



REPORT OF A DELEGATION
FROM
HONG KONG COUNCIL
OF
SOCIAL SERVICE
TO
THE UNITED KINGDOM
ON
SERVICES TO CARERS

11-15 May 1998

(First International Conference on
Family Care – “Caring for Carers” and Pre-event Study Visit)

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Tooting Neighbourhood Centre, Tooting, London, UK
Newham Social Services, Straford, UK
Crossroads, UK
Alzheimer Disease Association, UK

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Alfred Chan
Delegation Leader
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I. Background

The delegation was initially setting off to attend the First Carers Association Conference held in London, UK on 14th and 15th May 1998. In making the trip more worthwhile, a three days pre-conference exchange visits were arranged to look at a wide spectrum of support services for carers in UK.

The first visit was to a neighbourhood centre at Tooting, London. The centre was a multi-services base serving primarily a small neighbourhood of Pakistani and Indian people. Most of the staff were part-time paid carers – these tended to be women who received their basic caring skill training while in service – whose jobs were mainly going into people's houses to do all sort of household caring tasks right from cleaning to basic nursing jobs (e.g. assisted baths, injection, dressing). Incomes for the centre were from all sorts too: charging those who could pay, having a block grant from the local government, and being awarded with a contract to provide pre-agreed services.

The second visit was to Crossroads. This was one of the major national charity organizations providing both support for the carers and carers support in London. Four objectives were set down in this agency to achieve this aim: the Association of Crossroads develops new care schemes and projects, directly manages some services and gives essential support, guidance and advice to other existing schemes. This agency is providing care and support for over 28,000 carers in England and Wales.

The third visit was to the Department of Health (DH) in London. The Department is a government set up responsible for all health services in UK and is the executive arm for commissioning community health care related projects. Together with the Department of Social Services (DSS), they look after almost everything in health and welfare services. To aid a better coordinated policy-making process, a Health and Social Services Commission has been set up to govern the execution of policies in the two Departments. It was said that UK has now adopted a community care policy for both acute and long term care – where and when situation allows, appropriate care should be best provided in community at people's own homes. The new community care policy environment is one where health and social service organizations will be encouraged to develop new structures, with a considerable focus on designing new service models of care management. The most promising forms of care management approaches are taken as those attempts which improve inter-agency coordination, in principally health and social care services domains. This is done through initiatives such as joint care planning and joint financing.

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The fourth visit was to the Newham Social Services (NSS) in Straford. Newham is a borough within the East London District. Newham Social Services are under the Borough (local government) administration, their work is funded essentially by the DSS, with some from DH for joint planning and joint financing initiatives. The aim of NSS is to provide quality social services to service users, carers and members of the public. Complaints or suggestions of any kind of care services from the public can be made to and through it. The NSS through serving and collecting feedback from the population residing at their locality would formulate care plans for NSS provision. Current focus is put on groups who are homeless, in need of community care services and household services. A larger part of their direct services is provided by carers from different sources: contracts with local private agents, purchasing from voluntary agencies and from their own trained carers. NSS is therefore assuming the roles of both a direct service agent where it normally takes statutory cases, provides training to carers, and provides support to carers and carers associations; a commissioning agent where it negotiates and issues service contracts; and a purchaser where it buys services for those who need them. In addition to all these roles, NSS is also an inspectorate agent where it makes sure the minimum quality standards of all services are met.

The fifth visit was to the Alzheimer's Disease Society, London, arranged for us by the Department of Health. The society was established by carers taking care of those with Alzheimer's disease and is the leading UK care and research charity for the disease and its sufferers. Operating through a partnership between branches and support groups and other national organizations in England, Wales and Northern Ireland, the aims of the society are to help people with dementia and their family carers, and to provide the information resources (e.g. leaflets about the disease updates, training manuals for carers). As this is a membership organization, the more members she has the louder her voice will be heard. The Society adopts the service quality standards (SQS) practice and is guided by three principles: individualized care; dignity, respect and understanding for the cared and the carers; and supporting carers.

Alzheimer's Disease Society also provides direct services. The more important ones are the day care and home care services for people with dementia, awareness campaigning for improved health and social services, and a hotline service specialized in dementia and also fund raising for research and service.

By the end of our site visits, it was patently clear that there has been a paradigm

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shift in taking the carers, who were treated as part of the informal care system before, into the formal mainstream care service provision. Such a shift has long lasting impacts right from operation levels (say services to support carers to care) to policy levels (e.g. the funding formulas and re-prioritizing subsidies). It also cuts through professional boundaries in terms of transferring all the basic professional skills for human care to an individual, now called the carer, working at his/her own home or at other people's homes.

The following conference days gave us little new information but confirmed that the carers have 'arisen' from hidden places to the formal services platform, and are making their demands, as well as are being recognized for their effort. This is all over Europe, Australia and North America. Perhaps the greatest experience we had in this conference is having heard of the heart-felt feelings of the carers. A few did come to the conference and spoke in front of MPs and senior government representatives from other countries: their voices were their passions, their feelings and guidelines for recent changes in policies in providing support and recognition to carers in UK. In order to support these people in giving a better and a longer lasting home care, financial assistance, tangible services support (e.g. respite care), psychosocial support (e.g. carers support groups), training and skills recognition for carers have been considered as essential components of successful home and community care.

II. The Awakening

Carers for us, as helping professionals in Hong Kong, have been always just someone who are either family relatives or friends performing the caring tasks voluntarily i.e. without pay and public recognition. Care provided by these carers is taken somewhat as a good effort and as an expected reciprocal act through which the carers are only making their contribution back to their family and community. The level of care provided by these people hence is considered to be basic, non-professional and natural – in the sense that someone who cares ought to give the care.

Social services in Hong Kong by and large take the above perspectives. Carers have been seen as a self-sufficient informal care and have never been acknowledged that they are a major work force in family and community care. Support to carers and other issues relating to being short and long term carers therefore are seldom discussed.

The visit to London was an awakening experience. Although we all are aware that carers have been a major issue in Australia, USA, Britain and other western countries, we were not sensitive enough to visualize the impacts these people may bring if they were taken differently.

In the following paragraphs, the Delegation wishes to bring in front of you a whole series of re-thought questions about our carers, some of which we may have answers and recommendation for Hong Kong, but for most we may have not even formulated any views. We are going to use the London experience as a reference to compare and contrast what and where Hong Kong is, and which direction we should go.

III. Who the carers are, what the carers do and what do the carers need?

Carers can be described as people who provides care and support for a parent, partner, relative or friend who has a disability, is frail aged, or who has a chronic mental or physical illness. At some point in their lives, most people will either give away or receive care.

Carers can do a range of tasks. These may include shopping on a regular basis for a neighbour, preparing a meal every now and then, right through to giving 24 hours care which may include the full range of personal care such as helping with washing, feeding and taking to the toilet. This care may have to be given both day and night and therefore being a carer can be a physically exhausting and emotionally stressful task. Carers will often feel isolated, unsupported and alone.

Working as a carer is unpaid and it brings no status or contract of employment. Many people give up their paid job or reduce their working hours in order to care for someone. Therefore, they may often miss out on job opportunities and face the prospect of financial hardship as they have no chance to build up savings or a pension. Apart from this, carers often have to cash in insurance policies or eat into their savings to help meet the extra costs of caring.

For most people however, caring is not a matter of choice. Caring is to a great extent a family role. It comes through to people as the hardest of task as it involves the implacable combination of love and duty. Therefore, caring, we must assert is not a private relationship which should remain outside society's jurisdiction but part of a complex of social roles which enable those with disabilities to live and participate in society.

There is in fact a psychological effect between the reciprocation carers receive for their efforts and the extent of their satisfactory caregiving. Carers provide the necessary care, hoping to help people recover or at least get better physically or mentally. Lack of reciprocity is stressful and helpless when these caregivers realize that their caregiving may end up changing nothing for the better. The carers will then feel a sense of guilt because they think their caregiving is ineffective and insufficient. Clearly, carers' coping resources, coping strategies, and the social support they receive are all essential in delivering satisfactory caregiving. It has been argued, even from a cost-effective perspective within a market economy, that the society has a lot to gain from by supporting the carers in all aspects.

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In considering the market's recycling of resources, there are winners and losers. Carers are clearly the losers in the market while society as a whole is the winner. Carers very often give their services for free, as either they are not expected to, or they themselves think that it is disgraceful to, charge someone in need of their help. Let's consider the 'zero sum balance' of gains and losses amongst the three parties in giving long term care (i.e. government representing the society, the carer and the cared). Without the carer, the government will have to bear the full costs of caregiving (i.e. in meeting costs for community or residential care). With the carer's full or partial input, the carer would have given up either a full time job and/or some of the leisure time; the government also gains that part of services free. As for the cared, home care is always preferred for its readily availability, less bureaucratic and high commitment, moreover it is free of charge. So when care giving is considered to be a product of value, it is worth at least the total costs which or otherwise government would have to spend for those services it has replaced (i.e. replacement value R); and if other costs and gains are to be added on, the carers' full value in care giving (CV) would be the sum of R plus the loss of salary from employment (E) plus the psychological and social gains (S) (e.g. commitment, flexibility, trust); so as a rough formula $CV = R+E+S$. Such a calculation has already excluded the gains through extending the period in living at home and in preventing or delaying using higher level services (e.g. nursing home, hospital) pre-maturely.

