

What is most important? Reflections on support arrangements for people who are intellectually disabled.¹

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Retirement celebrations can be a strange experience: people say nice things about the retiree who often then uses the occasion to settle old scores! I won't do that but I do want to use the opportunity to focus on some of the big questions that have been with me throughout my career of more than thirty years – in effect this is an (un)settling of my personal 'old scores'.

1) The need to focus on what needs fixing.

For those of us who are striving to improve supports for intellectually disabled people there are many potential things on which to focus our attention. However, the one that affects all the others is the persistent and systemic disadvantage that intellectually disabled people face in all societies. It cannot be fixed overnight, but requires long term effort, strategy, and let's be quite clear about this, struggle. It is this disadvantage that underpins the problems of poor health care, abuse and the need for high expenditure from our economies that otherwise have little space for those who are perhaps the most disadvantaged of all. In my view we need to keep this problem of systematic disadvantage at the centre of our attention and frequently return to it in order to set direction for the more specific and concrete actions and initiatives without which the overall aim of reducing disadvantage is no more than a vague aspiration.

2) Public services and the NHS

Public services are both the solution and the problem. It seems strange to be finishing my career in the NHS the day after the government passed legislation that is set to destroy the NHS as we know it – a triumph of human need over the money and privilege that shares the risks of health and illness across the population, guaranteeing attention to all irrespective of accidents of birth or experience, the biggest achievement of the British labour and socialist movement. That principle of risk pooling – so we all benefit when we need to has been eroded since I started my career (the privatisation and commodification of social care, the flight from comprehensive education and the erosion of equality of access to higher education, the residualisation of social housing, reduction of welfare benefits with the demonisation and pauperisation of long term claimants.....) and this is set to continue in conditions of structural system crisis. What do you do when a government without a mandate passes a

¹ Remarks (slightly elaborated for the written version) made on the occasion of my retirement as Head of Manchester Learning Disability Partnership, 22 March, 2012.

law that will bring injustice and insecurity? We all have a responsibility, not just to our masters in the bureaucracy but to the people, now and in the future, and for this reason I consider it the duty of NHS staff and managers, and those in related sectors to engage in civil disobedience against the destruction of our common wealth².

But public services can also be clumsy, insensitive to people's interests, needs and wishes, particularly when distorted and pressurised by priorities that make little sense at the point of provision. So person-centredness is really important, but that does not mean that every problem can be fixed with a personal budget. They are a useful tool to increase control and unleash creativity yes, but at the risk of turning a fundamental human quality - care - into a commodity which it manifestly is not.

Together with person-centredness there is a need for continual non-defensive reflection, questioning, enquiry, against the basic question of what is life like for the people the services are there to support? Our systems can be resistant to challenge but it is only challenge from those most affected by them (in a variety of ways whether informal comments, formal complaints, organised consultation and advocacy or the sensitive 'reading' of behaviour) that can really drive improvement.

3) The fundamental puzzle

For me perhaps the fundamental puzzle has been to get effective practices into day to day care. There are some obvious barriers – low wages (a consequence of the systemic disadvantage of people with high care needs), stretched staffing, a performance culture that neglects what's most important.

Getting effective practice into routine care and support is about knowledge, about skill and about basic human kindness – not any one of these in isolation from the others.

I do think we got this pretty much right a lot of the time in the MLDP – I was proud of our in-house service, while recognising that perfection is difficult to achieve – a combination of values, commitment and hard won skill and knowledge, putting specialist knowledge together with basic practical know-how, and this is why we tried to build a culture of enquiry, in which we strove to embed research and development in the day to day operation of the service – not an easy task but one that we had some success with.

4) We've come a very long way

My first contact with formal services to learning disabled people was at a so-called hospital in the Midlands. The site comprised a series of wartime prefabs. In the dining area I witnessed a young man knock his meal to the floor. The attendant scraped it back onto the plate and represented it to him. Later in the

² This point was in my notes for my remarks but I overlooked it in my hurry to get through the whole.

course of trying to improve basic living skills in another institution in Greater Manchester we analysed the context of such skills. We found for example that there was no possibility of people learning to wipe their bottoms because there was no toilet paper in the cubicles. The reason? One person had the habit of blocking the toilets, so the residents had to request paper from the 'nursing' station, the majority of residents had such limited verbal skills that there was no possibility of them doing this, with the obvious consequences for personal hygiene.

Jim Mansell, who died earlier this year³ once challenged a group of us who were developing behavioural interventions in learning disability institutions. He recounted the conditions in a back ward in the South of England where children had nothing more than a broken Fisher-Price 'activity centre' to occupy them. The point was that without changing the overall system, replacing the institutions with systems of authentic support in ordinary community settings, our efforts would be completely irrelevant.

We've come a very long way indeed since those events in 1976, 1981 and 1982 respectively. Go out almost anywhere in Manchester today and you can see people with all degrees of intellectual disability, taking part in ordinary activities in the community, well supported by staff. Visit supported accommodation or adult placements and you'll find people proud of their homes, enjoying life. And in many cases people are far exceeding what we believed possible 30 years ago, as activists, artists, trainers and workers.

Of course there are still problems – not everything works, not everyone gets such a service, people (and their families) have to wait too long, and families carry too high a share in providing support, providing a hidden subsidy to the welfare economy. ***But the overall model is far from broken, and is easily affordable*** for a nation with one of the 10 biggest economies globally, whose rulers are proposing to spend billions on a new nuclear weapons system.

So this is a good time to go and a bad time to go. Good, because a lot has been achieved, and to defend and renew what we have perhaps requires different strengths, and bad, because there is a sense of unfinished business and a feeling of responsibility. But then maybe there never is a good time to go: none of us is indispensable.

You will need to work together in these challenging times. Inter-professional and inter-organisational rivalries have no place, and strong alliances need to be maintained, renewed and extended, with their creative tensions (the uncomfortable contradictions and disagreements), to protect and achieve what people need.

Closing remarks

I was going to make a list of people to thank, but there are just too many and I would be sure to miss someone out.

³ See <http://www.guardian.co.uk/society/2012/mar/16/jim-mansell>

Instead, you know who you are and I thank you all:

- Some have given me opportunities and had confidence in me.
- Some have shown me how to do things and taught me things I didn't know.
- Some have challenged me, and rightly so.
- Some have carried out practical tasks without which the cracks would have shown sooner and become much wider.
- And many have worked hard together with me – because that's why we are here, and you don't achieve anything by your self.

However, I would like to say a special thank you to Anna Fedeczko for organising this wonderful event and to thank you all for coming, and thank those who weren't able to come but who sent messages.