THE DEVELOPMENT OF TULLOCH ARD

Shand was severely disabled, confined to a wheelchair, and possessed very little arm movement. Virtually quadriplegic, he cajoled and pestered professionals to allow him control over his own care. Through collaboration and innovation, he gradually garnered support and successfully instigated the first Independent Living Pilot in Scotland, cleverly managing his staff to allow him quality of life in a sheltered Community,

Always full of initiative, he fundraised for the first computerised car in Scotland (now in the Glasgow Museum of Transport) and produced articles and speeches. He was a founder director of many disabled organisations, including LCIL and Freespace.

He was a Justice of the Peace, and, keen to have as normal a life as possible was willing to contribute what knowledge and skills he had to train others.

However, schoolchildren and bullying became problematic for him. He wanted to move out of the sheltered village where he could find no peace. He wanted to live in a "normal" environment: he wanted respite from the taunts of children. He wanted to be unafraid of fireworks being put through his door.

He wanted me to help him.

Enjoying the peace in his garden

<u>THE OBSTACLES</u>

FINANCIAL: There was not much money – Shand was unemployed and living on Benefits, so imaginative thinking was required to find a way round the various systems to bring about maximum quality of life.

LOGISTICAL: The property search took years. His criteria were extremely specific: no property built after the 1930's was of much use, so we could minimise our search. The bungalow pictured above was built in 1870, and needed virtually no conversion, apart from the occasional door and the bathroom.

ATTITUDINAL: There was understandable apprehension on behalf of the medical services at the arrival of such a severely disabled patient, who by now was also ventilated, There were Consultants to inform and new relationships to make.

INDEPENDENT LIVING FUNDING: There was the necessary debate over funding of care, and would the SWD continue to fund him in another LA area? It took determination and resilience.

THE ACTION/AIM

To develop High Dependency/Intensive Care in the Community with a ventilated patient and run this as a pilot project.

The aim was to find a facility where care and accommodation could be provided in the Community. This involved identifying a building, and converting it tastefully for use by a disabled person.

We would advertise for staff to allow him as much autonomy as possible.

My role was that of the linchpin/coordinator.

THE TEAM

This was in two distinct phases**:**

1. An architect who could understand and work with Shand's vision had to be identified.

In the beginning, contact had to be made with GP, Health Board, Social Work, Building Control, plumbers, joiners, decorators - it was a similar feeling to Grand Designs. There were many people to consult. Responsibilities had to be defined. Shand made the final decisions on furnishing, which staff he employed, the internal maintenance of the house and the garden were under his control. As the project became established, there were then the accessories, such as environmental controls, security cameras, and automatic doors– contacts were important and encouraging teamwork was essential.

We had to keep those working with us on side: this was severely testing as the days of moving in drew nearer.

2. The Personal Assistant (P.A) team developed and evolved over the years. My role encompassed teaching all issues pertinent to care; maintaining a safe environment; medication, and maintaining and arranging servicing for all medical equipment. When well, Shand wanted as much privacy as possible – when he became ill, he needed support. We required a flexible team to meet these needs. Gradually he emerged into an employer of some note – an excellent man manager, who cared for his staff.

P .A. s were interviewed and trained by us: a total of thirty were required over the years. (NHS and SW do not fund for training unless the trainer is employed by them. In Direct Payments, Shand was my employer, therefore training was provided at no cost.).We kept it simple by accepting a CV and requesting two references. Any matters of discipline, Shand dealt with, supported by me if required. Applicants were long term unemployed, single mothers, or people who had lost confidence through mental health problems. The wages were done by a wages clerk in a local joinery firm, for a small monthly fee. My remit was in medical matters, as none had a nursing background, and he trained staff about personal hygiene preferences, housework and gardening. The amount of work that he supervised the staff doing in the garden earned him 3rd prize in the Gardens competition.

There were eight members of staff at the time of his death: all required to be trained not only in ventilation but positioning, skin care, suction but also feeding, choking and appropriate use of equipment.

Team meetings were held as required and methods of the documenting of events were gradually fine tuned.

Staff were given the chance to shine. Everyone described it as “the best job I have ever had.”

The Outcomes:

- Empowerment for both the individual and the staff:
- It raised awareness of the barriers in the Community.
- It was an invigorating and stimulating environment.
- It created employment.
- There was no bullying, or physical abuse, as he was the employer.(CARE HOMES:TAKE NOTE)
- Access audits were undertaken to identify the difficulties of inclusion in the Community.
- Knowledge Transfer: His staff worked with him in hospital, and nurses depended on the skills of his staff.
- It generated confidence and maximised talent.
- It became a small cottage industry, as he encouraged staff to create a prize winning garden.
- A teaching programme was started.

THE SIMPLICITY WAS REWARDING

He took control, refused to be beaten by either vandals or the system, and became empowered. He discovered the possibilities of an Empowerment Centre.

In an Empowerment Centre, people with disabilities or the elderly are not passive recipients of care, but engaged educators of those who come to assist them. There they have status, express opinions and are treated with dignity and respect. It is easy to empower others if we take the time, have an understanding of what they want, and are prepared to listen.

Car driving was an amazing achievement, (partially funded by John Major's Government) .Not one Medical person would support him in this venture. He was immovable, adhering to the base of his research, although asking a friend, who was visiting America, to check that the system was possible for him. The positive feedback convinced him that the technology was available. Unable to feed himself or hold a cup, he drove all the way from Edinburgh to Silverstone and back.

From that day, he felt he was not merely the recipient of services – he had something to offer.

He could supply a lift home to friends after a party, or a meal out. He remained completely sober and was suddenly in great demand – his social circle widened, and the amount he offered Society grew exponentially. It was all he could do – drive. But the provision of the funds for the vehicle changed his life.

And when a local youth taunted him, saying: "You're just a raj in a basket", he merely laughed.

After all, he had been awarded the MBE by the Queen.