

Soteria Network

Charity Commission decision dated 29 February 2012

Issue

1. The Commission considered an application from Soteria Network ("Soteria") for registration as a charity. If Soteria is established for exclusively charitable purposes it is entitled to be registered in the Register of Charities in accordance with s.3A(1) Charities Act 1993.¹

Decision

2. The Commission having considered Soteria's governing document and the case put to it by Soteria including submissions and supporting evidence; other relevant information and the law; concluded that Soteria is established for exclusively charitable purposes and can be entered into the Register.
3. This decision was made under the Commission's decision review process and the decision was delegated to Alice Holt, Head of Legal Services, London.

Background

4. Soteria is an unincorporated association governed by a constitution adopted on 20th October 2007. It applied to be registered as a charity on 7th July 2010. It has the following objects:
5. *To provide, or further the provision of, support to persons who are experiencing, or have experienced, severe mental distress or disturbance, especially psychosis.*
6. *To advance a better understanding of mental health and mental distress, especially psychosis, by promoting research and by obtaining, making records of and disseminating information about the same to the public.*
7. Soteria described its activities in its application for registration in the following way:
'The Soteria Network was established to promote the development of drug free and minimum medication therapeutic environments for people experiencing "psychosis", or extreme states. We are part of an international movement of service users, survivors, activists, carers and professionals fighting for more humane, non-coercive mental health services. At present our priority is to raise awareness about the Soteria tradition by organising conferences and meetings around the UK which

¹ As it is established in England & Wales and has an income of more than £5,000

explore both the Soteria approach and other non-medical alternatives to psychiatric services. In addition to this we aim to support people who are trying to set up such alternative services, and at a local level, we are working towards establishing a Soteria House in the UK'.

8. Soteria's trustees include a locum Consultant Psychiatrist, a Professor of Community Mental Health, an Independent Mental Health Advocate, a former Mental Health Social Worker, a Psychotherapist, users of mental health services and a family carer and independent trainer and consultant on mental health issues.

Soteria method

9. Soteria advised the Commission that the first project following the Soteria approach was in California in 1970 and it ran for 12 years largely financed by research money as the central aim of the project was to evaluate its effectiveness in comparison to inpatient treatment. The central aim of the model is to help people get through acute psychotic episodes such that they can return to live independently. The emphasis in the model is on providing a safe supportive consistent and emotionally relaxing environment rather than engaging people in therapy as such an environment is believed to be a crucial factor in recovery.
10. The emphasis is on building relationships and from there discussing options including medication rather than (as Soteria explained it to the Commission) a traditional approach which starts with medication and then builds relationships. Soteria describes it as "being with" the person rather than "doing to". Soteria explained further that it is not a model that is anti-medication but one where the individual is supported to make an informed choice about medication within a safe supportive environment.
11. There are currently Soteria projects/houses running in Alaska, Switzerland, Germany and Hungary. The Swiss project has been running for 26 years and is well integrated with statutory medical services and funded partially by individual health insurance and partially through the State. The German project is integrated into an existing psychiatric hospital, there is a Soteria ward, and it is funded by insurance companies. The Alaskan project has s.501(c)(3) status in the US.

Activities:

12. Soteria plans to have two broad areas of activity:

- a. Setting up Soteria House(s) (and possibly community outreach programmes and wards in psychiatric hospitals) using the Soteria method.
- b. Carrying out research and holding conferences

Soteria House(s)

