



Presents

***CHOICE FOR INTENTIONAL
COMMUNITY***

12.00 – 13.30 September 15th 2015

Houses of Parliament, Westminster Palace

<http://www.camphillresearch.com/choice-for-intentional-community/>

Summary of presentation

Shared Living and Community are demonstrably components of the most successful models of support for learning disabled adults, and deliver tremendous value. Many of these models are under threat unnecessarily to the detriment of both the learning disabled in the community and the public purse.

The models employed by organisations such as Shared Lives Plus, L'Arche and Camphill all successfully deliver these components of community and shared living through a variety of different routes and methodologies.

The presentation will cover what benefits arise from these models, such as increased wellbeing to decreased costs of support, explanations of the different systems in use presently from these organisations, as well a literature round-up, medical overview and personal accounts and perspectives from learning disabled adults and their families. In addition to speakers, personnel from a wide range of organisations will be on hand to answer any questions.

Advantages include significant benefits to health, physical, emotional and psychological well-being for the learning disabled person being supported and decreased costs to the NHS and Local Authorities, as well as for direct support. Short presentations by the following speakers each highlight a different aspect.

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Introduction

John O'Brien

Centre for Welfare Reform



Assisting people to live with dignity and meaning is the ultimate purpose of social care. To serve this purpose, the experiences of Camphill, Shared Lives Plus and L'Arche can make important contributions to a critical question for policy and practice: how to assist and safeguard people without inhibiting them from living a real and meaningful life. Making the best of these communities, evolving responses to this question, requires humility enough among policy makers and commissioners to recognize the limits of the whole social care field's current answers.

I have not chosen life as a member of any of these small but deeply important social movements for myself, and I know many people with learning disabilities and families who would not make the choice either, but I am deeply grateful to those who have. They intentionally strive to live together in a way that embodies values that deserve to thrive in an open society.

Camphill and L'Arche are each founded on a different, distinctive understanding of human development, a thoughtfully developed sense of the significant contribution that people with learning disabilities can make to society, and the central importance of mutual relationships founded on respect for the dignity of the person as the foundation for realizing that contribution. Not everyone will agree with these ways of understanding, often because they draw explicitly from spiritual traditions and encourage spiritual development, but I know of no legitimate reason for rejecting them.

Both traditions are founded on shared-life households and both place great value on hospitality. Their boundaries may be distinct, but they are open and each has proud traditions of welcome for strangers and engagement with neighbours. Those who offer assistance and those who receive it strive for a relationship more personal than that of a staff member and client. The importance of mutuality influences the economics of the household: offering assistance is not understood as a typical job for pay.

Each tradition faces the question of adapting with integrity to a changing environment. Increasing awareness of the importance of people's own voice and choices raises productive questions, as does the challenge of keeping communities' animating spirit alive as the interests of potential life-sharers change. Like any human endeavour, it is possible for people to fail to live what they value, so safeguarding each household's expression of the tradition is a real and relevant question that each movement must take seriously.

Living the particular gifts of L'Arche and Camphill brings the sort of healthy diversity that enriches the possibilities for assisting people to live meaningful lives. The social care field as a whole would be impoverished without the choice of life-sharing in these two deeply rooted intentional communities.



Dr Simon Duffy

Centre for Welfare Reform

Simon founded The Centre for Welfare Reform in 2009. Previously he was CEO of In Control and led the development of personal budgets in England (2003-2009). Simon also founded and led Inclusion Glasgow in 1996 and helped to establish a range of organisations in Scotland, including Partners for Inclusion, C-Change for Inclusion, Neighbourhood Networks, Values into Action Scotland and Altrum. He led early work on individualised funding and brokerage in Southwark (1990-1994) and was a Harkness fellow, based in Denver, in 1994.

Simon is also Chair of the Housing & Support Alliance and acts as voluntary coordinator of Learning Disability Alliance England. He is also an Honorary Research Fellow at the University of Birmingham's Health Service Management Centre.

Simon is a philosopher and social innovator, best known for his work to reform the social care system in England. In 2008 he was awarded the RSA's Prince Albert Medal for his pioneering work on self-directed support and personalisation, and in 2011 the Social Policy Association awarded him for his outstanding contribution to social policy.

Simon's writings include the *Unlocking the Imagination: strategies for purchasing services for people with learning difficulties* (1996) *Keys to Citizenship: a guide to getting good support services for people with learning difficulties* (2003) *Women at the Centre: innovation in community* (2011) and *The Unmaking of Man: disability and the Holocaust* (2013). His doctorate was in moral philosophy and proposed an argument for the objectivity of morality.



Shared Lives Plus information – Synopsis

Shared Lives Plus is the UK membership body for Shared Lives and Homeshare. A Shared Lives carer shares their home and family life with an adult who needs care or support to help them live well and independently. Our UK wide network of 150 local, regulated schemes individually match trained and approved Shared Lives carers with people who need their support. Shared Lives carers work very autonomously in their own family homes, with the back-up of the scheme there if it is needed. There are 12,000 people in the UK getting support in this way, and Shared Lives demonstrates that it is possible to provide a combination of safe personal care and ordinary family life cost-effectively and at scale. Whilst there are differences, we share many values with the intentional communities movement, particularly the value we place on family and community relationships and our belief that ultimately, care is not something which can be commodified, but is something which people must freely choose to give and receive. In Shared Lives households, as in intentional communities, everyone has something of value to contribute. These models should be valued for the distinct choice of lifestyle they offer disabled and older people.



