A healthy way of life

Presentation at 'Choice for Intentional Community'
Palace of Westminster, 15 September 2015

When I did my GP Training on the York and Scarborough scheme, our course had (and still has) the nice habit of visiting Botton every other year. Each of us spent the morning in one of the work places. I worked in the garden, under the instruction of a lady with Down's syndrome who taught me how to prepare and spread the compost. Her confidence and the degree of ownership of her work was one of the most moving experiences I ever made. A supposedly disabled person told me what to do and how, and I was her farmhand for the day. She has become very capable and was quite clear that things had to be done a certain way to be right, and she laughed when I got it wrong. We had a wonderful time.

I left with a deep impression of having experienced something of great dignity and meaning, which is my prevailing feeling about Botton to this day.

In the afternoon we gathered to hear and discuss what the thinking behind Botton is: to create a village community where people with and without learning disabilities live together. More than just housing and support there are three creative intentions: it's about living together, about working together and about celebrating cultural events together. This is how Camphill communities generally work, and Botton, founded in in 1955, was the first of what are now over hundred worldwide.

I counted myself very lucky when a few years later, in 2004, I had the opportunity to become a partner at Danby Surgery, the practice that has been providing NHS primary medical services to this Camphill community for decades.

It was daunting prospect to be the GP of about 120 people with a learning disability, many patients with Down's and Fragile X Syndrome, Autism or Epilepsy. My contribution to this remarkable social endeavour would be to ensure good and reliable NHS medical care, even out here in rural North Yorkshire.

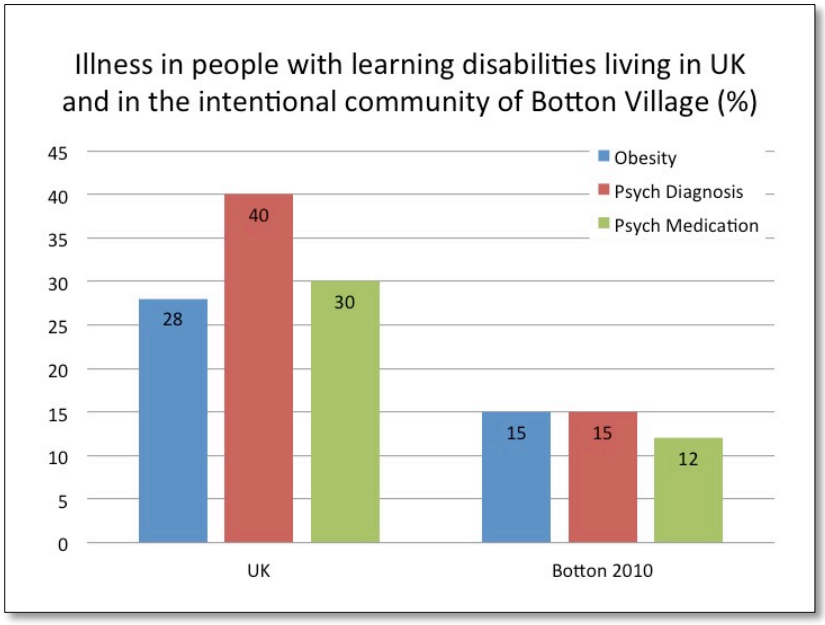
> *"It is well recognised that people with learning disabilities have poorer physical and mental health compared to others, and a lower life expectancy."*
>
> NHS England[1]

Nationally the problem was, and still is today, that people with learning disabilities in the UK not only have a disability and reduced ability to cope with the demands of life, but are also burdened with additional physical and mental illness. Amongst this group there are high levels of obesity - nearly a third according to a report by Public Health England[2].

They also have higher levels of mental illness, such as depression, anxiety and the phenomenon of challenging behaviour – 40% are diagnosed with these conditions[3]. 30% of all people with learning disabilities in the UK are being treated with psychotropic medication i.e. antipsychotics, antidepressants and sedating

medication, recently highlighted in a letter by Dr Dominic Slowie of NHS England[4]. This number may be even higher according to a study in the British Medical Journal two weeks ago[5].

We also know that statistically people with learning disabilities die 16 years earlier than the average population[1].



When I started work in Danby, the government White Paper 'Valuing people' was just launched and there was a call for people with learning disabilities to have health checks, which I began to offer on a regular basis and helped to roll out to all practices in the area. I soon realised that the mountain of illness that appears to exist elsewhere was not at all that common in Botton.

Over the years we gathered relevant data that support this impression[6]. Looking at the figures of 2010 for 110 patients on our learning disability register, we found that obesity and mental illness only affected 15%, respectively, and treatment with psychotropic medication was even lower. Access to primary care has always been excellent, including a weekly GP clinic held in Botton, as has access to the psychiatric learning disability team with nurses and a consultant visiting Botton.

