

SUBMISSION TO THE SELECT COMMITTEE ON SOCIAL CARE
August 2016.

CAMPHILL FAMILIES AND FRIENDS is a registered charity with 330 members. We support people with learning disabilities and their families. Many learning disabled people have chosen to live in Camphill intentional life-sharing communities because they offer a more holistic way of living, with meaningful work, social interaction, a shared home and spiritual awareness.

We write from a family perspective and reflect our members' experience and views.

Whilst families such as our members may not be actively providing year-round care – our relatives make their homes for most of the year in communities usually at a distance from us, as the fulfilling life they find there is not available locally – we need to continue to be involved in decisions around their care. We have a vital role in their lives, a life-long responsibility, and an unrivalled view of their whole history. Our families offer all kinds of support to their relatives, including often managing their finances, and challenging local authorities' decisions; and we offer much emotional support. Crucially, when difficulties arise or placements fail it is families who are left to pick up the pieces.

SUMMARY:

- Where families have the person's best interests at heart, they need to be fully involved in assessments and decisions. They are often their relative's most long-standing and best advocate.
- Wellbeing (see Care Act 2014) is an excellent concept, implying a rounded life with purpose and authentic relationships. The current system doesn't always work to promote wellbeing.
- Funding is insufficient, and focuses on limited, definable "outcomes", rather than a totality of experience, encompassing a real home, work, relationships and an investment in the lives of others as well as oneself.

- The “one size fits all” mentality in social care narrows options, and limits real choice.
- In the wake of the Winterbourne View scandal, living far from family is seen as undesirable in itself. But “local” doesn’t always mean “best” or most appropriate, as we know from our own lives.
- Sometimes it is necessary to relocate in order to find the best way of life for oneself. Funding should always be portable across local authority boundaries.
- There is an over-emphasis on risk and safeguarding, which can create a sterile and disagreeable environment in which to live and work, for both residents and support staff. This is not to minimise the importance of thorough risk assessments and evaluation of individual needs.
- We need to raise the status of people who work in care, and pay them properly. They carry the greatest responsibility.
- The eligibility level for funding is set so high that many who need it are left with little or no support. Long term this is costly to society in both human and financial terms.
- The success of life-sharing communities can be seen in Scotland: Camphill communities are awarded high gradings in all aspects by the Scottish Care Inspectorate, and recognised by the Scottish Parliament.
- The Better Care Fund and other such initiatives cost money which comes from people’s budgets; and they often re-invent the wheel.

1. CAMPHILL COMMUNITIES and “CARE AND SUPPORT” TODAY

1. Our relatives chose Camphill communities, usually with their families’ support, for very specific reasons. Camphill used to offer a **holistic therapeutic environment**, embracing work, home life, and a social and cultural life, sometimes known as Camphill Shared Living and Shared Working. The communities

were built around the understanding that **behind the disability stood a whole person**, who needed a certain context in which to flourish and find their path in life.

2. **Camphill were innovators.** At the heart of communities was meaningful, real work. Camphill products were much in demand and the focus was on care for the land and the environment, with sustainable bio-dynamic farming, and recycling, long before it was fashionable.
3. **Sharing of daily life and work, including shared meals,** between the people with a learning disability and those supporting them, gave the sense of a common endeavour and much **valuable “invisible” support.**
4. **The current “Care” environment seems to be making this kind of common endeavour increasingly difficult,** if not impossible, to the detriment of the quality of life of the learning disabled people living there.
5. Funding cuts have reduced “Care and Support” to “What is the minimum we can fund this person?” Families have been told by local authorities that **they only need to fund so that their relatives are “housed, fed, warm and safe”.**
6. In Camphill, and elsewhere, being supported to have **meaningful work** has always been recognised as important for wellbeing (see: Valuing People), giving people pride in their role – “I am a farmer”; “I am a potter” – and confidence through achievement. Funding cuts are putting that aspiration out of reach.
7. Communities used to provide the local area with organic vegetable boxes. Now the farms are closing and land is being sold. Why not put some money up front and offer business advice to small communities – perhaps to open a bakery or café offering real opportunities for work?
8. There is a **fear of real relationship building between paid carers and the people being supported,** which used to be a key element of Camphill communities. Shared meals and a

shared life are increasingly being edited out by soul-destroying bureaucracy, and life is the poorer for it.