Alex Fox, CEO Shared Lives Plus

Average net savings from a long-term Shared Lives arrangement per-person per year are £26,000 (learning disabilities) and £8,000 (mental health).

Expanding a scheme by 75 arrangements (50 for people with learning disabilities; 25 mental health needs), requires around £250,000 of up-front investment and should generate savings of c£1.5 million pa once capacity reached.

Source Social Finance *Shared Lives* July 2013

In a small scheme in Scotland 19 Shared Lives carers support 6 people long term, plus 500 short break nights & 37 day care.

In past year council has saved:

- £200k on long term care
- £35K on short breaks or respite
- £58k on day care.

If all areas caught up with the best performing scheme in the country, Shared Lives could reach an additional 32,770 people and grow to over 43,000 people. This would provide savings of around £120m.

Shared Lives carers are paid a modest amount to cover some of their time and expenses, but they are not paid by the hour and they often do significant amounts without being paid. There is no clocking on and clocking off. Other forms of care for adults can be focussed on keeping clear professional boundaries around the care giver/customer relationship. In Shared Lives, everyone gets to contribute to real relationships. The goal is ordinary family life.

Combining paid and unpaid contributions in an approach which offers both a family life and the back-up and safeguarding of regulated local schemes creates the potential for exceptional value for money. It is vital to recruit the right people to become Shared Lives carers, support caring relationships and help people move on when those arrangements end.

In 2010, England's care inspectors gave 38% of Shared Lives schemes the top rating of excellent (three star): double the percentages for other forms of regulated care. Shared Lives also has a strong safeguarding record. The Care Quality Commission logged 3,473 safeguarding alerts related to social care provision in England in the reporting year 2011/12. Of those, just one alert arose from Shared Lives.

Steve Briault

Chair of the Alliance for Camphill and Chair of Trustees, The Mount Camphill Community in Sussex.

Steve is a senior management consultant with 25 years' international experience of guiding, facilitating and implementing organisational and community development. Educated in London and Cambridge (MA 1976), his early career was in the voluntary sector: adult education, curative education, residential care management and refugee resettlement. He was a founder and Director of a Camphill community for children and young people with special needs, and has worked both as teacher and administrator in Steiner education.

Later he studied organisation development at The Centre for Social Development, Emerson College, Sussex, and has been engaged in lecturing and consultancy work since 1983. He is now a Director of Landing Point, a consultancy specialising in business improvement in industry and in healthcare. He has worked as consultant to organisations in many parts of the world, including Canada, Russia, New Zealand and Africa as well as Europe and Scandinavia.

Steve has acted as adviser and also as trustee in a range of schools and charities. His children all attended Michael Hall Rudolf Steiner School, where he has been the Chair of the governing Council. For many years he lived with his family in the Hoathly Hill residential community where he was also Finance Director of the housing association. He is currently Chair of the Trustees of The Mount Camphill Community, Wadhurst, and Director of Development at Emerson College.

Steve is the author of "Working It Out, a handbook for violence prevention in work with young people", and of "The Mystery of Meeting – relationships as a path of discovery". He is a founder member of the International Association for Social Development.

Synopsis of presentation



Camphill Communities: living, learning and working in partnership with the "disabled".

Steve Briault: Chair of Alliance for Camphill

For several years it has been my privilege to be a member and then Chair of the Trustee group at The Mount Camphill Community, which is an independent specialist College providing formal and social education, work training and care for around 30 young people with a range of moderate to severe learning difficulties. Several also have physical and/or language impairments. During their time at The Mount – usually three years – our students attend a varied programme of practical and classroom studies, in many cases achieving certification of the skills they acquire. A range of specialist therapies is available according to individual needs, and the students participate in a rich, shared cultural life including performances, trips, crafts and artistic activities. Residential care and support is provided in a number of households on the campus, where students live in small family groups with each other and with our vocational co-workers and their families, sharing household duties and social life in a warm home environment.

This way of providing support has been practised in Camphill communities for over half a century. The Camphill movement was founded during the Second World War, in Scotland, by a group of Austrian refugees led by Dr Karl König. Their pioneering work began with children who were then known as “mentally handicapped”, many of whom would otherwise have lived much of their lives in large hospitals. Dr König refused to accept that any child was uneducable, and he and his colleagues demonstrated this countless times by helping severely damaged children develop social and practical skills that would hardly have been considered possible. I witnessed this myself repeatedly when, as a young adult, I was a co-worker in three different Camphill communities.