In eleven years I have seen a degree of contentment and happiness and stability that I believe is unparalleled, as has been found by others[7]. I can add that the community is safe and resilient. There are also individuals with more severe autism or learning disability who enjoy life in Botton with no need for restrictive interventions or psychotropic medication. Many people in Botton live well into old age, leading an active life amongst friends. Also in the last days of their lives residents are effectively and lovingly cared for in their own community.

Discussion

We have seen important and relevant outcome data and the results are extremely positive. One could say that Botton has slashed the rate of obesity and mental illness by a half! There is nothing I could prescribe that would be even nearly as effective.

So how did they do it? Why were so relatively few people in Botton obese or have depression, anxiety or challenging behaviour?

The answer has to do with what we call the social determinants of health, which we have of course all heard about: a healthy diet, physical activity, a social network etc.

Their healthy diet is mostly derived from produce that residents have helped grow, prepare and cook, and meals contain much fresh fruit and vegetables, meat and dairy, mostly organic with plenty of fibre and nutrients. Regular mealtimes, enjoyed together and without a rush, are also social occasions.

Botton's way of life is very active rather than sedentary. Botton has always regarded itself also as a working community, with an emphasis on biodynamic farming, gardening and forestry and a connection with the land, providing for plenty of physical activity. I see many walking to work and back home. A healthy diet and physical activity are known to prevent obesity and reduce the risk of diabetes, heart attacks and strokes.

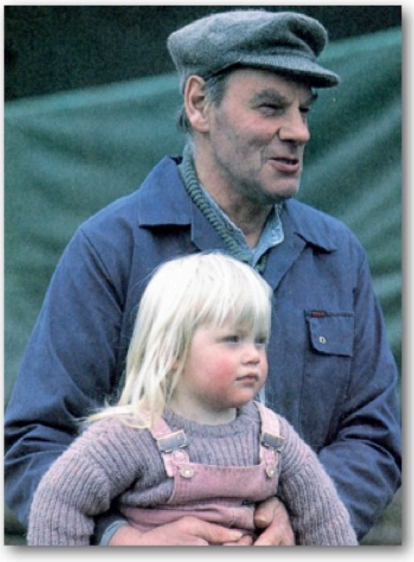
We all understand, and it has been shown, that a stable social network has a protective effect on mental health. Through living and working together people can develop a deeper understanding of the other as a fellow human being where ability or disability almost cease to matter.

Challenging behaviour, which is a common problem for people with learning disabilities and those around them, is often a way of saying: "You don't understand me!" I always find that Botton's co-workers understand the learning disabled residents they live with very well, which I believe helps to explain why challenging behaviour has not been very common.

The core principle of Camphill is their understanding of relationships as reciprocal and as continuous. When people live together they have a chance to live with children, even to see newborns joining the household; to live with the old, also in the last days of their lives, who are buried in the community with all in attendance, looking back on all their unique lives, naturally providing an experience of deep connectedness and a spiritual dimension.

Other factors contribute to good mental health, such as time spent in nature, green spaces. The calm ebb and flow of rest and activity, the routines of the day, the calendar of cultural festivals. Cycles of the day, the year, and as we have seen earlier, whole life-cycles, that progress and come round naturally, providing stability and orientation, allowing people "to blossom in a setting of predictable routine"[8].

The various elements are naturally part of and woven together to the experience of community. In this way much of the support is built-in, implicit, very effective indeed without constantly reminding the person who is the disabled party in this.



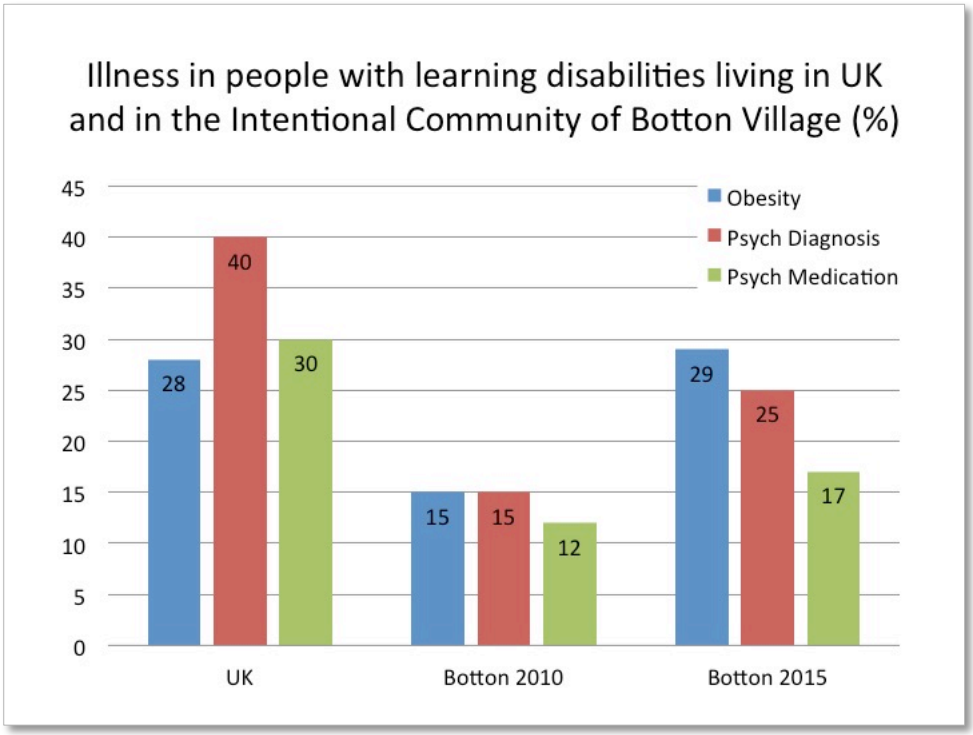
- Healthy diet
- Physical activity
- Work: pride, identity and contribution
- Relationships:
  - Reciprocal
  - Continuity
  - Young and old, birth and burial
- Routines of the day, the year, of life: stability and orientation
- Nature, green spaces
- Community