13. Soteria has yet to establish any houses but is in discussion in Bradford and in Brighton to do this. The houses will be safe places primarily aimed at people experiencing a first or possibly second psychotic episode. People will receive a clinical assessment and a risk assessment by a mental health professional before coming to live in the house and will receive ongoing assessments whilst they are residents. The houses will be staffed 24 hours by two staff members. The staff working directly with service users day-to-day ('being with' service users, maintaining the house, cooking, etc.) will not necessarily have a professional background (though they may), as the most important factor in their recruitment will be their life experience, interpersonal skills and ability to be with people experiencing acute states of psychosis, without preconceptions.
14. Staff will receive training before they commence their employment. They will be supported by a professional framework including an "on call" service to manage unexpected events and weekly group and individual supervision sessions. The model relies on non-professional staff as part of its philosophy. The approach 'emphasises the value of human relationships and the homeliness of a service.'
15. The assessment as to who accesses the service will be carried out by professionals, ideally but not essentially, in conjunction with local early intervention teams [statutory service] and professional staff would be managing the service and supervising the non-professional staff working directly with the people receiving the service. The need for medication would be considered carefully by a senior appropriately trained medical practitioner in conjunction with the person using the service.
16. Soteria say that "essentially the Soteria approach offers the opportunity for someone to manage their acute episodes with maximum interpersonal support and minimal medication. In this way they will be far less likely to be subject to complications/side effects of medication". Risk assessments would be carried out and a risk strategy adopted to manage risk. CRB checks would be carried out for all working with the project.
17. Ideally Soteria will want to have a close relationship with state services including having referrals from it and the ability to have people assessed by the state services. However, this close relationship is not

essential to the running of the house and Soteria argue that the value of the house is to some extent that it is an alternative option to that offered by the state. People will be able to self-refer to the Soteria House and they anticipate referrals from local statutory services. They have good links with early intervention services in Bradford (where they intend to establish the Soteria House) and have been told there are many people that they think will benefit from the service and 'who they would gladly refer to us'.

Research and conferences

18. Soteria confirmed that the research, although focused on the effect of the Soteria method, will be meeting the requirements of research as that term is understood in charity law. Soteria hope that the research is carried out by independent researchers but in any event assured the Commission that the research team will include independent researchers. It will be peer reviewed and in other ways meet academic research standards. The useful results both positive and negative will be published free to the public.
19. Soteria has to date held an annual conference considering the Soteria approach and other alternatives to existing treatments. Soteria advised the Commission that the purpose of these is to inform and educate people about new approaches, to allow a space for discussion and reflection and to encourage constructive debate. These conferences are open to anyone who has an interest in developing mental health services, and have attracted mental health professionals as well as service users and ex service users, their families and carers. A charge has been made, but places have been made available to those unable to pay the charge.

The legal background

20. To be a charity an organisation has to be established only for charitable purposes and these are defined in s.2 Charities Act 2006 (the 2006 Act) as purposes that fall within the descriptions of purposes in s.2(2) and are for public benefit (as charity law understands that term).
21. Where a purpose or purposes are ambiguous or novel and in any event in order to consider whether the purpose in any particular case is for public benefit, the Commission follows the practice of the First-Tier Tribunal and the Court in considering the factual background.²

² See Full Fact v Charity Commission First-Tier Tribunal Case No CA/2011/0001 for more detail about the Tribunal's approach

22. In considering whether a purpose falls within a description or descriptions the Commission notes that where any term used in a description has a particular meaning in charity law it has that meaning in the 2006 Act³.
23. In considering whether a purpose is for public benefit, the Commission follows the approach of the tribunal and the court.⁴ This includes assessing if benefit is demonstrated on the evidence and balancing it against the harm⁵.
24. The Commission has considered how the law applies to organisations that promote complementary or alternative treatments or therapies and its approach is attached as Annex A.

Analysis of Soteria Network

First object – promotion of health

25. Soteria's first object is the provision of "support" to people with particular health needs. Although potentially ambiguous as support might be financial support, when taking account of the factual background, support is understood by the Commission as a means of relieving sickness or promoting health. This object potentially falls within the description the promotion of health or the saving of lives (s.2(2)(d)) 2006 Act.

Efficacy of Soteria method

26. In 2008 a systematic review⁶ was undertaken of all the controlled trials that have assessed the efficacy of the Soteria paradigm and concluded as follows:

"The studies included in this review suggest that the Soteria paradigm yields equal, and in certain specific areas, better results in the treatment of people diagnosed with first- or second-episode schizophrenia spectrum disorders (achieving this with considerably lower use of medication) when compared with conventional, medication-based approaches."

