Melbourne Presentation for 2nd Annual Disability Conference 15th/16th September 2011.

SLIDE 1 - UK DISABILITY SERVICES

Hello and let me begin by thanking you for the invitation to come and talk to you today with reference to: UK Disability Services - From State Provision to Independent 'For Profit' Provision

As you can see from the program I have been involved in the UK care sector for over 30 years but in practical terms, perhaps the most important aspect of social care that I can offer, is my experience of owning and managing a UK nationwide home care company (for profit) Able Community Care, since 1980.

SLIDE 2 - ABLE COMMUNITY CARE

The services that my company provides in England, Scotland Wales and The Channel Islands is a service for people with high, dependency care needs who are at risk if left for any length of time.

The age range of my clients is between late teens and over 100 years of age.

I have listed the Dark Age as being from 1948, but I, to set it in context, would like to go back further in time to show how for hundreds of years, state involvement meant that nothing much changed in the care of anyone who had a disability and nobody really did care.

SLIDE 3 - ELIZABETH I

In the reign of Elizabeth 1st, the UK was made up of parishes and councils, just as it is today. During her reign, England was frequently waging war in many places and the result was that soilders were returning home with disabilities that made them unable to work or care for themselves. Additionally, were numbers of people who had been born with a disability or acquired one through illnesses.

SLIDE 4 - DAWN OF DISABILITY CARE PRE 1948

What to do? One answer that was put into practice was that some of councils provided a disabled person with a cap in order that they could beg and it is thought that the word handicapped comes from this practice. 'hand in cap'.

SLIDE 5 - POOR LAW - PARISHES

In 1601 Elizabeth 1st 's Government brought in The Poor law Act which required each parish to levy a rate to raise money to care for people who were deemed unable to work due to either old age or a disability.

The majority of parishes however, ignored The Act and those that did not would provide help in ways such as a weekly payment, clothing or perhaps paying a pauper woman to house and provide some limited care for a disabled person.

Very little actually changed on a nation wide basis and most people with a disability were at the very poor end of society and were stigmatised.

SLIDE 6 - POOR LAW - WORKHOUSES

It was not until the 19th Century, in 834, that an amendment to The Poor Law said that parishes were to group together, to form unions and to begin building workhouses.

Workhouses were meant to be places where you came in and left as you found work, but many handicapped people remained there for life.

SLIDE 7 - HENSTEAD WORKHOUSE

It is estimated that in Gt. Britain in the latter part of the 19th century there were around 500,000 adults in workhouses or similar institutions who were disabled either physically or mentally.

The Victorian era was the time of wealth for many people who had made and continued to make vast sums of money as a result of the industrial revolution. Many of these extremely wealthy people thought that perhaps they could book their place in heaven by spending some of their wealth in benevolent ways.

Hospitals began to be built, charities and trusts were set up to help and dispense care and medical care.

SLIDE 8 - POOR LAW - ASYLUMS

Children and adults with mental health problems or learning difficulties were grouped together as imbeciles or lunatics and special institutions called asylums became the vogue and in 1845 local councils were ordered to build and fund them. These were grim places indeed. Many people entering them, never left.

SLIDE 9 - BETHEL ST HOSPITAL

Religious organizations offered care services, voluntary hospitals and even community visiting services were introduced. However, these were local not national services and still the majority of people with any kind of disability led miserable, non independent lives.

SLIDE 10 - THE MODERN DARK AGE

The Second World War was the catalyst for the beginnings of the major change in the social care sector in the UK.

Soldiers returning home with horrendous mental and physical injuries were seen in every part of the country and the general public wanted them to be cared for, to be rehabilitated and to have a future. The new age had begun but relative to today, it was still a dark age.

SLIDE 11 - 1948-1989 (1)

At the end of the war, in 1948, The National Assistance Act formally abolished the Poor Law system which had existed since the reign of Elizabeth 1st and established a social safety-net for people who did not work and therefore did not pay National Insurance Contributions. The Act placed an obligation on local councils to provide suitable accommodation for those who through infirmity, age, or any other reason were in need of care and attention not otherwise available.

