ARCHBISHOPS' COMMISSION ON REIMAGINING CARE

A SUBMISSION FROM CAMPHILL FAMILIES AND FRIENDS.

1. INTRODUCTION AND SUMMARY OF CONCLUSIONS/RECOMMENDATIONS

We, the Trustees of Camphill Families and Friends ("CFF"), welcome greatly the initiative by the Archbishops in setting up this commission on reimagining care. We strongly support its aim "to stimulate a national debate about the nature and purpose of care and to offer practical recommendations to national and local government, policymakers, the care sector and society as a whole, about how to deliver this vision for care". We particularly support its aim "to address wider issues that affect the status and wellbeing of people in later life and adults with disabilities or disabling conditions." Our major concern is for the learning disabled.
The report can play a vital role in halting, and ideally reversing, the trend in recent years to narrow the choice of models for living which are available to the learning disabled.
We strongly believe that:

- there is considerable evidence that significant numbers of learning disabled people are being mistreated. This needs immediate attention.
- diversity of choice of living arrangements should be strengthened and this should explicitly include intentional communities as one of the options available for the learning disabled.
- public funds should be ring fenced and allocated specifically to staff training for those caring for the learning disabled.
- Care Quality Commission's (CQC's) remit should explicitly require that body to inspect all residential accommodation used by the learning disabled.
- further research on costings and effectiveness of different models of care should be undertaken. An informed public debate is important.
- support for the learning disabled should be given a much higher profile. The lack of public response from some national charities (which we would expect to support the learning disabled) to the BBC programmes needs to be further investigated.

2. BACKGROUND ON CFF AND THE CAMPHILL MOVEMENT

It may be helpful to provide a brief note about CFF and about the Camphill Movement.

CFF is a charity dedicated to supporting families and friends of people with learning disabilities who live in Camphill Communities in the UK. This submission has been prepared and approved by Trustees of the charity. Further details of what we do can be found on our website:
www.camphillfamiliesandfriends.com

Camphill is a worldwide movement with over 100 communities in twenty countries supporting people with learning disabilities and other care needs. The Camphill movement was started in Scotland in 1940 by Karl Konig and a group of refugees, based on the insights of Rudolf Steiner and Anthroposophy. Anthroposophy looks at each person as an individual, encouraging everyone to develop their own human and spiritual potential, and this focus on individuals and their development has always been a key feature of Camphill. There are 20 adult communities in England and Wales, 9 in Scotland and 4 in Northern Ireland. Each community is different. Originally volunteers, known as co-workers, were unpaid but claimed living expenses and shared their lives with people with learning and other disabilities. Religion played a central part with a weekly Bible supper and Sunday gathering. The pattern of the year was based on the major festivals. Community members were encouraged to attend Churches if they wished. In some communities co-workers have now been replaced by paid staff. Life sharing is important, meaningful work and the contribution made by each individual is valued. Camphill communities care for the land and the environment around them, following organic and biodynamic principles in their gardens and farms, recycling and using environmentally-friendly products and services where possible.

3.THE PRESENT CARE SITUATION.

We agree with the Archbishop in "Reimagining Britain" when he refers to "the crisis in social care provision, chronic for decades..." (RB p34). The BBC has performed an important public service in exposing what is happening in our provision for learning disabled adults. There are grounds for thinking that the situation is at best not improving, if not getting worse. We note the Panorama programme in 2011 which exposed serious abuse and cruelty being perpetrated by staff at a private hospital on patients, which ultimately led to some staff being given prison sentences. It was also clear that hospital managers and the regulator, the CQC, had been informed but the complaints had been ignored.

Two BBC "File on 4" programmes (On 2nd October 2018 and 10th November 2020 - still available as podcasts) paint a horrific picture of what is happening. The programmes show significant use of seclusion for long periods of time. Patients are locked in a room containing only a bed and chair, sometimes for days and sometimes many weeks. There is large scale use of a form of restraint where patients are held face down on the floor and what is termed prone, which is against guidelines. There is little sign of improvement between the programmes. A target was set that between 35-50% of residents would be moved out of this kind of placement by March 2019. We think this target was unacceptably low. We note that it had still not been met by the November 2020 programme. One contributor to the programme said the problem was a financial one. Local Authorities (LAs) simply could not afford to cover the large costs involved in taking on patients who were previously funded by the NHS.

