THE HANDICAP PROFILE OF THE SPINAL CORD-DAMAGED IN CASE FILE, COMMUNICATION DOCUMENTS AND POPULATION SURVEY

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Abstract. "Definitions" of handicap are given, with a classification of intrinsic (personal) handicaps, as well as Tables for the preparation of an individual's Handicap Profile, of use in population Surveys and in case files."

Key words: Classification; Handicap; Surveys; Questionnaire; Case records.

Introduction

THIS paper is Part II of one which I gave to this Society in 1975, titled 'An Inter-disciplinary Language for the Recognition and Evaluation of Handicap Arising from Spinal Cord Damage'. Part I presented, in the spinal cord context, the classification and nomenclature of Intrinsic (Personal) Handicap which had been published in a wider context, that of handicaps arising from all handicapping disorders, earlier in the year (Agerholm, 1975a, 1975b.)

Table I shows the definitions of handicap, and of its two broad divisions, extrinsic and intrinsic handicap, inside which the classification is based. Definitions are essential preliminaries to any classification. Here they enable us to distinguish handicap from non-handicap, and the enduring intrinsic handicaps from the escapable extrinsic handicaps of environment and circumstance.

Table II shows the classification of intrinsic handicaps, which are the more immediate concern of the clinician. There are nine 'Key' Handicaps, and 41 Components of handicap, each of the latter having its fixed place as a 'sub-group' of one of the Key Handicaps. Components of handicap are impairments, disorders, defects, etc. which can, according to their kind or degree in the individual, contribute to personal handicap.

The classification table provides a check-list of handicap enabling the clinician to record the final handicap status of his patients, in terms which are relevant to the individual's subsequent life-style, and which can be interpreted into presentation as 'difficulties' and 'special needs', which are the criteria of personal handicap. If a

TABLE I
The definitions of handicap

A handicap is a long-term disadvantage which adversely affects an individual's capacity to achieve the personal and economic independence which is normal for his peers.

An extrinsic handicap is such a disadvantage arising from the individual's environment or circumstances (e.g. poverty, maternal deprivation, racial discrimination, residence in a depressed or disaster area).

An intrinsic handicap is such a disadvantage arising from the individual's own characteristics, from which he cannot be separated.

TABLE II
Classification of the intrinsic handicaps (M. AGERHOLM, 1975)

Key handicaps	Handicap components
1 Locomotor handicap (the locomotor handicapped)	A Impaired mobility in environment B Impaired postural mobility (relation of parts of body to one another) C Impaired manual dexterity D Reduced exercise tolerance
2 Visual handicap (the visually handicapped)	A Total loss of sight B Impaired (uncorrectable) visual acuity C Impaired visual field D Perceptual defect
3 Communication handicap (the communication handicap)	A Impaired hearing B Impaired talking C Impaired reading D Impaired writing
4 Visceral handicap (the viscerally handicapped)	A Disorders of ingestion B Disorders of excretion C Artificial openings D Dependence on life-saving machines
5 Intellectual handicap (the intellectually handicapped)	A Mental retardation (congenital) B Mental retardation (acquired) C Loss of learned skills D Impaired learning ability E Impaired memory F Impaired orientation in space or time G Impaired consciousness
6 Emotional handicap (the emotionally handicapped)	A Psychoses B Neuroses C Behaviour disorders D Drug disorders (including alcoholism) E Antisocial disorders F Emotional immaturity
7 Invisible handicap (the invisibly handicapped)	A Metabolic disorders requiring permanent therapy (<i>e.g.</i> diabetes, cystic fibrosis) B Epilepsy, and other unpredictable losses of consciousness C Special susceptibility to trauma (<i>e.g.</i> haemorrhagic disorders, bone fragility, susceptibility to pressure sores) D Intermittent prostrating disorders (<i>e.g.</i> migraine, asthma, vertigo) E Causalgia and other severe pain disorders

[Continued]

Key handicaps	Handicap components
8 Aversive handicap (the aversively handicapped)	A Unsightly distortion or defect of part of body B Unsightly skin disorders and scars C Abnormal movements of body (athetosis, tics, grimacing, etc.) D Abnormalities causing socially unacceptable smell, sight or sound
9 Senescence handicap (the senescence handicapped)	A Reduced plasticity of senescence B Slowing of physical or mental function of senescence C Reduced recuperative powers of senescence

'disabled' individual has no extra 'difficulties', no 'special needs' arising by virtue of his disablement and 'disabilities', then he is not handicapped only impaired, and can go on his way without special help from the handicap services.

