

The same as you? 2000-2012 Consultation Report
Response from Camphill Scotland
September 2012



Scotland is home to 12 Camphill communities, supporting over 400 people with learning disabilities from the early years through to older age. Support is provided within intentional communities, where people who need support live and work alongside co-workers. People can choose to come and share life with others by living in the communities, or by working in the community for part of the week. Communities vary in size from supporting eight to 80 people, and can be found in rural and in urban settings; some are registered as care homes and some provide housing support/supported living.

Support in Camphill communities is increasingly popular with individuals, families and commissioners; almost all communities currently have a waiting list for places, and several communities are developing new living accommodation and facilities to try to meet rising demand. Recent research found that Camphill communities scored more highly than (a sample of) other voluntary organisations on the Care Inspectorate inspection areas of Quality of Environment, Quality of Staffing, and Quality of Leadership and Management¹.

We are very pleased to have the opportunity to contribute our thoughts and experiences to the consultation on The Same As You. We are very keen to raise the profile of our way of working with individuals who need support, and believe that this approach, which can at times be overlooked, dismissed or misunderstood, has a lot to offer in supporting people with learning disabilities now and in the future. We would be delighted to support future work in this area, including the new national learning disability strategy group.

In summary, our response to the consultation raises the following issues:

- We would like to see any future strategy for improving support to people with learning disabilities take account of financial constraints and be clear about who is responsible for developments.
- We believe that a range of support must be maintained, so that people can exercise meaningful choice and control over the type of support that is most appropriate for them. We think there is a danger in favouring some types of services over others, and that each support service should be considered on its merits for the individual, not on the basis of a label or registration category.
- We believe that this choice should also extend to schooling, where more residential school opportunities should be available to those for whom this would be most appropriate.
- We highlight the need for effective transitions planning throughout the life course, and note that for post-school transitions planning to be effective there must be a range of suitable opportunities which young people, particularly with complex needs, can access.
- We believe that everyone should have the opportunity to work, and that whether or not this work is paid is less important than the contribution that a person can make through work and the impact that this can have on his or her self-confidence.

¹<http://www.camphillscotland.org.uk/media/2153/QGratings%20professionals%20digital.pdf>

- We believe that there is still a need for support which people can access during the day, and that for some people this will involve going to a particular location. We believe that the label of day services can lead to unhelpful misconceptions.
- We support the call for investment in short breaks.
- We believe that planning is crucial to good care and support, and highlight some issues which we have faced in working with statutory authorities on this.
- We endorse the idea of involving support providers more in people's healthcare and raise some issues which this might throw up. We identify other suggestions for improving individuals' experiences of health care.
- We support the recommendations around older people and dementia, and highlight a need for more support around palliative care for people with learning disabilities.
- We raise some of the challenges that living in a rural setting can present to people with learning disabilities.

The need for pragmatism

We would like to foreground our comments on specific aspects of support for people with learning disabilities by making a general comment about the development of a new strategy. While it is very important to look back at progress that has been made during the lifetime of The Same As You, in developing a follow on strategy it is also important to consider the current context, and to look ahead. We live in a time of financial austerity, which is likely to get worse before it gets better. Many people with learning disabilities will be adversely affected by the change in welfare benefits at a UK level. With this in mind, it is important that any future strategy takes into account reduced government resources and (potentially) increasing need. That is not to say that we should reduce our aspirations for people with learning disabilities, but that we should be up front about if/when this will require new resources, and where these will come from. We are supportive of calls by The Learning Disability Alliance Scotland to focus during the policy development stage on how initiatives will be implemented.

Models of care

We have some reservations that 'community care' seems to be favoured throughout the document as the primary means of supporting people with learning disabilities. We are worried that an assumption that support which is not classed as community care is 'more restrictive', or otherwise less desirable, may lead to a lack of choice for individuals about the kind of support that they would like/would benefit most from.

We are concerned that too much emphasis is placed on labelling care services, as opposed to looking how suitable the support that a particular service can provide may be to an individual. Some Camphill communities are registered as care homes, and others as housing support/care at home providers, yet all are based on the same intentional community model; we therefore know that labelling services can at best be meaningless and at worst be harmful. For example, in supporting an elderly man who was beginning to develop dementia, one Camphill community was told that, as they are registered as a care home, if it became more expensive for the community to support him than for him to go into a nursing home he would be automatically transferred to the nursing home, even though he

had lived in the community for many years – because the service was registered as a care home, the same effort was not put into supporting this man to stay in his own home as it would have been had this particular service operated on an individual tenancy/housing support/care at home model.