9. **Risk and safeguarding have taken centre stage**, and this seems to put the disability, rather than the person, front and centre. It can lead to a narrowing of possibilities and particularly of social relationships. You can no longer go to a carer's house for a barbecue; carers shouldn't give people presents, and vice versa.
10. **"Care" has come to be seen as practical: "helping" people to do something**, often with a finite aim – making lunch, taking the bus. Bite-sized, definable "outcomes".
11. But **a good life is about a totality of experience:** relationships, feeling needed and having a purpose. It is about the contribution we make to the lives of others. People with a learning disability are no different. In Camphill, no matter how severe their disability, people were valued, had real roles, and were supported to fulfil them to the best of their ability.
12. Families are told their relatives need to be "independent". Who is making this judgement, and what does it really mean? None of us is independent of one another.
13. The aim of the support now offered appears to be towards doing the maximum independently, and **living "an ordinary life" alone** is seen as the greatest achievement. The risk to people with a learning disability living alone – depression, loneliness and turning in on themselves – is often unrecognised. As we know from the many incidents of "mate" and "hate" crime, isolated and vulnerable people are often seen as prey for financial or sexual gain.
14. Independence outside of a community such as Camphill can actually mean becoming more dependent, with more reliance on staff and the demands of their rotas. Life shrinks accordingly.
15. Camphill offered something else – an **interdependence** where people shared life and cared for each other. This brings

wellbeing and gives our relatives confidence to be more independent.

2. FUNDING and COMMISSIONING PRACTICES; UNMET NEED

1. **Local authority funding cuts** are having a damaging effect on the lives of people with learning disabilities. The burden of “austerity” is falling on those least able to withstand it.
2. The funding is not sufficient and seldom used creatively. The effect of the cuts – a shrinking of possibilities for people with learning disabilities – is **exacerbated by over-regulation and uniformity of provision**.
3. For instance, what does CM2000 (Care management 2000) telephone monitoring of the workforce, and similar strategies, cost?
4. Providers are rightly obliged to pay their staff the national living wage – little enough – but **no additional funding is given** to cover the increase. They have to fund it out of the shrinking care and support packages of the residents.
5. **Unmet need** is a serious problem in learning disability services. As the eligibility level for funded support by the local authority is set ever higher many people, in need of support yet not meeting the criteria of “critical”, receive little or nothing. They exist “under the radar” until a tragedy occurs, or they are signposted to free voluntary organisations who have also had their funding cut.
6. The problem is compounded by the **poor quality or non-existence of many assessments**. These are inclined to be mechanistic, tick-boxing exercises by people without knowledge of the person being assessed. There are now very few professionally trained and experienced social workers who, in the past, would have had a care for the whole person and a knowledge of their history. They had a case-load. These no longer exist.

7. **Funding decisions are now made by a panel of managers, who have never met the person** and whose brief is to cut local authority costs by reducing funding. In many cases social workers are not allowed to present to those panels and talk about their clients.
8. People with learning disabilities frequently have complex conditions, and are emotionally very vulnerable. **They can present as competent and confident, which belies their real needs.** They need familiar people, the certainty of what will happen next, a rhythm and a purpose to life, the warmth of a real home, all of which they often find impossible to create for themselves. Take away the invisible web of support and relationships that used to exist in Camphill communities and others like them, and people often regress and begin to exhibit challenging behaviour.
9. Theoretically, upon an assessment taking place, **an authority should identify and record unmet need.** This is often not done and presumably there is no method of knowing the extent of it.
10. Learning disabled people who are not well supported can easily succumb to loneliness, apathy and loss of confidence. Health issues, particularly obesity and depression, are rife.
11. There is a wider impact on society, with financial implications. Family breakdown, poverty, health problems, the effect on siblings, hate crime, about a third of the prison population – are **the result when people who need it are left without support.**
12. **Families should always be involved** in the assessment/review process from the beginning. They need to understand the funding that is attached, and have clarity around what can be funded and what cannot. Their life-long knowledge of their relatives in the round is vital to the process.

3. SOCIAL CARE: INNOVATION?

1. You ask about **“Innovative approaches to the design and delivery of adult social care, for example the use of “digital technology.” These terms say it all.** People with learning disabilities need love, human warmth, a sense that they matter to other people, and that they have something to give to others.
2. For example, with Tools for Self-Reliance, garden implements are repaired and sent to Africa, because “there are people who have less than I have”. People used to go out into their local community and support projects, such as gardening workshops for the elderly.
3. **In Camphill communities people were never passive recipients of care “delivered” to them.**
4. Digital technology should not be a replacement for human contact, but a tool alongside well-trained empathic workers. In Camphill in each house there used to be people sleeping in through the night. Now residents have a button to press or a pad to tread on. This can work well – until suddenly it doesn’t.
5. **Technology should be an addition to good human care, not a replacement for it.**

4. REAL INNOVATION would be giving up the “one size fits all” mindset of social care.

1. In spite of the jargon around “personalisation”, the **menu of choices offered is becoming narrower.** Communities such as L’Arche, Home Farm Trust and Camphill – all with a distinctive flavour, a particular way of life, which people chose for a reason – have been watered down to meet a standardised set of expectations set by regulating and funding authorities.
2. **Why must care be constantly and minutely monitored?** Some people do need careful and detailed monitoring. Our relatives and many others like them need a benevolent environment in which to share a real life that they are building;

not “receiving care” in the rigid and increasingly risk-averse way demanded by local authorities.