27. One of the authors of this review is a trustee of Soteria.⁷ This review has not been universally accepted and criticisms of it were made by

³ S.2(5) 2006 Act

⁴ Full Fact (as above) and R(Independent Schools Council) v Charity Commission/AG v Charity Commission [2011] UKUT 421 (TCC)

⁵ R(Independent Schools Council) as above @ 94 -110 in particular

⁶ Calton T, Ferriter M, Huband N et al 'A Systematic Review of the Soteria Paradigm for the Treatment of People diagnosed with Schizophrenia' Schizophrenia Bulletin 34: 181-92 2008

⁷ Calton T

the Centre for Reviews and Dissemination (CRD) at the University of York⁸. These were put by the Commission to Soteria and Mr Calton responded to it in a paper he submitted to the Commission⁹.

28. In this he argues that although the research base is small, and there are queries about its methodology in some regards and with regard to whether the research is relevant in the UK context, this does not render its findings null and void, but rather it constrains the strength of the claims that can be made in respect of the data analysed. He argues that the limitations don't mean the findings are inconclusive, and points out that the findings are not used to suggest that the Soteria method should replace traditional methods but rather that it would be unethical to ignore a method that could potentially be as effective, and in certain domains better than, traditional methods.

29. Soteria also pointed to the fact that the method is used in Germany and Switzerland with state services and funded by the state and insurance companies¹⁰. They argue that this is evidence that a body of responsible clinicians must consider it is of benefit, and that it has also been considered by the ethics committees of these countries. The reference to a body of responsible clinicians refers to the Bolam test¹¹ which is a test used to assess whether doctors are negligent. The Commission's view is that the test for whether a doctor is negligent is different to the test for determining if a treatment demonstrates a beneficial efficacy but recognises that it is of some relevance to that question¹².

30. Soteria also referred the Commission to research which it argues demonstrates the limitations of anti-psychotic medication¹³. This coupled with the rise of notions of consumer choice & values based practice which they argue, citing evidence¹⁴, sits at the heart of UK government health policy means that there is a growing interest in creating alternatives to traditional inpatient treatment.

31. Soteria argue that their approach is similar to that of other registered charities which provide therapeutic community services such as The

⁸ Centre for Research & Dissemination 2009 (www.crd.york.ac.uk)

⁹ July 2011

¹⁰ Evidence was supplied demonstrating two projects in Germany (dating from 1999 & 2003 respectively) which are integrated into psychiatric hospitals and paid for by insurance as well as other 'Soteria' wards. Evidence was also supplied demonstrating that Soteria Bern is a state supported mental hospital supported by the Bernese government.

¹¹ ***Bolam v Friern Hospital Management Committee*** [1957] 1 WLR 582 - "*If a doctor reaches the standard of a responsible body of medical opinion, he is not negligent*"

¹² The Commission has no jurisdiction to form a view on whether there is a sufficient body of responsible clinicians such that the Bolam test is satisfied in any event.

¹³ Lepping P, Sambhi, S, Whittington R, Lane S & Poole R. [2011] Clinical relevance of findings in trials of antipsychotics; systematic review *British Journal of Psychiatry*, 198, 341-345

¹⁴ *Refocusing the Care Programme Approach* – Dept of Health [2008]

Philadelphia Association, The Arbours Association and the Richmond Fellowship. The Commission noted this but also that the register is not a precedent source, and that the issue before it is to be considered in relation to this particular organisation.

32. The Commission sought the views of the Department of Health. It responded that it was not familiar with the Soteria tradition. It added that 'in general the government's view is that NHS and local government commissions should commission evidence based treatment and care which should be consistent with NICE guidelines.' It was not clear to the author of the letter how the Soteria method would fit within the guidelines. The view was given that this should not mean that the Commission should refuse charitable status, but rather that the department could not advocate for it. The Commission noted this view which it saw as broadly neutral but did refer the Commission to the NICE guidelines.
33. The Commission noted that there are "NICE guidelines on Core Interventions in Treatment and Management of Schizophrenia"¹⁵ and these do not refer to the Soteria approach. Soteria explain that this is likely to be because there are no Soteria houses in the UK and as a result there has been no consideration of its methods. These guidelines refer to treatments that are person centred and include the prescription of antipsychotic medicine but also refer to a range of psychological and psychosocial interventions.
34. **Conclusion:** Soteria has provided evidence of the benefit of the Soteria method which in summary is that its outcomes are at least equal to those of traditional methods and that it is integrated into the state systems in two European countries where it is paid for by those states and insurance companies. Although this evidence is not accepted by all professionals in this field, it is evidence of a quality that a court or Tribunal would acknowledge as demonstrating some benefit.

