



Katie's story.

Katie was born in 1980 and within a matter of months was diagnosed with a rare form of epilepsy with associated learning and mobility difficulties, including a lack of verbal communication which continues to be the case to this day.

At the age of 5 she joined, with great success, a newly formed special needs class attached to the local primary school, and thereafter attended appropriate special schools in Wiltshire and Devon which allowed her to achieve her potential in her own way.

In 2010 I finally and very reluctantly accepted the long-term view that Katie, now aged 30, should live her life with people of her own age away from home, and she became a resident in a carefully selected care home where her long-term increasing needs could be met by an excellent team of carers, along with the opportunity to make new friends in a safe and stimulating environment.

At her annual review since then she has been asked whether or not she would like to continue to live there. The reply has always been yes.

Ten years later, without consultation with her, her family or carers, an announcement was made by the care providers and local authority that a decision had been taken to close the home and relocate all the residents to unknown premises within the local community. The outcome of this would have resulted in leaving what had become her familiar home, her now well established friendship group and the carers that she had grown to trust and depend upon. Consequently her right to choose would have been denied, despite her very clear indication every year that this was her choice of home. The reason for this decision was apparently that the site was seen by the CQC to be a "campus", with too many people living in the same place. Their current policy is to not register homes beyond a certain size, but equally they claim to not wish to close "legacy" sites where the residents have already lived for several years. The site in question most certainly qualifies as a legacy site, and many of the more able and understanding residents were distraught for many months in fear of losing their much loved home.

Endless letters were written, emails sent and telephone calls made to those behind this outrageous decision but all to no avail. I and other family members were ignored, with no replies to correspondence and no 'phone calls returned. Finally a number of us came together to contest this decision and a lengthy campaign was

fought and successful legal action taken, but despite this It became apparent that if the home were to be saved it would be down to the families to undertake the task as no assistance was on offer from the “authorities”.

Two years later the campaign has been successful and the home has now been saved, albeit with a new site owner, new care provider and new housing organisation.

Had the proposed closure gone ahead the residents’ right of free choice would have been totally overridden, and without the determination and sense of justice from the campaign group, Katie and her fellow residents would have been moved to unknown premises scattered across the vicinity, with the risk of becoming possible victims of loneliness, bullying, abuse and misery, without the support of all that was safe and familiar to them.

We are constantly hearing stories in the media of the increase in mental health issues amongst non Id people, and how these can lead to depression and even suicide. Someone with a learning disability who against their will is subjected to a situation such as this which they don’t understand could be at considerably greater risk. This possible consequence is obviously not taken into account.

In our case the home has thankfully been saved, but there have been amendments put in place as the model of care has been obliged to change. The residents had previously enjoyed craft and horticultural activities in the purpose built workshops and grounds on-site, as well as being able to use shared transport. However the choice to retain these has been removed as neither of them are deemed to be appropriate to the new style of living which seeks to make everyone more independent, and therefore organise alternative transport and find their own activities within the wider community. Their choice in these matters has been denied and many of them would prefer to continue to use the facilities that they have previously enjoyed at home, and not have to rely on limited public transport or expensive taxis.

Elderly non Id people within our society are given the choice and actively encouraged to live in their own larger communities, but for Id adults the situation is the reverse and this choice is denied, but one has to ask what is the difference? Why should there be a different approach to different sectors of society? I can only assume this stems from a cost perspective. Construction companies stand to benefit from the sale of “village” developments geared towards the elderly, but surely local authorities would also gain if their resources were pooled rather than spread over larger areas and multiple smaller properties, resulting in deprivation of choice for the people who matter.