

Point of View

WELFARE BENEFITS FOR PEOPLE WITH A MENTAL HANDICAP: THE PROFESSIONAL'S ROLE

INTRODUCTION

"It would be a mistake to read into... legislative and administrative changes a picture of evolutionary progress in the ways the needs of the mentally handicapped have been met increasingly during the twentieth century; the steps to progress have been, and continue to be, steeped in contradictions" (Hardiker & Barker, 1981, p.251). This paper is concerned with just one of these contradictions — that of implementation of policies of 'community care' alongside contradictory provision of welfare benefits for the mentally handicapped. It is argued that the welfare benefit system does not support moves toward community care for mentally handicapped people with provision of adequate income and — just as importantly — with provision of the means to claim this income. Some suggestions as to how professionals, e.g. social workers, community nurses and health visitors, might improve matters are raised, and the need to consider wholesale changes to existing provision, if 'true' community care is to be realised, is discussed.

In order to examine these issues, this study discusses the findings of a survey of take-up of benefits among a small sample of people with a mental handicap. Reasons for the poor take-up of benefits are discussed to give an indication of the professional's role.

Various studies have demonstrated the association between 'general' disability and poverty (e.g. Harris *et al.*, 1972; Sainsbury, 1970; Townsend, 1982). Other work shows specifically the poor take-up of benefits among disabled people (e.g. Bennett & McGavin, 1980; Cohen & Tarpey, 1982; Cooke *et al.*, 1983; Phillips & Glendinning, 1981). As will be seen, the survey reported here shows the poor take-up of benefits among mentally handicapped people in particular.

TAKE-UP OF BENEFITS

The questionnaire. Members of Nottinghamshire Community Mental Handicap Teams (CMHTs) began a survey of need among the county's mentally handicapped residents in Autumn 1982. The questionnaire used in the survey consisted of four sections: (1) personal details; (2) services used and/or needed; (3) an ability assessment; and (4) financial position. The first three sections were used to ascertain for which benefits the respondent would be eligible. The fourth section gave information on benefits actually claimed. By comparing the latter information with the assessed eligibility, those benefits which were unclaimed were identified.

The sample. The social workers and community nurse of the Bassetlaw CMHT interviewed the primary carer of the 288 known mentally handicapped residents in the team's area. A sample of 30 was chosen randomly for examination in this study. Of these 30 respondents, 25 were living at home with parent(s). Of the remainder, 3 were in a long-stay hospital, one child lived with foster parents and one adult lived independently in a group home. Eleven of the sample were under 16 years of age.

Findings. Only eight of the 30 people were receiving all the benefits to which they were entitled. This includes the three people who were living in hospital; they received their 'pocket money' allowance.

Table 1 gives an indication of the value of unclaimed benefits. Overall, £5,576 per annum was unclaimed. Among the 22 people who were not receiving their full entitlement, this averages out at £253.50 each per annum. Given that the average income of those not resident in hospital was £2,285.90, the unclaimed sum would represent an 11.1% increase if claimed.

Table 1

The value of unclaimed benefits

	<i>Annual Value of each £ p</i>	<i>Number not Claiming</i>	<i>Total Annual Amount Unclaimed £ p</i>
Supplementary Benefit Additions ¹			
— Baths	£10.40	2	£20.80
— Laundry	£46.80	7	£327.60
— Clothing (wear and tear)	£26.00	3	£78.00
Child Benefit ²	£304.20	1	£304.20
Attendance Allowance ³ (Higher instead of lower rate)	£455.00	4	£1,820.00
Mobility Allowance ⁴	£951.60	3	£2,854.80
Road Tax Exemption ⁵	£85.00	2	£170.00
			£5,575.40

NB: The above values of benefits are based on October 1983 rates. The values for each supplementary benefit addition are estimates based on the amount awarded in known cases.

1. People receiving supplementary benefit who have needs above 'normal' living expenses are eligible for a limited range of additions to the basic rate of supplementary benefit.
2. This is a tax-free benefit for each dependent child, payable irrespective of parental income.
3. This is an allowance payable to anyone aged 2 or over who has needed 'more than normal' looking after for at least 6 months.
4. This is a benefit payable to people 'unable or virtually unable' to walk because of a physical condition.
5. People receiving mobility allowance are entitled to exemption from road tax on a vehicle used by and/or for them.

