



When did I become a **Wheely Bin?**

Chris Bennett CEO of Perthyn offers a providers perspective of the changes in service since the publication of Llais number 1.

When I was asked to write this article exploring the experiences of organisations and people who have been providing and developing services, it suddenly struck me that the last 25 years seem to have flown by, but has anything really changed.

All Wales Strategy

It is easy to forget that the All Wales Strategy, launched in 1983, was a response to the exposure of wide scale abuse in Mental Handicap Hospitals in the early 1960's; Ely hospital being the first to be reported in the News of The World. (oh the irony of it).

When the first issue of Llais was published in September 1987 the All Wales Strategy, whilst in its early stages, was already shaping the lives of many people with learning disabilities and their families in Wales. Sadly most of the long stay hospitals were still open for business and consultants had only just stopped sending out letters offering sterilisation to women with a learning disability.

The Students of Cardiff University and former patients of Ely who set up Kings Road, the first community based house that opened in 1974, showed us all

what could be done if you had the determination. The NIMROD project in the former South Glamorgan built on this and the AWS gave Wales the kick up the backside it needed to move into a period of reform that tried to do the right thing for the right reasons- not because some management consultant saw an opportunity to make a killing. The AWS gave us a process of reform based on values and principles, even though the Strategy talked about "rights" these were and sadly are still evolving.

Positive Relationships

What was positive at this time was the relationship between people who worked for the local authority now known as "commissioners"; the Voluntary sector partners now known as "providers" health care professionals who split into commissioners and providers and parents and people with learning disabilities now referred to by commissioners as service users, unit cost, low, high, critical and super critical. To those of us who share our lives with the people we support- well we just got used to calling each other by name, it seemed easier and more human.

In the Section 7 Guidance on Service Principles and Service Responses, issued in 2004, section 18 stated:-

"experience in many parts of Wales after the launch of the 1983 All Wales Strategy showed that joint working between local authority departments, health organisations, voluntary organisations, service users and carers had significantly improved. Effective partnerships in the planning, commissioning, development and monitoring/ evaluation of services, led to decisions, which had common ownership, were better informed and were more sustainable."

In the early ninety's County Councils were still expected to produce "the County Plan", this required all stakeholders to agree a joint plan investment and expenditure over the coming years- many an hour was spent talking in Local Authority meeting rooms thrashing out the plans and at times many of us thought we lived in the Metropole Hotel in Llandrindnod Wells!

The County plans of the early nineties talked about "working through change together". The changes discussed at the time



were described as more fundamental than the original launch of the Strategy.

A Vision

In completing our County Plans we had a vision for the future – well at least the next 10 years. It was a vision of a quality of life, supported by quality of service. It was a vision that we hoped went beyond the world of services; a world that had expectations of, and encouraged achievements by, people with a learning disability in a valued world of society and community. It was a vision of a world in which those providing services were expected to;

- Know the people with whom they were working, through actively seeking out and valuing their experiences and Acknowledge and respect the different needs of people with learning disabilities and their carers views
- Inform and consult with consumers and staff in the development of services at all levels
- Know the communities in which people live, in order to make full use of opportunities for enhanced quality of life
- Be flexible in the way services were managed and delivered so as to meet the changing variety of needs and opportunities.

In developing the plans all parties adopted a partnership approach. We all shared risks together, shared problems and solutions. The artificial market that has damaged so many positive relationships since did not exist. Yes disagreement occurred but they were constructive, there was

no threat of tendering and losing contracts if you had a different view. Relationships were robust, honest and innovative. When this culture existed we witnessed the greatest shift in attitudes and service development.

Changes

When the AWS was re-launched in 1990, the NHS was undergoing yet another change and we witnessed the introduction of “local Strategies for Health”, Unitary Authorities were being formed and The NHS and Community Care Act 1990 was introduced – little did we know that this was the beginning of the end of many partnerships, the start of the “market” and the split between “commissioners and providers” and the advent of eligibility criteria that de-humanised us all.

