



12/27/12

Greetings,

The following packet contains information from the initial development phase of Soteria-VT by Pathways Vermont, who has several staff contributing to its start-up.

In this phase, we accomplished:

- Completion of initial development plan
- Researching the original model, replicas, and similar approaches, including a site visit to Soteria-Alaska
- Setting up Soteria-VT infrastructure within Pathways Vermont and launching a website
- Authoring promotional materials, creating a comprehensive presentation and workshop about Soteria (available online), and promoting Soteria-VT within Burlington, statewide, and at a nationwide conference
- Connecting and establishing relationships with various local stakeholders and potential partners, as well as families and peers
- Forming an Advisory Committee of diverse interests
- Preliminary exploration of possible site locations
- Organizing a Harm Reduction Approach to Psychiatric Drugs training

The big developmental task ahead is finding and leasing a house and getting it licensed to operate. Then, of course: hiring staff, training them, and opening the doors.

Many people have contributed their expertise so far to this project's development, but I want to especially thank the Soteria-Alaska crew who generously shared their time, wisdom, and informational materials with me. And to Hilary Melton and Laura Sisson of Pathways, whose passion and dedication to seeing this project through is an inexhaustible source of inspiration.

Sincerely,

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## A NOTE ABOUT LANGUAGE

Throughout this document I use the term "psychosis," which I realize has a strong medical connotation as well as cultural association with danger that renders it offensive and inadequate to many people. "Altered states" and "extreme states" are two alternative terms that I have heard proposed, but which feel too broad and uncommon for purposes here. I strongly believe that alternatives to the medical model should strive to create or incorporate new ways of talking about psychiatrically-labeled phenomena that are empowering, accurate, and accessible. My hope is that should a similar report be written a few years down the road, an adequate term to replace "psychosis" will have emerged and become significant enough in the lexicon of health to be communicated with a broad audience. In the meantime, I have stayed with "psychosis" – mostly for convenience, and always as a categorical descriptor of a set of experiences, not an identification of disease, disorder, or illness.

For similar reasons, I have opted to use the term "antipsychotics" instead of lesser-known "neuroleptics," though the former is misleading propaganda that falsely implies a specific mechanism of action where one does not exist.

### BACKGROUND<sup>1</sup>

At the invitation of the Department of Mental Health (DMH), the original Soteria-Vermont proposal<sup>2</sup> was submitted by Steven Morgan in August 2011 and was supported by a broad range of stakeholders. Several weeks later, Hurricane Irene destroyed Vermont State Hospital, putting the system of care in crisis but also opening up significant funding. Working with recommendations from DMH, the Vermont Legislature came together in early 2012 to create *Act 79: An act relating to reforming Vermont's mental health system*,<sup>3</sup> which significantly reduced the size of a future state hospital by enhancing community supports and funding new initiatives. The following language to create Soteria-VT was part of this legislation:

"...the commissioner of mental health is authorized to contract for...a voluntary five-bed residence for individuals seeking to avoid or reduce reliance on medication or having an initial episode of psychosis. The residence shall be peer supported and noncoercive, and treatment shall be focused on a nontraditional, interpersonal, and psychosocial approach, with minimal use of psychotropic medications to facilitate recovery in individuals seeking an alternative to traditional hospitalization."

Because the Soteria model focuses on nontraditional supports, it was important to house it within an organization outside of the traditional mental health designated agencies to ensure the best chance at fidelity. Pathways Vermont – whose mission is to transform the lives of people experiencing mental health challenges by supporting their chosen paths to well being in an atmosphere of hope and mutual respect. We advocate for people's right to self-directed lives free from stigma and discrimination, and promote equal rights, community integration, health care, affordable housing, and employment for all – was awarded a contract beginning September 1<sup>st</sup> 2012 to develop this program. The annual appropriation towards Soteria-VT is currently \$1 million.