Does the benefit outweigh the harm

35. The Commission noted the indicators of harm it had identified generally in relation to complementary or alternative treatments (CAM) as set out in Annex A.
36. The Commission noted the potential harm that might flow from the method which include:
 - a. people might be more appropriately treated by the use of traditional methods;

¹⁵ On NICE website NICE clinical guideline 82 (2009) *Schizophrenia* - Quick reference guide emphasises a focus on promoting people's choices [The full guideline is also available on NICE website]

- b. people who need medication and/or psychological or psychosocial interventions might not be offered it as they will not be linked into the state systems;
- c. vulnerable people will be living in a house where the resident staff are not medically qualified professionals nor necessarily will they have any other relevant qualifications such as care qualifications.

37. The Commission noted that Soteria explained that the Soteria method:

- a. is to be provided as an alternative treatment and although Soteria want a close relationship with state provision, this is not essential;
- b. allows the person experiencing the mental distress to make an informed choice about whether to use medicine and although it does not actively discourage the use of drugs it is focused on ways of relieving sickness that reduce the use of drugs;
- c. does not involve the provision of medicine or invasive treatment except under the supervision of qualified medical professionals.
- d. distinguishes between the harm that might be a feature of someone's distress (self harm or violence to others) and harm that results from a particular intervention. Its approach to the former is to identify risk and manage risk as far as possible. Their approach to the latter is that it should not arise as one of its key principles is "first, do no harm". Their approach is "being with" rather than "doing to" and the approach involves a potentially lesser reliance on medication. The Soteria method does not exclude the possibility of people living in the house taking medication. 'We would want to prioritise the individual's choice in this matter';
- e. is provided on a day to day basis by people who may not be qualified mental health professionals, but the provision is within a framework supported by suitably qualified mental health professionals;
- f. the people who might benefit from this method are selected by a clinical assessment and a risk assessment by a suitably qualified mental health professional (and these are regularly reviewed) and the support at the house is given within a framework that is managed by suitably qualified mental health professionals. An "on call" service from suitably qualified mental health professionals is provided to deal with unexpected events and residents will be referred for assessment to state services where appropriate;
- g. is most widely used for those experiencing their first (and possibly second) psychotic episode but has also been used for people with enduring experiences of psychosis, and so it could be developed to include such people.

38. The Commission also noted that Soteria had advised it that research is a secondary purpose to the setting up of a Soteria House as its main aim is to provide services to those suffering from mental distress. It is, however, important to Soteria to evaluate the service it provides so that it can continue to improve its service. In addition in order to achieve sustainable funding it will need to demonstrate effectiveness. Soteria also confirmed to the Commission that if the research findings are such that the Soteria method is harmful or of no benefit in a UK setting, Soteria will cease to support the Soteria method.
39. The Commission also noted that the benefit would be available to all those who might benefit from the treatment. The trustees confirmed that “Unless we are able to provide the majority of places at a Soteria House free (or at least within the means of the poor) we will not be establishing services.

Conclusion:

40. The Commission concluded that as a result
- a. The potential harm that might be said to arise does not outweigh the benefit identified by the method.
 - b. The benefit is to a sufficient section of the public being those who might benefit from the treatment.
 - c. That in consequence this first object is a charitable purpose falling within the description the advancement of health and is for public benefit.

Second object – “To advance a better understanding ...”

41. Soteria’s second object potentially falls within the advancement of education (s.2(2)(c) or (m)) if it is carrying on research for public benefit. The Commission’s understanding of the law in relation to these purposes is set out in its statutory guidance “The Advancement of Education for Public Benefit” and its underlying analysis of the law, and its guidance “Research by Higher Education Institutions”.¹⁶ It would not fall within the charity law understanding of these purposes if the purpose of the education or research is not to educate or carry out research in a neutral balanced way but is rather to promote a particular opinion or point of view. If the purpose is to educate or provide information to promote a particular form of treatment or therapy this would not be education as the law understands this but it might fall within another description and particularly that of promoting health as discussed for the first object.