The File on 4 programme "No place like home – the inside story of supported living" (12th February 2019) presents a balanced picture of what happens when individuals are moved from institutional care to supported living. Individuals live, with two or three others, in converted properties and carers attend them in the day time. This is popular with LAs as government pays the cost of housing benefit which is up to one third of the cost. The programme shows an example of a successful move and two examples of where the moves went very badly wrong.

Part of the problem may be funding. It was pointed out that apart from some emergency funding, since 2010 some £7 billions had been cut from social service budgets. Some LAs assess all people's needs at the basic level, presumably because of financial constraints. Many care workers are paid at national minimum wage and some companies say the amount LAs pay them means they are unable to fund training for workers.
One of the cases which went badly wrong was of an autistic man who could communicate only by sign language. Over a five month period he had between 25 and 30 different care workers none of whom could use or understand sign language. In some instances, arrangements required places to be fully occupied in order to be financially viable and this resulted in people with incompatible needs being placed in the same accommodation. The other case that went badly wrong involved a learning disabled person being placed with another resident who had serious mental problems. On a visit parents had to call the police as the situation was totally unsafe because of the violence of the other resident.

We believe that even accepting the caveat that numbers of unexplained deaths and serious injuries can partly be explained by the rising numbers in supported living, the figures show how badly the system is working. Between 2011 and 2018 there were 2041 unexpected deaths: a rise of over 40%. In the same period there were 3,700 serious injuries: a rise of 279%. We are also concerned about the report of inspection procedures. Whilst registered care homes can be inspected, where residents hold tenancies there is no such right. Some carers say that in a period of 8 or 9 years they have never been inspected. An independent commentator estimated that between 60% and 70% failed to achieve the REACH standards expected, with 20 – 30% good.

In the light of this programme CFF was surprised to see little if any press coverage. Nor did it see any statements or action by charities who are supposed to be the supporters of the learning disabled.

4. RESPONSES TO CQC CONSULTATIONS

CFF has responded to consultations on "Registering the Right Support" and "Building the Right Support." We agree with the statement on page 3 of the first of these documents that "long term institutional care is not a successful approach to supporting people with learning disabilities". We were however concerned that the implicit model shown in the document "Building the Right Support" for successful

applications tends to be a small unit such as “a converted house in an ordinary street”. We see little evidence of other options. We note the Department of Health's 2012 document “Transforming Care” states “the norm should always be that children, young people and adults live in their own homes with the support they need for independent living.....Best practice is for children, young people and adults to live in small local community based settings” (Registering the Right Support p.4) On the same page Registering the Right Support states “We are seeking to work with providers to follow best practice, in order to underpin principles of choice, promote independence for all people with a learning disability”. The same document states “We do not wish to be overtly prescriptive and it is not our intention to create a one size fits all approach”. Some evidence suggests that what is considered to be best practice is applied prescriptively and overrides the principle of choice.

We can give two examples of this:

1. The case of AH Hertfordshire Partnership NHS Foundation Trust & Ealing PCT (2011). In this case a learning disabled adult had lived since 2001 in home farm type community setting provided by the Special Residential Service. The LA were proposing moving him to a supported living placement for the “advantages” it would supposedly provide for him. The judge ruled that supported living in Ealing did not hold benefits for him, and that “facing up to these realities does not in any way diminish or demean him” but values and respects who he is. The judgement also states: “This case illustrates the obvious point that guideline policies cannot be treated as universal solutions, nor should initiatives designed to personalise care and promote choice be applied to the opposite effect”.
2. One manager of a Camphill community has reported that a CQC inspector said that the community could not achieve outstanding because of a tribunal case, Centurion Health Care Limited v CQC (2018) 3264EA. Whilst we have difficulty seeing how this specific case could lead to such a conclusion, it is interesting to note the tribunal allowed the Centurion building development proposed and commented “They (CQC) have fallen into the very trap their own guidance warns against”. It then cites the reference given above regarding overprescription and adopting a one size fits all approach.