We note the SWIA finding, reported in the consultation report, that a range of service models is required to ensure that the different needs of people with complex disabilities and high support needs can be met. As providers of a support model which is not always made available to individuals we strongly endorse this recommendation, but in our view this range of service models and choice should not be restricted to people with complex or high level needs. People who are supported in Camphill communities have low, medium and high level needs (26%, 36% and 38% respectively) and have all, as individuals, been helped by community life to develop in the way that is right for them. For these people, a traditional individual tenancy in the local community, supported by changing staff who come at intervals during the day may not have been the right choice, and it is important that everyone with a learning disability, regardless of how that disability has been categorised, is able to access a range of support and enabled to make the choice that is right for them.

There are a range of reasons why support in an intentional community brings out the best in some people, whether they live there or come in during the day to work. We have explored some of these reasons below, and noted how they relate to some of the issues raised in the consultation report:

- People have a sense of belonging. This can be exemplified by the numbers of people who come to work in communities during the day and then, because they feel part of life there, express an interest in coming to live in the community.
- People make friends. The consultation report identifies shared spaces as places to meet people and build relationships, and this happens naturally within intentional communities. The report also highlights that some people living in individual tenancies can feel lonely and isolated, which is less likely to happen when there are always people around who you can be with/talk to if you wish. Of course, it is important that within a shared living space people have somewhere they can go for peace and privacy, and this is well catered for in Camphill communities.
- People develop social skills. Being around other people encourages individuals to develop their social skills. This helps them to make friends, and to integrate into the community, but can also be useful in other spheres of life such as accessing education and employment.
- People feel safe and secure. This relates both to physical safety, which we note from the consultation report is sometimes a concern for people living on their own, and the sense of security that allows someone to develop new skills and build up self-confidence. Within Camphill community life there is a rhythm, stability and consistency of staffing which makes people feel secure.
- People know they are making a contribution. The consultation report states that people should be encouraged to contribute to the community they live in, and we would urge that this should not only refer to geographical communities in their narrowest sense. Living and working in an intentional community means that people can readily see how their contribution has helped others, whether through work in the

- People are cared for holistically. When a person lives and works alongside other community members, they can be supported in ways that relate to every part of their wellbeing. For example, we note in the consultation report that ill-health can result from a reliance on reheated meals and a lack of exercise. In Camphill community life, however, people are encouraged to make healthy meal choices (often helped by the fact that, for example, people have been involved in growing vegetables themselves) and regular outdoor work and exercise are built-in to the daily routine. This is supported by Camphill communities' emphasis on social pedagogy, which attends to the person's holistic wellbeing, holistic education and personal development.

There are also advantages for families whose relatives are supported in Camphill communities. The consultation report notes that the impact on families of bringing up someone with a learning disability can be dramatic, including stress, impact on siblings, careers being held back and restricted income. For many people who join Camphill communities, this is the first time they have lived away from home, so for these families the change is evident. We have also experienced, however, that families whose relatives are supported in their own tenancies (who we come into contact with if their relatives come to work in Camphill communities during the day) also lead very stressful lives, battling with changing staff teams, endless inductions and anxieties, and a sense of never being able to let go as planned when the package of support was set up. Camphill families report feeling safe and secure in the knowledge that their loved one is being well supported.

Education

We endorse the finding of the consultation report that there is a lack of suitable school services for children with complex needs. In particular, we believe that residential education should be viewed as a positive choice for some children and young people, rather than a last resort, and that Scotland would benefit from more residential school provision. Many families find that local authorities can be reluctant to explore options outwith the mainstream; they tell us that they would like the assessment process to be more child-centred and less driven by politics/finance.

We also draw your attention to the needs of children who are too able for 'special school' but have needs which cannot be met by mainstream schooling. We have set up the St Andrews Project, part of Camphill School Aberdeen, to meet the needs of some of these children and young people, and receive many requests from families asking for support with their loved ones, who often end up excluded from mainstream schooling and receiving no education or support. We believe that there is clearly a gap in provision for these children and young people.

We are very supportive of the need expressed in the consultation report to ensure that people are well supported around options for leaving school, and that this transitions planning should start long before school-leaving age. We have experience of working with transitions teams in a number of local authorities, and would note that a key difference

between the teams at present is their level of involvement once a transition has been made: in some local authorities, a relationship is maintained until the person is well settled in the new support arrangements, while in others the transitions team closes the case as soon as a placement is made. This latter approach feels very task-centred, rather than person-centred, and means that relationships and knowledge which the transitions team build up are lost once a placement is made, leaving individuals, families and providers to start from scratch with providing information to a new contact should further help from social work be needed. Notwithstanding the different approaches taken by transitions teams, we recognise that these teams are an important resource in helping young people and their families to plan their next steps, and are concerned that these services may change under Self-Directed Support to more of a paid brokerage model. Finally, we would caution that, while moving from school to post-school is an important step, it is not the only time when people are in transition. The support available to people at that life stage should also be available for transitions throughout the life course.