Soteria-VT will be based on Soteria-California, an experimental program from the 1970s that was designed by Dr. Loren Mosher<sup>4</sup> and funded with a National Institute of Mental Health grant. The Soteria model differs from traditional hospitalization in its focus on "being with" instead of "doing to" individuals, its tolerance and flexibility to adapt to one's process, its cautious use of antipsychotic medications, its creative and non-professionalized environment,

<sup>&</sup>lt;sup>1</sup> Video overview: <a href="http://www.madinamerica.com/2012/08/a-brief-history-of-the-vermont-soteria-project/">http://www.madinamerica.com/2012/08/a-brief-history-of-the-vermont-soteria-project/</a>

<sup>&</sup>lt;sup>2</sup> See Appendix A: Original Soteria-VT Proposal

<sup>&</sup>lt;sup>3</sup> http://www.leg.state.vt.us/docs/2012/Acts/ACT079.pdf

<sup>&</sup>lt;sup>4</sup> http://en.wikipedia.org/wiki/Loren Mosher

and most importantly, its belief that psychosis can be a temporary experience that one can work through as opposed to a chronic mental illness that needs to be managed.<sup>5</sup>

Soteria-CA lasted for eleven years and was rigorously studied. Compared with controls at a traditional hospital, residents fared as well or better on every measure. In effect, it proved that interpersonal and psychosocial approaches alone can facilitate recovery for many persons on course to being diagnosed with schizophrenia.

Ideally, Soteria-VT will work with people having a first or second experience with psychosis who have not had substantial exposure to antipsychotic medication. Its primary service will be interpersonal relationship-building in a safe, flexible, empowering, and homelike environment. Additionally, Soteria-VT will offer trauma-informed peer supports, Naturopathic consultation, voluntary medication in selective instances, techniques for stress reduction, access to creative tools, skill development, gardening, healthy food, and the ability for folks to continue social roles. Based on data available, stays at Soteria-VT are expected to average three to four months.

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<sup>&</sup>lt;sup>5</sup> See also Appendix B: Promotional Materials

### THE NEED FOR SOTERIA

The case for creating Soteria-VT in part depends on understanding the limits of our current medical model approach to psychosis, about which several points can be made:

- Rates of diagnosis of early—onset schizophrenia are significantly increasing<sup>6</sup>
- Hospitalization is the only public option for individuals experiencing first-break psychosis who are extremely distressed and want/need a break from circumstances
- A hospital's approach to psychosis is almost invariably to prescribe, coerce, or force psychiatric medications upon individuals
- Clinicians at hospitals often see first-break psychosis as the first step towards chronic mental illness, so people are diagnosed with long-term chronic conditions, told to stay on medications indefinitely, and often internalize hopelessness
- By using coercion, sometimes force, the current system creates distrust in people and makes them more reluctant to seek help voluntarily in the future

Reflecting on this current state of affairs, Thomas Insel, the Director of the National Institute of Mental Health, exclaims:<sup>7</sup>

Treatments, especially pharmacological treatments, have been in wide use for nearly half a century, yet there is little evidence that these treatments have substantially improved outcomes for most people with schizophrenia.

Sustained recovery occurs in less than 14% within the first five years following a psychotic episode. Longer-term outcomes may be marginally better...Throughout Europe, less than 20% of people with schizophrenia are employed. A large US study found nearly 20% homeless in a one-year follow up. And a recent report from a patient advocacy group reported that in the US those with serious mental illness were three times more likely to be found in the criminal justice system than in hospitals.

With such poor outcomes for people experiencing psychosis, researchers are beginning to question the impact of antipsychotic drugs on health, with some prominent figures even calling for "the end of the psychopharmacological revolution." Data indicating the potentially harmful

<sup>&</sup>lt;sup>6</sup> http://onlinelibrary.wiley.com/doi/10.1111/j.1600-0447.2012.01913.x/abstract

http://www.nature.com/nature/journal/v468/n7321/full/nature09552.html

<sup>&</sup>lt;sup>8</sup> http://bjp.rcpsych.org/content/201/2/168.full

effects of antipsychotics is plentiful,<sup>9</sup> including recent studies that indicate significant brain matter loss from prolonged use. For example, a study in the Archives of General Psychiatry 2011 concludes:<sup>10</sup>

During longitudinal follow-up [of 211 patients], antipsychotic treatment reflected national prescribing practices in 1991 through 2009. Longer follow-up correlated with smaller brain tissue volumes and larger cerebrospinal fluid volumes. Greater intensity of antipsychotic treatment was associated with indicators of generalized and specific brain tissue reduction after controlling for effects of the other 3 predictors. More antipsychotic treatment was associated with smaller gray matter volumes. Progressive decrement in white matter volume was most evident among patients who received more antipsychotic treatment. Illness severity had relatively modest correlations with tissue volume reduction, and alcohol/illicit drug misuse had no significant associations when effects of the other variables were adjusted.