Particular cases in the sample illustrate anomalies in the present benefit system. The attendance allowance is payable at one of two rates; the lower where extra attendance is required only during the day and the higher for day and night attendance. All of those entitled to the allowance were receiving it, but whether the higher or lower rate was awarded seemed to be rather arbitrary. For instance, one 22-year old who has a fair degree of independence in being able to wash, dress and feed himself, has only occasional problems in toileting and shows no behavioural problems, was receiving the higher rate. A 19-year old, however, who needed to be washed, dressed and who was enuretic, was receiving the lower rate of the allowance. Two other respondents, one 8 and one 13, who can feed themselves but need help with washing and dressing, were getting different rates. The 8-year old with the more difficult behaviour was receiving the lower rate. The older girl, wheelchair-bound but with no particular behaviour problems and who was less incontinent, received the higher rate.

The mobility allowance also shows anomalies. The status of mentally handicapped claimants with respect to this allowance is ambiguous. Whether directional in ability — as opposed to inability to put one foot in front of the other — can be taken as relevant in deciding if someone qualifies for the allowance by virtue of being virtually unable to walk, is still unclear in the regulations (Douglas, 1981). The case of a 10 year old Down's Syndrome boy illustrates the problem. He is physically able to walk, but will not do so without supervision and direction. As a consequence, he was deemed 'able to walk' and his application for the mobility allowance was unsuccessful. Two older respondents who had similar difficulties in directing themselves were also not receiving the allowance. These latter cases differ in that respondents had not actually claimed the benefit.

What these cases show is that mobility allowance is not reaching all of those who seem to be its intended recipients. What is required is a clear statement of whether mentally handicapped claimants who are physically ambulant but cannot direct themselves, are to be catered for by the allowance. In the attendance allowance cases, people had actually been assessed for the allowance, but not awarded the rate commensurate with their characteristics as reported to the interviewer. One could speculate here that the Attendance Allowance Board's examining doctors do not gather the more relevant information picked up by the social workers who interviewed for the survey. Carson (1972) has questioned whether doctors are the best equipped to make decisions about the need for attendance. He argues that the relevant information is often factual and not medical. Bradshaw & Lawton (1980) found that applications for the AA from children with similar handicaps were being treated in different ways. The region in which the applicant resided and the social class of the family seemed to have more bearing on the outcome of the application than did the severity of the handicap. It is worth noting also that a large number of reviews of attendance allowance decisions are successful for the claimant — the success rate is about 60% (Baldwin *et al.*, 1981). In Baldwin's (1976) study, just under half of the families whose claims were unsuccessful did not ask for a review. Given the anomalies in the administration of the allowance, the importance of encouraging families to seek a review is clear.

This account of the position of a small number of claimants confirms data from other studies of take-up and illustrates the problems associated with particular benefits. The data, it must be emphasised, are not presented as exhaustive evidence of take-up levels, but as an indication of the likely pattern of take-up. We can now move on to outline possible reasons for poor take-up.

REASONS FOR POOR TAKE-UP OF BENEFITS

Three factors influence take-up: stigma, ignorance and complexity (National Consumer Council, 1976). On stigma, Ritchie & Wilson (1979) found that about one quarter of the claimants they interviewed felt 'ashamed at getting charity'. Blaxter (1974), studying claims for prescription charges, showed that if the claim was for a benefit for unavoidable need (e.g. sickness), stigma was less influential. How a person interprets 'unavoidable need' will vary of course. Some carers of people with a mental handicap would see their claims — particularly those which they relate directly to the handicap — as being unavoidable. Other carers, influenced perhaps by the stigma of the handicap itself and not seeing the need as unavoidable, may be deterred from claiming.

The effect of ignorance varies from benefit to benefit. Some benefits — particularly the means-tested ones — are more publicised than others. However, there is likely to be an interaction between stigma and ignorance. As Kay (1971, p.36) has said, "knowing one's rights can help to modify some of the deterrent effects of means-tested benefits". There is less stigma associated with non means-tested benefits and therefore knowledge of

them can be gained more readily (Lister, 1976). However, it is important to remember that as far as mentally handicapped claimants are concerned, the so-called non-means tested benefits, such as attendance allowance, mobility allowance and non-contributory invalidity pension, do require a means test — one of a psychological and physiological nature (Bolderson, 1974). Claimants need to submit to 'medical' examinations in claiming these benefits. The examinations can, for the carers who make the application as well as for the handicapped people themselves, take on the aura of means tests. As a result of this, we can expect stigma and ignorance to operate in claims by the mentally handicapped across the whole range of benefits.