We are concerned that, in some areas, there is a real lack of suitable opportunities for people leaving school, particularly people with complex needs. In the last 2-3 years the range of college courses available has dropped, for example, and colleges are very reluctant to support people with complex needs; we have also noted a reduction in suitable work experience placements with mainstream employers (see below). At Camphill School in Aberdeen, we have experienced so many pupils being unable to find a suitable next step that we have started a transitions project to support these young people post-18, but while this is helpful in supporting them for an additional few years and preparing them for the future, we know that in many cases this is not a long term solution and would love to see increased availability of suitable supports and options.

Employment

Work is, and always has been, an integral part of life in Camphill communities. We believe that everyone has a need to be useful and active, and that this need is often fulfilled through work. Work within Camphill communities gives people a shared purpose, and enables each person to make a meaningful contribution to the community and beyond.

We are supportive of moves to increase paid employment, but recognise that this requires a huge input of resources, particularly to be able to support those with complex needs into mainstream employment. We regret that there do not seem to be sufficient resources at present to do this, having noted a recent decrease in the number of work experience placements available. At the same time, however, we believe that people benefit most from the act of working and contributing, and that therefore whether or not work is paid is not the most important consideration. We believe that work, whether paid or unpaid, should be a part of everyone's support, and that definitions of work need not be narrowly cast as access to salaried mainstream employment.

Within Camphill communities, everyone has a role to play. Individuals are supported to be part of a project, or small enterprise, where they learn practical and social skills. Work is invested with meaning and purpose, and people can see the outcomes of their work for themselves and others. Knowing that they are making a meaningful contribution to the work

of a team, to the life of the community and to the wellbeing of others helps people to develop dignity, pride and self-respect. The work-based support provided in communities is supportive, educational and preventative. As support is not time limited (like a college course, for example) it can adapt to people's individual development over time. There is an increasing interest in this work-based support among commissioners and people seeking opportunities under Self-Directed Support.

Meaningful work provides people with a sense of safety, security and regularity, without which many of the people we support would not be able to manage their lives. One of the young men we support came to us suffering from depression, having been stuck at home for long periods without a sense of purpose; he now thrives on working full-time on one of our farms. In many senses, the work-based support we offer is preventative in nature, providing a sense of structure and meaning to people and their families, without which some individuals/families would go into crisis.

The support we provide can also be useful to young people who need help to develop the social and practical skills needed for work, without the pressure of going straight into a get ready for work scheme with the sole focus of finding paid employment. It can also be useful for older people who can no longer keep up with the demands of paid employment but are still keen to work productively and continue to derive satisfaction from this.

Day services

We have a concern here about terminology. The term day services is held by many to be synonymous with the kind of day centre support which was previously provided to nearly everyone with a learning disability and is now recognised as inappropriate for many individuals. However there is clearly still a need for day support, and this can take many forms; the work-based support described above which is provided by many Camphill communities is registered with the Care Inspectorate as day services.

The work-based support that we offer provides suitable support for people who like to have routine and structure. We find that having a base that people can return to several times a day for breaks and meals is also very useful in helping some individuals to feel secure, yet sometimes find that any building-based day support is pre-judged by those who put it in the same bracket as old-style day centres without finding out about the support that we offer. That being said, we are pleased to note that there is an increased interest in this work-based support from individuals and families who are looking for support using SDS. In some areas, we are also noting increased interest from commissioners, who often note a lack of other suitable alternatives (see 'employment' above for further details).

Short breaks

We are pleased to see the consultation report recommend investment in short breaks, as we have noticed a marked reduction in the availability of respite over recent years. Some Camphill communities have sought to provide respite, either on an ad hoc basis or through establishing a separate service. In our experience both of these approaches have their difficulties, with existing services not always having the capacity to provide the amount of

respite support they would like to and funding not always available for people to access respite services.

Planning

As support providers, we take our role in care and support planning extremely seriously. In a formal sense, we undertake six monthly reviews with individuals, their families and, where possible, social work staff. The Care Inspectorate requires that at least one review per year includes a social worker/care manager/reviewing officer, but it is increasingly our experience that local authorities, either explicitly or implicitly, will only send staff to a review in a crisis situation. Our planning can also be hampered by three further problems:

1. The high turnover of social work staff in local authorities;
2. Local authorities whose systems dictate that one social worker makes the placement but then hands the case over to another for reviews; and
3. Social work departments that do not always enact their parts of the plan, for example looking for suitable future placements.