Over the decades, the Camphill movement developed a wide range of communities throughout the UK and beyond: there are now over 100 Camphill places worldwide. They vary in size, geographical setting, age and type of beneficiaries; but all have in common that the so-called disabled are not seen as passive recipients of care, nor as “service users” who have a transactional relationship with their carers, but as partners, “living and working in community with those who provide support”, as it says in The Mount’s charitable objects. In a genuine Camphill context such as Newton Dee Village in Scotland, the learning disabled share households, work tasks and responsibilities, social and cultural life, on an equal basis and by agreement with their more able friends and colleagues. It is a common experience in such a context that the support is mutual and that the lives and personal development of all community members are enhanced by the diversity of qualities and abilities among them. This is the power and the potential of the intentional community model.

The Mount is regulated and inspected by CQC and Ofsted as well as several of the Local Authorities who place students with us. I am extremely proud of the standard of education, care and support provided at The Mount: I can also unequivocally confirm that the skills, professionalism, commitment and calibre of our unsalaried, vocational co-workers far exceeds what could be recruited or afforded for the same cost under a shift-based care worker system.

For many years, a high proportion of students graduating from The Mount have been able to go on to live happy and productive lives in adult Camphill communities. This has typically been the preferred future for about three quarters of our students and their families, although others have also moved into a wide range of other situations. Unfortunately in recent years a series of - no doubt well-intentioned - “reforms” has made the choice of an intentional community lifestyle more difficult for many learning disabled adults, and threatened the basis of some of the existing communities. This is a source of deep concern to us, to our students and to their families: we strongly believe that such a choice should continue to be available as one among a range of options for the disabled. As other speakers will describe, its benefits are broad, deep and well-proven. It can also be provided in ways that are safe, compliant, and cost-effective.

The Alliance for Camphill has recently been formed as a support body to speak up for the Camphill way of life, and is very pleased to host this briefing session today. A short introduction to the aims and principles of the Alliance is available as a hand-out sheet.

Dr Marcus van Dam

Dr M van Dam, MD DRCOG DPD, is a GP and Partner at Danby Surgery near Whitby, North Yorkshire. Since joining the practice in 2004 he has been the GP to over a hundred people with a learning disability living in nearby Botton Village, the largest of the Camphill communities offering a shared living environment for people with learning disabilities, including many men and women with Down's Syndrome, Autism, Fragile X Syndrome and Epilepsy. Dr van Dam has also developed and championed annual health checks for this population for nearly ten years.

Dr van Dam studied Medicine in Berlin and did his General Practice Postgraduate Training in Scarborough before joining Danby Surgery in 2004. In addition to Learning Disabilities he has an interest in Dermatology and works as a tutor for the Hull-York Medical School and as medical officer for the Royal Air Force. He is 49 years old, married and has three teenage children.

His interest in and support for the Camphill model stems from his direct observation of the substantial health benefits as well as the happiness and wellbeing of people living in Botton. He found that the Camphill shared lives model is capable of safely supporting also potentially challenging residents whilst reducing the need for medication and restrictive interventions. Dr van Dam has become an advocate for intentional communities to be recognised more widely as a valid choice for people with learning disabilities.

Dr van Dam will speak on the notable health benefits of shared living community based on figures from his practice and his extensive experience.

Synopsis of Presentation



Health benefits of shared living in an intentional community for people with learning disabilities

Dr Marcus van Dam, GP Danby Surgery, North Yorkshire

There remains staggering inequality with regards to the health of people with learning disabilities. NHS England recently wrote that “it is well recognised that people with learning disabilities have poorer physical and mental health compared to others, and a lower life expectancy”¹. A large proportion of people with learning disabilities in the **UK** is diagnosed with preventable or modifiable conditions such as obesity (28%)² and mental illness (40%)³, and 30% of people with learning disabilities are prescribed psychotropic medication (antipsychotics, antidepressants, sedatives) as recently highlighted by Dr Dominic Slowie⁴.

As a consequence, “people with learning disabilities in England on average die 16 years earlier than the rest of the population”¹. People with learning disabilities have also been more likely to be treated in long term closed institutions and their families often found they had little influence on such decisions. ‘Transforming Care’ is the current program determined to change this in the wake of the Winterbourne report⁵.

