

SOME THOUGHTS ON DEFINITIONS AND A METHODOLOGY OF CROSS-CULTURAL RESEARCH PERTAINING TO DISABILITY

Arthur Vreede

INTRODUCTION

In 1993 I set myself the task of compiling a bibliography of indigenous concepts, attitudes and practices regarding physical disability. While a lot of literature was found on related issues, the combination of the keywords *indigenous concepts* and *physical disability* turned out to be very unproductive. The majority of the literature consists of results of surveys on attitudes towards persons with a disability (PWD). Very few in-depth studies were found. Among these may *inter alia* be counted the studies by Stiker (1982), Burck (1989) and contributions in the books by Bruun and Ingstad (1990) and Ingstad and Whyte (1995). Besides in-depth studies, some articles are to be found which deal with the subject in a qualitative way, e.g. the articles by Scheer and Groce (1988), Ingstad (1988, 1990 among others), Walker (1981, 1986) and some contributions in monograph 53 of the IEEIR.¹ Many of these authors have stressed the fact that there is still little known about concepts and perceptions of disability, particularly on a local level, and that more needs to be done. Benedicte Ingstad (1995) for example has called attention to what she calls *real life situations*. It is necessary to investigate concepts and beliefs relating to disability and the disabled in their actual context.

The apparent lack of knowledge about concepts and beliefs regarding disability in different cultures and the ways these are interconnected with customs and practices on a community level was one of the reasons for organizing an expert meeting of researchers focused on cross-cultural research regarding disability. This expert meeting took place in Bonn alongside the symposium (cf. Introduction) and those present discovered that three days of discussion is hardly enough even to get an overview of bulletpoints for discussion and to discuss them very briefly. Agreement was reached to keep on talking, to found an international association for cultural research on disability and to reconvene in two years. In this

article, which was originally intended as a working paper for the expert meeting, some viewpoints are put forward regarding research on the subject matter at hand taking the DL-concept (DL = daily living, see annex) as a starting point. Firstly, definitions of disability which are deemed suitable for practical purposes of field research are discussed. Secondly, suggestions are made for a methodology of research.

DEFINITIONS

In the context of rehabilitation, the use of the International Classification of Impairments, Disabilities and Handicaps (I.C.I.D.H.), is well known.² Many researchers feel that this *impairment-bound* model does not meet their requirements for field research and analysis.

The following criteria for a researcher's definition are proposed: can the definition:

- be applied in various cultural contexts (as a tool for analysis).
- describe or make intelligible local concepts of disability in the idiom of the researcher.

It would furthermore be useful for the research to be able to describe the researcher's definition in a local idiom, but this is not a necessary criterion. A preliminary definition of disability is proposed here, one that is context-bound, i.e. which is related to the actual activities of daily living (ADL) in a given community; or, to be more precise, ADL (activities of daily living) that are considered usual and necessary activities in that community.³ Usual activities refer to prevailing norms and habits and these may differ greatly from one community to another; necessary activities are activities which have to be performed, regardless of whether one likes them or not: thus, bathing may be a painful activity for a person suffering from arthritis, but still be a necessary daily activity. Preliminary definition: a disability is a disturbed ADL (where ADL are understood as usual activities and are thus culture bound). Otherwise formulated: a disability is an inability to perform a *usual* activity (according to the prevailing norms).

Such a usual-activities-oriented concept, instead of an impairment-bound model, has obvious advantages for research purposes, such as the making it possible to distinguish between mere in-abilities (a general designation) and specific dis-abilities. Moreover, a usual-activities-oriented definition provides a strong incentive to first ascertain the *normal*, before focusing on disabilities proper. An expatriate surgeon who went to Uganda first travelled the country for one year before performing any

operations (Baine 1965). Because ADL vary from one culture to another, concepts of disability also differ from one region to another.

INTERMEZZO

Usual activities (ADL) are based on physical/mental functions and structures (ODL) and they are motivated by personal/social purposes (IDL). The actual form that usual activities take is dependent on contextual factors such as: where is the activity performed (place), at what time (period), and in whose presence (persons)? Although the activities of daily living are experienced as usual and one's own activities from the perspective of the (local) performers, they may appear alien to outsiders. Local people may not bother about mere disabilities, whereas disturbances of usual activities (i.e. disabilities) may have important consequences. An in-ability becomes a dis-ability (disturbed ADL) only if the inability leads to a hindrance in performing usual activities. Compare the following examples. (A disturbed IDL may be equated with a handicap, a disturbed ADL with a disability and a disturbed ODL with an impairment). Examples (simplified): A person afflicted with a refraction anomaly of the eyes that would prevent the person from reading without glasses.