Carers support can be strongly argued too from a social justice perspective for carers requires recognition of their role in a continuum of care which requires professional support. As mentioned before, it requires recognition that caring affects health, education, employment and personal freedom. Social justice therefore requires the development of systems to bring carers into the mainstream, help them back into employment if caring responsibilities end and provide financial recognition both of the additional cost of caring and the loss of opportunity to be self sufficient. In particular, social justice for carers has to address the particular advantage of women, more likely to care, less likely to have the continuity of employment and good pay, less likely to have savings or pensions and more likely to live into a dependent old age.

No one would deny the importance of carers in our societies nor that we should provide them with supporting structures so they can remain their caring role. Carers often reach the stage where they are physically, mentally or financially unable to keep going. The basic needs of carers can be outlined as follows:

1) Recognition

Carers needs are necessary to be recognized both by the carers themselves and by the others especially the helping professionals. If the carers do not see a need, they will not ask for help and will continue to suffer the strains of care. If the helping professionals do not recognize that caring for someone is requiring extra assistance, carers will not be given any support. It is a common assumption that carers are assumed to be self-sufficient and the care given to the cared by family carers are adequate. The worst part of this is that the carers themselves have often failed to admit the inadequacy of their care. Not until there is a turn of such an attitude, then the carers and the cared will have proper assistance. The recognition can be two ways.

a) As a valuable service to the community

At present carers are taken as either a family member or a friend who is willing to care. Thus carers are not something requiring public recognition. However, considering their contribution to the community and their commitment to care, they surely deserve a wider public recognition. It is a valuable service to the community if anyone is committed to care for some one at home.

b) As a skillful job which can be accredited, rewarded and extended to become an occupation

Carers start with their commitment and common sense to care, then slowly picks up special skills as they go along. Upon the death of the cared, we are left with a very skillful and caring person – who has also lost a job (voluntary or paid). It makes good senses to provide proper training to the carers when they need to provide care, adding all these ‘in-service’ training to form a qualification, and finally allowing these experience and qualification to become credentials for appropriate jobs or an occupation.

2) Financial Help

Money is always a problem for carers who need to care for their relatives. They themselves may have to resign or take time off from their jobs to provide the care, thereby reducing their own disposable incomes. The people requiring care, as their condition deteriorates, will need adaptations to their environment or need to buy special equipment or facilities – all these require money or other material resources.

3) Support Services

Even with the financial burden off the shoulder, carers still need other supports, for both physical and emotional relief within the almost 24-hours a day's work.

a) Relief for physical strains or time to do other things

The physical burden to care some one who is not well is obviously enormous. Carers would need assistance for instance for lifting the cared in and out of the bath, for a few days break or just a few hours to do other things (e.g. shopping). Carers do not often have holidays because of their commitment to care or having no money for holidays.

b) Information and training

Carers have a habit in working by themselves and never asked for formal help. Some of them get over their difficult problems by going round their relatives and friends, but some of them just get stuck with their problems. Information and advice are important for these carers to where they could cry for help in emergencies or for the problems in their care. Knowledge and skills for these carers in caring for special illnesses are minimal, and training is needed.

c) Psychological and social support

Increasing number of literature have established that carers can be easily burnt out by two things: care without appreciation and care without support. Carers mostly wish to be appreciated by those they cared for. But very often in irrevocable conditions, the people under their care express easily their anger, frustration and demands to the carers. As a result the carers also feel angrily, frustrated and depressed. Due also to the time needed to care, the carers are also socially isolated. The situation, without proper intervention, is likely to exacerbate to a total breakdown of relationship between the carers and the cared. Counseling supports to both parties are necessary for achieving the mutual understanding and tolerance; support groups amongst the carers are useful too.

As carers provide most of the care in the community, primary healthcare teams and social services departments need to work together effectively to ensure that they receive the supports they need.

4) Other needs

For those carers who have a full time job, they need understanding employers. Although it is difficult to fill the role of a carer and hold down a paid job at the same time, there are benefits for employers in being sympathetic to carers. They can retain the experienced staff they have invested in and they can enhance their corporate image. However, to instill such a message in a utilitarian society, a lot of effort is required in both formal and public education to change the attitude and values of our society.

If the needs of these carers can be fulfilled, the whole situation in society will be improved. Carers will feel more satisfied and the sufferers will feel they are really cared for. It is up to the government and the rest of society to enable this taking place. One way to achieve this is through explicit policy making such as enacting a legislation .

IV. Setting a Policy for recognition and support for carers: the British ‘CARERS (RECOGNITION and SERVICES) ACT 1995’

There are pros and cons in using legislation as a means to define policy goals. However, in a world of inequalities where equality of resource distribution is far, and amongst those least protected and the less vocal, ‘loading the law’ is the only way of making sure of their minimum interests and to effectively educate the public. The British ‘Carers (Recognition and Services) Act 1995’ (i.e. the Act) is an act of the Parliament enacted to recognize carers’ needs and status. In the following paragraphs, we will investigate, through the Act, the definition of carers, philosophy and history of the Act. Consideration on both gains and losses in applying similar legislation in Hong Kong will also be made. We need to put a note of caution at this stage to stress that we are not dealing with the Act from any legal perspectives, we are simply using the Act to tell a story – a story which shows how carers are recognized.

Those people who look after family or friends, without payment, in their own homes or elsewhere are considered as carers (Department of Health UK, 1993). They may involve fairly limited help like visiting and shopping, or they may involve carrying out personal tasks such as washing and feeding. Some carers spend only a

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few hours a week with the person they care for; others spend 24 hours a day. From the General Household Survey (UK) on carers in 1990/91, the majority of those carers are of working age. They are facing the pressure of maintaining both their working and caring lives. The size of carers is enormous too – Britain estimated for 6.8m (i.e. over 10% of the UK population) in 1994, of this 1.5m was giving care more than 20 hours a week. Counting only the total labour costs for the unpaid work hours, the British Institute of Actuaries estimated an annual value of 34 billion pounds (about HK\$428 billions). The majority of this caring population is women, some are elderly over 65 and some are youth under 14. It is clear with these figures that carers have made a sizable contribution to the health and wealth of the nation, but what do they get in return? Carers in Britain, like elsewhere, quietly worked away their lives unnoticed. Even the 1990 Community Care Act did not make it mandatory for local authorities (local government) and for national health services (NHS) to give practical supports to carers.

The History and Philosophy of the Act

In UK, starting from late 80s, the government has put much of their attention in broadly defined community care service domains – within which carers were considered as a partnership force. According to the 1989 White Paper “Caring for People”, the second key objective is “*to ensure that service providers make practical support for carers a high priority*” and that “*assessment of needs should always take account the needs of caring family, friends and neighbours*”. However, the 1990 Community Care Act and the National Health Services, as mentioned before, did not take on the carers. As a reaction to the rising demands to care for the carers, the Government did issue a guidance note to all local authorities in 1990 that : “*...carers who feel they need community care services in their own right can ask for a separate assessment. This can arise if the care plan of the person for whom they care does not, in their view, adequately address the carer’s own needs.*” At a later year in 1994 (May) when the Carers National Association published their report “ *Community care: Just a Fairy Tale* ”, formal supports to the carers were proven to be minimal. It was reported that only 13% of the carers received a separate assessment, and 80% felt that community reforms did not make any difference to their lives.

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Malcome Wicks, a member of the Parliament, took up the issue and presented it as a Private Member's Bill. The Bill was heavily amended in the initial Committee stage, but got Government support in its second reading. In 1995, the Carers (Recognition and Services) Act 1995 became a new Act of Parliament which came into force on 1st April 1996. The act concerns with an assessment on carers' ability to care, and subsequently to connect the carers to appropriate services, and is consistent with the UK Government's policy aims for the community care. What it does not include is the carers' defined rights to financial rewards and other resources. The main idea of the Act is to make sure that service providers provide practical support and enough resources to the carers. The main achievement of the Act, comparing to previous community care assessment measures, is that during the process of assessment of the service users, the carers have a say in the care plan. The Act also makes clearer definition that anyone who looks after or helps someone with difficulties is a carer; this includes help and support to someone with physical disabilities; an older person; someone with a learning disability, or a child or young person who is helping to support and care for a member of their family. The carers do not have to live in the same household as the cared.

The Act, though provides only an entitlement for a separate assessment, does successfully pull the carers out from being unnoticed to being recognized by professional service providers and the public. What the Act can do is perhaps less important at this moment of time, more importantly is that the Act represents a paradigm's shift in the caring philosophy.

There are two underlying philosophies of the Act:

1. We should not assume a willingness by the carer to continue care.

Although in most cases, carers are relatives and friends of the service user, we should not assume a willingness by the carer to continue care. They have their own lives and responsibilities. Government has the responsibilities in helping and caring for its members, both for carers and the cared. Government's responsibilities do not cease at the point where a member requiring care is cared for by another. The monitoring of care, assistance to facilitate better care and care for the carers are all responsibilities of the Government.

2. Carers can provide effective service to the service users:

Since carers have more time to spend with the cared than any other service providers do, they should have a better understanding of their needs. Therefore, in assessing the users' needs, the opinion of the Carers should be considered. In addition, if the carers were given sufficient training, support and respite to enhance their skills and well being, they are the most cost-effective care package for the service users.

These are philosophies requiring special acceptance of professional service providers. In the process of recognizing the carers' commitment and ability to care, professionals need to make possible competent caring skills performance by the carers, which may be previously considered as inappropriate for non-professionals to perform (e.g. injection, drugs handling, counseling support). If accepted in welfare policy making, these philosophies will also revamp the exiting mode of providing services.

