

## **5 Epidemiological Data**

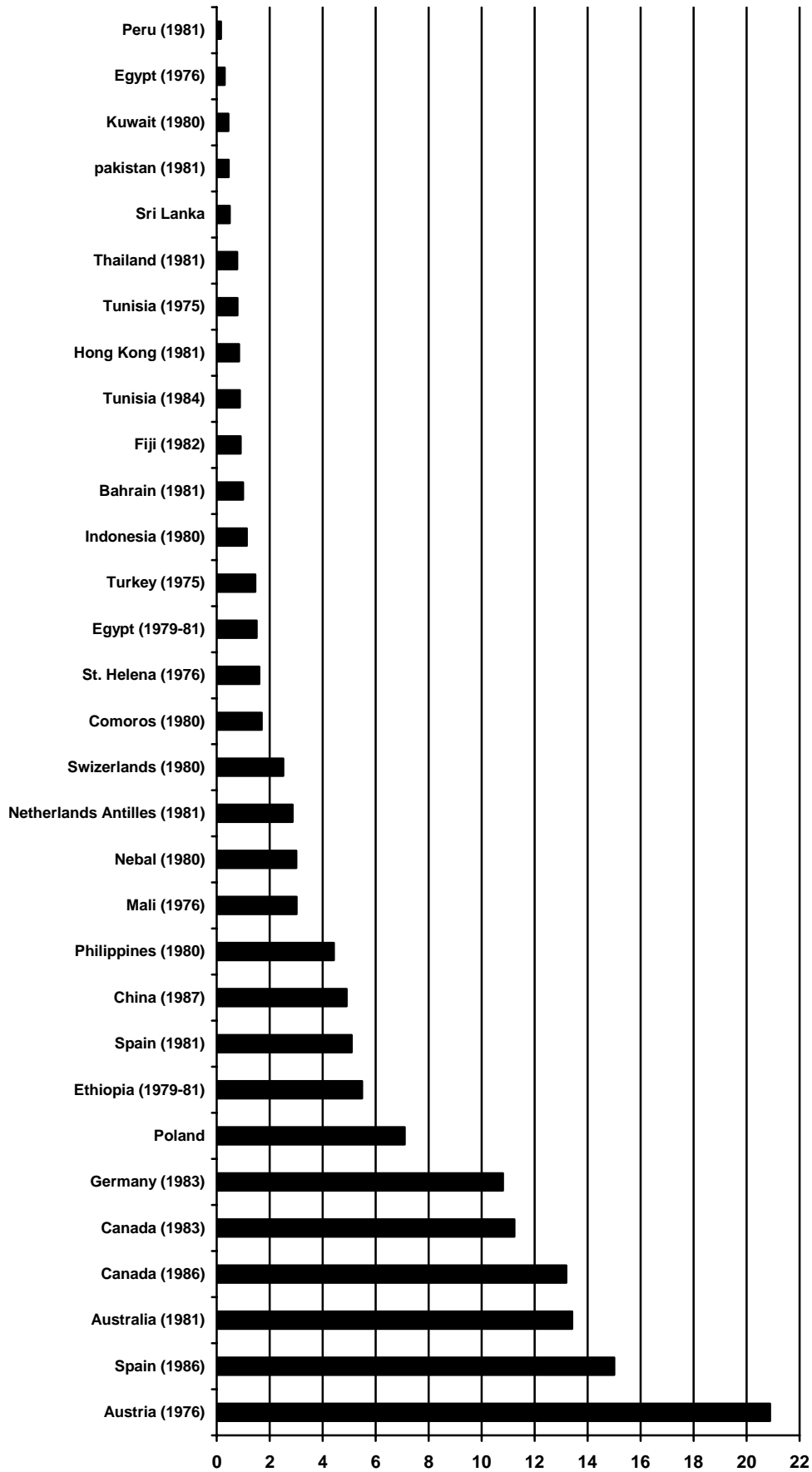
### **5-1 *The epidemiology of childhood disabilities***

Data on the magnitude of disability is and in many ways continues to be an international problem. The main problems are the lack of a standardized definition of disability, the lack of standardized tools and the lack of standardized methodologies. The last two points depend very much on deficiency in the first.

The lack of a standardized definition reflects the differences between societies in what is considered a deviation from the normal to a certain society at a certain time of its development, and according to the prevalent social and political system. This fact is also related to what the different societies are willing to provide, their priorities, and hence what the cut-off point is between what is considered normal and what is considered abnormal.