5. THE PEOPLE WHO WORK IN CARE

1. The people who work daily with learning disabled people and have a real impact, for good or ill, on the quality of their lives are very poorly paid, often on zero hours contracts, unvalued by society – and frequently by their employers – and are, it seems, often without proper professional training.
2. **It is usually the care worker who carries the responsibility** for the burdensome and endlessly repetitive paper work, and who can be easily dispensed with when a mistake is made or things go wrong. **There is always more money to be found for CEO’s, managers and administrators.**
3. In some Camphill communities now we see a constant turn-over of staff, which is not surprising. The use of **agency workers to fill the gaps** is extremely expensive and disturbing for our relatives. They dislike being regularly confronted with new support workers who don’t know them or understand their needs.
4. **Increasing layers of bureaucracy, more paperwork, and more micro-management** do not improve the quality of the lives of learning disabled people. They create a sterile and disagreeable environment in which to live and work.
5. **When people are allowed real relationships**, responsibility for each other comes naturally. Those going into the care profession are often not academic, but want to bring something valuable to the lives of disabled people. The pressure of clocking on and off shifts, time wasted on mind-numbing form-filling, and the constant fear of reprisals takes away from creative work with the people.
6. **It is becoming a job that no-one wants.** Support workers who have initially come with motivation and a desire to improve people’s lives frequently tell us: “there’s a lot of pressure and for the money I’d sooner work in Tesco”.

7. In Camphill everyone used to have a responsibility for the community as a whole. The possibility of **flexible input which came from goodwill is going.**
8. **What kind of care would we like if we were vulnerable?**
Would we like someone clocking on and off, and “handing over” at the end of a shift, no matter what might be happening in our life at that moment, as though we were in hospital? These are supposed to be people’s homes in which they have tenancies.
9. People should be able to pool their budgets, choose staff and decide how they would like them to operate.
10. **We need to raise the status of care workers, rediscover trust and allow people to take responsibility and use their common sense.**

6. THE BETTER CARE FUND AND SIMILAR INITIATIVES

1. We are understandably cynical about the Better Care Fund, when we look back at “Care in the Community” and “Supported Living”. Both initiatives promised better care and more funding but within a fairly short time the funding for both was cut dramatically.
2. An example of how the Better Care Fund is apparently “improving people’s lives” is “information sharing where appropriate”. **This should have been best practice anyway.**
3. What will the new team of “Better Care Managers” cost the public purse? If they are “highly experienced managers”, why aren’t they themselves managing better services, which would obviate the need for this role?
4. The “Better Care Exchange” is being promoted as an on-line community workspace and learning hub. Care workers tell us that they have insufficient time as it is to complete their basic paper work in order to allow them to do their jobs properly and spend quality time with people, let alone take part in a “vital virtual networking tool”.

5. When families and care workers look at the plethora of “tools, data collection, performance indicators, operating guidance, better care managers” they wonder **what has happened to common sense**, and why people’s lives really aren’t “better” – while at the same time there is **less and less money available to be spent on their relatives’ actual lives**. Money is being wasted on what one parent described as: “aspirational soundbites”.

7. FUNDING SHOULD ALWAYS BE PORTABLE ACROSS LOCAL AUTHORITY BOUNDARIES

1. The local area doesn’t always offer what a person needs. For instance Camphill communities are not available in every authority, so if this way of life is what a person chooses they will need to relocate.
2. Whilst the Care Act has improved portability of funding for some people, for those without capacity there continues to be a lack of clarity about who is responsible for funding the placement when a person moves to a different local authority.
3. This potentially gives rise to lengthy, distressing and financially wasteful disputes between the originating and the receiving authorities as to which one will pick up that person’s funding.
4. If people with a learning disability are to enjoy the same human right to move home as the rest of us, **all personal budgets should be genuinely portable across local authority boundaries**.
5. We hear anecdotally of providers refusing people from “out of county” for fear of upsetting their local authority who would have to fund them.

8. ACCOUNTABILITY

1. Existing legislation and guidance already cover many aspects of care, including the rights and responsibilities of all parties. How are these enforced?
2. When breaches of, for instance, the Care Act or the Mental Capacity Act occur, by the provider or the local authority, where do people go for redress? Short of legal action there is nowhere to go.

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