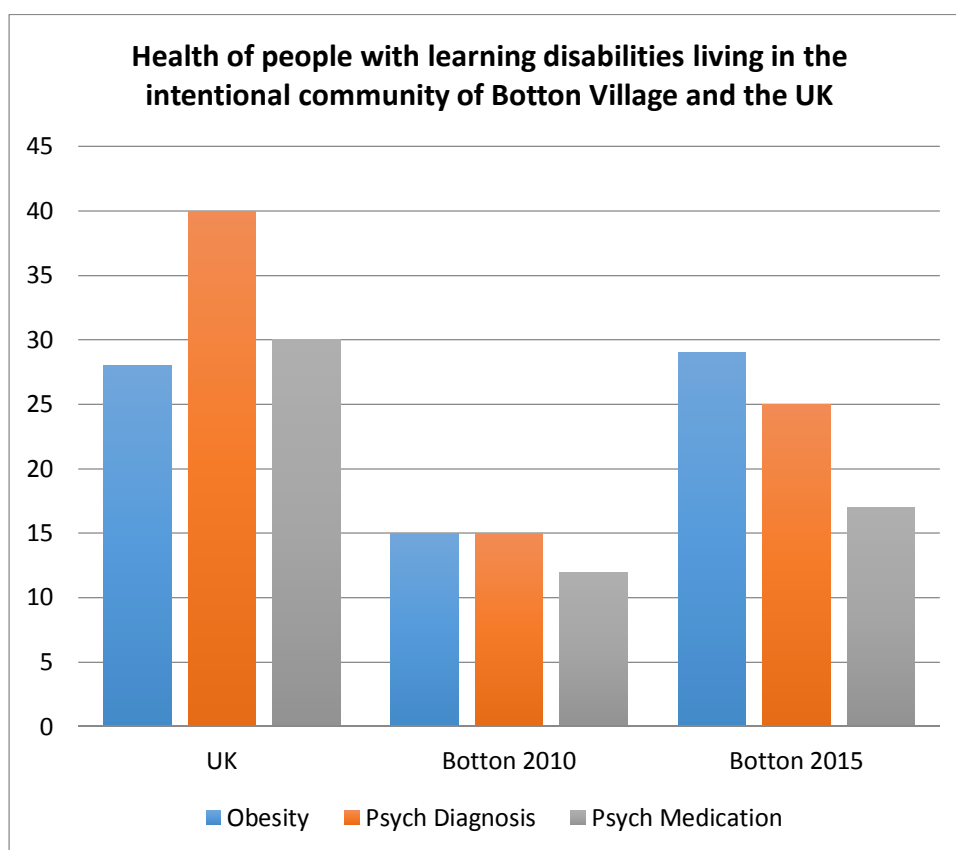
Our findings in Botton Village, an intentional community for people with learning disabilities

Shared living in Botton Village is a popular option for people with learning disabilities who live there and warmly embraced by their families. Botton in North Yorkshire is the first and largest of over a

hundred Camphill communities worldwide and is celebrating its 60th Birthday this year. Danby Surgery has been providing primary medical care including, for nearly ten years, regular annual health checks to well over a hundred people with learning disabilities in Botton.

In our **Botton 2010** audit of patients on our learning disability register, we found that 15% were obese, about half the prevalence of the UK, with Type 2 Diabetes being rare (1%). Our impression is that people in Botton live well and into old age.

Similarly, mental illness and challenging behaviour have always been less prevalent in Botton (15%) and psychotropic medication required less frequently (12%). We consistently observed that people were remarkably happy and settled, capable and confident about their work and social life.



Values are in %. UK = UK wide studies Refs 2, 3 and 4. Botton Village 2010 n = 110 and 2015 n = 99. Obesity = BMI of 30 and over. Psych Diagnosis = Depression, Anxiety, Psychosis, Challenging Behaviour. Psych Medication = Antidepressants, Antipsychotics, Anxiolytics/Sedatives.

There are also several individuals with severe autism, moderate learning disability or some with dementia who have enjoyed a stable and healthy life in a Botton shared home with no need for restrictive interventions or sedative or psychotropic medication.

Our overall assessment is that people with learning disabilities living in the Botton Village community enjoy excellent quality of life, physical and mental health and that relevant measured outcomes are clearly superior to those in the UK.

Discussion

In addition to their intellectual disability a large proportion of people with learning disabilities in the UK are additionally burdened with preventable and modifiable illness; illness that is lifestyle dependent. Our findings in Botton (2010) are in stark contrast to this and we believe they are a direct result of the healthy lifestyle that is characteristic of the Camphill community model. To look at some of these lifestyle factors, the typical Botton meal in a shared household is rich in fresh fruit and vegetables, high quality meat and dairy, and unrefined products, mostly home grown and home cooked. Residents have regular mealtimes, enjoying their meals together and without a rush. These 'family' routines are part of an active working day with plenty of physical activity, walks and often work outside. In combination, this helps prevent obesity, type 2 diabetes and cardiovascular disease.

With regards mental illness, we know that depression, anxiety or behaviour that challenges can result from adverse social factors, whilst people get and stay well in a beneficial and stable social environment. Botton residents share their lives and homes with and are supported by people who know them well and understand their particular needs, providing a sense of home and family, not least as, often, children are part of their homes. Botton's social environment is a network of stable human relationships in a supportive community, where all have a role and job that is a valued contribution whatever the individual's ability or productivity; a healthy culture of eating and physical activity; green spaces and time spent in nature; with calm predictable routines of the day and the cyclical nature of Botton's cultural calendar.

All these combine to keep people well and stable, physically and mentally. It is not one key ingredient; it is how several are combined to a whole. A review article about Down's Syndrome in the British Medical Journal last year confirmed what Botton demonstrates so nicely, that "people with Down's syndrome generally do well with consistent schedules and can blossom in a setting of predictable routine".⁶ This is also the case for people with autism.

A fair choice

Our findings and longstanding experience resonate with the Rt Hon Normal Lamb's statement⁷: *"We know that many people feel happier and safer in intentional communities, and we fully support these communities when they offer choices and good quality care."*

He went on to say that, *"we aim to put people with learning disabilities and the families who care for them in control of their care, including where and with whom they live."* The UN Convention on the Rights of Persons with Disabilities⁸ expects that "persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement."