Britain has, at its almost bankrupt welfare infrastructure, conveniently adopted the new philosophies for supporting the carers. The corresponding changes in service provision redefine (or make blur) the relationships between informal and formal care, and between governments and other frontline service providers.

Implementing the Policy: aspects and models

It is patently obvious that though the changes noted in this section are to a larger degree effected by the Act, there are other social forces in this moment of time influencing the outcomes described. Amongst these the strive for total quality management (TQM) and for good privatized care are particularly evident.

1. Re-structure of formal services

One of the main themes of discussion and debate in recent years has been the relationship between formal and informal care. Formal care usually refers to care and services provided by bureaucratic organizations including government departments and voluntary agencies through professionals. Informal care usually refers to care and services provided by natural and social networks. Formal care is usually taken as more professional, more bureaucratic and therefore more powerful over the decision

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processes, while informal care is seen to be non-skillful, voluntary and readily available. Many people agree that the relationship between formal care and informal care is complementary and mutually supportive to each other, and therefore the necessity of combining both caring systems to serve different needs is seen. Despite the agreement, formal and informal care workers have been clearly marked by professional service providers in terms of their training, skills and responsibilities. The recognition of carers as a pivotal work force in the caring profession has made a few shifts.

The local government through its social services departments provided a fair amount of direct services in past years. Now the shift is to support the carers to care better for their clients. So local authority social workers are now functioning more as managers of care resources rather than as direct service practitioners.

The care is now rested upon the carers. What if carers at home cannot manage, say help for lifting is needed or they need time to have a holiday break? The government works on the same principle by introducing paid carers – these are people who normally live in the nearby neighbourhood and worked part-time for an agency, have some training and get paid for their work. Local authority normally does not provide cares but it can access the service by giving block grants to an agency to carry out carers projects, by contracts (commissioning) with an agency, and by individual purchases. So the shift is in the context of care – the carers are now caring for the others in others' homes, paid for.

All these changes have made formal and informal care less distinguishable. Perhaps the distinction was that we never should have been concerned with professional boundaries.

2. Funding arrangements: for the service provision for carers and for individual carer

Unlike budgetary considerations in established domains where allocation of funds normally follows a formula, service and resources demands made by carers at frontline levels always differ from case to case. So to meet the demands, budget allocations need to be more flexible.

Funding is for both sides: the costs for providing the carers support and supports to carers, and subsidies or allowances for individual carers who does not get pay.

For projects providing carers support or support to carers:

a) Directly run or subsidized by government

Some local authorities run their own carers projects and therefore have 100% grants. There are projects which attract both local or central government grants, but these are likely to be joint-initiatives - in the sense that the projects cut through responsibility domains of Department of Health (DH) and Department of Social Services (DSS).

b) Block grant

Projects considered by the local authority to be worthwhile for the benefits of the carers and the cared may get a time-specified block grant. Project operators can be charitable agencies or service operators recommended by relevant local authority departments. Normally the projects are given a life span of one to three years. The full or part of the grant can be renewed subjected to evaluations of the local authority.

c) Contracting (commissioning)

The local authority is allowed to commission any agency (including business operators) to provide carers support or supports to carers. The terms of provision is defined through a service contract which the local authority commissioning team is designated with the responsibility to monitor.

d) Strictly a private purchase

The local authority, if it has an accurate estimate, can come to an agreement with the service providers (profit or non-profit making) for a fixed number of job purchases (e.g. 100 meals-on-wheel a day). Individual purchases on demand are possible but it would be more expensive.

e) Mix-modes

There are projects receiving funds from a variety of sources including one or more of the above.

f) Needs assessment & quality standards

In attempts to evaluate projects fairly and efficiently, there are project assessment and quality standards developed for the purpose. Content coverage includes quantifiable criteria right from length of contact with clients to adequacy of training.

For individual carers

Except for social security payments including the Carers' Allowance are paid out from the central government funds, almost all costs incurred at an individual level are born by the local authorities. These include the administration and

compliance of the Act.

a) Needs assessment (assessment & care plan)

Needs assessment itself does not directly involve giving money directly to the carers. What it does is to formulate a care plan in which carers are assured to get what they need in the process of caring for their relatives, friends or clients. The majority of carers would need financial assistance (for themselves and for the cared), equipment, adaptations to home, and special transport arrangements. This all means money resources going to the individual carers. At present the area teams of the local Social Services Department are responsible for the needs assessment, and thus taking up the gatekeeper's role in connecting resources.

b) Need for income

As said, most of the carers are at working age and are capable of earning an income. Many countries including Britain make available in recent years a Carer's Allowance to subsidize the carers expenses. A Carers Allowance is paid to those who have not an income and are normally caring for their relatives. The amount is about 25% of the median income, and is meant to be a recognition rather than as an income support. For those who have spent life long years looking after their relatives, by the time they retire, they will not have earned any pension, nor paid any national health insurance. In view of this, there is a willingness, though not yet matured enough to formulate policies, for the government to upgrade the carer's allowance to a level comparable to the amount the government would have been paid for all services in order to keep the cared at home or in an institution.

c) Access and right to support

The carers' right to access of services and to appropriate support now has become undeniable under the Act. Local authority in addition to the established needs assessment teams sets up special teams to deal with carers' requests for separate assessments.

3. Training of carers: whose responsibilities?

Training, for a recognized carer, is important in maintaining a high level of care. Considering a carer caring at home, she/he is a housekeeper taking care of all household tasks from tidying up, shopping, cooking to representing the cared. As a carer serving for the personal routines of the cared, she/he is an amah, a nurse and a friend/relative. In representing the cared, she/he is a negotiator, a connector to services and a representative. All these roles have implications for formal training.

a) What aspects for training?

The training required for a carer caring at home cuts through two major caring professional boundaries: nursing and social work. Before the carers' having a legal status, nursing and social work were pretty controlling of what a layman and other workers can or cannot do, e.g. nurses were against anyone who do not have a nursing qualification to do injections or other nursing duties. The Carers' Association has now successfully negotiated with the Royal College of Nursing and other nursing bodies that there are just four things carers cannot do at home: intravenous injections, ear syringe, haemodialysis and handling of scheduled drugs. All other caring tasks the carers can now do with proper training.

b) How is the training done?

Most of the basic training is organized on a one evening a week basis in a convenient locality. Skill demonstrations are often carried out at where the carer is upon requests. This is thought to be more convenient for the carers, as well as making the training more practical and realistic. At present training is carried out by quite a few agencies including the local Carers Association and the local authority. Mutual support groups are usually run alongside these training sessions so as to address to carers' psychosocial needs. Most of this training is free of charge and funded by the local authority.

c) Recognition of training and qualifications?

There is just an informal recognition among agencies providing carers support, in which they hire carers with these training and experience in caring. Vocational training institutes in Britain are moving towards recognizing these training for carers via a separate system called 'National Vocational Qualification' (NVQ). The NVQ is an incremental accreditation system (different levels) where anyone can submit evidence of training and experience for vocational assessment. Level I of the NVQ represents an attainment which is skill based. People assessed with level I attainment then can go on to level II, and so on. The NVQ is trying to get recognition for Level III to be equivalent to a secondary school graduate academically. If successful, carers attaining level III NVQ will be able to select a more established occupation via professional training entries (e.g. nursing, social work).

d) Making training a life long career: for the trainers and the trained

With the above insertion, training can be a life long task. Starting as an ordinary housewife, one could be trained to look after one's disabled child or husband, then carrying on with the training to become a qualified professional, and then train the others. For the professionals, training of carers is also a continuous

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task – basic skills, emotional supports; then higher level skills, friendship; and so on. Professionals may need to let go of their direct services, but in return they are entrusted with even more skillful tasks: as a trainer, a friend and a resources manager.

All the above require an authority to make recognition and to make resources and changes available for the training, such a responsibility and authority cannot be anyone's but the government.

4. Carers as a Career

If one thinks along what has been discussed, carers now in fact can be career tomorrow. A carer who is so committed to care, and has acquired so many caring skills over the years is a valuable asset for the community.

a) Employment consideration

A carer having cared for someone for long years must have acquired good caring skills. With proper training they are a quality work force for the caring services. Caring service providers in Britain are now awakened to consciously seek for these people to work for them.

b) Caring consideration

A carer may start caring for their relatives for nothing at all. After the relative's death, she/he can continue to care for the neighbouring friends with a small honorarium and finally she/he can be hired to work as a home helper. One thing for sure is that a good carer for their relatives is equally a good carer for others.

c) Professional consideration:

As a career, carers need to be placed into a career structure within which they should have a job description and a line management position including:

- a list of caring tasks need to be done at home care level: from household chores to personal (physical, psychological & social) care
- providing basic home care at where the service consumers are, guided by professionals
- a status which has professional/vocational recognition and a stated line of accountability

V. Adopting a similar policy in Hong Kong ?

Hong Kong has a similar infrastructure to those advanced countries, it is inevitable that we shall be confronted with similar carers' issues. As a proactive move towards policy-making in response to the British experience, our Government, while remaining executives-led, needs to consider two questions: Are carers a crucial labour force to be recognized in community care? Is legislation necessary at this moment of time in assuring the status of carers? While answers to the latter are likely after debates between lawyers, politicians and other professionals, we are expecting readily positive responses from executives. Positive responses imply that supports and resources for carers as aforementioned will be forthcoming. If that is indeed the case, potential benefits of implementing such policy and practices as well as other areas of concern shall be examined.

Potential Benefits

1. Quality care to the cared

The service and care provided by close relatives and friends is believed to be the best quality. They are the best caring workers with proper training.