The 2004 Section 7 Guidance clearly states that “individuals should be consulted whenever possible about their housing, tenancy and support arrangements” yet over the last few years we have witnessed and continue to witness wholesale re-tendering of “supported Living” services with no consultation with the people within whose homes the support is to be provided. Commissioners are increasingly turning to ‘procurement consultants’, most of whom do not understand what we are trying to achieve for people. This approach turns people into commodities. In many cases the strategic intent is focused on a ‘price per head’ rather than choosing providers, who are committed to, and able to, deliver quality outcomes for people.

It has to be said that we as providers have colluded with this. The new order has let in the minimum wage, no pension and statutory sick pay providers. In competing with this many current providers have had to make significant cuts in their management, quality and training budgets. What this has meant is that the fabric of quality services woven over the last 25 years is being unravelled and turned into thin and badly made garments under the falsehood that it is value for money and making resources go further. The reality is that these will wear thin and fall apart relatively quickly and somebody is going to catch a very bad cold.

It would be fair to say that not all local authorities in Wales, or England, have gone down this road. Some have sat down with providers and worked with them to make the savings necessary in ways that maintain the underpinning outcomes that everybody aspires too in line with the original vision of the AWS.

Occasionally we have been dragged back together for the common good, the introduction of the Care Standards Act 2000 was a great example of this, with the threat to supported living coming from the potential imposition of the registered homes regulations all parties including providers joined an all Wales working group to help draft standards for Wales.

Whilst this was a good piece of work we would welcome further collaborative work to draft a new set of regulations for supported living services specifically as opposed to the mix bag we have now.



Policy Development

One of the most significant policy initiatives has been the publication of the Challenges and Responses report. Its key message, built on the work of Professor Jim Mansell, was that local authorities should stop putting people with challenging and complex needs in expensive, out of county placements, often miles away from family, friends and local support networks. To achieve this they needed to invest in developing skills and expertise and support structures. This, in the main, has been ignored. People continue to be sent miles away and are often abandoned to their fate. Sadly the result is far too often the type of abuse seen in the Winterbourne scandal.

Finance

The All Wales Strategy recognised that in order to make change happen significant investment was needed to develop and support community based services. This new investment was allocated to services that demonstrated that they were supporting people to have 'ordinary lives' in the community, were designed around individual need and engaged the community at large.

I am saddened by the fact that I now hear key professionals saying that 'Supported Living' is an unsustainable model of care! They have totally missed the point. Living in your own home, either as an owner-occupier or a legal tenant is NOT a model of care; It's a basic right that ALL of us demand.

And so.... Things have changed. Working in partnership and sharing a vision is increasingly being replaced with being seen



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as no different to a contractor providing laundry services. Investing in staff, providing comprehensive training, offering the best pay we can and contributing to pensions and sick schemes is seen as profligate and 'expensive'. Defending basic service principles and the rights of people with a learning disability results in charges of providers 'not wanting to change' or of feathering their own nests. New providers, many large multi-national private organisations, who offer minimum staff terms and conditions and whose allegiance is ultimately to the bottom line and shareholders dividends, are seen as the white knights who will save local authorities from fiscal disaster. It is interesting to note that this rarely applies to their in-house services which are far more expensive than anybody else.

Lesson Learned

An examination of the Ely Scandal of 1969, the Macintyre scandal, the Cornwall Partnership NHS

Trust 2006, Sutton and Merton Primary Care Trust 2007 and now the Winterbourne Castlebeck scandals 2011 highlights some basic facts. Services that: Dehumanise people by seeing them as 'product'; Minimal management infrastructure; Have little or no quality control; Have low expectations of staff; Have low expectations in relation to outcomes for individuals; Marginalised or ignore whistle-blowers and where there is no fear of being caught because of lax external monitoring systems will inevitably fail the people who use the services and result in abuse, and eventually death. If we have learned anything it is let's get back to what we do best in Wales. Let's work together and let's care about what we do and what this means to others. Let's get the vision back, refuse to compromise on rights, skill up commissioners and planners to work in partnership again. By doing this we can say goodbye to the here today gone tomorrow consultants and create and deliver a vision that is owned by the people of Wales.

I recently talked to a young man whose services are being re-tendered and who has not been consulted at all. I asked how he felt about this and he replied "When did I become a wheely bin?" If I had to identify two fundamental actions to stop people becoming 'Wheely Bins' they would be

1. Implement Challenges and Responses right now
2. Develop citizen directed support. Empower individuals to choose what makes sense to them.

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