

Alan Duncan 1955 – 2009

‘Pioneer’



Alan Duncan passed away recently. A sad event for those who knew him of course, but why should anyone else be interested? Well, not many people know that Alan was a member of a small group of pioneers who, in 1974, led the way from the institution to the community. Alan's story is the story of the development of community care, and Alan's life contains valuable lessons that we forget at our peril.

Those who cannot remember the past are condemned to repeat it.

George Santayana, *The Life of Reason*, Volume 1, 1905

History

Alan was born in Cardiff on September 9th 1955. He was born with Down Syndrome, and back in the 1950s and early 60s it was not a good time to have a learning disability. Well-meaning professionals with brief-cases used to call on parents and tell them that their son's and daughters would be much better off in a special residential school for the handicapped. And so, whilst still just a young boy, Alan was admitted to the children's ward at Ely Hospital where there was a real possibility that he could

have spent the rest of his life.

It is important to remember that up until 1948 Ely 'hospital' had been a workhouse. Sadly its transformation into a hospital did not transform it into an institution of social enlightenment. In 1967 a staff member at the hospital sent a dossier of allegations of serious abuse to the *News of the World*. The subsequent enquiry and report gave rise to raft of other investigations across the UK into allegations of ill-treatment, and criminal proceedings followed throughout the late 60s and early 1970s.

Reviews

These Inquiries confirmed the picture painted in the Ely Report: appalling physical conditions, crude and neglectful care, rough handling and ill-treatment, managerial indifference and incompetence. This contributed to a major policy review which led to the 1971 White Paper *Better Services for the Mentally Handicapped*. It was fitting then that as the Ely scandal had opened up 'mental handicap hospitals' to public scrutiny, Cardiff would be at the forefront of developing new models of care.

Llais

At the beginning of the 1970's, in response to the Ely report, a group of students from Cardiff University who were members of a student society called CUSS (Cardiff Universities Social Services), began to visit a Ely hospital residents and take them out for the day. Professor Jim Mansell was one of those students. As he recalls,

For me, the story starts in a large room: a hot, stuffy room in which the smell of sweat, and urine, and excrement, was overpowering. The room was sparsely furnished and much of what was there was damaged or broken. Sitting on the chairs around the edge of the room, or laying on the floor, or standing in a corner, were children and young people. Some of them had their heads shaved; some were nearly naked. High on the wall in a corner a television competed with piped radio music for attention. There was nothing - absolutely nothing - to do. A member of staff sat in a corner doing her best to keep the peace, or got on with housekeeping tasks. Hour after hour, day after day was like this.

The clothing was communal, and laundry so primitive that much clothing was destroyed. In a side room, the charge nurse kept a set of 'best' clothes for each person, to be protected from the laundry and so to be hardly ever worn. When people went out, there was not enough under-clothing. Trousers were held up with pins and string. People wore gabardine raincoats, shiny with spittle and stinking of sweat. In the street, people turned away in embarrassment or silently pressed money for ice-creams into one's hand.

It took a group of committed and passionate students to start asking the really awkward questions. Why are people in 'Hospital'? Why can't the people we visit live in the community with a bit of help and support? Radical ideas at the time. As Jim Mansell says:

Ely Hospital's first reaction to the idea that Alan and the other people he lived with on Pine and Rose Villas could leave the hospital was disbelief and outrage. How could people with disabilities this severe live in a house with students? How dare people suggest that there was no need for institutional care?

'One small step for man. One giant leap for mankind.'

CUSS

But with constant pressure, and help from the Regional Hospital Board, small steps were taken. In 1972, side rooms on the wards were converted so that five 'patients' (Alan Duncan, John O'Brien, Paul Evans, Heather Howard, and Jackie Morgan) could live more independently. When it proved impossible to overcome the hospital routine, a student flat was rented during the vacation and for two weeks people had a holiday living with students in central Cardiff. Then, in July 1974, using a house rented from the University, all five young people left the hospital, carrying all their possessions in black plastic bin bags. They set up home with four students, initially returning by bus every day to a local authority day centre near the hospital.

Adrian Roper, Chair of Learning Disability Wales, recalls the day he visited them

The student house in Cathays was known locally as 12 Ruthin Gardens, but across the world it had become known as the CUSS Group Home. That's where I met Alan, one spring evening in 1981. I had been invited as a brand new CUSS volunteer to come round for dinner. I had never met anyone with learning disabilities before, but when I walked into the dining room and was introduced to Alan, John, Heather, Paul and Jackie, I had the best welcome I've ever had anywhere, with Alan drumming on the table and leading the cheering. That was the start of a great friendship.

At first, the hospital held its breath predicting catastrophe; but after a few years, it became clear that the CUSS experiment was a great success. The Hospital's response was to suggest that this new approach only applied to the five people who must have only "mild" disabilities and that the rest of the people in hospital still needed "continuous medical and nursing care".