Even the dominant biopsychiatric worldview that posits schizophrenia as a tangible and discrete brain disease is being reconsidered,<sup>11</sup> tempered by neuroscientific findings that suggest the brain is complex beyond comprehension, capable of producing the same results through multiple pathways, inextricably connected to and influenced by the body, and ever-changing in response to the environment.

New research suggests that people at "ultra-high risk" of psychosis should not be placed on psychiatric drugs as a preventative measure, 12 and subtle brain abnormalities in people who first experience psychosis are greatly exaggerated once taking them. For instance, the chart below is from a recent meta-analysis that compares brain differences in first-episode antipsychotic-naïve patients versus first-episode medicated patients: 13

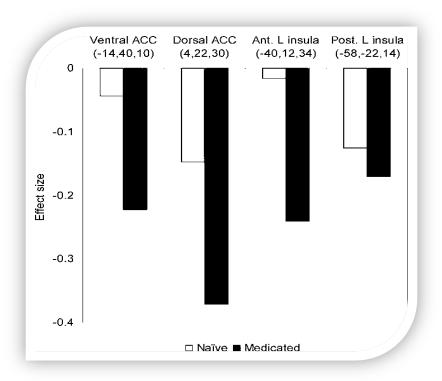
<sup>&</sup>lt;sup>9</sup> See Robert Whitaker's book, <u>Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America</u> for an excellent overview; his website <u>www.madinamerica.com</u>; and this review: <a href="http://www.madinamerica.com/2010/04/schizophrenia/">http://www.madinamerica.com/2010/04/schizophrenia/</a>

<sup>10</sup> http://www.ncbi.nlm.nih.gov/pubmed/21300943

http://www.ncbi.nlm.nih.gov/pubmed/23172002

http://article.psychiatrist.com/dao 1-login.asp?ID=10008115&RSID=13596727969411

http://www.ncbi.nlm.nih.gov/pubmed/22910680



As demonstrated, brain abnormalities in antipsychotic-naïve patients from controls are small, but any observable difference are greatly accentuated by the drugs.<sup>14</sup>

In addition to evidence that antipsychotics carry significant neurological risks, their basic efficacy is now in doubt. In the CATIE trials – the largest study ever of antipsychotic efficacy for people diagnosed with schizophrenia, 74% of participants (1061 of 1432 people) quit taking their initially-assigned antipsychotic within 18 months, mainly due to ineffectiveness or intolerable side effects. Of these unsatisfied participants, about half (509 people) dropped out of the study altogether, while the other half entered a second phase in which they tried a different antipsychotic. During the second phase, 44% of participants assigned to clozapine (20 of 45 people) and 75% of participants assigned to another antipsychotic (282 of 378 people)

<sup>&</sup>lt;sup>14</sup> It is worth noting that studies of antipsychotic-naïve patients often define "antipsychotic-naïve" as having not used the drugs above a certain threshold of time, sometimes as long as thirty days. Thus, it's possible these researchers included studies of antipsychotic-naïve patients who were not truly antipsychotic-naïve (they do not address this problem in their article), in which case the small brain differences in antipsychotic-naïve patients may not exist but rather represent short duration of drug use. It is also possible, according to the researchers, that those small brain differences in antipsychotic-naïve patients "…represent the neural correlates of the high levels of stress and anxiety that are usually associated with the first onset of frank psychotic symptoms" instead of any disease process, in which case the accentuation of them when taking the drugs indicates an amping up of stress and anxiety from usage.

<sup>15</sup> http://www.nejm.org/doi/full/10.1056/NEJMoa051688

again discontinued it within 18 months. These poor outcomes were recently reproduced in a study of antipsychotics in older populations that found:

Overall results suggested a high discontinuation rate..., lack of significant improvement in psychopathology, and high cumulative incidence of metabolic syndrome (36.5% in 1 year) and of serious (23.7%) and nonserious (50.8%) adverse events for all atypical antipsychotics in the study.

Employing a study design that closely mimicked clinical practice, we found a lack of effectiveness and a high incidence of side effects with 4 commonly prescribed atypical antipsychotics across diagnostic groups in patients over age 40, with relatively few differences among the drugs. Caution in the use of these drugs is warranted in middle-aged and older patients.<sup>18</sup>

Furthermore, data from multi-country World Health Organization studies indicates that people diagnosed with schizophrenia in developing countries where antipsychotic-drugs are hardly used have almost twice the recovery rate of similar people in developed countries where antipsychotics are widely used. The WHO suggests the better outcome "...[is] unrelated to drug treatment since many in the developing world [do] not receive continuous treatment. Psychosocial factors, such as better family support, community tolerance, extended networks and more favorable job opportunities, have been postulated as the reasons for this observation."