2. Maintaining high quality community care

If the quality care can be maintained by providing support and resources to the carers to care for the cared in the community, the period of community care can be lengthened, thereby cutting the demands for institutional care

3. More appropriate use of care level service types for the cared

Assuming support and resources are adequate for the carers to provide home care, accidents and inappropriate use of high level services (e.g. accident and emergencies admissions, residential care) would be better avoided. To the other extreme, those who are not aware of appropriate services will be enabled.

4. Increasing employment opportunities

The experience gained by caring one's own relatives can be transferred to caring of the others. That is, these caring techniques and experiences could help the carers to become skilled carers for people in need. In reality the carers can be given stipends or allowance to care for their own relatives, then continue to care for the neighbouring friends voluntarily or with an allowance, and then join the pay roll of paid workers. Provided that these people have been offered systematic

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training, in time they will become a pool of both active and reserve labour forces for the welfare sectors. It can be seen that the employment opportunities created through this channel could provide jobs for thousands, especially those middle aged displaced manufacturing workers.

5. Relief high level professionals shortage

Professionally trained workers are always in demand and in shortage. Recognizing the carers in caring out some of the lower level duties can relief the shortage. Example includes using nursing aids or enrolled nurses to relief some of the duties of registered nurses.

6. Low cost for high quality care

The cost to maintain carers (both for allowances and for paid work), as seen elsewhere, would be much lower than paying establishment workers. While we urge our Government not to equate the recognition of carers to cutting the costs, we would wish to point out the real cash can be saved if the supports and resources to the carers are adequate.

Other Areas of Concern

1. Re-engineering of service organizations

The established organizational structure for providing care is based on policy-driven models and therefore staffing standards and service types are pretty standard and resistant to changes. Recognizing the carers and meeting their needs are by nature a consumer-driven model which demands flexibility in resources allocation and evaluation. Re-engineering or re-structuring of relevant departments and service units are expected should the policy to recognize the carers be implemented.

2. Impact on family and social relations

Though it is widely acknowledged that the Carer Payment is largely a form of recognition for the valuable work of the carers, introducing a monetary value to the caring relationship may affect the social fabric of family and social relations. It may erode the Chinese tradition where it is emphasized caring for your relatives, especially your elders, is a virtue and obligation.

Voluntarism is said to be at stake too. At present, the carers are caring for others for free and out of their own goodwill. Volunteer work has been taken for no monetary returns, their rewards are their own and others' appraisals. This

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philosophy has been dominating our welfare sector for years and will be difficult to change. Giving monetary rewards to carers may affect other volunteer schemes.

3. Cost consideration

Although costs may be saved in a long run as it has been demonstrated in other countries, the initial adoption of the policy may involve more money. As the current system needs to run side by side with the new system. All parties concerned should be guaranteed to accept the new policy at a no-worse-off basis, allowing the new system to mature and eventually to take over if proven effective and efficient.

VI. Conclusion:

The present report has noted a unanimous wish of our delegation that carers in Hong Kong could have the same, if not more, level of recognition as their counterparts in Britain.

To many carers at home, the caregiving role came in very sudden and they are caught unprepared. To fulfil the caring tasks, many of them have to give up their jobs, their leisure activities, their child-rearing plans or even their life goals. Without effective support, they may experience burn-out and eventually become incapacitated to take care of their dependents. Given the importance of carers in the provision of care in the community, argued from both cost-effective and social justice perspectives, they have been largely neglected and should be protected from further losses.

The British Carers (Recognition and Services) Act 1995 acknowledges that the majority of the carers take on their caring responsibilities willingly, but their lives can be made much easier if the right supports is there at the right time. The Acts represents a key responsibility of statutory service providers for assistance and support to carers. It ensures that service providers make practical support for carers a high priority and that assessment of needs should always take account the needs of caring family, friends and neighbours. In essence, quality of lives of both the carers and their dependents can be improved if they can be relieved from various stresses and burden. There can be various kinds of supports to carers, such as financial assistance, support services, training, etc.

Having worked for such commitments and long periods, carers' caring skills ought to be recognized too. They should be recognized as a valuable service to the community and that they are providing a skillful job, which can be accredited, rewarded and extended to become a formal occupation. In the process, issues of training the informal carers to formal carers, and, accreditation of qualifications was beginning to be dealt with flexibly in Britain by introducing the National Vocational Qualifications.

At present, there are no specialized services at home for the carers, let alone legal protection. As our population continues to grow old and more people are living to an age where the prevalence of chronic illness is high, more and more people will find themselves involved in caregiving. It is prime time for community as a whole to look at a separate focus of care - supports to carers.

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As a cautious endnote, there is still a long way for the carers at home to achieve similar status as their counterparts in Britain. Perhaps it is time for us, as caring professionals, to actively encourage them to learn from others' success, to awaken themselves into internal mobilization, to actively participate and initiate a similar movement in Hong Kong.

First International Conference on
Family Care - "Caring for Carers" and Post-event Study Visit
(Study Visit: May 11 - 13, 1998, London, United Kingdom)

AGENCY VISIT RECORD

Tooting Neighbourhood Centre

1. **Date of visit** : 11 May, 98
2. **Address** : 28 Glenburnie Road, Tooting, London, SW17 7PY, U.K.

3. **Contact Person :**

- Mrs. Rose POWELL - Manager,
- Ms Yvonne MEIKLE – Outreach worker (Befriendly),
- Ms Yvonne LANGLEY – Senior Supervisor
- Rev. Bishop, Melvin L. POWELL - Chairman

Telephone no: 0181-7671619

Fax: 0181-6824322

4. Description of Agency

4.1 **Type of service** : provides services subject to physical, social, psychological and spiritual needs of the local community.

4.2 **Target served** : The Black and other Ethnic Minority Groups of various ages.

4.3 Programs :

- **Luncheon Club**: mainly provides balanced nutritional meals for the elderly clients, with recreational cultural and educational activities in a warm and friendly atmosphere.
- **Home Care Service for the Elderly**: clients are assessed and referred by the social welfare or professional members of staff of the Agency. The services include cleaning, laundry, ironing, shopping, preparing and cooking food, grooming, bathing, washing and dressing, collecting pensions for clients etc.
- **Community Care for the Elderly**: on a befriending basis, the outreach worker and volunteers offer service to the infirm and housebound elderly.
- **Youth Club**: to serve those aged between 11 & 21 and provide them with a wide range of recreational activities, such as: computer training, video-making sessions, group discussions and counselling.
- **Mental Health Club (Hope Project)**: to enable people to develop a positive self-concept and lead independent lives in the community. The agency provides emotional and practical support, advice, organizes cultural and social activities subject to the special needs of some minority multi-races in the community, e.g. African, Caribbean, & Asians, helps them to integrate into the local community through warm caring and friendly means.

4.4 **Staffing** : 3 full time, 1 cook, 21 part-time staff, about 50 volunteers (15 are stable and more active).

4.5 **Funding Sources**: Local Authority (Wandsworth Borough council) and fund-raising.

4.6 Special Facilities:

- **Drop-in-Centre**: opens from 4 p.m. to 7 p.m. (5 days a week) and provides meals

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at cheap rate for 1 pound 50 pennies for lunch.

- ***Easter & Summer Playschemes:*** caters for children between 5 & 11 years during the school holidays through activities such as: art & craft, drama and video workshop, football coaching and outings.

5. Content of Meeting :

- funding for projects can be terminated for there are competitors running same project.
- contribution of volunteers is tremendous and they have greatly enhanced the work at Tooting Neighbourhood Centre.
- membership fee is 4 pounds a year.
- about 15 volunteers take patients of hospitals for outings or shopping.
- volunteers with commitment to serve at least 3 months an interval.
- recruitment of volunteers through publicity in local community, advertisements, posters at Churches etc.
- clients are mostly West Indians.
- about 20% of the local population are Black, Semi-White, Chinese or Asians.
- receivers of Home Care Service for the Elderly are mainly the Black and Asians. There are now 54 clients receiving the service.
- volunteers are paid volunteers.
- staff together with the clients work out the Care Plan in Home Care Service for the Elderly. One copy of the Care Plan will be left in the clients' home for their reference.
- to enhance service quality, staff may conduct spot checks and questionnaire to the clients.
- currently serving about 16 young people and about 60 adults.
- home care service is provided round-the-clock subject to case merit.

6. Observation :

The agency's main priority goes to the elderly persons, then mentally-ill persons (with stable mentality), expected for expansion as there is growing need within the local community.

7. Recommendations :

It is worthwhile to visit the agency again for observing how the services are running.

Crossroads : Caring for Carers

- 1. Date of Visit** : May 11, 1998
2. Address Venue : Crossroads Caring for Carers, Appeals Department,
Dlike House, Malet Street, London WC1 7JA

3. Contact Person :

Ms Alison Thompson (Chief Executive)
Telephone no. : 0171 637 1454

4. Description of Agency :

- Crossroads is one of the major national charity organizations providing help for carers.
- The agency is developed from the television soap opera of the same name, when a story-line featured a disabled man being cared for by his mother. ATV donated £ 10,000 to start up the first scheme providing respite care in such situations.
- The objectives of the agency are :
 - To relieve stress in families or persons responsible for the care of disabled persons and exceptionally, in suitable circumstances, to help such disabled persons who live alone.
 - To avoid admission to hospital or residential care of such disabled persons should a breakdown or other failures occur in the household.
 - To supplement and complement, not to replace, existing statutory services and to work closely with them.
 - To strive and maintain a high standard of care.
- The Association of Crossroads (national organization) is the central body to which all Crossroads care schemes are affiliated. The Association develops new care schemes and projects, directly manages some services, including six Young Carer Projects, and gives essential support, guidance and advice (such as expert advice, fundraising and PR services) to existing schemes, through its Divisional offices across the country.
- Through a network of almost 220 affiliated Branch Schemes, the agency is providing care and support for over 28,000 carers in England and Wales. Each branch schemes serves its local community and is an independently charity. They are completely autonomous, but linked to the national organization, and administered by a coordinator. The coordinator is responsible for assessing the family's needs and for supplying the practical help at times required by the families.
(A sample of the care assessment and care planning is attached.)
- Care services provided by Crossroads' schemes can include :

Domiciliary Care	Palliative Care
24 hour emergency respite care	Day Centres
Carers drop in centres	Drop in centres for people with care needs
Moving and Handling training	Helplines

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Night Care
Work with ethnic minorities

Holiday respite care
Befriending

- To request for services, the agency can be approached directly or through care management.

