

Radio 4 Four Thought

A Lonely Society

Delroy, was a highly feared young man of great reputation, often known as one of the 'Gloucester Boys', who spent some 20 years of his early life locked up along with 100s of others just outside Bristol. He couldn't carry a back pack big enough for the vast range of negative labels attached to him by the people charged with responsibility for him.

One day in 2008 he left the institution and was given a crack at life as we understand it, living in a flat in a Somerset village where he began to build a future.

Getting a job was a particularly challenging issue for him, but he had a passion for recycling and soon was making himself invaluable in his local village by collecting tins and plastic etc. from his neighbours and taking them to the recycling centre, where he was paid by the weight. In time he set up a small business and a few years later he was recommended for and won a major 'Green' award at a black tie dinner in London!

Most likely, you think I am talking about a man leaving prison, having paid the price for some serious misdemeanour and then his successful journey back to an ordinary life.

Tragically I am not. I am telling the real story of a man I know who was locked up in a long stay hospital simply because he has a severe learning disability. He was known as a 'Gloucester Boy' because he lived on the locked Gloucester Ward with 30 or so other men who were deemed to be 'challenging' simply because they had some combination of profound learning disability and autism and were living in a setting that made no sense to them.

18 years after the Community Care Act was implemented he literally got his freedom, along with more than ¼ million other people with learning disabilities before him.

It is clear to see that 'the system' got it wrong once; many 1000's of people with learning disabilities were failed badly. But ... I've begun to worry deeply that following a career spanning the period ushered in by Community Care until now, we may have got it wrong again!

So let me re-trace my steps. Soon after I left University I found myself in a job that involved preparing people with learning disabilities to leave the long stay hospitals, and move into ordinary homes in local communities with support.

While I saw endless shocking and often inhumane scenes within the hospital walls, I was full to the brim in confidence about the active and rich lives that those leaving would in time establish in their new lives. To be fair, this confidence was rewarded time and again with heart-warming stories of people growing in independence and

having lifestyles that matched in many ways those of society around them, from the mundane to the complex; Jane choosing and shopping for her food for the first time, Peter decorating his bedroom, Michael growing his vegetables, Alan having a pint at his local, Margaret seeing the bright lights at Blackpool and John visiting his brother in Australia. I have absolutely no doubt that this was a major change in the right direction. But ... where has this all ended up today?

25 years on, we like to believe that we live in an enlightened, modern and democratic society of equals where everybody is valued and involved, yet there are some members who have no voice. This horrific fact miserably remains the overarching story of people with learning disabilities in the UK.

Here people with learning disabilities are invisible; 93 out of every 100 have no job, many experience 'hate and mate crime' and over 3000 are still literally locked up within notorious 'so called 'Assessment and Treatment Units'.

All too often they are not to be found where the rest of us are; doing the stuff of life that the rest of us are doing. And ... our limited exposure has led to most of us not even knowing what a learning disability is and worse still filling in the gaps with a range of unhelpful, ill-informed and negative stereotypes. When our paths do cross, we feel uncomfortable and all too often categorises them as 'the other'.

At Brandon Trust the learning disability charity I work with today, we celebrated our 20th anniversary in 2014. As part of this we brought together 300 people with learning disabilities at the Emirates Stadium in London to ask them about their achievements, the quality of their support and what they hoped to achieve in the future. When talking about their futures there were many hopes expressed that did not surprise us, such as the desire to work. However, by far the biggest issue for many was the desire to develop relationships and friendships with people beyond their paid staff and families. To be truly connected to society meant not just to be doing stuff in their communities but to be meaning something to people in their communities – is this not a basic human need common to us all? To put it simply, they told us they were lonely!

As a result at Brandon we are now having extensive and ongoing conversations with those we support about relationships, learning more about people's sense of loneliness and exploring how we can support people to make genuine connections with people in their communities.

Barbara, somebody we support, recently shared her story with me; she spent 25 years between various long stay hospitals and care homes. For much of this time she lived in locked settings and almost always had what limited personal possessions she had (including her clothes) locked away. She lived without the basic freedoms we all value and in almost total isolation from society at large.

Today, following the right kind of carefully developed support, Barbara lives in her own flat with support in a small town in Cornwall where she has become the heart and soul of the community. She is out and about volunteering in her nearby charity shop, swimming with the local swimming club, attending church coffee mornings and using the local shops. She cannot walk down her street without being stopped for a conversation!

Sadly, while Barbara's story has moved on and she experiences a genuinely connected and integrated life with a wide range of rich relationships, this is not the case for many. What seems like such a normal thing is in reality a distant dream for most! While the large institutions are closed; and most people are physically living in their communities, all too often they remain isolated. What a tragedy!

On top of this, this very loneliness and isolation perpetuates the ignorance so rife amongst the rest of us, and deprives our communities of their invaluable contributions.

And so today like many elderly people, many learning disabled people, will only interact with those paid to care for them; professionals like me and my colleagues. And while I would always stress how important and rewarding I find the relationships we build, they simply aren't enough. We all need to see and know people who are interested in us, for us, not because they are paid to look after us.

As someone who has spent my whole working life in one way or another, providing support to people with learning disabilities, with the aim to enabling them to live with greater independence and autonomy, I find myself asking whether I, the organisations providing social care and the Sector itself have actually become part of the problem.

In my 20's I was 'bright eyed and bushy tailed' championing the end of the big institutions brought in by the Community Care Act in 1990 and naively thinking that small scale community based support would automatically lead to integration and connectedness. While there are some excellent examples of where this has become a reality, how wrong I have been in terms of the extent to which this has become the norm for all.

In stepping in to provide support, however well-meaning, I am starting to believe that much of this very support all too quickly becomes an end in itself. If the support does not act as a catalyst, connecting people on to other non-paid people in the community, we are simply creating a form of dependence, furthering isolation and in our own ways creating yet another institution, even if a somewhat more benign one.

Equally, I have always been a passionate supporter of the principles of the Welfare State and its role in creating a fairer society. While I am not about to throw the baby out with the bath water, I wonder whether in its own way it has created a dependence on formal support and been a contributor to the eating away of communities and the sense of our personal responsibility towards others. Indeed, how often do we hear people who care for family or friends talk about the money they are saving the Government?

The last coalition Government touched on some of these ideas with its short-lived policy of the Big Society agenda. While it was greatly mistrusted by many, the principle of a strong community as the bedrock of a healthy and integrated society must surely be a good one.

These challenges are leading me to re-think our priorities at Brandon Trust; I am convinced that we must respond to peoples' deep cries for relationships. We have to find ways of enabling people to genuinely connect with others in their

communities who can see beyond their disability, share common interests and recognise their shared humanity.

To this end, we are establishing a range of volunteering programmes aiming to connect people we support to buddies. Our strap-line is 'Live Free' and we are now seeking to help those we support with disabilities metaphorically escape over the wall of these modern institutions and finally take their proper place in life.

However, it is not enough or indeed right to leave this to charities alone. If these ideals are to work at last, we also need a society that is ready to change, ready to welcome Delroy, Barbara and the 1000's of others.

So... it's over to you, the audience, to play your role. Know your neighbours. Speak to them, make friends. In many places this already happens, but too often it doesn't. Organisations like us can offer opportunities to get involved and even training, but as citizens, neighbours, family and friends we all need to do more. We need to play our part.

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