Part II (this paper)

At this meeting I should like to report two further developments, since 1975, in this area of identification of handicap, and its evaluation and recording in a language which crosses the disciplinary barriers between professions and also reaches the understanding of the layman—including that important person, the handicapped individual himself.

1. *Translatability of the classification and its nomenclature into different languages*

In the Part I paper I stipulated that, to be acceptable as a fundamental contribution to any field of work, a classification must be translatable into a wide range of 'tongues'. I expressed the hope that members of this multi-lingual Society might help me in this matter. And, sure enough, I can now express publicly my gratitude to Dr Michaelis who promptly offered his help, and his valued encouragement, too, for this enterprise of mine; and skilfully demonstrated that translation into German, at any rate, presented no linguistic problems. Since then, I have had the help of various colleagues, some contacted by Brian McGinnis at the DHSS on my behalf, and the following translations are now available: Finnish, French, German, Hebrew and Norwegian. I also have promise of an Italian, and the assurance that a Polish translation presents no linguistic problems. In fact, where linguistic problems do arise, they appear to be non-specific, that is, characteristic of any translation from English into that language, rather than peculiar to the classification itself.

So the preliminary exercise suggests that the classification *is* translatable, meeting only the difficulties of translation generally.

2. *Application of the classification to recording the difficulties and needs of handicapped people*

In 1975 I reported that a Questionnaire form, based on the classification and its definitions, was about to be used in a pilot population Survey of handicapped

people. This Questionnaire was intended as a tool, previously lacking, for the identification of handicapped people, in the context of provision of services, cash benefits, equipment, etc. to handicapped people. In this context, it is important not only to identify individual handicapped people, and so to count them; but to identify their kinds of handicap, and so the kinds of difficulty and the kinds of needs which they signify.

The Survey, a true pilot without statistical significance, was carried out in the square mile of the City of London, an atypical population of 6500 residents in approximately 2000 households. The Survey technique (volunteers, briefed interviewers, two-stage saturation, etc.) had already proved its virtues for the identification of handicapped people in the hands of a voluntary organisation, OUTSET. But there was dissatisfaction with the harvest of information obtained through the current Questionnaire design. Hence the pilot study of this Questionnaire.

The harvest on this occasion was happily most rewarding: it has been written up elsewhere (Agerholm *et al.*, 1976). It has led on to use of the Questionnaire by invitation of statutory Authorities aware of their duties to the handicapped and of their inability hitherto to discover the basic information on which to build appropriate services and other provisions for carrying them out. A population of $\frac{3}{4}$ million, was followed by a population of $1\frac{1}{4}$ million, currently begun and to last 2 years; and the best encouragement, perhaps, lies in the present approach from the neighbouring Authority to the $\frac{3}{4}$ million, for a similar Survey—using the OUTSET survey techniques and the Questionnaire, which have clearly together encouraged confidence in the value of these exercises.

This is not the place to discuss the principles of Questionnaire design, and why this particular design has proved such an effective tool for harvesting and interpreting information previously so difficult to harvest and interpret. It is, however, the place, to bring the Questionnaire, and its value in clinical as well as Survey work, briefly to your attention, as a useful tool which you may care to use in the rehabilitation and resettlement contexts of your work with spinal cord-injured patients. Briefly, the Questionnaire as used in Surveys, and in smaller numbers in casework by statutory and other agencies concerned with rehabilitation and resettlement of handicapped people, draws a handicap profile made up of three sections:

The Handicap Profile (Table III, a and b)

Section I records the individual's *Personal Characteristics*, relevant to the handicap context: his age, his code number, his/her sex, his disorder (*e.g.* lame, stiff hands, ageing, in a wheelchair, blind); his diagnosis (if available, *e.g.* multiple sclerosis, spinal cord damage, 'stroke'); and that important characteristic his 'kind of mobility', since mobility affects so many activities.

