



Notes from Open Meeting 23 April 2023 on Zoom

Welcome and general announcements

Mary Pearson (Chair) welcomed everyone to the meeting.

- Trustees had invited a representative from the CQC (the Care Quality Commission, which regulates and inspects health and social care providers in England) to speak at our meeting, but unfortunately they failed to provide anyone. We decided instead to have a general discussion of matters of interest to us all, beginning with a short presentation about the 'Our Life, Our Choice' campaign, plus further discussion around the Report of the Archbishops' Commission on Re-imagining Care and also around the topic of Healthy Living in Camp Hill communities.
- Please save the date for our 2023 AGM & Open Meeting, which will be held in person on Saturday 18th November, 2023 at the National Council for Voluntary Organisations (NCVO), 8 All Saints Street, King's Cross, London N1 9RL.

Mary introduced David Wilks, who represents a campaign called 'Our Life, Our Choice', defending residential choices for people with learning disabilities and/or autism.

More information on this campaign: ourlifeourchoice.co.uk

- David's personal connection to the campaign is that his brother, who had Down's syndrome, had a happy life at an intentional community 'village' called Stanley Grange. David was very active as part of a group of relatives who successfully fought the threat of community closure. They raised funds, found a new care provider, invested in the site and restarted daytime activities that had been lost.
- However, around 40 similar villages in England have been closed in recent years, as they did not align with current CQC guidelines.
- Two other communities have also been saved by family action in the last five years: Ravenswood and Furlong Close. The families involved have now joined forces with families who campaigned to save Stanley Grange. Under the auspices of Rescare, they have launched the 'Our Life, Our Choice' campaign, which aims to persuade the CQC to change their guidelines.
- The campaign argues that people with learning disabilities and/or autism should have the same choice about their care and accommodation as anyone else.
- The CQC inspected Stanley Grange in 2020; their report was full of praise in every respect about the care and quality of life provided for the residents. However, in the opening paragraph of the report, it says the community is not in line with current and modern models of care, and this style of service delivery is not the current best practice. David wrote to the CQC Chief Executive to ask how they could justify such a statement.
- He was given a list of all the government and CQC guidelines that were supposed to justify the CQC's position, plus nine academic papers that were used to form the basis of government policy in this area. On further investigation, all nine papers

referred to the context of the closure of large campus mental hospitals. Where they do reference intentional village communities, they mention them in a positive light, as an exception which provides a good service for a small minority of learning disabled adults.

- The campaign team has initiated discussions with the CQC, highlighting that – having read all their documents - there is no justification for the policy guidelines that they are giving their inspectors.
- They have so far had two meetings with CQC representatives (the most recent in February 2023); the CQC haven't yet challenged any of the documentation that the campaign team have sent them. They have promised to look again at the guidelines to see if they can tweak or amend them to address some of the concerns raised, but nothing has happened as yet. They have agreed to discuss the issue in an internal meeting and to feed back any response to the team.
- In parallel with this approach, the team have raised sufficient money to appoint a KC, to get guidance regarding potentially challenging the rulings via a judicial review. They have also employed a Campaign Officer (2.5 days a week) and got preparations underway to launch a national publicity campaign if the CQC don't amend the guidance.
- **Ways you can help:**
 - There is a national petition you can sign, on [their website](#) to show your support.
 - Please let them know if your Camphill community has had a CQC report which says the community village model isn't in line with guidelines: the more examples they can find, the better.
 - Please let them know if you know of someone who wants to live in a Camphill community but is struggling to get funding because local authorities are arguing that the community model does not follow best practice. It may be that someone might even wish for support to take their individual case to a judicial review, with legal aid funding.
 - Visit their website to view a list of all the academic papers they have gathered which support the cause. If they have missed any, please let them know.
 - If you know of someone who has, or you yourself have, a personal story which would support the cause as a featured case study, please get in touch.
 - Contact details: contact@ourlifeourchoice.co.uk / 07789416604

Discussion then moved to include those attending the meeting, with David responding to questions, and the following additional points were made:

- The CQC seems to be in opposition to the way the water is flowing, with many pointing to the benefits of intentional communities.
- Scotland still has many intentional communities which seem to be supported by Scottish authorities.
- What is Camphill Village Trust (CVT) doing to align themselves with campaigns like this? We should encourage CVT to support the campaign. It is vital we all work together.
- The Our Life, Our Choice campaign hopes to reach their goals by amicably reaching out to the CQC to point out their guidelines aren't supported by evidence. Should this fail, they are prepared to launch a political campaign, although they realise it may be a challenge to achieve national publicity to raise their profile.
- The threat to freedom of choice is so important; Camphill Families and Friends and Camphill Village Trust should work together to support the campaign.

Mary Pearson thanked David for his time and valuable contribution to our meeting.

The meeting then continued by revisiting the topic of the Archbishops' Commission Report which was published not long after Debby Ounsted, one of their commissioners, spoke at our previous Open Meeting.

