

# Camphill Families and Friends

## Response to the Call for Evidence on the Future Funding of Care and Support.

January 2011

### Who we are

Camphill Families and Friends is a registered charity, mostly comprising the parents and siblings of people who live in Camphill communities. Camphill communities are noted for the enthusiasm and support that they elicit from families.

Camphill, a world-wide movement, runs over twenty life-sharing intentional communities in England and Wales, supporting approximately 800 people with learning disabilities. There are many types of community, large and small, urban and rural, all putting into practice the idealistic educational and social principles of Rudolf Steiner. Vulnerable people live on equal terms with non-disabled co-workers, who devote their lives to achieving the full potential of all community members through the community life, work and personal development. All communities are work-centred, based on farms, gardens, a variety of workshops, cafes and shops, with life-sharing at their heart. Many have built up strong connections with their local community and are well integrated.

Camphill is known for its very high standards of care and for the meaningful, well-rounded life enjoyed by its beneficiaries both within the community and in the wider world.

Accompanying this submission is a short film from Camphill, to be delivered separately. It will show better than words how well these communities work, greatly magnifying the value of paid support hours, because people live together and help each other. Costs can therefore be kept down.

### Our particular interest in responding to your consultation

We write from the particular viewpoint of people with learning disabilities and their carers. As such we face serious funding issues throughout the lives of those for whom we care and throughout most of our own lives. We confine our remarks to those issues which affect our own concerns. Your paper mentions the desirability of consulting specific demographic groups. Families bear the brunt of the burden of care and most certainly should be consulted.

## General factors

- It is truly heartening to note (p5) that you are not ruling out any funding model options. We think that this is a very important line to take, even if it means changing some inadequate features of existing models of local funding.
- Regarding assessment (p21 2<sup>nd</sup> bullet point) we are of the firm opinion that the Law Commission's current clarification should remain the baseline and no future initiative regarding assessment should supplant the primacy of the Law Commission's work.
- Regarding researched evidence (p21), in a Government commissioned study by Professor Emerson, intentional communities emerged as an essential and valued option in the range of acceptable accommodation.

## Responses to questions

### *Question 1.*

*Do you agree with the Commission's description of the main opportunities and challenges facing the future funding of care and support?*

Yes. We would like to highlight particularly the following points:

### Changing care needs

We agree that the demand for informal care by families will be greater than the supply. As the burden on family carers grows, and carers' expectations rise, the package of support should likewise increase.

### Changing social and technological trends

If anything, there is an upward trend in loneliness and depression in society in general. Computers, electronic alarms etc bring the danger of further isolation, in particular to those with learning disabilities, many of whom need constant care and support. No electronic technology can take the place of a human presence with its warmth, companionship and understanding.

While our relatives who live in intentional communities do not suffer loneliness, we are only too aware of the suffering of others in less fortunate circumstances. This is not always recognised by professionals and officials.

## Question 2

*Do you agree with the Commission's description of the strengths of the current funding system and its potential shortcomings? Do you think there are any gaps?*

### Strengths

#### 1. Safety net

Any system must provide a safety net and this is particularly important for people with learning disabilities. It should be recognised that families and informal carers also provide an even bigger safety net in this case. Their commitment is life-long.

#### 2. Personalisation

Reforms should support personal budgets but should also safeguard those for whom personal budgets are not relevant, desirable or applicable. We would strongly support the concept of **pooling personal budgets**, with the consent of individuals, in certain situations, e.g. intentional communities and other forms of shared lives. This would have financial advantages as well as increasing responsibility and human contact.

#### 3. Prevention

We agree with preventative action.

#### 4. Partnership

This is particularly important in the learning disability world where families in effect often perform the role of protecting the interests of their relatives who usually cannot do so for themselves. The role of families is not always recognised by local authorities.

#### 5. Responsiveness to local needs

We all know that the needs of learning disabled people are fairly universal. Therefore the current system - whereby local authorities determine eligibility levels, below which needs are not met, according to their own financial and other considerations - inevitably creates unfairness. **Responsiveness should be to individual, rather than local needs**

### Shortcomings

#### 1. Loss of income and assets

This applies mostly to elderly people.