Section II records his *Difficulties* arising from the characteristics recorded in Section I, as answers to the Question, 'Do you have difficulty with . . . ?' related to ten selected Activity Headings (those Activities in which a certain level of proficiency is required if an individual is to achieve the personal autonomy expected of and by every individual human being). Each Activity has sub-headings, which can be ignored or included, according to whether difficulty is recognised in that activity generally.

Section III records the special *Needs* created by the difficulties. This Section, unlike Sections I and II which have general profile application, can be varied

TABLE IIIb

SECTION III HELP NEEDED AS RESULT OF HANDICAP (Services and equipment)			
		Has	Wants
A. PERSONAL HELP AND SERVICES			
1	Shopping		
2	Collection of pension		
3	Medicines		
4	Other (state)		
5	Library service		
6	Occasional transport		
7	Home help		
8	Mails on wheels		
9	Laundry service		
10	House maintenance		
11	Garden maintenance		
12	Social outings		
13	Visitors		
14	Better contact with G.P.		
15	District nurse		
16	Health visitor		
17	Physiotherapy		
18	Chiropody at home		
19	Chiropody at clinic		
20	Services for the deaf		
21	Services for the blind		
22	Speech & communication training		
23	Social worker		
24	Occupational therapist		
25	Other (state)		
ADVICE ON:			
26	Cash benefits, rebates, etc.		
27	Services		
28	Aids and equipment		
29	Prosthetics		
30	Education		
31	Employment		
32	Holidays		
33	Recreation		
34	Housing		
35	Own disorder or handicap		
36	Special voluntary organisations		
37	Other (state)		
REGULAR PERSONAL HELP FOR:			
38	Mobility in house		
39	Dressing		
40	Toilet		
41	Bathing		
42	Foot care		
43	Feeding		
44	Injections		
45	Surgical dressings, etc.		
46	Applications		
47	Other (state)		
FREQUENCY OF HELP NEEDED:			
48	Less than once a week		
49	Once a week		
50	Twice a week		
51	Once a day		
52	Twice a day		
53	Through the day		
54	In the night		
55	Other (state)		
SPECIAL CENTRE NEEDED:			
56	Centre attendance		
57	Sheltered work		
58	Sheltered facility		
59	Sheltered housing		
60	Residential care		
61	Other (state)		
B. EQUIPMENT OR ITS MAINTENANCE			
MOBILITY		Has	Wants
1	Mobility aid outside the house (stick, long cane)		
2	Guide dog		
3	Mobility aid inside the house		
4	Ramps and rails outside house		
5	Ramps and rails inside house		
6	Spatial handles, switches, etc.		
7	Lift between floor levels		
8	Hoist (for ceiling, etc.)		
9	Wheelchair, push		
10	Wheelchair, self-propelled		
11	Wheelchair, motorised indoor		
12	Pedal tricycle		
13	Motorised bicycle (Invacar)		
14	Motorised wheelchair (outdoor)		
15	Car or van		
16	Car or van modification		
17	Exemption from Vehicle Excise Duty		
18			
19	Garage or garage modification		
20	Cash help with mobility needs		
HOUSING AND HOME FACILITIES			
21	House modification or addition		
22	Relouping		
23	Household appliance		
24	Washing, laundry, etc.		
25	Kitchen aids or modifications		
26	Bath aids or modification		
27	Shower aids or modification		
28	Toilet aids or modification		
29	Commune		
COMMUNICATION			
30	Amplifier		
31	Voice amplifier		
32	Telephone or telephone adaptation		
33	Typewriter		
34	Communication board		
35	Visual magnifier		
36	Large print book		
37	Talking book		
38	Braille equipment		
39	Call or alarm system		
40	Control system		
PERSONAL EQUIPMENT			
41	Aids for dressing		
42	Feeding		
43	Other (state)		
44	Special clothing		
45	Special footwear		
46	Elastic stockings		
47	Truss, brace, corset, caliper, etc.		
48	Artificial limb		
49	Bedpan		
50	Urinal/bottle		
51	Fitted external urinary appliance		
52	Catheters, collecting bags for bladder, etc.		
53	Fitted bowel appliance (including colostomy, etc.)		
54	Absorbent pads		
55	Waterproof bedding, etc.		
56	Waterproof clothing		
57	Sored laundry facilities		
58	Disposal system for dressings, absorbencies, etc.		
59	Special life machines e.g. respirator, kidney machine, aspirator, pacemaker, oxygen etc. (state)		
60	Other (state)		