Changes

Social care has changed in recent years: the amount and mechanisms of funding, regulation, safeguarding; choice and personalisation, independence and inclusion have become the new goals. Provided they are applied sensitively, these principles have the potential to improve the lives of many.

Furthermore, some Camphill communities, including Botton, are going through additional changes. Many co-workers who had been living with the learning disabled residents in shared homes have been replaced with support workers that do not share life with them. This has unsettled the homes and communities profoundly.

When we look at the same health outcomes this year we find there has been an increase in obesity as well as anxiety, depression and challenging behaviour.



There are two things that we can learn from this:

1) When looking at the 2010 data, we now have an image of what good physical and mental health for people with learning disabilities can look like, and have an idea of an environment, a way of life that allow these to flourish.

2) The more recent data show that we can't take this success for granted.

Halving the number of people with obesity and mental illness will also produce huge cost savings to the NHS, especially in the long term due to a reduction in diabetes,

heart disease and arthritis. There will be a substantial reduction in costs for hospital admission as well as care.

In summary, there are good medical and economical reasons for embracing and supporting this way of life. There are very many people who want to live in one of these communities and they have the right, as citizens, to choose where they live, how and who with[9].

I will conclude with an anecdote that illustrates a point I would like to make. One of Botton's co-workers told me about their visit to the speak-up forum in Scarborough with a learning disabled person. When asked to register on arrival and to indicate who is a 'service-user' or 'service-provider', he asked: "Which box do I need tick?"

She asked him: "Which one do you think you are?"

He said: "I do a lot for others but they also help me a lot - I think I am both!"

This is an important issue. The language of social care creates a virtual reality, however, people with learning disabilities are not service-users.

Camphill is a way of life that builds on the simple reality that people with learning disabilities are human beings who want to live life with other human beings. Better health as we observed is only one of many positive outcomes.

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References

1. NHS England, "Improving Health Outcomes" (2015) www.england.nhs.uk/ourwork/qual-clin-lead/ld/imp-health-outcomes/

2. Public Health England (2015) "Obesity and disability – adults", http://www.noo.org.uk/uploads/doc/vid_18474_obesity_dis.pdf

3. Cooper SA, Smiley E, Morrison J, Williamson A, Allan L (2007) "Mental ill-health in adults with intellectual disabilities: prevalence and associated factors", *Br J Psychiatry* 2007;109:27-35

4. Dr Dominic Slowie (2015) "The use of medicines in people with learning disabilities", Letter of 14 July 2015, www.england.nhs.uk/2015/07/14/urgent-pledge/

5. Sheehan Rory et al. (2015) "Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study" *British Medical Journal* 351 :h4326 http://www.bmj.com/content/351/bmj.h4326

6. Values in the two Charts are in %. *UK* = UK wide studies Refs 2, 3 and 4. *Botton Village* 2010 n = 110 and 2015 n = 99. *Obesity* = BMI of 30 and over. *Psych Diagnosis* = depression, anxiety, psychosis, challenging behaviour. *Psych Medication* = antidepressants, antipsychotics, anxiolytics/sedatives.

7. Randell M and Cumella S (2009) "People with an intellectual disability living in an intentional community", *Journal of Intellectual Disability Research*, 53:8, 716–726, http://www.researchgate.net/publication/26267171_People_with_an_intellectual_disability_living_in_an_intentional_community

8. Jensen Kristin M, Bulova Peter D (2014) "Clinical review: Managing the care of adults with Down's syndrome", *British Medical Journal* 349:g5596

9. United Nations, "Convention on the Rights of Persons with Disabilities", Article 19, www.un.org/disabilities/convention/conventionfull.shtml