5. Content of Meeting :

- The coordinator, Ms Alison Thompson, introduced the agency and its work to the delegates. Her presentation was supplemented by slides and agency leaflets.
- The meeting was one of mutual sharing where the delegates on the one hand, learnt from Ms Thompson more about Carer services in UK, and on the other hand, shared with her the Hong Kong experience.
- Delegation members also showed great interests to the training package designed by Crossroads, which were available for sales. A set of copy was ordered for the Council's library.

6. Observation :

- The success of the carer support programs of Crossroads could serve as a reference to Hong Kong whose carer service is still developing.
- NGOs in HK could not only learn from their service contents, but also know how to work with the formal/governmental social service bodies, as well as how their central structure render supports to the sub-branches.
- To safeguard their service quality, they insisted on a minimum standard of staff quality and refuse to unrealistically cut down the cost. Although this had resulted in their lost of some programs for the government, their dedication to service quality should be appreciated.

7. Recommendations :

- The agency is worthwhile to be visited again.
- It has been very fruitful and rich in information to discuss with their colleagues as well as reading their documentation.
- Yet, visitors might be a bit disappointed if they expect to see some direct services since the agency is more an coordinating association, instead of a direct servicing unit.

Department of Health

1. **Date of Visit/Meeting** : May 12, 1998 & May 15, 1998
2. **Address/Meeting Venue** : Wellington House, 133-155 Waterloo Road, London SE1, U.K.
3. **Contact Person** :

Name & Position : Mr. Raymond Warburton (Head of Department of Health)
Telephone no. : (0171) 4724100 Fax : (0171) 9724487

4. **Description of Agency:**

4.1 **Aims and Objectives of Department of Health:**

(As published in the Department Report on April, 1998)

- The overall aim is to improve the health and well-being of the people of England, through the resources available, by:
 - supporting activity at national level to protect, promote and improve the Nation's health;
 - securing the provision of comprehensive, high quality health care for all those who need it, regardless of their ability to pay or where they live;
 - securing responsive social care and child protection for those who lack the support they need.
- The Department of Health is committed to making progress by working across Government, local agencies, NHS programs and local authorities, with resources and guidance.

4.2 **Aims and Objectives of Social Service Inspectorate:**

- The Inspectorate is a division of the Department of Health. It is independent of the local authority, voluntary and private sector providers of services and mainly responsible to provide professional advice on government policy, implementation and review of social services and on the quality of social services provision. In addition, it also carries out the responsibility for inspecting personal care services provision and exercise statutory powers on behalf of the Secretary of State.

5. **Content of Meeting** :

5.1 **The agenda of the meeting** :

- | | | |
|-----|-----------------------|---|
| (1) | Mr. John McCracken | Royal Commission, carers |
| (2) | Mr. Raymond Warburton | Assessment, Commissioning, Information |
| (3) | Mr. Marion Hutt (DSS) | Social Security Benefits |
| (4) | Mr. David Ellis | Disabled People, Independent Living, Young Carers |
| (5) | Ms. Annette Goulden | Nursing Perspective |
| (6) | Mr. Peter Dunn | Elderly People |
- The meeting on 12/5/98 were jointly held by different service division of the Department and presented by 6 different speakers. Due to the limited time allowed, only brief introduction of agenda item 1, 3, 4, 5, 6 were given with information provided to the delegation for reference. While 2 meetings were scheduled on 12/5 and 15/5 for more discussion and better understanding on

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“Commissioning and Assessment in U.K.” upon request by the delegation for the use of policy making.

Summary of Agenda Item 1,3,4,5,6:

Agenda Item 1: by Mr. McCracken

He introduced on how the short-term and long-term care for elderly is funded in U.K., both in their homes and other settings.

Agenda Item 3: by Mr. Marion Hutt (DSS)

He shared us the Social Security Benefits concerning the aspects of citizenship pension and home cares service development. Details can be referred to given pamphlets.

Agenda Item 4: by Mr. David Ellis

He briefed shortly on services provided to disabled people and the rising concern on young carers. He pointed out that different authorities would have different mode of service delivery. Also as there are great market on home care, much private sectors were established to carer for the needs of the elderly. In view of this situation, the government regulated these private nursing homes according to the outcomes standard which was shown in “White Paper”, as a guide on supervision, replacing the use of physical standard guide.

Agenda Item 5: by Ms. Annette Goulden

Ms. Goulden was kindly responded a few questions related to nursing perspective. She told us that no nurse would be served at the residential care homes while there are nurses serving the nursing homes. For the carers, the training courses by CNS would be provided for those informal carers.

Agenda Item 6: by Mr. Peter Dunn

Mr. Dunn shared us that many young carers participated in caring elderly people and more supportive services for them were delivered through giving allowances, organizing mutual support group or any other services for relieving their caring responsibilities.

Agenda item 2: by Mr. Raymond Warburton

Mr. Warburton summarized the policy and practice of “Carers (Recognition and Services) Act 1995” with the following aspects: (details could be referred to this Act)

- > Scope of the Act;
- > Information documented including needs assessment and care planning;
- > Role of care manager;
- > Care Management and Assessment:
 - To adopt an integrated approach to conduct the assessment which involves both user and carer;
 - To give user and carer the opportunity for discussion with the worker;
 - To negotiate a resolution or to resolve difficult situation by involved a multi-disciplinary team;
 - To review regularly to meet the changing carers’ need;
 - To plan and effectively provide services to the carers resulting from

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accurate assessment.

In respond to our concerns, Mr. Warburton was kindly prepared a paper on “Assessment and Care Management” for our information.

- He stressed that the government would pay a lump sum to the local authorities to carry out the responsibilities for nearly 99% social service delivery in relation to carers and other service recipients. As the UK parties controlled all local authorities, the parties’ direction and its composition would directly affect the implementation on care management or care services. In most authorities to provide a process to fit all cases, there becomes an administrative emphasis on care management and not a targeted approach. Self-audit kit would be provided for the use of local authorities as assessment tools for evaluating their performance;

Moreover, the qualified social workers and also the nursing staff with required training could take up the post of care manager.

Finally, he pointed out the following possible areas for improvement:

- Multi-disciplinary assessment and integrated services involving consultants, nurses, OTs, PTs, and social workers in working together should be pursuit in order to deal with continuing care and rehabilitation;
- The assessment should not focus on functional abilities e.g. ADL, especially for those elderly and thus little attention was paid to carers’ needs and user’s levels of cognition and mental state;
- The assessment and care management information was often not reliable. There are a great deal of variation in the content and quality assessment and care management documentation, with a tendency to describe service users’ problems rather than analyzing them. So the worker should devise the plan and conduct the assessment with the consideration of their physical and mental functioning and their life changes and location.
- Better re-cooperation of rehabilitation field is needed to ensure a smooth running of the service provision and effective care planning on service users. Now, there is a lack of health care input in the documentation and process of care management, with the exception of hospital discharge.
- More investment on preventive service rendered rather than remedial rehabilitation service being funded;
- There is insufficient time devoted to monitoring the review and mush focus is put on the short term activity of assessment.

6. Implications & Recommendations:

- Our delegates really appreciated the delightful presentation of each speaker especially Mr. Warburton. His information given and sharing enabled us to have better understanding the Commissioning and assessment, the rationale and the importance of this policy, the problems encountered and its application processes and effective care management, etc. All these areas discussed can be further developed in local practice. Seeing that Hong Kong put less resources and services on supporting carers in different service field such as elderly or rehabilitation, and also less on preventive service mode, so more effort in promoting the quality services to carers, empowering the carers and recognizing them are recommended. Following this direction, seminar on introducing the philosophy and content of Carers Act, the feasibility and possible way of

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implementation in Hong Kong and different services rendered would be arranged. All in all, it is worthwhile to visit the Department of Health and meet with the representative of Social Service Inspectorate.

Newham Social Services

- 1. Date of Visit** : May 13, 1998
2. Address : Gable House, 27a Romford Road, Stratford, London, U.K.
3. Contact Person :

Ms. Frances Martineau--Head of Initial Contact Services
Fax: (0181)-537-886 E-Mail:@Newham-gov.uk

4. Content of Meeting :

- Brief history on the setting up of Carer liaison officer and the outreaching team and its service delivery model.
- Carer coordinating group with members from different carer group who help in awareness raising activities, developing service standards encourage user participation.
- Carer's Act, Carer's Assessment and Status
- Empowerment on Carer by involving them in training, profession worker, informal carer to formal carer, provide preventive group work; supporting carer through special funding e.g. in kind support.
- Promotion through registration, GPs, Mass media

5. Observation :

- Newham Social Service Centre- the ICS staff has impressed me of the vim and spirit of striving for excellence. They are highly motivated, has a clear vision and direction and strategy to foster community care and support to the Carer. The Centre is customer and result oriented. The can be observed as we stepped in the Centre. The Carer Service has 5 years experiences and is striving for continuous improvement of service and performance.