The final stage of the exercise was the design of an effective information storage and retrieval system. After some flirtation with computers and their print-outs, we have settled down happily with the Kalamazoo punch-card system, which accepts direct transfer of the information without 'interpretation'. It carries only the Code Number into the open statistical analysis 'exposures' of

people's characteristics, difficulties and needs, and so helps to preserve confidentiality of personal information about individuals without losing the undoubted statistical value of some of the information obtained. In those areas where Surveys are carried out by this method, we shall have a good indication of how many people in the area are *actually* handicapped by such disorders as spinal cord damage, spina bifida, multiple sclerosis, mental handicap and visual handicap (to quote a few) as opposed to those carrying the diagnoses on hospital records, death certificates, etc., while at the same time, protecting people from idle identification by epidemiological scrutineers. Handicapped people need the protection of privacy as much as, or perhaps more than, the rest of us.

An innovation has been the 'self-carbonisation' of the Questionnaire, which allows every interviewee providing handicap information to keep his own copy, and so to know what has been recorded about himself. This prevents recording against the individual's wishes; it is, after all, he who is providing the information. Also it provides a useful document for him to hand to subsequent assessors in different contexts of handicap, and offers 'passport' information when he moves from one area to another, or between one activity and another, thus avoiding repeated assessment.

Conclusion

I express the hope that perhaps someone may be tempted to initiate in some other part of the world than the U.K. or in some other context than Surveys, a study to confirm or refute my original claim that handicap is the same 'round the world and down the centuries', or, as put by a colleague since, that handicap records can be 'culture-free'.

I believe that, using this questionnaire soundly based on the classification of handicap, we could build up a fascinating picture of handicapped people round the world, with the variations of patterns of handicap according to local prevalences of handicapping disorders, which could not only teach us a great deal about the needs of handicapped people in different parts of the world, but also teach us about the handicapping significance of the various handicapping disorders, and help us to distinguish the most urgent priorities of prevention of such disorders.

SUMMARY

Two developments are reported in the classification and nomenclature of handicap:

1. Translation of the classification and nomenclature into other tongues than English has presented no special linguistic problems and encourages confidence that the classification could have international use. Finnish, French, German, Hebrew and Norwegian translations are already available and others are in preparation.
2. The classification has been used as basis for construction of a Questionnaire form which elicits and records handicap information in three Sections: personal characteristics, difficulties and needs.

The completed Questionnaire presents a Handicap Profile which can be used in a variety of contexts, *e.g.* population survey, casework file, education and employment records, or as a Handicap Passport to identify eligibility for special provisions, *e.g.* services and cash benefits. The information can be transferred directly to computer or, better, to punched card (Kalamazoo) system for storage and retrieval, with built-in coding to conserve confidentiality of personal information.

The three sections of the Questionnaire are presented for international consideration. In the United Kingdom an initial pilot Survey, using OUTSET door-to-door interview techniques and the Questionnaire as tool, has led on to larger and larger population Surveys

(up to 1½ million so far) with growing evidence that the techniques and tool together yield a bountiful harvest of directly relevant information on handicapped people and the handicapping disorders, including the important group of spinal cord lesions.