This fact can be clearly demonstrated by the tendency of many northern countries to give much bigger estimations to the magnitude of disability as compared to southern countries. Moreover, the problem in definitions is in turn reflected in the fact that different countries tend to make different categories of disabilities in their societies

Figure 6 overleaf shows international differences between estimations of the size of the disability problem.



Source: United Nations Disability Statistics Data Base, 1975-1986: Technical Manual (United Nations Publication, Sales No 88. XVII. 12).

This problem can be clearly demonstrated in Egypt. Most published data to date is widely discrepant and extremely variant from International estimations.

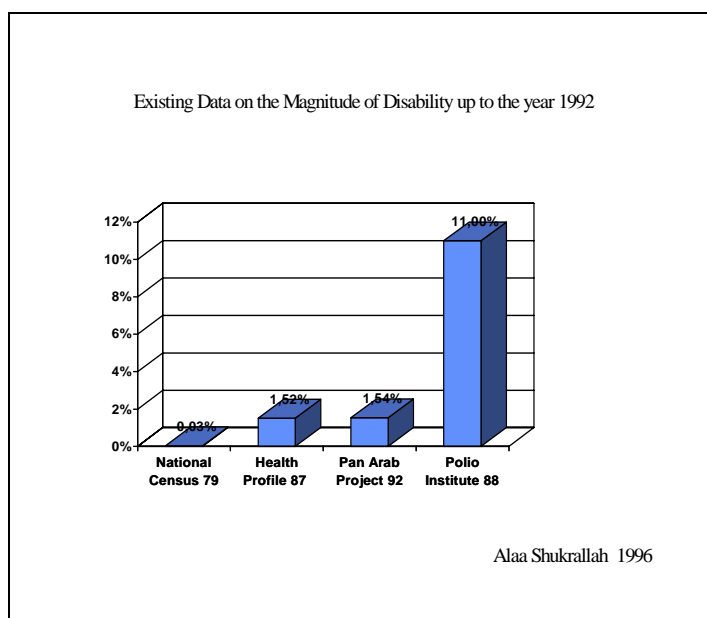
In addition to the structural deficiency of registration procedures in the available health or social authorities, most studies to date suffered from important flaws.

Estimations ranged from 3 per thousand according to the Census of 1979, to 1.52 % in the Health Profile of Egypt 1987 to 1.54% in the Pan Arab Project for Child Development in 1992, to 11 % in a study conducted by the Polio institute in 18 schools in six villages in Giza in 1988.

**Figure 7 below shows the discrepancy between existing data:**

**Causes for the discrepancy were multi-factorial, among which stand the following:**

- Lack of a standardized definition of disabilities. Different studies defined disability through different categories. Obviously this was among the most basic underlying factors leading to discrepancy in criteria for inclusion of cases, as well as in the types of tools developed for measuring the disabilities.



- In most studies, the methods for identifying disabilities was through the subjective reporting by family members of the presence of a disability in the family, an opinion which reflected and embodied their own knowledge and attitudes towards the question.
- In most of the above mentioned studies, disability was only an appendage to a wider survey with little attention and consideration given to the complexity and problems arising in its identification.

**Recent studies using the basic standardized categories of the “International Epidemiological Study on Childhood Disability” (IESCD).**

In 1994, two new epidemiological surveys commenced in Egypt to measure the magnitude of disability. The first was the (NCCM-French) childhood epidemiology survey [a joint study conducted by the National Council for Childhood and Motherhood and French Institutes], (NCCM & CIE, 1996). This was conducted in three Governorates, namely: Giza, Aswan and Kafr El-Sheikh. The second was the Ain-Helwan carried out on a smaller scale, in a poor area in South Cairo, by AHED<sup>2</sup>

<sup>2</sup> AHED, the Association for Health and Environmental Development is an NGO which was established in 1987, and declared under the number 3527. The Association has been working since its

in collaboration with Unicef as part of developing a demonstrative model in the project Area (Shukrallah, 1997).

Both studies adopted and adapted in varying ways the tools developed in the International Pilot Study of Severe Childhood Disability (IPSSCD) and its follow up study, “the International Epidemiological Study on Childhood Disability” (IESCD).

The prevalence in the NCCM-French study was estimated as follows; Giza 1.2%, Kafr El Sheikh 1.9% and Aswan 4.5%. Average prevalence is 2.53%.

