

# ISSUES AND OBSTACLES IN DISABILITY RESEARCH IN SAUDI ARABIA

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## ABSTRACT

*Despite the growing awareness in the public, the health and education professionals about the economic, psychological and medical impact of disability, limited research has been carried out on disabilities in Saudi Arabia. This paper reviews the issues related to the progress of research on disabilities in Saudi Arabia and the deterrents that have limited its progress.*

## INTRODUCTION

Disability can be defined within the context of an interaction between the functional decrease and the demands and conditions of the environment. Historically, disability studies have examined how people with disabilities have been rehabilitated, or they have delineated the nature of their treatment progress. These studies can be viewed through a medical model in which people with disabilities are perceived as sick and in need of a cure (1,2), through a sociological model where people with disabilities are labelled and characterised by others, through a psychological model where their experiences have been individualised, or through a combination of both a medical and social model or other perspectives (3).

More modern disability studies seek to examine the social, economic, and political forces that serve to marginalise and oppress people with disabilities. The field has evolved over the last several years, drawing on theories and perspectives from sociology, social science, women's studies, cultural studies, and education. It often focuses on the idea that people with disabilities are a minority group that has been discriminated against. In this sense, the study of disability is similar to the study of race, class, and gender inequalities. In addition, disability studies provide the intellectual and methodological tools needed to create disability research and policy. The theories and philosophies of disability studies can then be applied to real issues in law, in community inclusion, and in public policy (3).

Issues in disability research cut across many disciplines simultaneously, which is why much disability research is interdisciplinary, and includes health, economics, sociology, and law. In order to understand some of the disability issues, often integrated data sets are needed, where topics from these varied disciplines can be addressed.

## DISABILITY RESEARCH IN SAUDI ARABIA

The topic of disability in Saudi Arabia is an important societal issue. Depending upon the definition used, it is currently estimated that 3.73% of the population has functional disabilities which limit their independence (3). To address disability issues one must make better use of the existing information about the prevalence of disability. Further, it is necessary to address the gaps in existing knowledge concerning the nature of disability, and to develop appropriate support programmes to address the needs.

In the Saudi society, the incidence of consanguineous marriages is high. As a result, the risk of disabilities associated with genetic causes is significant. Further, the awareness of inborn errors of metabolism among parents is very low. Over 50% of parents, in response to a questionnaire, had no knowledge of the causes of their children's diseases, their symptoms and their inheritance patterns (4).

Saudi society's view of people with disabilities is based on a simple notion of disability, and comprises helplessness, continuing dependence, being home-bound, low quality of life and lack of productivity. In accordance with these attitudes, small scale educational programmes are provided for the parents of children with disabilities. Most of these programmes are arranged by charitable organisations supported by the Ministry of Labour and Social Affairs. There are also a few programmes on Saudi TV or radio for children with disabilities and their carers. How effective and helpful these educational programmes are in minimising the impact of disabilities on the family and community and in changing the attitude of the community toward disabled people, are issues that are yet to be answered. Therefore, studying the prevalence, characteristics, psychosocial aspects and economic impact of disabilities in Saudi Arabia would be of great value, to help to guide policy and programmatic decisions as well as to enrich the understanding of disability. It can also help to develop a more effective approach to the adequate assessment and management of disability.

In order to have a global national vision about disability in Saudi Arabia, research in disability should also consider demography, epidemiology, health status, access to health care and its costs and coverage, employment and earnings of people with disabilities, social services, benefits, and activity. Research in disability should also consider the impact of impairment on employment and the range of life functions, the ways in which people with disabilities participate (or not) in public and private programmes, and the values and attitudes of disabled and non-disabled people about disability. A few limited attempts at research have considered some of these issues (5,6).

In a research study in Qaseem in 1993, incidence of disability was assessed in 13,841 children below the age of 15 years. According to this study, the most common disability was physical disability, comprising 1.7% and mental retardation, comprising 1.4% (7). The results of this study prompted the Disabled Children's Association to establish a branch in Madina. Recently a national survey on disability showed that there are 3838 disabled children among the 60,630 children surveyed, representing 6.33% (6). These research surveys involved only children, not adults. In these three studies (6,7) that investigated the incidence of disability among children, there is high variation in the incidence figures. This may be due either to varying levels of medical and educational services provided between regions or to the use of different definitions of disability. Methodological errors or high / low percentage of consanguineous marriages in the different regions may be other factors for such variation in disability incidence. Therefore, any interpretation from these studies should be made with caution.

### **OBSTACLES IN DISABILITY RESEARCH IN SAUDI ARABIA**

There are a number of difficulties associated with conducting research on disability related issues in Saudi Arabia. Some of these difficulties are associated with the characteristics of Saudi society such as the high incidence of consanguineous marriage (4), the high incidence of car accidents, and the fact that some families feel ashamed about having a child with a disability and as a result, tend to avoid participation in such research.

Perhaps the most important obstacle is the complete lack of appropriate epidemiological research. Such research could contribute to information about prevalence, type and distribution of disability in Saudi Arabia (5,6,7). How many people with disabilities are there in Saudi Arabia? Information specialists in government or in disability statistics research have difficulty answering this question, because there is no simple, single answer.

Another shortcoming that has limited the nature and extent of information about disability is that much of the research that has been conducted consists of surveys (5,6,7). There is limited research on intervention management or early identification of disability (8). Also, there is no standard outcome measure used to assess or identify the degree of disability. As a result, there is little validity in comparing the outcomes of two or more different treatments in a clinical trial, or of the same treatment in two or more reports from literature.

Poor data collection procedures and other issues including data linkages, data matching, data analysis, sampling, and international comparability are another problem. The development of better statistical information will obviously be a long-term project, involving a number of researchers with different backgrounds.

Two national surveys showed that the incidence of disability in cities is higher than in villages and small cities (5,6), though this is in seeming contrast to the fact that medical services and health education programmes are better in large cities than in small ones. These results probably reflect more accurate reporting practices in cities as compared to rural areas. Finally, there is no specialised institute for dealing with or collecting data such as those in the USA where specialised studies offer a good basis for understanding disability statistics. There is also the absence of library services on disability issues that provide reliable scientific information about the field.

### **FUTURE DIRECTIONS IN DISABILITY RESEARCH**

In order to expand research on disabilities in Saudi Arabia, it is necessary to determine the exact incidence of disabilities and their nature. Well established programmes for rehabilitation and disability prevention also

need to be initiated, followed by frequent and systematic reviews of these programmes by a qualified expert committee. Finally, the authors recommend that a committee on disability statistics should be created to coordinate ideas and to develop research funds for disability-related issues. This committee might also consider issues such as the addition of more specific disability questions to national surveys. Without clarity of definition, interpretation of measures for policy purposes is difficult.

## CONCLUSION

There are great opportunities in Saudi Arabia to develop new information about disabilities, particularly their nature, their incidence, and their impact on society. These research efforts could be conducted to the betterment of science and society as well as to contribute to the development of new and better services and supports for persons with disabilities and their families.

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