One of the areas that concerns us is that Camphill communities, and all intentional communities, may be thought not to conform to definitions given in “Registering the Right Support” (2017). The guidance offered says that new services should not be developed as part of a campus style development. It defines campuses and congregate settings as follows:
“Campuses: group homes clustered together or on the same site sharing staff and some facilities. Staff are available 24 hours a day”.
“Congregate settings are separate from communities and without access to the options, choices, dignity and independence that most people take for granted in their lives”.

It is possible that some Camphill communities might be considered to be campuses and this might rule out the development of new communities.
We will argue below that this fails to recognize the tremendous benefits of life in Camphill Communities and why they are chosen by many families.

5. POSSIBLE FUTURE DEVELOPMENTS

It is not our place, as non-specialists, to engage in academic discussion on developments. A number of our members have been impressed by the work of Robin Jackson of the Centre for Welfare Reform. We would like to bring a number of issues to your attention raised by him in two papers "Who Cares" ("WC" 2015) and "Back to Bedlam" ("BTB" 2017):

- Jackson notes "Shakespeare has highlighted the fact that, in the UK, the social model of disability has been largely developed and promoted by a group of men and women from academia who themselves have a mobility impairment - not an intellectual disability" (Shakespeare 2005). Thus "extending their analysis to other groups, such as people with an intellectual disability or mental health problems, is not a straightforward approach" (WC p18). What is the evidence base for the adoption of this model for the learning disabled? Jackson states that "the policy of promoting inclusion is an unsophisticated policy which takes little account of the profound differences within the population" (WC p11).
- "The fact that charities are financially dependent on public funds may deter them from departing from stated government policies (e.g. inclusion)" (WC p26). "Ways in which successive governments have succeeded in muzzling the voice of the larger national charities are identified" (Summary BTB). The same document calls on the charities to be "more assertive in challenging government policy" where it disadvantages people with a learning disability. Does this explain the lack of reaction by the charities to the BBC programme "No Place like Home"?
- It is sometimes claimed that the group of people with a learning disability is too small to warrant government attention. There are very frequent changes of Ministers for Disability. Jackson notes the "low status" of the government department and (in 2015) "over the last seven years there had been no fewer than six Ministers of Disability" (WC p11).
- Cuts to the service have been severe. Simon Duffy, in the introduction to "Who Cares", gives a figure of 30% between 2009 and 2015. The situation now may well be worse.
- "CQC a failed enterprise" is a Section Heading in "Back to Bedlam". In "Who Cares" Jackson states "The prediction by Dame Platt that the CQC would prove an ineffective social care regulator has been clearly demonstrated not least by the growing number of cases of abuse and maltreatment in a variety of health and care settings and by the highly scathing judgements of CQC made by a succession of Parliamentary Select Committees" (WC p31). Dame Denise Platt is a former Chair of Social Care Inspection.

• Jackson argues that "There is a strong case for broadening and not restricting the range of day and residential options for people with a learning disability" (BTB p 67). He states "What is being argued is that a range of options should be made available, so that a person with a learning disability is offered a genuine choice – a right to which s/he is morally and legally entitled". (BTB p67). It is not an expensive option. Jackson states that "it has been estimated that the cost for adults with disabilities in intentional communities is between one-half and one-sixth the cost of state-funded or other private options (Larson et al, 2010)." (BTB p69). We do not have up to date figures to verify if this is still the case.