6. Recommendations :

- Newham Social Services is a show case of Total Quality Management. Other than the Initial Contact Services, it also provides a variety of services. Therefore, it is worthy spending more time there.

Alzheimer's Disease Society (Caring for Dementia)

1. Date of Visit : May 13, 1998

2. Address/Meeting Venue: Gorden House, 10 Greencoat Place, London SW1P 1PH

3. Contact Person:

Mr. Steve Milton (Senior Information Officer)

Telephone no: (0171) 3060606 Fax: (0171) 3060808

E-Mail: 101762.422@compuserve.com

4. Description of Agency :

Alzheimer's Disease Society (ADS) was established in 1979 by carers of people with Alzheimer's disease. Many carers can be isolated at home, caring for someone 24 hours a day under great stress. The ADS is a membership organization. The more members she has, the louder her voice will be heard. Since then a nationwide network of local 300 branches and support groups has been developed and Society has quickly grown to 20,000 members. In fact, there are 650,000 Alzheimer patients over age 65 and 70,000 under age 65 in UK. All ADS service provision aims at helping people with dementia and their family carers.

ADS services included:

- Support for carers through helpline and bi-months newsletters
- Provide information and training for professionals
- Services for people with dementia such as day care service
- Standards and training for care work and lobby for better facilities in day care, residential homes and sitting services
- Awareness campaigning: for improved health and social services and great public understanding of dementia
- Fund raising for research and service

Helpline service:

This service has served over 40,000 people since 1996 and is opened from 8am to 6pm, Monday to Friday. Many callers are caring for someone with Alzheimer's or are worried about someone who is becoming confused, some may have had a diagnosis of dementia, and others have a professional interest. The Alzheimer's Helpline is staffed by nearly 10 trained advisers and now includes specialists in welfare benefits and medical and scientific issues. The service aims at answering any questions about dementia. In 1997, helpline service received totally 19559 calls and the statistics could be referred to appendix 1. The answering machine could transfer calls to specialist and provide advice on specific care (e.g. what is Alzheimer's disease? fact carer concern, aggression handling, ...), social service advice, legal issue and research aspect. On the other hand, ADS also provides 24 hours freephone information on dementia concerning about Alzheimer's disease, handling over-reaction, aggression and wandering, communication skills, formal service information, legal and financial information through recorded audio tapes.

Home care, Day care and respite service:

ADS had developed a package on care learning programme with videotape and manual. ADS will provide free training on dementia care for the family carer who could be benefited from the training and take up caring duty at home. On the other hand, ADS had contracted out 40 day care and respite centre including nursing care and domiciliary care. All the care workers should be trained and credited by ADS's own accreditation scheme and ADS established quality standard on those centres. (Refer to: "Setting up and running a sitting service-Guidelines on providing relief care in the home", 1993) 3-4 working staff would serve 10-15 demented people at one time and the carer assistant would be paid for 2 pounds per hour.

Funding resource:

Mr. Steve claimed that the funding situation is very good from sponsor body but small grant from Department of Health. Through a donation leaflet (Will you remember those who can't? - making a bequest to help people with Alzheimer's disease), a legacy officer would provide legal support if someone has a will to help. ADS is a registered charity and therefore a legacy to the Society is free from inheritance tax. In UK, inheritance tax is normally charged at 40% of the value of person's estate if it is over a certain amount that could be known through solicitor or citizens advice bureau.

5. Content of Meeting :

- Introduction of Alzheimer's Disease Society: establishment, nature, main objective and service provision (Referring above information)
- More sharing in helpline service and day care and respite service (Referring above information)
- We exchanged Hong Kong service and dementia situation

6. Observation :

- Helplines: hotline service specialized in dementia is lacking in Hong Kong
- Contract out day care program and trainer role: Quality and comprehensive on-job training is lacking in Hong Kong
- Fund raising - Legacy officer role: HK Alzheimer Disease and Brain Failure Association may seek funding in this way

7. Recommendations :

- It is worthwhile to visit the agency again because the agency had developed nearly 19 years and many experiences had been accumulated. If time is available, Awareness campaigning should be paid more attention because we are also lacking in this experience in HK.

Report of a delegation from HKCSS to the UK on services to carers (11-15 May 1998)

First International Conference on
Family Care - "Caring for Carers" and Post-event Study Visit
(Conference: May 14 - 15, 1998, London, United Kingdom)

Sub-plenary session reports

Young Carers

Date: 14 May 1998

Facilitator: Saul BECKER (The National Handbook of Young Carers Projects)

Notes:

- in 1985, there were 68 million people aged 16 or over with characteristics:
average age: 12 80% between 5-15 years old, 57%: girls, 43%: boys
14% from minority communities, 54% lived in lone-parent families
- tasks performed . mainly basic domestic duties to every intimate care: 12% were caring more than 1 person
- most young carers (YCs) (63%) caring for someone with physical illness/disability, then mentally health problem (29%), learning difficulty (14%), sensory (4%)
- outcome:
 - ~ lack of understanding from peers
 - ~ limit opportunity for social / leisure activities
 - ~ stigmatize
 - ~ children's and parents' fear of what professionals would do
 - ~ keep "silence"
 - ~ emotional difficulties
 - ~ health problem
 - ~ late / miss a great amount of school or have other educational difficulties
- age group:

proportion in school program	1995	1997
5- 11 (primary)	20%	17%(b)
11 – 15 (secondary)	42%	35%(a)
- policy issue: befriending, counselling, group work, advice, raising awareness in training and education, joint service with other agencies
- responsibility of professional:
 - ~ 11% of YCs have never been assessed
 - ~ identify YCs
- main influences on what YCs do or don't
 - ~ nature and extent of illness / disability: domestic care; intimate need; emotional support (more likely)
 - ~ family structure: 50% in lone-parent families; or caring for mother in absence of other adults
 - ~ co-residence: 57% (girls); 43%(boys); caring mainly for mothers
 - ~ age / status of YCs
 - ~ ethnic / regions
 - ~ nature, quality of external support
 - ~ cash & care: play a key role of determining the need of YCs
 - ~ recognition & respect
 - ~ information or: care planning & management; on medical conditions; on practical chores & how to do them
- right of YCs: UN Convention in principle as carers
- children's view on social worker: not working, pestered, threatening(bring to court), not listening not understanding,

Older Carers

2 speakers shared older carers situation in UK and Australia. At the end of the sub-plenary, two questions should be answered through discussion:

- A. What are the five common difficulties facing?
- B. Three changes of policy which would most benefit older carers?

1. UK older carers

A qualitative study on older carers had shared:

- **Lower % of elderly have learning difficulties with sole carer and those have learning difficulties will be living longer.**
- Key issues in supporting older carers: (without priority)
 1. Fear of future: "I dies before s/he dies:
 2. Inter-dependence: married couples (47%), lone man (45%), lone woman (9%)
 3. Smaller support network
 4. Negative experience of the formal service sector
 5. Reluctance to seek help
- Older Carers expectations towards the formal service sector: (without priority)
 1. Continuity in personnel and practice
 2. Continuity in service provision and planning: formal after informal breakdown
 3. Partnership
 4. Respect
 5. Known point of contact (e.g. helpline)
 6. Appropriate, flexible and Quality services especially transport, social activities and financial support
 7. Information such as any options, any choice

2. Australia older carers

- In Australia, aged 65 have 19% would look after 1 or 2 children under 12

- **Table** Supporting older carers: a health promotion approach to public health issue

Health Promotion Strategies	Older Carer	Family and Friends	Community	Policy makers
Building health public policy	Older carers as part of client group	Carer polices In workplace	Volunteer programme to Support family Specific service for older carers	All public department with polices for favourable impact on older carers
Create Supportive environment	Adequate home based service and support	Supportive workplace, education programme	Transport, Holiday, Meals on wheels, etc.	Contributions from public, corporate and community sectors
Strengthen community action	Give older carers a day value	Develop neighbourhood networks	Provide forums for older carer advocacy	Polices based on “hearing” the older carer
Develop Personal Skills	Counselling education, etc.	Counselling education	Provide access to education and group support	Resource for service provides supportive programme
Reorient community services	Opportunities to ask for what is needed	Available and accessible care centre	All community service looking out for older carers	Consultation processes in place to ensure for older carers and their friends

3. Discussion

Sometimes, participants argued on the unclear definition on “carer” in terms of employed carer and family relative carer in HK, we have used “formal care” and “informal care” terminology to distinguish between two types of carers

A. Difficulties faced by older carers?

First five agreed difficulties

- Lack of finance
- Less red tape and information
- Lack of communication/Collaboration between services, Quality
- Isolation, Language/cultural appropriateness
- Health of Carer, Social and Legal recognition, Anxiety, Stress, Quilt (Sense of failure)

Other mentioned difficulties

- Services – not preventive
- Judgmental themselves as good or not?
- Confusion re-accessing/redressing services (re-changes)
- “Hidden” Carers
- Representation
- Asian care (UK)
- Women workers/culture
- Vulnerability

B. Three changes of policy which would most benefit older carers?

First four agreed changes:

- Preventive approach (early intervention)
- National Quality Standard + International
- Provide finance support carer and carers’ organization through assessment/pension increment and cost increment
- Consultation: responsive service, involve carers (equal opportunities), policy monitoring, advocacy and accessibility

Other mentioned changes:

- Compliance & Act (implementation)
- Long-life plans on family

4. Implication in HK

- Research on older carer in Hong Kong to understand their burden may be valuable
- Older carers face the fear of future, counselling and life planning should be enhanced.
- Referring to Australia experience, supporting older carers: a health promotion approach to public health issue should be considered to enhance community concern

The Princess Royal Trust Carer Centres

Conference workshop on May 15 afternoon session

Speaker: Mr. David Bulter CB (Chief Executive)

Organisation: The Princess Royal Trust for Carers

Address: 16 Byward Street, Tower Hill, London EC3R 5BA

Telephone: (0171) 4807788 **Fax:** (0171) 4814729 **E-mail:** PRT4C@aol.com

A) What is the PRT for Carers?