One of the few modern studies looking at recovery rates among people diagnosed with schizophrenia who self-select to be on or off antipsychotics clearly shows better outcomes for the latter:<sup>20</sup>

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<sup>&</sup>lt;sup>16</sup> http://ajp.psychiatryonline.org/article.aspx?articleid=96510

http://ajp.psychiatryonline.org/article.aspx?articleid=96511

http://article.psychiatrist.com/dao 1-login.asp?ID=10008114&RSID=86690782058284

<sup>&</sup>lt;sup>19</sup> http://www.ncbi.nlm.nih.gov/pubmed?cmd=Retrieve&db=PubMed&list\_uids=1565705

http://www.ncbi.nlm.nih.gov/pubmed/22340278

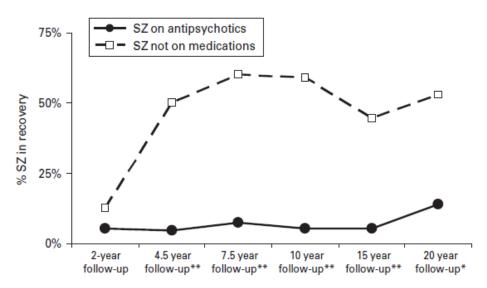


Fig. 1. Relationship between recovery and use of antipsychotics in schizophrenia (SZ). \* p < 0.01, \*\* p < 0.001.

According to this data, at any point over twenty years the chances of recovery for people taking antipsychotics is extraordinarily poor: in the realms of 5 - 10%.

While a more comprehensive analysis of standard psychiatric treatment is needed to fully realize its efficacy and limitations, such is beyond the scope of this report. For purposes here, it is important to note broad trends in research that shows:

- 1. Antipsychotic drugs have severe side effect profiles, can contribute to early death, cause extraordinary rates of diabetes and metabolic disorders, and often rob vitality
- 2. Many antipsychotic drugs significantly shrink brain volume (and cause other physiological brain changes) in proportion to the dose and frequency taken
- 3. Long-term antipsychotic drug use often makes individuals *more* vulnerable to relapse, and to withdrawal psychosis
- 4. Since the advent of antipsychotic drugs, rates of long-term disability due to mental illness have been increasing, not decreasing
- 5. The majority of people quit taking antipsychotics after a short amount of time anyway (mostly due to intolerable side effects), which then places them at high risk of withdrawal syndrome

In light of these concerns, many consumer/survivor/ex-patients, advocates, researchers, writers, mental health workers, and family members are asking what can be done differently. Enter Soteria.

## RESEARCH

Many papers have been written about Soteria-CA<sup>21</sup>, some published and some not. The Soteria book, *Soteria: Through Madness to Deliverance*, <sup>22</sup> is an indispensable resource for reviewing the outcome studies, learning the dynamics of the house, and understanding how the community responded to crisis. It is the best "How to Create a Soteria House" manual available. Also, the Soteria-VT website<sup>23</sup> hosts a multimedia presentation called *Rethinking Psychosis: The Soteria Model for First Break*<sup>24</sup> that reviews much of the content in this report.

In addition to the book, the following is a recommended reading list of journal articles and Soteria-specific documents:

- A systematic review of the Soteria paradigm for the treatment of people diagnosed with schizophrenia. Calton T, Ferriter M, Huband N, Spandler H. Schizophr Bull. 2008 Jan;34(1):181-92.
- At issue: predicting drug-free treatment response in acute psychosis from the Soteria project. Bola JR, Mosher LR. Schizophr Bull. 2002;28(4):559-75.
- <u>Soteria and other alternatives to acute psychiatric hospitalization: a personal and professional review.</u> Mosher LR. J Nerv Ment Dis. 1999 Mar;187(3):142-9.
- <u>Soteria-California and its Successors: Therapeutic Ingredients.</u> Mosher LR. In Ciompi L, Hoffmann H, & Broccard M (Eds.) Wie wirkt Soteria? Ein atypische Pssychosenbehandlung kritisch durchleuchtet (Why does Soteria work? An unusual schizophrenia therapy under examination) Huber: New York and Bonn pp. 13-43, 2001.
- <u>Soteria Project Final Progress Report.</u> Mosher LR, Vallone B. Submitted to NIMH. Mar 1992.
- <u>Treatment of acute psychosis without antipsychotics: two-year outcomes from the Soteria project.</u> Bola JR, Mosher LR. J Nerv Ment Dis. 2003 Apr;191(4):219-29.