However, as Sir Stephen Bubb wrote in his report⁹, the reality is often quite different: *"People with learning disabilities and/or autism and their families have an array of rights in law or Government policy through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on... [but] the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored."*

Botton and other intentional communities have recently been subjected to reforms that affected their way of life and model of support and who residents are able to live with. Many residents and their relatives feel they were not consulted or listened to when these reforms were planned and carried out and many reject the changes made. It is likely that these changes to shared living and the community, to the composition of the households and to the work and meal routines have played a role in the recent changes observed in the residents' health in **Botton 2015**: there is now an increase in the proportion of patients being obese (29%) and of patients being diagnosed with mental illness (25%) with a slight increase in prescribing (17%). This is regrettable considering the excellent health most people in Botton used to enjoy previously and a step in the wrong direction. The medical consequences of obesity, such as diabetes, cardiovascular disease and arthritis, and of mental illness, and the financial burden on the NHS and society of these modifiable conditions are enormous². There are therefore substantial cost savings associated with the healthy lifestyle and positive outcomes we observed in Botton.

We hope that the success and benefits (health, wellbeing, financial) of intentional communities like Botton will now be recognised and endorsed more widely, so that people with learning disabilities, supported by their relatives as appropriate, can have a real and fair choice as to how, where and with whom they would like to live.

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Dr Stuart Cumella

Dr Stuart Cumella is a social scientist, who is Honorary Senior Lecturer in the School of Social Policy at the University of Birmingham. He has a BSc(Econ) and PhD from the London School of Economics, an MSc from the University of Strathclyde, and a social work qualification from the University of Stirling. He has worked for Birmingham Social Services Department, Lothian Region Social Work Department, the Civil Service, the MRC Social Psychiatry Unit, as an NHS manager, and as Head of the Division of Neuroscience in the University of Birmingham Medical School.

At the University of Birmingham, he set up and led an innovative multi-disciplinary distance-learning Masters programme in Learning Disability Studies, and a distance-learning module on research methods for the academic clinical fellowship programme. He also delivered teaching courses in Hong Kong for health and social care professionals working with people with a learning disability.

He has published research on public policy for learning disability and mental health, housing and community care, the mental health of children in homeless families, and evaluations of social work in primary care. He was a member and joint author of several reviews by the NHS Health Advisory Service, including those on child and adolescent psychiatry, substance abuse among children and adolescents, services for deaf people with a mental illness, services for people with acquired brain injury, early dementia, and Huntingdon's Disease, and continuing care for elderly people.

Now retired from the University, he continues teaching for the Royal College of Psychiatrists, is a tutor with the University of the Third Age, a volunteer with the Citizens' Advice Bureau, and is Vice Chairman of his Parish Council.

Dr Stuart Cumella - synopsis of presentation

Review and Summary of literature and research into shared lives and intentional community

Public policy in the UK has sought to attain a fulfilling life for people with a learning disability by placing them in dispersed housing schemes. These are houses or flats in urban settings, with support staff employed by private agencies to work in the home or visit on a regular basis. This became the dominant type of accommodation for people resettled from the former mental handicap hospitals, although some were also placed in 'residential campuses' of homes managed by the NHS on the sites of the former hospitals. By contrast, few former inpatients moved to intentional communities based on shared-life principles. These are a diverse group of settlements in which 'co-workers' (Camphill) and 'assistants' (L'Arche) are motivated by a personal calling to work alongside people with a learning disability, sharing their homes and family life.

However, research, which has compared the quality of life of people with a learning disability in different types of housing, has found that shared-life communities have similar outcomes for their residents as dispersed housing schemes. In some respects (especially friendships with other people with a learning disability, employment and personal safety), shared-life communities are superior. Shared-life communities also provide a better quality of life on almost all measures than the NHS-managed residential campuses, even though both characteristically comprise clusters of small houses dispersed across a shared landscape. This indicates that the size of a residence and its location is less important in determining quality of life than the pattern of social relationships within each residence.

Studies which have explored the distinctive pattern of social relationships that exist in shared-life

communities have found that residents appreciate the diverse range of employment and leisure opportunities, their wide friendship network with other people with a learning disability, and their sense of being part of a community in which they have an important part to play through shared decision-making and rituals. Friendship is facilitated by the availability in the community of several other people with a learning disability and by the sense of personal security it provides. Living in extended families with co-workers/assistants enables residents with a learning disability and their supporters to acquire and build skills in each other's pattern of communication - the essential step if a person with a learning disability is to learn of the world and express choices about what they want to do in it.

Shared-life communities are therefore an appropriate option for people with a learning disability who prefer this type of accommodation. The choice of how and where to live has in the past often been denied to people with a learning disability, is defined as a right under the United Nations Convention on the Rights of Disabled People, and should be respected by public agencies.

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Sally Murray-Jones Parent of learning disabled adult living in an intentional community

Sally Murray-Jones is a writer and educator. She is a former Head of Special Needs at Highgate Wood Secondary School in Haringey. She lives in North London. Her son David, who is 26, has physical and learning difficulties and lives in an Intentional Community.

Sally Murray-Jones – synopsis of presentation

Sally will give an account of her family's individual experience of the benefits of shared living and intentional community. Sally's son David has lived in Camphill communities since the age of 18.