Strategy

The NIMROD project, which piloted multi agency, community based teams, started in 1981 and by 1986 it was supporting 150 people with a learning disability. The All Wales Strategy was launched in 1983 and saw the implementation of the Nimrod principles on a national scale, and the proponents of the 'Hospital Model' were silenced. One small step had certainly led to a gigantic leap!

Llais



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In 1985, the CUSS Group Home moved to Kings Road in Canton, and dropped the "group home" title. Jackie moved back to Swansea to live with her parents. Alan, John, Paul (who sadly passed away some 10 years ago) and Heather quickly established themselves as 'Canton Locals'. Alan was also establishing himself on the local band circuit. Adrian Roper, who is also bass player with a local band, said.

Alan became a popular part of the live show of one of Cardiff's top rock and roll bands. Back in the 1980s, the Spasm Band were playing to packed night-clubs, and through friendships with band members, Alan moved from being an occasional fan to being a regular guest singer. Somewhere there is film footage of Alan and the Spasm Band's lead singer, hugging a microphone together, drenched

in sweat, whilst the audience went wild. Most of them had probably never met someone with a learning disability before, and once more, there was Alan, helping people to feel not just tolerant, but really happy, and full of respect. He last sang with the band only a couple of years ago, and the whole band is gutted that he can't do it again.

Revolution

This isn't the end of the story. Revolution was still the order of the day. By the mid 80's Alan and his co-tenants became disillusioned with their local day centre. To everybody's amazement they rebelled and stopped going. There was a lot of pressure exerted to make them go but to no avail. Alan's feelings for the Day Centre were summed up in a song he used to sing with the band.

And oh that Centre
Makes me feel so blue
Makes me feel like I want to do
Some real damage
To you know who

One of these mornings
I'm gonna stay at home in bed
Cos that Centre does my head in
Centre does my head in
Centre does my head in
So uniquely.
(abridged)

Protection

I have learned over the past 30 years that professionals spouting theories, or distributing glossy pamphlets and flyers do not change the public's attitude to people with a learning disability. The only people who really change attitudes are people with a learning disability themselves. This was borne out by an event I witnessed some years ago.

Llais

Alan and John used the same pub as I did as their local. It's a pub with a variety of clientele who, whilst not hostile to the Alan and John, weren't demonstrative in their affections. One Saturday Alan and John arrived to at the pub to watch a rugby game. The pub had recently had a new landlord who, after Alan had bought the drinks and sat down, turned to a couple of the locals and whispered "Don't worry lads that's the type of people I'll be getting rid of". Before I could formulate a considered response one of the locals (a very large and muscular individual) reached across the bar grabbed the landlord by his collar and tie and said with quiet menace, "they are locals, you ban them you'll have to ban all of us"

It was an enlightening moment for me. It showed that merely being present in the community, being out and about, being seen and respected as a 'local' brings more protection than all the professional 'safeguarding' measures put together.

Alan lived in, and through, interesting times. He knew the horror of the institution, and he experienced a quality of life that could never have been imagined when he was first placed in the hospital. Of course he is not alone; thousands of people with a learning disability across the world have now trod the path that Alan, John, Paul, Heather and Jackie pioneered. It would be good to think that Alan's death marks the death of the institution. Sadly it



doesn't. As Jim Mansell writes:

Even though it is feasible to provide good services for everyone it takes commitment of time, imagination, energy and money. We are beginning to see a failure of that commitment as services for people with learning disabilities drift back to the margin of policy-makers' concerns. We are beginning to see transinstitutionalisation - closing hospitals not by developing decent services for the people in them but by moving people to other institutions.....

The most important lesson from the closure of Ely Hospital is that institutional attitudes do not die when the hospital closes. The institution - in the sense of the prejudices and weaknesses that produced it in the first place - is in us all. The most important part of the legacy of Ely is to realise that decent services for people with learning disabilities - or for any vulnerable group in society - require that we always strive to meet high ideals and that we pay close attention to every step on the journey. That is to say that "the price of freedom is eternal vigilance".

Remembering Alan's life is part of that vigil. Adrian Roper said at Alan's funeral:

I'm sure that everybody who lived at the Group Home in Cathays or who befriended Alan and his house-mates after they moved to Kings Road, and more recently Fairwater, will have great stories to tell. Someone should gather them all together and make a book. A film would be good too. We could call it "Five Flew Out of the Cuckoo's Nest". And someone like Jack Nicholson, only with more personality, could play Alan, and show how he got to live a long and happy life, and made so many people laugh and feel good, despite getting dealt some tough cards by life. Alan liked heroes, but he was a true hero himself.

It's a great idea!!!!!!

We would like to thank Professor Jim Mansell for his memories and for letting us use his paper 'A Spur to Action' but particularly for being there in the 70's for Alan, John, Paul, Heather and Jackie when no-one else was'

The friends of Alan