell her that she is 'malformed'? And how can we decide the disability of that six-fingered girl?

If it does not cause any impediment except for its appearance, would it be right to think of it as a 'disability' or a 'problem'? On that criterion, obesity or anorexia nervosa can also be considered as disabilities because, though they may not necessarily be disagreeable in appearance, they impair a person's physical and social functions.(4) We do need to be careful of the words we use: "Everyone has heard of severely disabled people being described as 'human vegetables'; but no one calls tall thin people 'human carrots' or those who are short and fat 'potato beings'. Why are disabled people the only ones to be referred to in horticultural terms? It can only be because to some extent the people who say such things think disabled people are actually somewhat less than fully human".(5)

If we say that impairment must surely be a part of any definition of disability, it raises the question -but what if an abnormality does not cause impairment of function, what if it only makes a person ugly, do we still consider it a disability? Who will judge the level of ugliness, the individual or society? Let us imagine a schoolgirl who suffers from polydactylism (more than five fingers on one hand), or a young man with alopecia universalis (absence of all scalp hair, all the eyebrows, eyelashes and beard), or a teenage girl who suffers from ichthyosis vulgaris (a severe skin disorder). If such conditions do not cause any impairment of function, if others have got used to seeing the people affected, they may not perceive themselves as ugly and would therefore not feel distress. But if their appearance does disturb others and they feel distressed as a result, should we describe them as normal or disabled? A little girl in a nursery school may be afraid of holding up a polydactyl hand because of the reactions it provokes; his co-workers may be upset sharing a workplace with a man suffering from alopecia universalis; a hair dresser may not want to cut the hair or manicure the nails of a girl who suffers from ichthyosis vulgaris. How can we judge such reactions to these 'abnormal' persons who are trying to make their lives worth living despite their difficulties?

When we look at the case of polydactylism, what kind of inconvenience may it cause? It may be difficult to wear or take off clothes and it may be difficult to write with that hand. But in spite of

these minor inconveniences, the girl can continue her life comfortably enough. However, she is still labelled as abnormal, because all humans are expected to have no more than five fingers on one hand. If this girl feels distress and desires corrective surgery, is it right to take the risk of surgery? The main difference between polydactylism and the other two examples (ichthyosis vulgaris and alopecia universalis) is that the last two conditions cannot be corrected by surgery. Therefore, could it be suggested that the correctibility or incorrectibility of a condition may affect the perception its 'abnormality' and how the individuals affected then feel about themselves?

We need to ask ourselves whether the lives which we assess as not worth living are actually not worth living because of the medical conditions those lives carry, or because those who are 'normal' make the people affected that their lives are not worth living? Do we try to show them the positive aspects of their lives or do we make them conscious of their disabilities the whole time? Some may say that society is responsible for the negative feelings about the quality of life of disabled people. People with disabilities have been the targets of discriminatory attitudes and behaviour almost since the beginning of time. Having a disability has meant that individuals have been devalued. At various times, persons with disabilities could be disposed of, given inadequate medical care, denied education, refused meaningful employment, isolated, segregated, and ignored.⁽⁶⁾ Self-evidently, given such circumstances, it is extremely hard for the disabled to manage their disabilities so as to enjoy their lives as a whole. According to Davis: "The terms 'disability' or 'handicap' are really just general terms, used to describe a large number of people who have in common only one thing -that they do not function in quite the same way as those considered to be 'normal'."⁽⁷⁾

Subjective Perception or Social Labeling?

Plainly, clinical definitions alone do not define or cover disability. Sociological reflections and subjective perception are equally important. Sometimes it is more relevant to ask how people around a particular individual perceive that individual, and thereby affect his or her self-perception.

than to ask how medical science defines his condition.

Earlier, situations where individuals do not feel handicapped and find their lives valuable and worth living, but people around them are upset by them and label them as disabled were discussed. In contrast to this, there are also cases in which individuals considered medically 'normal', perceived as 'normal' by society, and whose condition does not cause any impairment, nevertheless that a particular part of their bodies is a problem and then seek a 'solution'. Those 'solutions' are an important part of the plastic surgeon's workload.

It is not easy to explain the circumstances that disturb people so much that they take the risk of surgery. But we may infer from this another factor to define disability namely the psychological state of the individual. The individual may not have any physical abnormality, but psychologically he or she 'feels' abnormal. Hospital records abound with such nose, ear, lip and breast operations to satisfy this 'felt' abnormality.

On the other side, there are world-renowned cases of individuals whose very real disabilities proved no bar to the greatest achievement. Stephen Hawking is an example from our own time. Beethoven became severely deaf towards the end of his life yet continued to compose wonderful music. Cicero used to stammer in the early part of his life but became one of Rome's greatest public speakers. Of course, such individuals are exceptionally gifted, and their peculiar talents or genius do not directly relate to their disabilities. But their lives are a demonstration that, with enough effort, and the chance to develop potential, disabled people can lead rich and full lives as valuable as a 'normal' person's.