Complexity is the most self-obvious of the reasons proposed for poor take-up. As well as the complexity of the regulations governing the benefits, there is also the complexity of the claiming procedure. Supplementary benefit, for example, requires contact with DHSS and Local Authority offices and perhaps arrangements for visiting officers to see the claimant's home circumstances. Other benefits, such as attendance allowance and mobility allowance, necessitate contact with the Blackpool administrative unit and with Designated Medical Practitioners of the DHSS. Non-contributory invalidity pension often requires the regular submission of medical certificates. The picture is further complicated when one considers that people claiming on behalf of a mentally handicapped person may themselves be claimants (e.g. unemployed or pensioners). Also, there is the range of other 'welfare' agencies, such as Social Services, Health and Education, with which carers and the mentally handicapped person are likely to have contact.

The reasons for poor take-up among the mentally handicapped are, then, various. There is scope for further research, but sufficient has been said to give some indication of the useful role professionals can play.

REMEDIES — THE PROFESSIONAL'S ROLE

Remedies can operate at two levels. As Townsend (1982, p.106) has said, "there is a powerful argument for improving the wretchedly inadequate system of benefits, but there is also a powerful interim argument for making a better job of that system". Firstly, then, how can professionals hope to 'make a better job of the system'? The main requirement is a recognition of the importance of claiming one's full entitlement. Social workers, community nurses, and health visitors, etc. can often be heard arguing that welfare rights work is not within their professional domain. This attitude can all too easily translate into a view that welfare rights issues are not important. As far as our clients are concerned, this is blatantly not true. Welfare rights, when employment prospects are as poor as they are for the mentally handicapped, are of fundamental importance to a person's life-style. Professional concern to implement policies of community care, supposedly based on principles of normalisation, are meaningless to the client, unless the need for adequate financial provision is accepted. Without this, community care merely becomes family care, or care by women (Wilson, 1982). To achieve *true* community care, we need care *in* the community, *by* members of the community and *for* the community (Walker, 1982). It follows that the community (or, 'the state') must also provide the financial support which will allow people with a mental handicap to achieve the independence they need to take advantage of this 'true' community care.

So, it is crucial that professionals accept the value of welfare rights work. We must divorce the claim that it is a complex area outside of 'our' professional expertise, from the claim that it is of lesser importance than 'our' work — be that social work, community nursing or health visiting. Having done this, the work we do should then strive to minimise the problems our clients face in claiming their entitlement to benefits. This can

be done by firstly ensuring that the client's status as a claimant is openly recognised and accepted. Steps to overcome the stigma previously discussed can then be taken. Ignorance and complexity can be tackled with knowledge of local specialist agencies (e.g. CABs), to which referral can be made for further advice and assistance with claims.

Other direct steps to increase take-up of entitlement can be made through the various reviews in which people with a mental handicap are involved. Blunden (1980) proposes an 'individual plan system' (IPS) to plan the services a client will need to attain his or her full potential. The IPS generates individual plans for each client, plans which should be reviewed at regular intervals. Inclusion of review of the financial 'services' which a client is receiving would do much to facilitate take-up and ease the claiming process. Many ESN schools, ATCs and LA hostels use regular reviews; the commitment to consider benefit entitlement within these reviews would be of great help to clients. Accepting and treating welfare benefits as just one of the services to which people with a mental handicap are entitled will help to reduce stigma and ignorance.

The second level at which professionals need to consider remedies is in terms of wholesale changes. The Disability Alliance, for example, was formed in 1974 with the aim of persuading 'society to pay an income as of right to all people with disabilities, as part of transforming their position and status. This should be paid regardless of age, sex, cause, type or origin of disablement, to eliminate poverty and financial hardship among disabled people'. Along with the Disablement Income Group, the Disability Alliance is calling for a comprehensive disability income scheme (CDIS) to replace the present array of 'disability' benefits (Walker, 1981). The CDIS is put forward to cater for the disabled as a whole; an evaluation of its merits specifically for the mentally handicapped shows that it would be a vast improvement (Sumpton, 1983). Whilst working within the present network of benefits, it is therefore important to realise that fundamental changes should be the long-term goal. Professionals' support for campaigning organisations and for individuals coping with the present arrangements is essential.

SUMMARY

This article describes the position of people in Britain with a mental handicap as claimants of welfare benefits. Examining a sample of claimants, it shows that there are severe problems of take-up of benefits and anomalies within the existing system. It is argued that professionals who support the move to community care must acknowledge the importance of welfare rights issues for their clients. Some ways in which professionals and carers can help to overcome the problems faced by mentally handicapped claimants have been outlined. Furthermore, the need to consider longer-term changes to the system of benefits is raised.

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