The Princess Royal Trust for Carers aims to provide, through its network of Carers Centres, the help and support that carers need at times and in ways that they most want. It also aims to raise awareness of the needs of carers and to encourage more carers to seek the support that will make their role easier.

Established in October 1991 its objective is to establish a Carers Centre in each local authority area, in partnership with a local voluntary organisation. There are now 65 Princess Royal Trust Carers Centres across England, Wales, Scotland and Northern Ireland. It estimates that the network of Carers Centres is in contact with around 35,000 carers on a regular basis, and this figure continues to grow.

Princess Royal Trust Carers Centres provide information, support and advice to carers within their local area. The precise range of services will be determined through local consultation with carers but may include access to respite care, information on benefits, training in lifting and handling, as well as drop-in centres, a help-line, advocacy, time for the carer to talk over their own stresses and frustrations without feeling guilty, and social events.

Each Carers Centre is funded primarily through local statutory authorities, although PRTC may be able to assist the Centre to secure additional funding. Support and training are provided through PRTC.

The PRTC also runs a 'Carers in Employment' programme, advising employers on the development of flexible policies to enable carers to continue in paid employment, together with a number of direct grant schemes including: educational bursary scheme, carers hardship relief fund, development fund and rural carers transport fund.

The Princess Royal Trust for Carers depends for the majority of its income on voluntary donations, from individuals, companies, fundraising groups, and charitable trusts, and has received a grant from the DoH.

(National charity; Fundraising- best use of money; Helping carers; Local partnership; Statutory partners; Carers centres- help the partner to develop centre; Other actions)

B) What is a carers centre? (stop funding after 3 years)

Typically a carers centre is a "one stop shop" for the help and support of carers. Each is run by a local voluntary organisation through a management committee, which includes members who are carers or ex-carers.

- Local partnership
- "One stop shop for carers"
- Voluntary sector management
- Core services
- Carers involved

C) What do carers centres do?

The Trust expects all centres to provide three core services from the start.

- Information and advice about all issues affecting Carers, including benefits, respite and support services, carer assessment procedures, aids & adaptations.
- Support-befriending, counselling, emotional support - providing opportunities to carers to share their problems with staff, trained volunteers and other carers who understand their situation.
- Community consultation: providing carers with the unified voice within the local community to ensure that they have an impact on decision making. a) community care plan; b) assessment (discharge obligation); c) consult carers

In addition to the core services Carers Centres may also provide.

- Advocacy: at tribunals, assessments or whenever a carer needs a friend or supporter
- Practical help: such as transportation scheme, shopping
- Relief care: the centre will usually act as contact point for local respite services
- Education: responsibilities in training such as lifting & handling, or personal development (in process of medication e.g. injection)
- Fun-health, therapeutic, opportunities for social contact and self-re-discovery

D) Developments

- Centres must be pro-active to reach carers
- Project activity is way of development
- Importance to statutory funders (difficult to persuade local authority on prevention)
 - * consultation
 - * preventative work
 - * social welfare benefits
 - * partnerships
- Quality: may use network among carer centre to facilitate communication and exchanging experience to improve quality

E) Quality and standards: the PRTC role

- The network- exchanges e.g. cooperation
- Monitoring standards- management boards, statutory funders
- Training & professional development
- Added value services
- Training in quality
- Good practice guides (service delivery and management)

F) Issues for discussion:

1. How to set up Carers centre: (It needs to take 2 years for negotiation and linkage on the following first six items)
 - Set up a board and contact PRT
 - Fundraising
 - Persuade statutory agency support
 - Make sure local VA who support carers want intervention
 - Locality
 - Active voice from carers
 - Start with specific target first such as young, disabilities
 - Size and configuration- premises which should be easy accessing, have drop-in, activities, counselling, ...

2. How to survive after stopping funding
 - External fund raising to develop training

3. How to reach carers?
 - Newsletter- social services, libraries, doctors who may meet carers first
 - Carers recommend carers (e.g. shopping centre)
 - Introducing service to GPs, OT, PT
 - Helplines service- some people found not effective; some would use volunteer to handle telephone system/telephone conference around local network; some felt helplines could serve as safety net especially for semi-suicidal cases.

Raising Awareness

Date: 15 May 1998 Notes:

- primary carer: 4 hours/per week - 1.8 millions households in Victoria, Australia:
 - ~ estimated no. of primary carers: 84,000
 - ~ estimated no. of total carers: 250,000
- awareness indicators:
 - ~ receiving nursing benefit: 9,300
 - ~ receiving carers' payment: 6,000
 - ~ issuing Carer Support Kit since 1993: 1,000 copies
- help carer to identify themselves as carers
- help their neighbours to recognize their role and difficulty
- members of public are extremely, ignorance on this aspect
- six basic steps to run a successful campaign:
 - ~ **setting a campaign aim (what is the issue)**
decide what you want to achieve with, send a questionnaire to carers, hold a meeting to discuss campaign issue, discuss with other organization to see if you have common concern and ensure that: has a positive message or put forward a constructive solution; your campaign aims are realistic & achievable; all those in your organization are clear about your objectives
 - ~ **doing your homework (research)**
collect fact and figures to support your campaign; collect some testimonies from carers to support your campaign, such as: carers, gov't politicians, libraries, health and social care professionals, other organizations; some questions to ask: what is current gov't policy on the issue? Is it necessary to change the law to achieve your aim? if not, what needs to happen to achieve your aim?
 - ~ **aiming your campaign at the right people (targeting)**
who you know as well as what you know that matters. who you aim your campaign at depends on, and how can that be achieved. possible people that you will aim & your campaign aims at; gov't officials, advisors, social & care professionals, legislative, other organization etc.
 - ~ **planning & managing your campaign (coping)**
made it easier by setting up a small committee to co-ordinate; any example of a campaign that went right/wrong
 - ~ **the campaign (strategy & methods)**
early & accurate diagnosis (who is the target? what tools will you use? what research will you do?)
 - ~ **measuring success**

(For details, please refer to the booklet attached :

Influencing public policy ~ Alzheimer's Disease International)

Carers' Helpline

Discussion on the topic "carers themselves acted as the helpers of the helpline":

Pros

- can relate to the problem
- emotional exchange
- experience / skills
- useful for carers since it give them opportunity / confidence to re-enter work
- provide awareness to paid-workers
- provide local information

Cons

- too close to the situation
- need practical advice
- callers may expect "professional" help
- may have personal prejudice
- availability of suitable volunteers to perform such role
- volunteers may have other priorities

Issue related to CONFIDENTIALITY:

-Carers' helpline would be better if it was operated by non-governmental organizations since if it was run by the government, there maybe cases in which helpers had the obligations to report to the government e.g. criminal offence.

Regional VS National Helpline:

-Delegates in general preferred to have regional helpline instead of a national one, because:

1. It offer immediate help if needed. If it is a national one, before the assistance is available, the problem may already solved.
2. Availability of regional / local information

Opening hours of the helpline:

Mon-Fri : 10:00am - 12:00n

2:00pm – 4:00pm

The service provided was not round-the-clock, why?

1. Lack of manpower: at present, it only have 5 full-time paid advisers, one of whom also have to coordinate the works. They did not use volunteers since the service did not have sufficiently large premises.
2. Service needs of the carers: past experience of carers' helpline open at off peak times i.e. evenings and weekends suggested that the services have not been widely used at these times.
3. Availability of supplementary services for carers: callers may phone other helpline e.g. 24-hour hotline service of Samaritan if they faced with serious emotional disturbances during the off peak times of the Carers' Helpline.

Factors which you have to consider before the setting up of the helpline:

1. Purpose: what are you offering carers – emotional support, information, advice, counselling?
2. Management: how is the line to be managed – resources, insurance, accommodation, training of workers, their support and supervision, will you evaluate the effectiveness of the helpline, if so, how?
3. Equal Opportunities – how will you ensure that your helpline reaches out to marginalized carers such as ethnic minorities, disabled carers, young carers and lesbian and gay carers.
4. Confidentiality – calls should be confidential, but you will need to establish how far your national laws allow confidentiality e.g. in the case of reporting a crime such as child abuse. In what circumstances will you breach confidentiality.
5. Promotion and Publicity – how will you promote your line, who are you aiming at, will you be able to deal with a flood of enquiries.
6. Information Resources – how will you gather these, what administrative arrangements will you make to ensure that it is up to date.
7. Staffing – can you raise money to employ paid staff – or will you use volunteers. Volunteers need expenses, and training, so they may not be quite as cheap an option as you think. How and where will you find your volunteers? Are carers the best people to support other carers? What selection procedures will you use?
8. Training – what training will your staff need – e.g. training in welfare benefits, listening skills, counselling etc. How will you arrange and pay for this? Will you have a probationary period?
9. Supervision and support – your workers will need to have someone available for them to talk to after taking a difficult call – either in person or via a telephone call. Will you have workers working from home – if so, how will they get support? How often will you arrange formal supervision and will you provide this in house or arrange for external supervision? Formal supervision should be a chance to meet privately away from the helpline to discuss the work, training needs and to focus and reflect on how calls were handled.
10. Dealing with the calls – the principles for good practice are to treat callers with respect, to accept them and their lifestyle without judging them, to employ skilled workers who respond appropriately to callers, to respect their right to disclose only what they choose to. You will need to ensure that they have access to information on referral sources. You will also need to ensure that you have a policy on dealing with abusive callers and repeat callers.
11. Evaluation – you need to monitor how things are going on your line – are you meeting your aims, are you efficient, etc.? You will need to review your policies and practices and their impact on callers.

