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# A Charter of Rights - Not Charity

**Parents of mentally handicapped children are increasingly concerned about the future adult needs of their aging offspring. In Ireland, where service provision for people with a mental handicap has traditionally been regarded as a moral rather than a political issue, parents are determined to call for a charter of rights for mentally handicapped adults.**

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## INTRODUCTION

The Parents' Association for People with a Mental Handicap (PAM) was formed in 1987 by a group of parents and relatives who were alarmed at the cutbacks on services for mentally handicapped people. Many of the service-providers also appeared fearful for the future of these children. For years they had campaigned for increased funding for the mental handicap services, but they were unable to protect these services from the effects of the 1986/87 cutbacks. Waiting-lists were growing and there was an increasing sense of crisis in the service.

## NO GUARANTEE

Many parents felt that a higher public profile and a more active campaign were needed to highlight their concern about the falling level of services offered to their children. As a new organisation, PAM set about identifying the issues which most concerned parents and families. Over and over again we were shocked at the shortfalls in the services, and the trail of human misery which resulted. We discovered that in the present circumstances no person with a mental handicap could be guaranteed a service from the cradle to the grave.

## ETERNAL CHILDREN

In Ireland the responsibility for caring for people with a mental handicap has always been thought of as a moral, rather than a political issue, perhaps because the religious orders were the first to provide care in this area. Also, the earliest specialist services catered for children who attracted most public sympathy. But nowadays most of these children grow up to be adults who have a wide spectrum of abilities and needs. Many will be able to live a relatively normal life, provided support structures are present; others will require a high degree of care and supervision; a small number will be totally dependent for every need. The majority of mentally handicapped people will outlive their parents or their parents' capacity to look after them. In nearly all cases the person with a mental handicap will require a special service if he or she is to have as full a life as possible.

We are determined to make politicians face their responsibilities towards people with a mental handicap.

Services cost money, and families cannot provide for their handicapped members from their own resources.

## RIGHTS NOT CHARITY

Parents who have a child with a mental handicap travel a never-ending road of disillusionment. Not only do they have to adjust to their child's disability, they also find that the services needed to optimise that child's development are available only patchily or not at all. Our children are seen as objects of pity or charity, not as individuals with rights. PAM is opposed to the concept of charity. We demand rights for all people with a mental handicap. Neither ourselves nor our children should have to beg for the basic services of education, shelter and care. Ireland is the twenty-sixth richest nation in the world, and can well afford to cater for the needs of its mentally handicapped citizens.

## A CHARTER OF RIGHTS

The Constitution affords no specific protection to people with a mental handicap, therefore legislation is needed to give such people statutory rights. We call for the introduction of legislation in the Oireachtas which would guarantee the rights of all handicapped people to education, training, suitable employment, day or residential care depending on their needs. We would like to see Government schemes to encourage employers to keep a quota of 5% of jobs for people with a handicap.

PAM would suggest the following charter of rights:

1. Assessment and a place in an appropriate service for every child.
2. A day-care or training place on leaving the children's service (at 18).

3. An employment or day-care place on leaving training.
4. Specialist services such as speech therapy, physiotherapy, and independence training to be available particularly in the early years.
5. A guarantee of a long-term residential place, either in a group or community home or in a special centre, depending on the person's needs. Such a place to be made available on a phased basis when the parents decide it is necessary. A specific agency should be designated to provide such a place immediately, where a sudden family crisis occurs.
6. A guarantee of the quality and suitability of the care provided. This should be done by providing an independent Service-Ombudsman, and by giving the person and his/her parents a say and a choice in the type of service provided. Where the person with a handicap has no family, an advocate should be appointed. All services which receive state funds should be inspected regularly by the Department of Health.

We would suggest that the systems operating in Sweden and Holland should be studied as models.

## A FUNDED PLAN

We want to see the present crisis in mental handicap services resolved. This can be done through Government commitment to a planned and co-ordinated programme with guaranteed funding over a number of years. We are demanding the following action:

1. Investment in the programmes outlined by the Central Planning Committees of the Health Boards, and the Government Review Group on Mental Handicap Services.
2. A Bill of Rights for people with a mental handicap.
3. Consultative rights for parents on planning committees and voluntary agencies.
4. Publication of a White Paper on services for people with a mental handicap.

## HANDICAPPED ADULTS

At one time, any sort of handicap meant a short life-span; but this is less true today. The change in age-profile of people with a mental handicap has not always been taken into account and the public still tends to regard them as "eternal children". Yet in 1987 almost 25% of those classified as being moderately and severely handicapped were over 35. These adults often have different needs from children partly because their family situations are different. The Government and the service providers must take into account the changing life-cycle of the family, and should recognise that the majority of adults with a mental handicap will require some form of residential care before they die. If families are to care for their handicapped members for as long as possible (which seems by default, to be Government policy) it is essential that comprehensive respite care is available so that parents can get regular breaks like other professionals. It is also important that a residential place in a group or community home is available when parents deem it necessary.

## ONE VOICE

In PAM parents and families of mentally handicapped people have for the first time a single national voice to press their case. We make no apology either for our demands or the manner in which we make them. Our demands are just and our children's needs are real. All we ask is that they be given the facilities to reach their potential, that they are cared for in a manner that respects their dignity and allows them a secure future.

We continue this campaign out of love for our children, and out of fear and concern for their future.