New welfare organizations, in addition to state provision, sprang up to offer help, from small local charities raising money from whist drives and jumble sales through to national organizations such as the National Association for Mental Health.

Accommodation however, continued to be provided on a largely institutional basis and could be poor, non rehabilitational and in the main unsupervised to any great extent.

During the late 50's and 60's the idea took hold that to provide welfare and support to disabled people would be better provided in the community and not locked away in long term institutions or hospitals, many of which dated from the Victorian era.

The thoughts were that the caring for people should be more co-ordinated, joined up and not as it was then, in sectors. A sector for elderly welfare, physically handicapped welfare, mental welfare, children's welfare, etc.

SLIDE 12 - SEEBOHM

In 1968 The Seebohm Report, by Fredrich Seeborn, a banker by profession, advised that the current situation in place wasted large amounts of financial resources and manpower and that there was a better way for the end users of services to have a better deal.

As a result of this report The Welfare Service departments became the Department of Social Services with new local management structures and one overseeing directorate.

A plethora of legislation followed but the practicalities of the new system were not in place.

The new 'social workers', many of whom had just had a name change, were short of the required training to deal with the variety of their new caseloads and lacked the knowledge of what they were meant to be providing. As a result many people were still sent to the institutions of old mental health hospitals and long stay hospitals and never to return to the community.

SLIDE 13 - MARGARET THATCHER

It was not until the Conservative Government of Mrs Thatcher that the realization came that with an increasing number of older people, many of whom would lose the ability to care for themselves, an increasing number of people with a disability surviving and living longer, the need to have services provided on a level playing field regardless of where and whom they were provided by, new pathways to care needed to be put in place. At this time, the majority of care was free whether this was in hospital under the NHS or via the local council. For

example, my grandmother had a home help who came each day in the winter to light her fire and once a week turn her feather mattress. The State paid.

True there had always been services and professional help for those who wished to pay, but these were used by a minority.

From home helps to nursing services, from hospitals to the majority of aged, mental or physical disability homes, the services were free, paid for and provided by the State.

As I said earlier, I began my home care company in 1980. At that time I was only one of half a dozen companies and in the decade of the 1980's only a few more for profit, home care companies dipped their toes in the water.

SLIDE 14 - SAINSBURYS

Mrs Thatcher's government in 1983 commissioned Sir Roy Griffiths, a former director of the supermarket Sainsbury, to look into, consult and report on the best way forward for The National Health Service.

SLIDE 15 - 1948-1989 (2)

He produced his report in 1987 titled Care in the Community

The result of the publishing of the Griffith Report led to the 1990 NHS and Community Care Act, and heralded the era of the purchaser/provider split.

SLIDE 16 - THE NEW WORLD 1990-2009

The Griffiths Report saw the meteoric rise of the 'for profit' sector in care. People who needed care were to be given the choice, where do you wish to be cared for and by whom? State or independent provider? At home or in a home?

For people under the age of 65 with a disability, a wonderful Fund had been put in place.

The Independent Living Fund (ILF) was set up in 1988 as a national resource dedicated to the financial support of disabled people, enabling them to choose to continue living in the community rather than move into residential care.

The local councils who had provided the majority of almost all social care in any setting up to then were told that they had to cease being the provider and purchase from the private sector or the charitable sector that could almost certainly provide it cheaper and more efficiently than they could. Adults receiving money from the ILF were probably some of the first recipients of care provided by the 'for profit' sector.

Council run organizations such as care homes were sold off to the 'for profit' providers, care franchises were sold, often to people who had no knowledge of care themselves but did have redundancy money, charities began to deliver increasing amounts of care for local councils, nursing agencies diversified into providing non nursing care.

The downside was that many of these new companies went for council block contracts, for example, 1000 hours per week in a town, 100 in a village, etc. and when in a short time, contracts came up for renewal, many having only their council as their customer, went under if they did not win the contract. Contracts went out to tender and the cost of care went down as many councils went for the cheapest option.