Life in a shared-living community has provided David with continuity, stability, ongoing friendships and the opportunity to participate in family life; an opportunity that is unique in the care sector. David's shared-living community has also provided him with an opportunity to engage in meaningful work.

James Skinner

James is 34 and comes from Ashford, Kent. He is autistic. He has been in a shared-life home in an intentional community for ten years. He is living with another three residents where there are three co-workers; he appreciates all of the others as wonderful friends.

In the morning he works in the Wood Workshop, where he does several tasks such as cutting and drilling to make wooden toys. In the afternoon he works in the Seed Workshop, where he does some gardening work and also cleaning/packing seeds. He is very keen on environmental issues and is in charge of sorting out recycling in the house.

James is very talented and does very precise drawings of cathedrals and their windows and had an exhibition in the Hall in Botton. He has two sisters whom he visits when he goes on holiday to his parents.

Lucinda Riis-Johannessen

Lucinda is a lively, outward going young lady who is very bright, optimistic and alert, always having great ideas and putting them into action wherever possible. She is a great communicator and will reach out to all and sundry; she knows no barriers and can research effectively on the internet. She likes to be independent and feels she does not need carers to look after her. She did not like living in supported independent living, but now appreciates the stability and warmth of shared living in a large community.

Frank Walters

Frank has lived in Botton for 24 and a half years, and has been part of the Stormy Hall household for 7. He loves living with his Botton family and his cat Mousy.

At the weekends Frank often helps with the cooking. Frank is a very skilled gardener; in the morning he works in the Inner Garden where he is in charge of the strimming and lawn mowing, and composting the leftover food from all the houses. In the afternoon he works in the Seed Workshop where he does a lot of weeding and has just completed training to use the power harrow.

Frank takes part in all the cultural activities in the village, and most recently he played Moonshine in an extract of 'A Midsummer Night's Dream'. He has lots of good friends in Botton and loves going to the other houses for lunch.

Synopsis of presentation



Frank Walters, James Skinner and Luci Riis-Johannessen

Luci, Frank and James will give a personal account of shared living and what they like about being able to live with a family and have work in their community.

Anthony Kramers **Community member, L'Arche Edinburgh & Regional Leader for L'Arche Scotland**

Richard Keagan-Bull **Community member, L'Arche London & Chair of the L'Arche National Speaking Group**

Anthony Kramers celebrates 30 years as part of L'Arche this year. L'Arche communities are people with and without learning disabilities, sharing life together. As well as Edinburgh and Inverness in Scotland, there are 10 in the UK and 147 round the world in diverse cultures. Anthony's present role is to lead L'Arche's activities in Scotland. This includes exploring the scope for creating a third community in a new area, in response to potential interest from adults with learning disabilities, employees, local volunteers, and professional partners in Social Services. His working roles include time spent in the leadership team of other social care organisations as well as L'Arche.

Anthony is married with three adult children, and employed by L'Arche as a live-out assistant. He sees community life as founded on mutual relationships and trust in God, when lived in ways that respect and celebrate the unique individuality of each person – whatever their religious or humanist values. Community creates the space for the possibility of friendship - within a context that respects the support commitments made to the person, and to society (through those who commission and regulate care in the UK, as well as relatives and advocates).

L'Arche welcomes this initiative by a cross-section of people concerned for the future range of care provision in the UK to engage with members of the House of Commons, and the Lords – to help ensure that national and local processes of planning and of resource allocation continue to favour choice and diversity among organisations who aim to respond to the needs and gifts of people with learning disabilities.

It is represented by Anthony Kramers of L'Arche Edinburgh, Richard Keagan-Bull of L'Arche London (and Chair of the National Speaking Group), and David Race (Chair of the National Board).

Synopsis of presentation

L'Arche in the UK - Shared lives

Anthony Kramers & Richard Keagan-Bull L'Arche Scotland



L'Arche is a grass-roots organisation that builds community networks from the ground up across the locality: people with and without learning disabilities share their lives together. This ethos of shared lives creates the space for the possibility of friendship, while mindful of the commitments involved in commissioned support and care.

Over forty years old in the UK, the first community in the UK was in Kent formed in response to the local needs expressed. L'Arche has grown since 1974 to include commissioned and individual-budget-funded services to 215 people with learning disabilities in ten locations, offering support to people to live at home, and also to access day and work-related activities.

The ten UK locations are Kent, London, Bognor, Ipswich, Brecon, Manchester, Liverpool, Preston, Edinburgh and Inverness. 'L'Arche' means 'the ark' in French – the name of the first community

founded in France by Jean Vanier in 1964. L'Arche in the UK are Christian communities, open to all who share its values and mission, whatever their outlook and beliefs.

L'Arche's ten settings are urban or small town, and those who are part of it are dispersed across that locality, rather than all being geographically next door in a campus setting. Both the people with learning disabilities, and the employed assistants, live in diverse settings – some choose the shared houses that L'Arche helped pioneer in the UK since 1974. Some choose to live in a flat – sometimes those flats are off a common stairwell, sometimes they are dispersed round the locality. Some people live without any support being formally commissioned from Social Services – and their involvement is voluntary, like that of other local people without learning disabilities. Many L'Arche communities also offer work and day opportunities to people.