¹⁶ On Commission’s website – Some of this guidance may be impacted by a recent decision *ISC v Charity Commission*, however the aspect relied on in this decision is not impacted.

42. The Soteria method is capable of being a subject of study and the Commission noted that part of Soteria's motive in setting up a Soteria house is so that it can be the subject of research into the effectiveness of the Soteria method.
43. Soteria's campaigning activities: Soteria confirmed that it is not a campaigning body and is not established to directly influence NHS policy. It hopes in time to engage with the NHS more, to work with them to develop a wider range of services for people experiencing psychosis and perhaps to work with it to develop an evidence base for the Soteria method.
44. The evidence before the Commission, as summarised in this decision demonstrates that the education and research is for public benefit.
45. **Conclusion:** The second object is an object to carry out research for the public benefit and is a charitable purpose.
46. **Right of appeal:** There is a right of appeal to the First-tier Tribunal (Charity) against the Commission's decision to enter an institution in the register of charities. More information about time limits, form of notice of appeal and how to make an application can be found on the Tribunal website: <http://www.justice.gov.uk/guidance/courts-and-tribunals/tribunals/charity/appeals.htm>

There are time limits to making an application to the Tribunal. An application to the Tribunal should be made within 42 days of the date on which the notice of our decision was sent to the applicant or, if the applicant is not the subject of the decision, 42 days from the date when the decision was published.

Promoting health and relieving sickness using alternative or complementary methods.

The Commission's approach

The Commission's approach in considering whether or not any particular alternative or complementary method is capable of promoting health or relieving sickness for public benefit is based on the law. The law requires a link between the benefit claimed and the purpose and that the purpose be for public benefit. The law also requires that benefit be demonstrated by evidence.

The Commission has taken notice of the importance the law has given to benefit being proved in this area because of the risk of harm from treatments that have not been rigorously tested before being available for use. It also noted that the law has recognised that people who are ill may be more willing to try (and to pay for) treatments or therapies in order to be cured and that harm may occur as a result.¹⁷ The Commission also noted that if it gives recognition to a treatment this may be seen by some as a "kite mark" for that treatment although this is clearly not its function in considering whether an organisation is a charity. The Commission's functions include promoting public trust and confidence in charity, and there is a risk that this would be compromised should the Commission accept treatments as being capable of promoting health either where this benefit is not clearly proven or where the risk of harm is great and safeguards are not in place.

The Commission therefore takes the view that clear evidence to support any benefits claimed is required before it can be satisfied that benefit is demonstrated and that any potential for harm should be minimised before it can be satisfied that the benefits outweigh the real risk of harm.

Terms used:

The Commission recognises the difference between alternative and complementary treatments or therapies and uses these as follows:

Alternative – that the treatments or therapies are offered separately from conventional medicine.

Complementary – that the treatments or therapies are offered alongside or as complements to conventional medicine.

The same treatment or therapy may be being offered as an alternative or as a complementary method depending on the facts of each particular organisation.

The Commission also recognises the difference between curative, diagnostic and palliative treatments or therapies and uses these as follows:

¹⁷ s.4 Cancer Act 1939; House of Lords Select Committee Report on Science & Technology 1999-2000 paras 4.8, 4.21, 7.3, licensing regime of NICE (National Institute for Clinical Excellence)

Curative – that the treatment or therapy is capable of curing the illness or condition being treated

Diagnostic – that the treatment or therapy is capable of diagnosing illness or conditions

Palliative – that the treatment or therapy does not cure or diagnose but provides relief from symptoms of illness or condition.

The Commission's approach in more detail

Benefit – link between the treatment or therapy and the benefit claimed

The Commission considers the aims of the organisation that applies to register as a charity having identified these in accordance with the law.¹⁸

It will then look for evidence proving that the particular therapy or treatment is capable of curing, diagnosing or providing palliative relief in respect of any particular illnesses or conditions according to the claims made by the organisation seeking registration.