Carer and Employment

- Statistics of carer in work force - limit women in labour force
- Effects of Caregiving studies found:
- 37% women prior working have given up work
- 60% needs time off for leaving work
- When returning to the work force feel lack of confidence
- Reasons: Away from the labour force for too long; approaching or at retiring Age
- Equity in labour force - respite service
- Adoption of better practice in Employer
- flexible hours- job sharing
- carer break
- part-time job
- casual leaves
- Mandatory Retirement has restricted caregivers from returning to labour market
- Corporates react slowly to the needs of Carer employees
- Labour market - retraining, re-entry to employment
- Changing in Families

1. Dual Career Families

- * 60% couples with dependent children work in 90's
- * 1 in 5 families have lone parent
- * Impact of 'lone' children

2. Rise in Carers

- * 6.8m people care for mentally ill, sick, elderly or disabled.
- * 3m children with stepfamilies

● Changing in Work Place

1. 24 hours service - Employment Growth
2. Information Technology - Growth in Part-time work
3. Globalization and competition - Biggest job creation will be in small firms with fewer than 50 employees
4. Rapid turnover of products
5. Fewer jobs for life

● Effects of Good Practice

1. Save retraining and training cost
 - £ 5K bank clerk in Midland Bank
 - £ 10 to replace store duty
2. Retention of skills and experience
 - £ 1m in additional sales
 - 20% of registered nurses by 2000 approaching retirement
3. Reduced absenteeism
 - Sick leaves costs employers £ 11 billions p.a.
4. Improve Productivity/focus on the job
 - Employees using "Life Works" information and referral service spend significantly less 'work time' sorting out domestic problems
5. Increase Employee commitment - willing to go the extra miles

Report of a delegation from HKCSS to the UK on services to carers (11-15 May 1998)

At Classic Cleanness, flexibility is a two way process with benefits to both business and employees.

"Planning and organization is the key"

Initiatives by Papworth Hospital - Family Friendly Policy 1. flexitime 2. Part-time work, job sharing, vs full time

3. Work during school hours and term time only

4. 'Shift swap' scheme

5. Childcare Information scheme

6. Holiday play scheme

7. Family friendly posters

8. Enhance maternity leaves

9. Mentorship for returnees

- Benefits to Papworth
 - * Recruitment incentive in area of severe staff shortages* Specialists skills retention
- Initiations* Carer emergency leaves
 - * Childcare allowance when doing overtime* Continuity of staff
- Market Concept to Small Business
 - New Zealand - National Assessment Service good practice essential for Carers to have a resting time
- "Carer friendly" Practices in US
 - no pay leaves for carer- utilization for elderly care is small
- Areas need to pursue
 - Work place groups for carer
 - More research on effects of caregiving on productivity-Public policy for those who return to the labour force
 - Carer needs are still in the closet
 - Raising awareness of the public in Carers' need in Elderly and Child Care

Appendix: The UK Carer Movement

Issue	Action	Achievement	Recognition to Carers
(1950's) Mary Webster, had had to resign from her job as a Congregational Minister as her parents had become ill and in need of care.	<ul style="list-style-type: none"> • Wrote to newspapers, journals, to Members of Parliament (MPs) • Hundreds of letter from women in similar situation received • Organized a meeting in the House of Commons 	1963 Founding of the National Council for the Single Woman and Her Dependants	Beginning of the Carers' Movement
1960's & 70's Collaborative efforts to improve financial situation of carers	<ul style="list-style-type: none"> • Wide-scale campaigns by the National Council for the Single Woman and Her Dependants 	1967 <ul style="list-style-type: none"> • Tax concessions + pension credits (granted for women obliged to give up a job to care for a parent at home) 1976 <ul style="list-style-type: none"> • Invalid Care Allowance 	First Financial Assistance <ul style="list-style-type: none"> • The Invalid Care Allowance is the first allowance paid directly to carers • It placed carers as a group on the social security map
1981 Judith Oliver, carer of both her disabled husband and her young children, found herself no where to ask for assistance when she had to go for an operation in the hospital	<ul style="list-style-type: none"> • Carried out a small research study to find out more about carers' experiences • Appealed to carers through media • Called for the first carers meeting in London 	1981 Formation of the Association of Carers	First organization of carers shared by all carers, not defined by the disability or illness of the person receiving care
1985-86 The ICA campaign - to extend ICA to married persons, not confined to single women & men	<ul style="list-style-type: none"> • Sponsored a test case in which a claim by a married woman for ICA taken to the European Court of Justice 	<ul style="list-style-type: none"> • Government's concession on ICA, making ICA also available to married people 	<ul style="list-style-type: none"> • Winning the battle made the carers feel more empowered • A strong feeling that they want not just cash, but recognition and a sense of identity

Report of a delegation from HKCSS to the UK on services to carers (11-15 May 1998)

Issue	Action	Achievement	Recognition to Carers
<p>1985 Government initiative – “Helping the Community to Care” ~ in response to the pressure from the carers</p>	<ul style="list-style-type: none"> Established the “Informal Caring Support Unit” 	<ul style="list-style-type: none"> Carers’ forums – consultative mechanisms for carers to voice their opinions “Carers Impact” – work on service development for carers 	<p>Government recognition of needs of the carers, to be heard and to be supported through tailor-made services</p>
<p>1986 Disabled Persons Act</p>		<ul style="list-style-type: none"> Made the framework of policy much clearer by saying that “one should be looking at the needs of the carers alongside the needs of the person being cared for.” 	<ul style="list-style-type: none"> First Legal imperative for carers
<p>1986-88</p> <ul style="list-style-type: none"> The Audit Commission Report : ‘Making a Reality of Community Care’ The Griffiths Report – A Review of Community Care 	<ul style="list-style-type: none"> Reviewing the actualization of community care 	<ul style="list-style-type: none"> Carers are recognized as the main providers of community Carers are found to be in need of support 	<ul style="list-style-type: none"> Formal Recognition of the social status of the carers
<p>1988 Merging of the Association of Carers and the National Council for Carers & their Elderly Dependants</p>	<ul style="list-style-type: none"> Building one voice for carers 	<ul style="list-style-type: none"> Founding of the Carers National Association (C.N.A.) 	<ul style="list-style-type: none"> A United front for all carers
<p>1989 White Paper ‘Caring for People’</p>		<ul style="list-style-type: none"> Local authorities and health authorities have to ensure that carers receive adequate recognition and practical support 	<ul style="list-style-type: none"> Policy recognition
<p>C.N.A.’s continuous effort to press for carers’ legal rights</p>	<ul style="list-style-type: none"> Lobbied MPs for private Bill 	<p>1995 Carers (Recognition and Services) Act</p>	<ul style="list-style-type: none"> Legal Status recognized → Carer’s legal right to have their own needs assessed

Report of a delegation from HKCSS to the UK on services to carers (11-15 May 1998)

Issue	Action	Achievement	Recognition to Carers
C.N.A.'s continuous effort to press for recognition		1995 <ul style="list-style-type: none"> ● Jobseeker's Allowance → previously unemployment benefits → Former carers able to claim JA on the basis of their contribution record before becoming a carer 	Carers' experience formally recognized as equivalent to that of paid job.
Continuous lobbying and awareness raising	● National Carers Week (June each year)		
Continuous political lobbying		Chief Executive of C.N.A., Jill Pitkeathley, appointed to the House of Lords	Political Representation

After thirty years of advocacy, the carers have successfully mobilize themselves and allied into a united front. They have gained the following recognition to their invaluable contributions to the society :

- 1. Legal Status**
- 2. Social Status**
- 3. Financial Allowance**
- 4. Caring Experiences recognized as equivalent to paid job**
 - **Jobseekers' Allowance**
 - **National Vocation Qualification (N.V.Q.)**
- 5. Political Representation**

The carers have turned a seemingly private trouble into a public issue. The movement has evolved from one of soliciting passive recognition to requesting active participation in policy making and service developments. At present, they are still working hard to speak up for their own rights, and that of their dependents, such as:

- (1) Increasing the amount of the Invalid Care Allowance so that more carers can be truly relieved from financial hardships;**
- (2) Extending the Carers (Recognition & Services) Act to also protect their rights to services after assessments.**

Report of a delegation from HKCSS to the UK on services to carers (11-15 May 1998)

From the above review, two critical factors are key to the success of their movement :

1. **The self-awareness of the carers** – their self-initiation and internal mobilization of the whole movement, as well as their subsequent active participation, have all made their efforts never ceased.
2. **The unity of the carers** – Before 1981, there were quite a number of different carers' organizations. Their determination to ally into a single, but powerful voice, urged them to join into one association – The Carers National Association (C.N.A.).