A particular feature of L'Arche is that most of the shared houses are ones in which a proportion of the team of employees also live in, alongside the tenants with disabilities. This is one reflection of the core value placed on shared lives. The first L'Arche community in France in 1964 began with a small group of people making a commitment to living and sharing life together. This ethos of mutuality was sustained as the charity quickly grew through offering further provision, resourced by teams that included employed members who lived locally as well as those who live alongside. Little traditions sustain the spirit of community – times when people eat together, share stories, meet to reflect or pray, or to celebrate.

The vision has spread to 38 countries to date - 147 communities round the world.

Choice and diversity

L'Arche communities have adapted and evolved, in response to the changing hopes and needs of the people supported, and the development of new commissioning and regulatory structures. L'Arche adapts, so it can continue to offer support to a person long-term, if they so wish.

When L'Arche consider the options for a new community - in Nottingham, Flintshire and in Scotland - the key criteria are whether there is a local desire among people with learning disabilities and their networks of relatives and advocates for what a L'Arche community may be able to offer. Also whether that desire is matched within Social Services, health and regulatory bodies – and third by the interest shown by local people getting involved as volunteers, to take forward the interest and provide skills for future project development and governance.

Growing from the grassroots in this way leads L'Arche to favour commissioning structures based on maximising choice and local diversity through individual budgets and self-directed support, and to build relationships with people with disabilities who have an attraction to the shared lives model of support. L'Arche also fulfil all the accreditation steps, referral arrangements, and support provision regulations that go with the provision of 'personal care' or other types of registered care services with the Local Authority and the regulator of Care.

Parliamentary Event, 15th September 2015

L'Arche welcomes this initiative by a cross-section of people concerned for the future range of care provision in the UK to engage with members of the House of Commons, and the Lords – to help ensure that national and local processes of planning and of resource allocation continue to favour choice and diversity among organisations who aim to respond to the needs and gifts of people with learning disabilities.

Richard Davis Vanguard Consulting Organisational Psychologist

Richard Davis is an organisational psychologist. He has worked as a consultant and researcher for Vanguard Consulting for over 20 years. Vanguard has specialised in identifying how organisations design themselves to enable best performance for customers/citizens and staff.

They have consistently shown how many traditional assumptions about good organisations actually undermine good performance. Richard has applied the Vanguard research and change framework to organisations in the private sector, public and voluntary sectors and has been particularly concerned in recent years with how to design systems that help citizens develop good lives. Unsurprisingly this has proven to be a lot cheaper and better than traditional services.

Richard Davis - Synopsis of presentation

Regulation and Assessment



The issue of regulation is critical to these conversations. Should we have regulation? Of course - it's public money and we have to keep people safe and help them prosper.

The question is what sort of regulation. If you ask people what regulation is for, I suspect many will say it's to stop and/or catch organisations doing bad things or catch bad organisations. This approach requires experts to determine a specification and then requires inspectors to inspect for compliance. This works well when the experts work on data and evidence and the outcome required is absolute unvarying consistency. There will be occasions where this is right and wherever the consequences of bad things are likely to be catastrophic, like nuclear power plants, then that is probably all you need. For organisations that deal with people, this doesn't work because the essence of what matters to people is highly variable and you have to design organisations that can meet that variability. Specification and inspection creates a one size fits all which inevitably does not fit many of the organisations to be inspected.

One of the most plausible issues is that of safety. Understandably it is a concern that residents should be kept safe. There is a difference though between being safe and seeking to do things safely. A Motorway police officer told me that he could keep all motorways safe - by enforcing a 15 mph limit. But that's obviously not possible - the purpose of the system is to get traffic where it's going. The focus therefore is on understanding risk and designing accordingly.

A better way to look at the purpose of regulation in our sphere, however, would be to catch all organisations doing good things, help them all do better things and help them, where appropriate, learn from each other.

This requires understanding what each organisation is trying to achieve: what would it look like for the people it serves when they get it right? The methods of these organisations can vary, as long as they achieve what matters - indeed if they do vary then you have far more opportunity to learn what might work better. Methods and processes do not transfer very well - only principles travel well.

So, for intentional communities, the regulators can start by finding out how well each organisation understands what matters to the residents and to the care workers? What does 'good' look like? What does a good life look like?

The next task is to find out how well their particular methods are delivering what matters and whether the organisation has data and evidence that is helping them learn and improve. The most helpful part of such an inspection is ensuring each organisation is learning from its own evidence.

Clearly, part of this is to ensure everything is being done safely and legally but the purpose is not to ensure the organisation is 'safe' or that people are 'safe' per se but that the daily work is being done safely.

Monmouth social services has been doing some amazing work - finding out from all who contact them what a good life would look like and what problems they want to solve. They meet all their demand, they meet it faster than ever before, they provide a far better service to all than they've done before. And they have saved £1.5m in the first full year. It would be great if the regulators had helped them do that and had helped others to learn how to do it too.

Anita Bennett Chair of Rescare and parent of learning disabled adult



Anita Bennett began her career in the UK as a researcher, then PR at Amnesty International, followed by Thames TV and the Sunday Times Insight Team.

