CAMPHILL
FAMILIES AND FRIENDS

Notes from Open Meeting
24 April 2021 on Zoom

Welcome and general announcements
Mary Pearson (Chair) welcomed everyone to the meeting and introduced our first speaker.

Speaker 1: Maurice Collins of Reserve Power (mauricecollins@msn.com)

- Maurice has a daughter with learning disabilities. When she was a child, he set up a charity organisation called 'Kith & Kids' which primarily functioned to help provide activities for young people with learning disabilities outside of school.
- The group of parents involved in this charity were concerned about what might happen in the future, when parents are no longer around to look out for their son or daughter. In 2000, 10 families subsequently created a limited company called 'Reserve Power', a lifetime advocacy support scheme. The parents meet as a monthly committee.
- Three advocates are hired by Reserve Power, on a self-employed basis. They are younger than the parents involved.
- The advocates provide a friendship and advocacy service for the participating learning disabled individuals and their families. They act as a support to the disabled family member when the parents are unable to undertake that role for reasons of incapacity or death. They also work to ensure the best possible quality of life of the member with a disability by monitoring lifestyle and, whenever a need arises, advocating to the care organisation or to funding authorities. They ensure that all financial legal entitlements and grants are available to the member and, if not, to advocate to obtain said grants. Each advocate gets to know the family and their son or daughter well over time.
- Each family contributes money every month to fund the service (around £3,000 each year). The more money a family puts in, the more time their son or daughter's advocate spends working with them; it is usually around two to three hours each week. They visit in person or, in Covid-times, make contact virtually,
- There are currently 12 families in Reserve Power. 40% of the people being supported are living in independent accommodation; the rest live in residential communities.
- When Reserve Power began, it was mainly focused on legal advocacy but it has expanded into something more personal as each advocate got to know the person very well.
- Local authorities are informed that the Reserve Power advocate should be recognised as an advocate for the person, and that they are acting on behalf of the parents.
- The advocates report back to relatives after each visit, with an update as to how the person is doing and what was done if there were any issues needing addressing.
- A few parents have sadly passed away since Reserve Power began, and the system is working. Money had been left in their will to continue contributions and/or siblings are getting involved. The advocates are therefore able to continue their

visits, to the benefit of the son or daughter with learning disabilities.
- 60% of the Reserve Power committee is now made up of siblings getting involved with running the company, to ensure its future.
- Advocates have changed over the years, with new employees hired to replace them.
- Reserve Power has set up an independent learning disability expert to act as an advisor should any disagreements arise between advocate and family.
- In 2009, Kith & Kids set up a version of the Reserve Power model, called 'klasp' (Kith & Kids Life-time Advocacy Support Project) as an advocacy service for Kith & Kids service users. Initially 30 families joined the scheme; there are now 26. It was set up as a charity and it raises 80% of its funds through two charity shops. Parents are encouraged to contribute if they are able, but the charity can also cover costs. klasp now has two full-time advocates.
- As with Reserve Power, advocates meet with relatives and the person with learning disabilities to really get to know them and understand their needs. The advocates are involved in many aspects of improving and maintaining a quality of life: from being a friend to helping with arranging a package of care. They help arrange a programme of activities to ensure days have meaning.
- The klasp (charity) model works as well as the (company) Reserve Power model, but with less budget, so advocates may visit every two-to-three weeks instead of every week.
- Overall, Reserve Power and klasp are both highly successful.
- Maurice has set up a trust which offers a grant of £1,500 to any group of parents setting up a lifetime advocacy scheme, to assist in getting them started. Interested parties are welcome to contact him

Maurice took questions at the end of his talk and the following points were made:

- Advocates are recruited, when needed, via an advert in The Guardian or by word of mouth, with subsequent interviews. They look for people with a background in social care or experience as a social worker.
- Reserve Power advocates are regularly sent on training, funded by the central pot of money.
- The advocates are very involved in the lives of the people they are supporting. They attend local authority care review meetings. There has been occasional reluctance to recognise their authority, so parents have had to be insistent and assert that they do want the advocate involved.
- So far, none of the advocates have acted as legally-recognised appointees; local authorities have all eventually recognised the validity of the advocate without the need for this.
- Maurice advises that, from his experience, the optimal size of group for a Reserve Power model is between 10 and 15 families and the optimal size of group for a klasp model is around 18 families.
- If anyone has any questions or wants further advice because they are thinking of setting up a lifetime advocacy scheme themselves, they are welcome to contact Maurice directly.

Mary Pearson introduced our second speaker.