**Table 6 Frequency of disabilities reported by the NCCM-French Study:**

| Categories of disabilities | %  |
|----------------------------|----|
| Compound disabilities      | 33 |
| Mental                     | 27 |
| Musculo-skeletal           | 22 |
| Hearing & Speech disorders | 8  |
| Blindness                  | 7  |

The Ain-Helwan Survey, conducted in a poor area in Cairo, studied the prevalence of six types of disabilities, namely: Motor, Hearing, Speech, Visual, Mental retardation and Fits. The prevalence in the area between 2-15 year old children was 5.7% for the above mentioned categories.

**Table 7 below shows the frequency of the disabilities reported in the Ain-Helwan study**

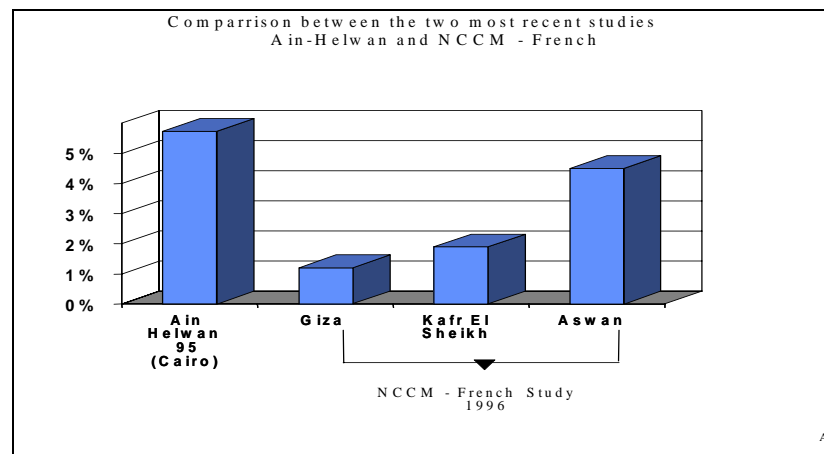
| Categories of disabilities | %  |
|----------------------------|----|
| Visual                     | 34 |
| Speech                     | 20 |
| Hearing                    | 14 |
| Motor                      | 13 |
| Fits                       | 11 |
| Mental retardation         | 8  |

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inception to develop and promote policies and strategies capable of responding to the health needs of Egyptian people under the international slogan “Health For All By The Year 2000”. In doing so, the Association has been engaged in action-oriented research, providing technical support to partners on the grass root level and supporting the development of demonstrative models on the grass root level. In addition, the association helps in developing networking and interaction between NGOs and governmental bodies concerned with health, disability and environment.

During 1994, AHED cooperated with UNICEF, and other national partners, in developing the first phase of the demonstrative model in “Ain-Helwan”.

**Figure 8 below shows comparison between prevalence in the two latest studies namely, the NCCM-French results and the Ain-Helwan results**



### Needs as compared to services in the Ain-Helwan Study:

In the Ain-Helwan study, from all the children identified as disabled only a minority of the visually impaired had glasses, only one child of those with hearing impairments had a hearing aid which was not used, and none received any form of training, and none of those with speech received speech therapy and none of the mentally retarded children received any special training. In general, none were receiving special education. However, most of these children had been exposed to a variety of medical practitioners and medical specialists and had received and spent a huge amount of money on medical treatment. In most instances, the medical interventions and drugs were highly expensive and unnecessary.

### 5-2 Summary and conclusion

Achieving a consensus on the accurate magnitude of disability is a question fraught with difficulty. The major question is, what is the cut off point between “Normality” or absence of disability, and Disability? The second point is, what are the categories or conditions which are to be grouped under disability when a study is conducted?

Most census and surveys have used different definitions and categories, in addition to different methodologies and tools. Naturally, a great discrepancy between figures exist.

Available figures range from 3 per thousand (1976 National census) to 11% in the Polio-institute study 1988. However, the latest two studies, in which, to a certain degree, categories discerned from the new international Classification of Disabilities produced by the WHO, have shown different estimations. In the NCCM - French study, the average prevalence came to 2.5%, while in the Ain-Helwan study it came out to be 5.7%. Aside from the different study sites, among the factors seemingly responsible for the variation, the levels of disability were differently identified. The NCCM study measured mainly moderate and severe disabilities, while the Ain-Helwan study measured in addition mild disabilities.

However, all the latest studies show a prevalence between 2.5% - 6%, which corresponds to the majority of new international estimations.

Moreover, the Ain-Helwan study showed that most children identified in the survey had no previous proper rehabilitation aside from highly expensive, and in many

instances, unnecessary medical and surgical interventions, mostly in the form of drugs.