Within this formal process, some Camphill communities have incorporated independent advocates, to help protect the interests and rights of individuals. They have found this extremely useful in helping individuals to contribute meaningfully to their reviews, particularly when what they want may be different to what their family carers and/or social workers want for them.

Alongside these formal processes, however, we believe that person-centred support should be flexible to people's hopes and dreams, which may be expressed ad hoc between meetings, or which the person may not feel comfortable raising in a formal meeting. When co-workers and people with learning disabilities live side by side, informal conversations over dinner or remarks made during work activities can be opportunities for planning which can be just as valuable as six-monthly reviews or structured life story sessions.

Complex needs

Having noted an increase in the number of people with complex needs who are referred to Camphill communities in Scotland, we can only endorse the need for more support to be commissioned for people whose behaviour challenges services. In our experience, however, it works best when people are supported alongside others with a range of levels of need, and for this reason communities are not always able to take as many people with complex needs as commissioners might like. We would be wary of people with complex needs ending up in support situations which are only for people with complex needs, as we have found that peer support and learning behaviours from others are extremely valuable (as one of a whole range of support mechanisms) in supporting people with complex needs.

Healthcare

In general, the people we support have good experiences of accessing health care, however we believe that this is in large part due to the support that we provide in helping them to do so. Accordingly, we are in favour of the proposal that support providers should

play a greater role in helping people to access health care services, but would note that at present support providers are hindered from playing a potentially important role in this: many of the people who work in Camphill communities experience real frustration at not being able to contribute their knowledge of an individual's condition or preferences during medical consultations. While we understand that there are, quite rightly, legal restrictions on who can make decisions about a person's treatment, for example, it will be important to consider, if providers are indeed to play a greater role in helping people to access health services, how a balance can be struck between encouraging the person who is being supported to take a lead role for themselves in consultations and appointments, and harnessing the knowledge that support providers may have, particularly in relation to people with communication difficulties.

Our generally positive experiences apply to mainstream services such as GP appointments, checks and screenings as well as specialist services such as diet, speech and language, community nurses, psychology, psychiatry, occupational therapy etc. We have however experienced:

- excessively long waiting times (18 months) for psychology services in some areas; and
- a possible need for training in liaison nurses, who in our experience are not always well equipped to deal with people with a learning disability.

Some health professionals with whom the people we support come into contact are very well trained, and able to deal with people's communication difficulties and other special needs. We believe that it would be beneficial if people with learning disabilities could, so far as possible, be seen by the same health professionals on each visit, so that the health staff could develop a good understanding of their needs. Where we have experienced this kind of consistency, for example in a local dental practice, this has greatly reduced people's anxiety and improved their healthcare experience.

Older people/dementia

We endorse the recommendations in the report relating to older people and dementia. As Camphill has been in existence in Scotland for more than 70 years, many of the Camphill communities in Scotland now support older people who have lived in the communities for many years. We are developing experience of working with older people, and particularly people with dementia. In almost all cases, however, people with dementia end up having to leave the community and move to a nursing home as their condition deteriorates; this can be very distressing for the person, for any family they may have, and for those living with them in the community. As noted above (under 'models of care'), local authorities can have different approaches to supporting people to remain in their community depending on whether that community is registered as a care at home/housing support service or as a care home: it is our experience that if the community is registered as a care at home/housing support service the individual is more likely to receive adaptations and supports to stay in the community than if the same individual lives in a community classified as a care home. We find this distinction totally unacceptable in an age of person-centred care.

Many communities have accessed excellent training and support around older people with learning disabilities and dementia, but we have noted a gap in support around palliative care

and learning disabilities (there is plenty of material about end of life care, but not much which is specific to learning disabilities). We would also like to see more care provision and specialist resources for adults with learning disabilities and dementia needing end of life care in order to avoid inappropriate placements in mainstream nursing homes.

Other issues –rurality

As many of our communities are based in rural locations, we would also like to note that any follow up to The Same As You should consider the rural dimension in making recommendations. The additional challenges faced by those living in rural areas are not new or groundbreaking, but it is important to bear them in mind when developing new policies and recommendations. Particular issues that we would like to bring to your attention are that many good services and activities are based in towns and cities, and that many local authorities are phasing out (or have already stopped) funding for transport, with people facing charges in the region of £15 per journey (depending on distance) to travel to appropriate supports or activities.

Kirsten Hogg

Facilitator, Camphill Scotland

September 2012

Kirsten@camphillscotland.org.uk