Reviewing the original data can be confusing because there were two separate periods of study. Each captured a different phase of Soteria-CA's life, and each was influenced by demands from the National Institute of Mental Health that affected the evaluation, design, and inclusion criteria between the two. Mosher believed the changes adversely shaped the results.

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<sup>&</sup>lt;sup>21</sup> See Appendix C: Articles and Studies about Soteria for a more comprehensive list of Soteria studies and articles

<sup>&</sup>lt;sup>22</sup> http://www.amazon.com/Soteria-Deliverance-Loren-R-Mosher/dp/1413465234

<sup>&</sup>lt;sup>23</sup> <a href="http://pathwaysvermont.org/Soteria.html">http://pathwaysvermont.org/Soteria.html</a>

http://www.yout<u>ube.com/watch?v=uaawL-135pE</u>

At the end of the day, however, the outcomes were always favorable. A review of Soteria studies published in Schizophrenia Bulletin provides this summation:<sup>25</sup>

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.

In other words, Soteria was rigorously studied against treatment-as-usual (taking psychiatric drugs) at the local hospital, and on every measure people at Soteria did as well or better. Also, people at Soteria didn't get the message that they have an incurable brain disease, so they left with a different idea of who they were and could become than people at the hospital who were diagnosed with chronic schizophrenia.

Now, let's look at specific data, starting with six-week outcomes:<sup>26</sup>

Table 5.
Six Week Outcome Data
Psychopathology and Medication

	Experimental N=45			
Global Psychopathology (Mosher et. al., 1-7)	3.5	3.5 3.5		
Global Psychopathology (Change from Admission)	y -1.6 -1.8 t =		n =39,50 t =0.86, ns	
Global Improvement (Change from Admission) (Mosher et. al., 1-7)	2.5	2.5	n =39,50 t =0.15, ns	
Continuous Neuroleptic Drug rx	12%	98%	n =42,55 X <sup>2</sup> =48.4, p<.01	
Substantial Neuroleptic Drug rx (>7 days)			n =42,55 X <sup>2</sup> =50.9, p<.01	
Any Neuroleptic Drug rx	33%	100%	n =42,55 X <sup>2</sup> =70.8, p<.01	

<sup>&</sup>lt;sup>25</sup> Schizophrenia Bulletin 2008: A Systematic Review of the Soteria Paradigm for the Treatment of People Diagnosed With Schizophrenia

<sup>&</sup>lt;sup>26</sup> Table 5 from *Soteria Project Final Progress Report* 

These numbers represent the second study cohort and are conservative.<sup>27,28</sup> For instance, "In the original [cohort], only 24% of the experimental group received any medication during the initial 6 weeks of treatment (as opposed to 100% of the hospitalized control group), with only 16% of these receiving "substantial" drug treatment, ie, > 7 days."<sup>29</sup> Data from the first cohort was more impressive, but I reference these figures to err on the side of skepticism.

As you can see, at six weeks people at both Soteria-CA and the control hospital had similar and significant reductions in "Global Psychopathology" (a measure of psychiatric symptoms). The striking difference is that Soteria-CA residents had far lower rates of using antipsychotic drugs, demonstrating that many people having an early experience of psychosis can expect a reduction of "symptomology" primarily from psychosocial supports, and perhaps time.

Now, onto two-year outcomes:<sup>30</sup>

Table 9.
Two Year Outcome Data
Psychopathology and Medication

	Experimental Control N=55  3.0 2.8		n =31,45 t =0.52, ns	
Global Psychopathology (Mosher et. al., 1-7)				
Global Improvement (Mosher et. al., 1-7)	2.6	2.3	n =29,46 t =0.60, ns	
Continuous Neuroleptic Drug rx	50%	50% 70%		
Substantial Neuroleptic Drug rx (>7 days)	59%	83%	n =32,30 X <sup>2</sup> =3.2, p<.10	
Any Neuroleptic Drug rx	59%	83%	n =32,30 X <sup>2</sup> =3.2, p<.10	

<sup>&</sup>quot;It appears that previous reports from Soteria have underestimated the benefits of experimental treatment through omission of important control variables," Treatment of Acute Psychosis Without Antipsychotics - Two-Year Outcomes From the Soteria Project

<sup>&</sup>lt;sup>28</sup> This outcome data was taken from the later years when the project was under substantial financial stress in the wake of reduced NIMH funds.