Speaker 2: Cate Searle, solicitor (cate@ms-solicitors.co.uk)

- Cate is a community care law solicitor. Her background includes working in a home for adults with a learning disability as a key worker. This experience inspired her to specialise in this area of law, to ensure that people have a voice when negative decisions are made by health or social services. She is now Head of Community Care Law at her firm.
- The Mental Capacity Act 2005 was implemented in 2007, addressing the issue of whether a person has capacity to make decisions, and setting out the best interest decision-making process if the person lacks capacity to make any specific decision for themselves.
- As a relative of an adult with learning disabilities, you might consider applying for a Health & Welfare Deputyship. However, this is much less commonly granted than the other type of Deputyship (Property & Finance).
- Recently, a group of families got together to run a test case – challenging the court's low likelihood of granting a Health & Welfare Deputyship. The conclusion was that the Code of Practice being followed by courts needs to be revisited, so that it isn't only granted in the most extreme cases.
- The judicial view is that deputyships shouldn't be needed. We shouldn't need a deputy when it comes to a significant decision in our relatives' lives, because if there is any doubt, a Best Interest Meeting should be arranged by those who care for them. A Best Interest Meeting is a multidisciplinary meeting that is arranged for a specific decision around a person's life, when that person is deemed to lack the mental capacity to make the decision for themselves. However, some care providers resent family members having a voice in such instances.
- If you do apply for a Health & Welfare Deputyship, Cate's advice would be to make sure you emphasise awareness of your son or daughter's wishes and feelings. Don't imply that you want to continue your parental responsibilities now they are an adult. Stress that you aren't applying because you are a parent, but because you genuinely believe that you are the best person to enable and empower them to make decisions or have their voice heard, as you know them so well.
- Note that you can apply for a joint appointment (two people share the deputyship) but if that's the case, this arrangement ends when one of the two passes away. It is better to apply for a joint and several deputyship, which allows for it to continue with just one person if needed.
- Even if you have Deputyship or a Lasting Power of Attorney, many major decisions will rest on funding which will still have to be negotiated with the Local Authority (or in some cases, the NHS Clinical Commissioning Group), so there is no "magic bullet" that ensures families can make unilateral decisions for their relative.

Cate took questions at the end of her talk and the following points were made:

- It is not possible to formalise every decision about a person's life. However, if there is a big decision, or if there is potential for something to go wrong, it is always advisable to hold a Best Interests Meeting.
- There is a common issue where our relatives are making what we think are unwise decisions, often doing things which affect their long-term health in a negative way, and we think that they lack capacity on that particular point. It is lazy for care providers to simply argue that they have the right to make unwise decisions, as a sweeping statement. Cate advises asking to see the risk assessment in regards to the particular issue; as part of a best practice capacity assessment, care providers

should have assessed if the person fully understands the risks that flow from unwise decisions – do they fully comprehend the potential reduction in their quality of life?

Mary Pearson thanked both speakers.

Other matters raised:

After a break for lunch, discussion continued, led by general questions from attendees; the following points were made:

- Meeting attendees voted and approved the proposal that Camphill Families and Friends will hold one in-person Open Meeting and one Zoom Open Meeting each year (when Covid safety allows). This will replace the previous system of two in-person meetings each year. Including a Zoom meeting will reduce the need for travel and save money.
- Camphill Families and Friends will endeavour to record the speakers at future Zoom Open Meetings, where possible; the videos will then be made available to members. For privacy purposes, these videos will not include subsequent sections of meetings where attendees are invited to speak.
- In addition to the twice-yearly Open Meetings, it was also agreed that the recent Camphill Families and Friends Coffee Morning Zoom session was a success which should be repeated regularly. Around 20 people attended. These sessions are a chance to connect online with other members and supporters of Camphill Families and Friends, with no agenda or theme. They are an opportunity to drop in, meet others, say hello, or just listen. Details of the next Coffee Morning will be circulated in due course.
- Trustees are also currently considering the best way to facilitate putting members who have relatives in the same community, in touch with each other via community email groups (if they would like to do this). More information will be available on this, once a plan is in place.
- There was a discussion about the varying experiences we have all had, with regards to how each Camphill community is dealing with the pandemic, including arrangements for visiting our relatives and consideration of how many support workers have been vaccinated.
- There was a discussion around how a group of parents might follow the Reserve Power or klasp model outlined by Maurice Collins to create a similar scheme. It was suggested that the Lantern community has a volunteer advocacy project, so they might also be able to advise on this issue.

The Chair closed the meeting and thanked everyone for attending.