RÉSUMÉ

Le communiqué concerne deux faits nouveaux à ce sujet de la classifications et nomenclature:

1. La traduction de la classification et nomenclature en d'autres langues que l'anglais n'a pas posé de problèmes spéciaux sur le plan linguistique et permet d'espérer que la classification serait susceptible d'être adoptée à l'échelon international. On possède déjà la traduction en allemand, en finlandais, en français, en hébreu et en norvégien et la traduction en d'autres langues est en cours.
2. La classification a été employée comme base pour l'établissement d'un questionnaire qui permet d'obtenir et de noter l'information relative à l'handicap dans trois sections, à savoir: caractéristiques personnelles, difficultés et besoins.

Le questionnaire, une fois rempli, fournit un profil de l'handicap qu'il est possible d'utiliser dans toutes sortes de contextes comme, par exemple, le recensement, la fiche de cas individuel les dossiers concernant l'enseignement et l'emploi, ou comme 'Passport d'Handicap' pour déterminer l'éligibilité pour certaines prestations spéciales en ce qui concerne, par exemple, les services fournis et les allocations. L'information peut être transmise directement à l'ordinateur ou, encore mieux, au système de cartes perforées (Kalamazoo) en vue de sa mémorisation et de sa recherche avec un code incorporé permettant de garantir la confidentialité des renseignements personnels.

Les trois sections du questionnaire sont présentées en vue de leur examen à l'échelon international. Au Royaume-Uni, une première enquête pilote basée sur l'emploi des techniques d'interview de porte en porte et le questionnaire a abouti à des recensements démographiques de plus en plus importants (couvrant jusqu'à maintenant 1,500,000 habitants) et ceci manifeste de plus en plus que c'est là un moyen permettant de récolter une grande quantité d'informations directement pertinentes concernant les personnes handicapées et les maladies à l'origine de l'handicap, y compris le groupe important des lésions de la moelle épinière.

ZUSAMMENFASSUNG

Bericht über zwei Entwicklungen auf diesem Arbeitsgebiet der Klassifikation und Nomenklatur:

1. Die Übersetzung der Klassifikation und Nomenklatur in andere Sprachen abgesehen von der englischen, hat keine besonderen Sprachprobleme mit sich gebracht und gibt Grund zur Annahme, dass die Klassifikation internationale Verwendung finden könnte. Finnische, französische, deutsche, hebräische und norwegische Übersetzungen stehen bereits zur Verfügung und andere sind im Vorbereitungsstadium.
2. Die Klassifikation wurde schon als Grundlage zur Erstellung eines Fragebogens verwendet für die Ermittlung und Erfassung von Behinderungs-Einzelheiten, welcherin drei Abschnitte gegliedert ist: persönliche Eigenheiten, Schwierigkeiten und Erfordernisse.

Der ausgefüllte Fragebogen gibt ein Behinderungsprofil das man auf verschiedenen Gebieten verwenden kann, z.B. bevölkerungsstatistische Untersuchungen, Einzelfallunterlagen, für Erziehungs- und Arbeitsnachweise, oder für die Ausstellung eines Invaliden-Ausweises der zu besonderen Leistungen berechtigt, z.B. Sonderdienste und finanzielle Unterstützung. Die Angaben können direkt in den Computer eingeführt werden oder noch besser in ein Lochkartensystem (Kalamazoo) zur Speicherung und Wiedergabe, mit eingebauten Schlüsselsystemen zur Wahrung der Vertraulichkeit der persönlichen Angaben.

Die drei Abschnitte des Fragebogens werden hiermit der internationalen Begutachtung unterbreitet. In Grossbritannien hat eine anfängliche Probeuntersuchung unter Anwendung des OUTSET Haus zu Haus Interview Systems mit dem Fragebogen als Untersuchungsmittel zu immer umfangreicheren bevölkerungsstatistischen Untersuchungen

geführt, (bisher bis $1\frac{1}{2}$ Millionen), mit zunehmenden Beweismaterial das daraufhindeutet, dass das System und Untersuchungsmittel zusammen einen reichlichen Ertrag von unmittelbar zweckdienlichen Informationen über Behinderte, Behinderungsleiden, einschliesslich der bedeutenden Gruppe von Wirbelsäulenverletzungen erschliessen.

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