In order to provide care in the community for people with any kind of disability it was recognized that care had to be appropriate and that any company providing care had to have the ability to do so.

The problem was that each local authority decided that they would have their own criteria as to what safe and appropriate care was and put into place their own specifications that care companies had to sign up to and work with.

This would cover factors such as training, health and safety, risk assessment, recruitment, financial viability, documentation, etc.

For a company such as Able Community Care, it was an expensive minefield as each authority re-invented their own wheel. For example if I worked in the County of Hampshire I had to provide in the homes my carers were working in a circuit breaker, as in the past, one care worker in the mist of time, had electrocuted herself plugging in the hoover. No where else did I have to provide this.

My company was accredited with over 50 local authourities over a period of around 6 years and most of it was nonsense and unnecessary.

This I believe was a fundamental mistake, to give individual authorities the right to bring in their own specifications. It wasted time and money for everyone concerned, money that could have been spent on services.

In the new millennium, this changed. The Government legislated for a national commission to bring in standards which would be across the UK thereby enabling all people who needed care to have the same standards of care wherever they were living.

The Commission for Social Care Inspection came into being in 2004. Its aim was to encourage and implement the improvement of the care services registered with it, all social care companies had to be registered to operate, but it also had the remit to inspect the quality of local council social services commissioning and care management. Now replaced by The Care Quality Commission (CQC)

This replaced the local authority specifications, the CSCI inspected all care companies from all sectors against the 29 standards laid down. The inspectors came to the provider organizations, met with clients receiving the service and met with care workers before making any recommendations for change if needed and they had the power to close companies down who did not or could not comply.

Overall the standards of care provision became something that as a nation we could be proud of.

The number of care companies had now risen to around 5,500 of which the majority were 'for profit' providers.

Services were offered with high standards, services were flexible and appropriate. For any disability a care service could be found to provide good care.

Consumers of care, service users, clients are a few words used to describe disabled people who require care but the bottom line had now become for the companies providing the care, that these people were customers.

Customers who had the right to buy care from which ever company, organization or residential establishment could provide them with appropriate care tailored as the customer saw to their need.

Innovative ideas have come in, for example, a new social care word has sprung up, buddies, which in the main provide a greater social element to a person's care, the role mainly based on days out, learning new hobbies or being able to return to old ones for say, a person with learning difficulties or a person having acquired a head injury in an accident.

Customers automatically bring competition into the work place and as a result the care sector in the UK is in competition with itself. Care providers across the entire sector continue to raise their standards of care, are flexible, add additional benefits, improved communications with their customers, go the extra mile to increase and retain their level of service provision. To survive they have to make a profit and as a result both customers and care workers benefited.

SLIDE 17 - TREVOR

The care system for a person with a disability during this period can be simply and effectively shown by telling you about Trevor.

Trevor had been a market trader, in some ways a wide boy, and in his 40's he was diagnosed with MS.

Alone, after a divorce, he had an elderly Mother and a sister, neither of whom could provide care for him.

His care requirements had begun slowly, a social worker was appointed who organised few hours care each week and his financial benefits.

Independent advocacts for people in the UK had been an increasing service since the nineties and Trevor obtained one to be on his side as he saw it.

His illness progressed and via his advocate and his social worker he obtained a 2 bedroomed, adapted flat. He also applied for and received an adapted vehicle for himself under the Motability Scheme.

Since he had been unable to work, the cost of his everyday living expenses were picked up by the State.

Trevor's illness progressed, his hours of care were increased, he was choosing to go into a respite care centre and two or three times a year he would choose to go 'on holiday' to an MS Centre or to a holiday park in an adapted chalet/caravan.

In 1995 Trevor was re-assessed as being at risk 24 hours a day. His spasms were difficult to control and were the main problem around which risks were centred.

His social worker offered him the choice of residential care but Trevor with the help of his advocate preferred home care and his social worker eventually agreed. (a more expensive option).