When in an illiterate context:

- has not got a disturbed ODL
- has not got a disturbed ADL
- has not got a disturbed IDL

When in a literate context, but unable to read:

- has got a disturbed ODL
- has got a disturbed ADL
- has got a disturbed IDL

In a literate context, able to read with glasses:

- has still got a disturbed ODL
- has not got a disturbed ADL
- has not got a disturbed IDL

N.B. If the glasses are broken:

- has got a (temporarily) disturbed ADL
- may have a (temporarily) disturbed IDL, unless it is time to relax

A person with no anomaly of the eyes, but unable to read (never learned to read) – in an illiterate context:

- has not got a disturbed ODL
- has not got a disturbed ADL
- has not got a disturbed IDL

In a literate context:

- has not got a disturbed ODL
- has got a disturbed ADL (outside view)
- may have a disturbed IDL, depending on how personally experienced. In some remarkable cases, the person wears empty glasses, pretending to read, but holding the book upside down.

METHODOLOGY OF RESEARCH

In what follows it is taken for granted that the researchers want to know more about local concepts and beliefs pertaining to disability and the disabled.

Statements for discussion:

1. a usual-activities-oriented approach (ADL-investigation) is an appropriate method for research on indigenous concepts and beliefs regarding disability.
2. research tools: to those of modern anthropological research (mentioned by Patrick Devlieger [p. 297ff.]) may be added:
 - intervention trials to establish a scaling of priorities (= most preferred IDL)
 - nicknames
 - seeming contradictions

ad 1: ADL-investigation is simple and accurate: observe and record the actual activities. Just note down very precisely: what is done, where, by whom, how, when, in whose presence. In short, the contextual factors (period, place, persons, product and performance in the idiom of the DL-concept) are recorded as well. Observations (and interviews) don't have to be focused on the disturbed ODL (impairment). On the contrary, the daily life of the community as a whole is studied. After having acquired a general picture of the ADL, attention can be focused on concepts and beliefs pertaining to disability. Using the definition of disability proposed here, this would imply the question: when is an inability considered a disturbed ADL? In other words: which disabilities lead to a hindrance in daily life? The advantage of this kind of investiga-

tion is that it can be applied in different cultural settings and that activities are studied within their actual context. Indeed, all the contextual factors mentioned above, as well as the other dimensions of the DL-concept (see annex), are inherent in any activity of daily living. At the same time this is a good opportunity to test the usefulness of the researcher's definition. The researcher may even try to falsify his or her definition from an inside perspective on the local culture. Last, but not least, the researcher may investigate personal experience in terms of the life satisfaction of the persons he/she is interviewing, using the ADL-approach as a method of research.

ad 2: priorities refer to most preferred purposes in daily life (most preferred IDL in the language of the DL-concept). These purposes or IDL, which relate to highly valued activities, may be scaled by using intervention trials, which present realistic and mutually exclusive choices, as a method of research. The scaling of IDL is valuable information for the personnel of rehabilitation projects, because it bears relevance to the experienced quality of life of persons with a disability. For example: market vendorship, having children and worship may all be IDL. The most preferred IDL, however, e.g. market vendorship, is the one at which the rehabilitation intervention should be directed. If the person concerned prefers to perform her work while squatting, the rehabilitation intervention is directed at this position. This may imply, as is true for all rehabilitation interventions: no intervention at all. So, besides an ADL-investigation, study of IDL should also be part of the research.

EPILOGUE

The relationship between 1. researchers on disability, 2. people responsible for the planning, funding and execution of projects and 3. organizations of persons with a disability is not well developed. I believe that a co-operation between these three parties would be fruitful for the well-being of persons with a disability. It indeed seems that many Northern-based NGOs think that they manage well enough without being well-informed about the needs, beliefs and ways of life of the community members. The kind of ADL-research that is proposed in this article is transcultural in nature in the sense that activities of daily living are regarded as culture-bound. Persons who have knowledge of both disability issues and local cultural backgrounds have been until now very seldom engaged in rehabilitation projects. The need to involve transcultural ex-

perts on disability (be they rehabilitation anthropologists, transcultural doctors, researchers, either disabled themselves or not) is obvious when one hears the stories told by expatriate rehabilitation workers.

ANNEX: THE DL-CONCEPT

What follows are quotations from *A Guide to ADL, the activities of daily living*, Eburon Delft, C.F. Vreede ed., 1993.