- *An organisation claims to diagnose and cure all illnesses by offering treatment X. CC will want evidence to demonstrate it can diagnose and cure all illnesses.*
- *An organisation claims to cure a particular illness, for example addiction to substances. CC will want evidence to demonstrate that the particular treatment cures substance abuse.*
- *An organisation claims to provide palliative relief for a particular illness by reducing stress and pain. CC will want evidence to demonstrate that the particular treatment does provide this palliative relief.*

It will be more difficult in practice to demonstrate on evidence that a particular treatment or therapy that is offered as an alternative to conventional medicine is capable of diagnosing, curing or providing palliative relief.

The evidence will need to be evidence of the quality that a court can recognise. This means evidence such as peer reviewed research in recognised medical journals or acceptance by the Department of Health or other governmental health regulatory or health provision body. At the other end of the scale, testimonials from individuals who claim to have been cured or otherwise benefitted are of minimal, if any, evidential weight. For some treatments this evidence is already accepted by the law, and caselaw and in those cases the Commission will not require further evidence.¹⁹ The Commission is also aware of the House of Lords Report that considered some therapies and treatments in 2000 and will take its conclusions into account

¹⁸ Full Fact v Charity Commission 1st Tier Tribunal (Charity)

¹⁹ The fact of regulation of some treatments such as osteopathy and herbal medicine by statute reflects this acceptance. The Commission recognised that spiritual healing may be capable of giving palliative relief in its decision National Federation of Spiritual Healers available on the Commission's website.

where relevant²⁰. The Commission is aware that not all forms of alternative or complementary treatment may lend themselves to conventional research methods²¹

Benefit or Harm

The Commission recognises that there is more potential for harm in the following circumstances (this is not an exclusive list):

- Alternative treatment or therapy. This is because people seeking these treatments or therapies may not seek, or may delay seeking conventional treatment as a result.
- Treatments that claim to cure or diagnose.
- Treatments that are not regulated – the hallmarks of regulation are: a professional qualification (and ongoing professional education); professional standards; a regulatory body that can remove the ability to practice; a complaints system; insurance to cover mistakes;
- Treatments that claim to be effective for all illnesses or conditions;
- Treatments or therapies that involve people taking medicines or receiving treatments that are invasive;
- Treatments or therapies that involve people removing clothing or otherwise making themselves more vulnerable to abuse.

It will look for evidence to demonstrate that these indicators of harm are minimised or reduced in assessing whether public benefit is demonstrated. For example:

An organisation uses a particular therapy which does not involve medicine, invasive treatment or require people to remove their clothes to relieve sickness. It offers it as a complementary therapy and claims it is palliative as it relieves stress for people in hospices but does not diagnose or cure illnesses or conditions. It requires its practitioners to give out a leaflet that clearly tells people this and advises them to see their GP as well as receiving this treatment or advises them to see their GP first. It also has a clear and comprehensive regulatory regime. [It provides an article from the Lancet which concludes that the therapy is capable of relieving stress for people in hospices.] The CC accepts that the link between the therapy and the benefit claimed is proved on evidence and that the potential harm is relatively low and minimised by the way it is being offered. The CC accepts that public benefit is demonstrated as a result.

The organisation claims that the treatment will cure a particular illness. The people giving the treatment have no particular training. There is no regulatory regime and no requirement for insurance. The treatment involves people adopting a particular diet and drinking a proprietary drink. It will not say what is in the drink as this is a commercial secret. The organisation produces articles from magazines written by GPs that endorse its treatment.

²⁰ 6th report of the House of Lords Select Committee on Science and Technology 1999-2000

²¹ 6th report of the House of Lords Select Committee on Science and Technology 1999-2000 para 7.3

The CC does not accept that the link is made as the evidence is not of sufficient quality to demonstrate that the treatment is curative. It also does not accept that the treatment is not harmful as there are insufficient safeguards.

The Commission recognises that statutory (including self-regulation) of a method is likely to be relevant in demonstrating that harm is outweighed by benefit where:

- Regulation requires professional training to qualify and remain qualified as a practitioner of the method
- Regulation involves a supervisory and complaints regime
- Regulation ensures compulsory insurance to protect those receiving the treatment