Some may be very uneasy about the judgments of the non-disabled or 'healthy' on the quality of life of all others. It is true that someone, say, born blind or with a likelihood of future disease, might be so depressed later on as to commit suicide, but it is also true that the great majority of those who are visually impaired, or who experience serious chronic illness, nevertheless lead active, independent and fulfilling lives. Bernard Carr, who is a physicist and a close friend of Stephen Hawking's, stated that: "Death is with all of us. But

more so with Stephen. It does provide a strong motivating factor. The question people always ask is, if he had not been disabled, would he have made such a great or an even greater contribution to science? It is not clear to me that his being disabled has actually worked in the direction of hindering his scientific output; it is possible that he might not have produced so many good results if he had not been disabled. So I would say his disability works both ways."(8) Although similar information is not available to us about Beethoven and Cicero there is no reason to believe that their disabilities did not affect their achievements positively.

Types and Causes of Disability

Despite much research, to date the actual causes of neonatal anomalies/congenital malformations have not been identified accurately, and the aetiology of 54% cases is unknown.(9) Approximately 3% of all infants are born with a genetic disorder or congenital anomaly that will lead to severe mental or physical handicap or early death.(10) About one-third of all cases are contributed by genetic factors (25% is caused by multifactorial inheritance, 8% have monogenic or single gene causes, 6% are chromosomal abnormalities), and environmental factors are effective in 7% of cases. Between 20 to 30% of all children who are admitted to hospital have a congenital disorder.(11)

Goodman and Gorlin defined 200 different malformations in their book.(12) But this number has been increasing day by day with new discoveries that according to some research, some 2500 genetic disorders have been confirmed in man.(13) About one-third of disabled infants do not see their first birthday and half of them die in the first week. The rest who survive have abnormalities at different levels, and almost 80% need either corrective surgery or lifetime therapy. In terms of prognosis, 51% of handicapped newborns have a bad prognosis. The rest of them who are labelled as mild are faced with suffering.(14) About 3% of newborn babies have one or multiple congenital anomalies and this ratio increases by the end of the first year. This is because of abnormalities that were present but indiscernible at birth.(15) Most of prenatal abnormality cases are not detected or known even by

mothers or health care professionals. Up to 83% of first trimester spontaneous pregnancy losses are associated with gross structural abnormality. Therefore, malformations account for 20-25% of pregnancy loss, perinatal mortality and childhood death up to the age of 10 years. Approximately one in forty babies has a major malformation identifiable at birth, with a similar proportion becoming apparent in infancy or early childhood.(16)

Most of the disabilities that arise are detectable. In many cases, although it may be hard to do an exact diagnosis, it is possible to predict disability before birth. The distress caused by such illnesses has led to attempts to identify cases as early as possible. Despite all measures and methods of elimination, disabled babies continue to be born. Maybe attention should be directed to treatment and rehabilitation. Although it is not always possible to correct the impairment completely, quality of life can be improved through a variety of rehabilitation methods.

As remarked earlier, almost half of handicapped newborns die in the first year of their lives and 80% of the rest need corrective surgery, or treatment that will continue during their lifetime. For this reason, treatment and rehabilitation are costly options. But following the improvement in surgical techniques, especially plastic surgery in recent years, the remediability of many conditions has increased. For example, congenital cataract (which can cause severe sight problems, even blindness) was considered irremediable twenty years ago. But after the progress and successes in intraocular lens operations, it is now considered remediable. While cleft lip and cleft palate were very serious problems before, they can now be repaired very successfully in terms of their functions and appearance.

Remediability or irremediability of disabilities is of crucial importance in determining the treatment offered to handicapped newborns. Decisions about remediability or irremediability of disabilities are made by doctors. The reasoning and judgments of philosophers, theologians, sociologists, ethicists, and other experts (as well as, of course, the parents) are informed by data supplied by doctors. The objectivity of that data is not unquestion-

able, and some reports verify this belief. Freeman said that: "It concerns me greatly that a given child born in Sheffield has a 75% chance of being dead; that same child born in Baltimore.... has a 95% chance of being alive. And yet this is a decision made by the parents on the advice of either Dr. Lorber or myself. That is scary."(17)

Conclusion

In this article, I have tried to discuss some definitions of disability, handicap and related terms. It has proved difficult to give an exact definition or meaning for these concepts. However, it is accepted that disability is a condition nobody would like to be in. Despite the difficulties of definition, it is important to answer the question of "Who is normal?" and "Who is disabled?" For, when we mark someone as disabled, his or her medical, social, legal and religious rights and responsibilities are affected. Social attitudes towards disabled people are not the same as those towards the non-disabled, and there is special legislation for disabled persons.

I also tried to find out whether self-perception or social labelling is more important in defining disability. I argued, while presenting other relevant information, that the most important criterion to define disability is the individual's self-perception.

It appeared from the discussion that disability is an important human health problem, albeit nature often prevents its emergence by early spontaneous abortions. It could be argued that, with rapidly developing medical technology, the remediability of disabilities has improved. Thus, we now have more reasons to support these people to live.

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