My company was commissioned to provide 24 hour care for Trevor on a fortnightly, live in care worker rotational basis. To comply with legislation our care workers had to have a break, their own time, whilst caring for Trevor, and his advocate managed to negotiate on Trevors behalf for a local care agency to cover each day.

Once our live in care workers moved in, Trevors life became increasingly independent. He was a lover of musicals, he could go with his care worker, at one point he had seen every live show in London, he could visit his mother in her aged care facility when he wanted, he could visit his Fathers grave and he could attend his local church.

However, possibly the greatest perk for Trevor, was that he could, in part go back to his true roots, that of a market trader. With his care workers he would go to car boot sales, going as a customer one week, a seller the next. The advent of Ebay gave him more satisfaction, as any piece of pewter for example, he could place on Ebay, apparently he told me, the Americans loved it.

SLIDE 18 - TREVOR AND SUE

In 1999 we introduced a care worker to Trevor, called Sue. Sue became a fierce advocate for Trevor, managing with his advocate to update equipment, negotiate with his social worker when the funding needed to increase, etc.

Sue worked with Trevor for twelve years working on a rotational, live-in basis. She was with him when he died. Trevor died on a cold bright day from a heart attack. He and Sue were just setting up his stall for the day at a boot fair, in some ways, the perfect ending he would have chosen.

The UK care system that enabled Trevor, and others like him to have a full and satisfying life is something I am proud of. The cost to the state was high but the achievement great.

SLIDE 19 - THE HICCUP

So what could go wrong? Quite simply, the money has run out.

Those people such as Trevor who have received funding, from the early days of the ILF will continue to receive it, but for new applicants, say for a Trevor mark 2, the application list has closed.

In some areas if you are disabled and have an assessed need for care it may be provided, in others less might be offered. Older people in particular are financially assessed and it may be that they are asked to pay up to £20 pw in one city but for the same service in another city they may be asked to pay 10 times more. The national standards for care extend nationally and there is a financial level where over this you can be asked to contribute or fully pay for your care service.

SLIDE 20 - 4 LEVELS OF DISABILITY CRITERIA

For care to be provided for a person with a disability there are four levels of criteria: low dependency, medium dependency, substantial and critical.

In the 1990's most disabled people who had a dependency that was low, would have received some help if they wished to live in the community. It may have been a few hours of home care a week, attendance at a day centre or a luncheon club.

However, as the money has begun to run out, only people on the top or second level can expect care to be provided and either paid or partly paid for from the majority of councils.

Again however this is a postcode lottery as there are still a few authorities funding lower levels of care provision.

Increasingly the NHS is playing a part in that if a person's disability is deemed health rather than social, then the NHS contribute to the care bill. This has led to a financial lifeline for some people and their families.

The current plans are to integrate social care and health care on a more practical basis instead of both areas often covering the same grounds, e.g. assessments, risk, etc

Recently a commissioned report, The Dilnot Report, has been published and pages and pages of press coverage, television and radio coverage have been given to it.

However, it has not addressed the fundamental problem, of how care will be paid for.

SLIDE 21 - THE VISION

Having been in the UK care sector for over 30 years and traveled every inch of the road of change, I am optimistic.

The first few years of this millennium we were getting it right for so many disabled people.

The fact that the number of disabled people in the country needing care and at what level was not comprehensively researched coupled with the current financial downturn in the UK has led to our present problems.

However, customer power, which is now well established and individual empowerment given priority, disabled people will demand the services, the equipment, the right to a personal and family life (European Union Human Rights Bill) and are and will continue to be an increasing vocal force.

Politicians and future politicians, who as never before are now true public figures, will want every available vote and know that eventually they will have to bite the bullet, and enable services, funding and choice of care provision to all those who are assessed as needing it.

It may take a couple of more years, but my feeling for people with a disability in the UK, the future will again be bright.

Thank you.

Angela Gifford

Able Community Care
The Old Parish Rooms
Whitlingham Lane
Trowse, Norwich
Norfolk NR14 8TZ
United Kingdom

0044 1603 764567
ablemg@aol.com
www.uk-care.com