6. THE VIEW OF CAMPHILL FAMILIES AND FRIENDS

Our members are very strongly supportive of the Camphill Movement. Most of us spent considerable time on visiting various Camphill communities, as each is different, and other options with our learning disabled family member. The choice was an informed one. We paid particular attention to the feelings of the family member about which place s/he would like to live in. Some communities in rural settings, giving opportunity for work such as farming and caring for animals, met what was wanted. For others, communities set in towns fitted the bill. What particularly impressed families was much more than the six points discussed by Jackson in "Back to Bedlam" p67-69) – Mutuality, Rhythmicity, Well-being, Tranquillity, Ecological sensitivity and Economic sustainability – although these were very important. Families liked the family atmosphere in the traditional communities and the life sharing with the families of co-workers. We saw the continuation of the love our family member experienced at home. The work opportunities offered are meaningful and provide dignity and self worth. We know how happy our family members are. Experienced social workers are pleased with what they see at annual reviews. For many residents and their families the spiritual dimension of life is very important. A number of us have attended the Sunday morning gathering and shared meals which are so important in setting the tone and atmosphere of the community. Life has a pattern as communities work towards the major Christian festivals. The life experience of community members did generate "a non economically based sense of human value and dignity" (RB p49).

We agree with the Archbishop that "The values of solidarity and the common good are expressed not simply by funding..... but also by practices that reduce isolation" (RB p127). Camphill residents are not isolated. They have a rich social life. They are involved in a range of activities and in the wider community. We have a number of examples of how supportive local churches have been.

Much emphasis is placed in regulations on local provision. Families would argue that what they want is the right and appropriate provision and this is more important than locality. Families are prepared to travel to visit their family member. Some families may also move when they are able to do so, to be close to their family member in a

Camphill community.

We have heard, in past years, a small number of complaints about Camphill communities on individual issues. More recently, in communities which have moved to paid staff, we now hear a significant number of reports concerning the higher turnover of staff or managers. Undoubtedly this is linked to the great responsibilities upon staff and remuneration which may be close to the minimum wage. We have heard a very large number of complaints from families about some recent changes which some managers claim must be made to satisfy CQC. Camphill was chosen by the learning disabled person and their family because it offered a different, and in many ways an extraordinary, life and what made it special is being removed. The effect of these changes is to negate this choice.

There is evidence to show that Camphill communities have been very successful. An example of this is provided by Camphill Scotland Research Paper 1 (2012). A study of inspection grades awarded by CQC for Scottish communities, Local Authority provision and private providers clearly placed Camphill communities in first place. Private providers came third.

A number of us attended a session provided by the senior GP in Danby which serves Botton Village Camphill Community. He showed the evidence to prove that residents at Botton Village had far better health outcomes than average for people with LD in society at large.

We agree with the Archbishop that the "crisis in care.....has cast doubt on our self-image as a caring society" (RB p35). The evidence we have presented from the BBC should make us all reflect on the society we are becoming. We also accept the Archbishop's criticism of "postmodern and radical individual autonomy" (RB p287). It may be, as Jackson claims, that "At the heart of disability politics there has been an emphasis on individualism that opposes collective welfare provision" (WC p17) . We agree with the Archbishop's support for the voluntary sector, "participation in the sort of institutions that build social capital and provide rich soil for the development of virtues, values and practices" (RB p287). We believe Camphill to be such an institution.

7. CONCLUDING REMARKS

We hope that the commission will consider the following suggestions:

- The evidence of mistreatment, unexplained deaths and serious injuries of learning disabled people given by the BBC warrants immediate attention. Figures like those provided by the BBC should be published annually.
- The range of options for provision should be broadened for learning disabled people. It should be made clear that living in intentional communities is an option to

those who choose it. Prescription is not acceptable. A clear statement of values and rights should reflect this.

- Provision of public funds should be adequate to ensure staff are properly paid and a proper service is provided. We were particularly concerned to note the claim there was insufficient funding to provide training. Lack of staff training may be the cause of some of the bad practice exposed in the BBC programmes.
- The role and brief of CQC needs to be re-examined in the light of criticism given above. CQC must be able to inspect all accommodation lived in by learning disabled people and not just base reports on records and paperwork.
- Further research on costs and effectiveness of different types of support is needed. Has this large scale privatisation worked? An informed public debate is essential.
- Support for the learning disabled should be given a much higher profile. The lack of response from some national charities (which we would expect to support the learning disabled) to the BBC programmes needs to be further investigated.

On behalf of our members we would be keen to contribute further to the thinking of the commission if that were thought helpful.