You can find the [notes of that meeting here](#) on our website and [the final published report is here](#). You can also watch a recent [House of Lords debate on the future of social care here](#), which built on both the Archbishops' Report and the [report prepared by the Lords' Select Committee entitled "A gloriously ordinary life"](#).

Mary talked through some thoughts about the report, having attended its publication launch event back in January 2023:

Opportunities

- The report's general approach and the type of language used, seem to align with the traditional ethos of Camphill. There's a sense of a goal opening and perhaps this may be an opportunity. The report is seeking a renewed sense of mutuality and community, drawing on Christian values and the idea of interdependence as people live full lives, not just being recipients of care. Care is not just seen as safety-related and practical tasks.
- It recognises different options in housing, including the value of intentional communities.
- It highlights the importance of personal choice where possible, but also argues that families and advocates should not be excluded.
- It was very encouraging that the Archbishops' Commission team visited the Esk Valley Camphill community.
- The report seems to be seeking an answer to 'what is community?' and we know that many of our relatives have experienced 'community' in Camphill.

Threats

- A key problem however, is that the report does not address the money side of things. Public spending on social care is about £22billion; private spending is about £11billion, and the financial contribution from unpaid carers – often family – is £132billion. Family carers outnumber professional carers by two to one.
- Another issue may be that the report emphasises voluntary care and support, which could be dangerous as it could be used as an excuse for cuts. Already, families are doing a vast amount of the care, and they can't/shouldn't take on much more.
- The report also doesn't address the restructuring necessary to solve some of the problems being identified. It focuses on the wider concepts but doesn't go in to detail on actions needing to be taken.
- It doesn't address the link between the crises in care and the NHS.

There was then a general discussion around reactions to the report, and ideas as to how we might make the most of its publication:

- Perhaps we could help draw attention to this report by writing to our MPS, or to the director of social care in our area, or to our Camphill communities to ask them to get involved?
- We may need to consider the political angle – it may be incorrect to argue that there

isn't enough money: there could be enough money if public sector funding was increased.

- There was a suggestion that as individuals we may not carry much weight, but we would if we work together as a collective group.
- Ruskin Mill (Camphill-esque educational facility in Stroud) is a great example of a place that is working to build up evidence and codify best practices of care and community living, which could be useful and is very encouraging.
- The pre-election build up could be a good moment to try and decide on any actions related to political platforms.
- We need to stress the importance of long-term planning: each individual with learning disabilities needs the stability of a lifelong plan.
- We need to move away from the outdated idea that everybody in a local community will help each other: it is slightly naïve. For similar reasons, it is important to be clear on the impact of rhetoric around independent choice; although choice is vital, this concept can be badly applied and cause damage.
- The Care Act may be useful to use as a tool to focus attention on human rights legislation.
- We need to be able to prove the benefit of intentional communities for individuals and also to wider society.
- We should remember that intentional communities wouldn't be suitable for everyone; they make up a minor percentage of care settings overall: we are a small minority.
- We also need to consider the provision of care available for older people as their needs change – many Camphill communities don't include a clear path to provide such care.
- Camphill Families and Friends needs to be very clear on what we are trying to achieve in any action we take in regards to reacting to the report. It needs careful consideration.
- Trustees will now explore ways of working with others, e.g.: CVT, Our Life Our Choice to exploit this opportunity to press the case for the benefits of intentional communities.

The meeting then continued by revisiting the topic of healthy living and weight management

As a follow up on [our previous meeting in March](#), at which we looked at how we can support healthy living and weight management in Camphill communities, we invited a brief discussion to ask for ideas as to how to continue the progress made so far.

- Sturts Farm is an example of a Camphill community where weight management and healthy living seems to be less of a problem. Perhaps this could be held up as a model for best practice.
- The Lantern Community could also be used as a best practice example.
- Careful work needs to be done around the issue of choice. There are ways to offer a choice which still help direct people to select healthy options: "wouldn't it be nice to go out in the sun and do some harvesting instead of being stuck inside watching TV?"
- Helping to prepare food is a really important part of encouraging healthy food choices; home cooked, nutritious meals are needed, where everyone can eat together as a communal social event.
- Exercise is also important: we need to be aware that changes to work in many

- communities mean that workshops involve less outdoor exercise.
- We could consider somehow supporting a pilot study in a community, either to gain ideas about best practice or to identify areas for improvement – or both.
 - We could approach Sara Thakkar (CEO of Camphill Village Trust) to see if CVT could be involved.
 - We can draw on the findings of Dr Marcus van Dam (who spoke in [our meeting in March 2022](#)) to show the link between healthy lifestyles and the culture of traditional intentional communities.
 - Trustees aim to set up a pilot study in one or two communities and hope to work with CVT on this.

The Chair closed the meeting and thanked everyone for attending.