## 2. Unmet need

This is a massive problem in learning disability, as it presumably is in other demographic groups. 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 counting up the total.

Unmet need is a true tragedy. Anything identified as falling below the level of eligible need within the Government's eligibility criteria is unmet. The local authority sets the eligibility level, which tends to be set high, often only funding critical and substantial needs, and leaving unmet the moderate and low categories of need. This leaves many people's real needs unfunded and much human suffering results.

There is also 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.

This problem is compounded by the poor quality or non-existence of many assessments, the serious lack of information and the inability of carers to put forward their relatives' requirements.

The effect, as you recognise, is an extra burden placed upon already overburdened carers.

## 3. Value for money

We appreciate that further research is needed on this aspect. Local authorities around the country agree and are often surprised that Camphill communities are excellent value for money.

## 4. The low awareness and complexity of the current system

We thoroughly agree with your analysis of several of the current system's problems. While authorities are supposed to provide full information about how the system works and what it provides, this is not often done, leaving individuals and their families ignorant and disempowered.

Information is needed on a major scale to empower people. As many aspects of the system are not variable between authorities, there is a case for a central body to produce the information that people truly want and need.

The questionnaire mentions as an example of complexity the need for further assessments and funding changes when people move to different authorities. We address this in the Gap section below.

## 5. Unfairness of the system

We agree that the system is unfair on the various grounds you identified, particularly the postcode lottery. In addition we would highlight the following, which often prevent individuals from reaching their true potential and achieving the forms of care and support that they choose and need:

- individuals' and families' lack of information
- the negative attitudes of individual social workers towards certain acceptable forms of care and support, in our case intentional communities.

### *Do you think there are any gaps?*

Yes. Your questionnaire twice raises the matter of the new arrangements that come into being when people wish to move from one authority to another. This raises the twin matters of the **portability of assessment and of funding.**

The matter of the portability of assessment is, as you recognise, outside your brief and is currently within the brief of the Law Commission. Portability of assessment would be really desirable but it would not guarantee that portability of funding would follow. **Funding should follow the individual** and we are sure that all parts of Government would wish to guarantee this as a human right.

This is of particular importance to Camphill Families and Friends. Camphill intentional communities are not to be found in every locality and therefore require people to relocate. In 2009 the regulations for Ordinary Residence were clarified by the Government and are having a very adverse effect. While people with learning disabilities have the right to move from one authority to another, the responsibility for fresh re-assessment, care planning and – of course - funding is then transferred to the receiving authority with no commitment to replicate the original assessment and funding.

Funding unfortunately does not follow the individual. Authorities with residents seeking to move away are often pleased to place them elsewhere, e.g. in an intentional community, because they gain financially by the transfer. Individual receiving authorities, however, do not always accept people who relocate and this causes real anxiety and suffering for them and their families. Disputes between authorities are also very expensive and waste money which would be better spent on support of a kind chosen by the person concerned.

We would request the Commission to look into ways of ensuring that funding becomes portable across local authority boundaries. Clearly some **centralised system of funding** is required. In addition this would prevent the use of money intended for the learning disabled, which is no longer ring-fenced, being spent on other local needs.

### *Question 3*

*Given the problem we have articulated what are your suggestions about how the funding system should be reformed? How would these suggestions perform against our criteria that any system should be sustainable and resilient, fair, offer value for money, be easy to use and understand and offer choice.*

## Suggested changes

To summarise, we would ask you to consider particularly the following:

- We urge the Commission to find a means of achieving **portability of funding** as well as portability of assessment. Both are essential to allow people with learning disabilities the human right to live in whichever authority they wish in the same way that everyone else does. Clearly some **centralised system of funding** is needed. This would obviate much of the unfairness, particularly the postcode lottery, to which you refer and which is endemic in the current system; and it would stop wasteful disputes between authorities.
- To exempt some people from personalised budgets if these are not suitable or desirable and to **enable personalised budgets to be pooled**, with individuals' agreement, in certain life-sharing situations.
- To establish a system to **collect information about unmet need**. It is essential knowledge for Government to make acceptable provision for all demographic groups.
- We feel that it is absolutely crucial to provide individuals and carers with **full and comprehensive information from a central source**.