She then made films for Channel 4 and ITN on Kurdistan, Mozambique, Brazil, child sex abuse and various medical subjects. Anita became involved in the choice movement for learning disabled children and adults after the birth of her daughter, Isabel, now 28, who has Down's Syndrome.

Anita retrained as an Alexander Technique teacher (STAT) & combined that work with caring for her daughter. She did PR for Camphill Village Trust from 2005-2006, published a Guardian article about the family lobby to save Camphill Coleg Elidyr and organised its presentation in Parliament.

For CVT's Botton Village, together with ARC and L'Arche, she prepared a Westminster Choice Symposium. Anita was a trustee for Camphill Families and Friends from 2002-2014. She is currently Chair of Rescare, which lobbied successfully for the inclusion of the right to choose village and intentional communities into Valuing People Now.

Rescare was founded in late 1984 by a group of parents and relatives of residents at the former Cranage Mental Hospital, as it was known then, in Cheshire. At the time there was no body to represent the views of the families of the 40,000 residents of institutions like Cranage. Within 12 months, similar groups of parents and relatives of residents at 25 institutions like Cranage elsewhere in the UK affiliated to Rescare.

As the NHS closed institutions like Cranage, Rescare campaigned for the conversions of the sites into village communities for the former residents. The campaigns included lobby meetings at Westminster.

Rescare has not favoured one form of residential care over another, nor over supported living. Instead it has also campaigned for the right to choose the most appropriate form of care for the learning disabled person, whether it be supported living in the community or a residential setting.

Rescare also provides a welfare service through a free helpline, which provides advice and support on all aspects of learning disability, whether it be special needs education, entitlement to benefits or housing.

Anita Bennett - synopsis of presentation



Role of Families – legislation:

A brief description of the way that Parliament has recognised the importance of families through mental capacity and mental health legislation, as well as the recent Care Act.

Role of Families - expertise by experience:

A brief overview of the different problems that families face, from calls to Rescare's Helpline. After our children turn 18, parents are often shocked to discover that suddenly their family member is presumed to have capacity unless proven otherwise, and parental views are often sidelined. There is a dramatic increase in family applications to the Court of Protection to obtain deputyship in order to have it recognised that they represent the best interests of their family member. Rescare fields many requests in this growing area, and has engaged in advocacy training.

Housing - village communities:

Prior to the formation of the NHS a number of stately homes were given over by philanthropists for the lifelong care of those unable to care for themselves. They were taken over by NHS, who in turn has sold off a number of these valuable properties, some of which are now gated communities for the wealthy. Rescare now campaigns to convert redundant NHS institutions into village communities—before more are sold off. The Demos-sponsored Commission on Residential Care has now called for surplus NHS land to be used for care facilities.

Housing – choice:

The 2001 White Paper, "Valuing People" and the Statutory Guidance recognised the importance of choice for housing and the role that village and intentional communities have as housing options, beyond simply, for example, the popular small houses of two or three. Over the years a number of village communities have affiliated to Rescare, including Acorn Village, Ravenswood, and the National Autistic Society. The Royal College of Psychiatrists features Community of Communities, to which Camphill and other therapeutic communities have affiliated over the past.

Housing with Care:

Another Commission recommendation was the separation of housing from care, which Rescare supports. Housing with Care can provide a different range of options to suit the different needs of people and provide for their wellbeing.

Conclusion:

A summary which will reiterate points about families, choice of housing options and the importance of village and residential communities as housing options.

About the Alliance for Camphill



The Alliance for Camphill (AfC) is a formally constituted independent association of individuals who support the core principles of the worldwide Camphill movement; specifically:

- Self-managing intentional communities, schools and colleges based on the image of the human being and society articulated by Rudolf Steiner and Karl König;
- Collaborative collegial working, including non-salaried, vocational status where this is freely chosen by co-workers and acknowledged as legal and compliant by the authorities;
- In the case of adult communities, partnership in life and work with (rather than primarily care provision for) people of all abilities and support needs;
- Living arrangements including shared households based on individual needs and preferences;
- Full and appropriate engagement and empowerment of stakeholders in governance, supportive and advisory structures.

The Aims and Purpose of the Alliance are:

- To promote the above principles as an important contribution to society and to the dignity and freedom of human beings with all types of ability and disability;
- To campaign, lobby, represent and where appropriate negotiate in defending, preserving and further developing communities based on these principles.
- To provide positive practical and financial support to individuals and groups working to uphold the core principles, and to request, collect and distribute funds freely given to support these aims.

Suggested Further reading

Shared Lives Plus

<http://sharedlivesplus.org.uk/news/press-and-media/item/149-thousands-of-vulnerable-adults-offered-homes-with-local-families-as-part-of-innovative-social-care-scheme>

The unintentional destruction of intentional communities

<http://www.centreforwelfarereform.org/library/by-date/regulation.html>

University of Birmingham research

<http://rab.bham.ac.uk/pubs.asp?id=bf2de1bb-eeaf-43a7-a0b1-5f4b23434d70>

Cultivating thinking hearts

<http://thechp.syr.edu/resources/rsa-publications/>