The Facets of ADL

The term *activities of daily living* can be more precisely defined by breaking it down into three facets. The facets constitute the first dimension of the structure of ADL. Moving legs, walking and going to the market represent three levels of the very same daily performance of an imaginary woman. These three levels can be labelled ODL, ADL and IDL, respectively. The highest level, IDL, implies a purpose: to go to the market (to sell her products); the middle level, ADL, implies an intention: to walk (to go to the market); only the lowest level, ODL, may be considered quasi-automatic: to move her legs (in walking).

Definitions

ODL (Operations for daily living) denote the physical or mental functional exertions and appearances applied in ADL, insofar as they can be performed or experienced consciously, although in practice this need not always be the case. For example: bending knees; moving one's hands; skin colour; staring.

ADL (Activities of daily living) denote the actual intentional activities usual to an individual or group of individuals. For example: squatting; throwing at a target; different bearing when in uniform; concentrating on a subject.

IDL (Ideas in daily living) denote the pursuits which subsume a value or common social purpose, in so far as they are described concretely and can therefore be analyzed in terms of ADL. For example: being a market vendor; playing marbles; dressing up in order to impress; listening to music.

This three-tiered concept of usual exertions, activities and pursuits constitutes a hierarchical system. An ADL *can* not be performed unless the required ODL are available, and *will* not be performed unless it forms part of an IDL. Moreover, ODL, ADL and IDL form a set of

subsystems of increasing complexity, for an IDL always comprises several ADL, and an ADL in its turn comprises several ODL. The concept of a multi-dimensional structure of ADL will be denoted by DL. Thus, this DL concept also includes the two dimensions discussed below.

The Components of ADL

An ADL always takes place within a given context. The context or specific occasion within which an activity takes place is determined by a combination of components which we call the five P's: *performance, product, place, period and persons*. The components are inherent to ADL; together they constitute the second dimension. Note that period may either be a particular point in time, or it may refer to the duration of a period. Persons refers both to people who are present and to people who are conspicuous by their absence. Performance and product have been considered constituent components of ADL ever since the term was introduced. The importance of place, period and persons has not, however, received much attention. The fact that these three P's are inherent components of any ADL can best be illustrated by taking a closer look at the Korsakoff syndrome. An individual suffering from this disturbance, which may develop after prolonged alcohol use, becomes disorientated as to time (read period), place and persons, and may indeed innocently pass water in a crowded room at a party, which no-one in his right mind would do. Thus, this cerebral dysfunction results in a loss of decorum – and hence in a degradation of ADL. Conversely, any proper ADL implies these three components in addition to performance and product.

The Aspects of ADL

An activity which is a usual daily performance for a particular person may be strange to another individual. It therefore appears necessary to make a formal distinction between what is felt to be usual, or own, and what is considered unusual, or alien. As we have done in the foregoing, the distinction between own and alien will be represented by a terminological abbreviation, namely A (mere activities) for alien; whereas ADL will continue to be used for own.

Definition of A

A denotes any humanly feasible activity irrespective of the system in which it may take place. In other words, an A is not considered system-bound. Upon closer examination, we see that ADL and A do not fully coincide with own and alien, respectively. As mentioned above, own and

alien are aspects of ADL. That is to say, they denote the distinction between usual and unusual activities. This distinction is conditional on the point of view of the observer; it does not result from an intrinsically different structure. ADL and A, on the other hand, denote a structural difference, namely whether or not something is system-bound, or to be more precise, whether or not the fact that it is system-bound is acknowledged. The fundamental distinction is thus between DL and A.

For most practical purposes, however, own may be equated with ADL (specific, system-bound) and alien with A (general, not system-bound). Moreover, both ADL and A denote concrete activities which are, or may be carried out by someone in some place at some time. Note that A does not signify an anomaly. In other words, the term as such is used to denote facts, it is not a moral valuation. To conclude, we draw attention to the fact that a logical consequence of the above definition of A, is that a so-called *ADL list* does not make much sense. Professionals should either use general A-lists (which are no more than mere checklists), or specified ADL inventories. Such inventories should be drawn up separately for men and women, adults and children, different professions, social classes, cultures or even individuals. However, under *normal* home circumstances, the soup need not be eaten as hot as it is served. In this light, it is worth repeating that the meaning of the terms ADL and A depend on the point of view of the observer: are we looking through the eyes of the performer or the onlooker, and who is the observer?

NOTES

- 1 IEEIR: International Exchange of Experts and Information in Rehabilitation.
- 2 Although the World Health Organization is now trying to introduce the sequence impairment – activities – participation instead of impairment – disability – handicap, impairment is still the building stone. This classification was and is intended to be used in a primarily medical context. I will call this the impairment-bound model.
- 3 See annex for a discussion on the concept of daily living (DL-concept).

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