<sup>&</sup>lt;sup>29</sup> Schizophrenia Bulletin 2008: A Systematic Review of the Soteria Paradigm for the Treatment of People Diagnosed With Schizophrenia

<sup>&</sup>lt;sup>30</sup> Table 9 from *Soteria Project Final Progress Report* 

At two years, former residents of Soteria and former control hospital patients had similar "Global Improvements." Though not detailed in this chart, "significantly more experimental subjects [Soteria-CA] became more independent in their living arrangements between 1 and 2 years post admission (40% vs. 11%)..." Antipsychotic drug use is much higher at 2-years than at 6-weeks for the Soteria-CA cohort, reflecting that some former residents chose or were forced to take them in circumstances after leaving the house. It is still much lower than the control group, whose decrease in numbers at 2-years from 6-weeks reflects that some patients quit antipsychotics once discharged.

One disappointing piece of data in the overall Soteria research: 78% of people at 2-year follow-up had been rehospitalized (though only about one-third of the people who did not take antipsychotics at Soteria were rehospitalized). This figure is lower than the control hospital's 87%, but is still disappointing. Aside from a sober reminder that Soteria is no one-stop panacea, it implies that Burlington's local emergency room and screeners may see some former Soteria-VT residents in distress shortly after leaving the house, which could impress upon them that Soteria-VT is ineffective and create a cycle whereupon they refer people less often. This dynamic apparently happened at Soteria-Alaska according to an Interim Director's analysis. To ensure long-term success, Soteria-VT should regularly engage staff at the local emergency room and accurately convey the strengths as well as limits of the model. Also, it is possible that a greater attention to aftercare at Soteria-VT will help former residents stay out of the hospital.

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<sup>&</sup>lt;sup>31</sup> From Soteria Project Final Progress Report

<sup>&</sup>lt;sup>32</sup> From Soteria Project Final Progress Report

<sup>33</sup> http://www.madinamerica.com/2012/09/some-observations-of-soteria-alaska/

### CULTURE

Establishing a culture at Soteria-VT will be the program's greatest initial task, sustaining it the greatest ongoing challenge. Since the Soteria approach is different from conventional interventions, the house cannot rely upon traditional frameworks for understanding psychosis and human behavior nor resort to its language of mental illness. It equally cannot impose artificial boundaries between individuals based upon assumptions of expert/patient. All of these dynamics – paradigms for understanding, language used, nature of relationships – will be governed by organizational and house culture.

Elements of Soteria-CA culture were (reluctantly) summed up by Mosher:<sup>35</sup>

Despite the abundance of outcome related processes cited it must still be said that it remains difficult to narrow them down to the few most important ones... What is here is an abstraction, and as such, only partially valid. With this apology I will provide a ninepoint summary of what I believe to be the critical therapeutic ingredients of the Soteria environment:

- 1) Positive expectations of recovery, and perhaps learning and growth, from psychosis.
- 2) Flexibility of roles, relationships and responses on the part of the staff.
- 3) Acceptance of the psychotic person's experience of psychosis as real-even if not consensually validatable.
- 4) Staff's primary duty is to "be with" the disorganized client; it must be specifically acknowledged that they need NOT do anything. If frightened they should call for help.
- 5) The experience of psychosis should be normalized and usualized by contextualizing it, framing it in positive terms, and referring to it in everyday language.
- 6) Extremes of human behavior should be tolerated so long as they do not represent a threat to the person, other clients or the program.
- 7) Sufficient time must be spent in the program to allow for relationships to develop that will have a lasting impact through the processes of imitation and identification.
- 8) These relationships should allow precipitating events to be acknowledged, the usually disavowed painful emotions experienced as a result of them discussed until they can be tolerated, and then put into perspective by fitting them into the continuity of the person's and his/her social system's life.

<sup>&</sup>lt;sup>34</sup> People at Soteria-CA used lay terms (i.e. "spacey, freaked out, bummed" to describe experiences)

<sup>&</sup>lt;sup>35</sup> Soteria-California and Its Successors - Therapeutic Ingredients

9) A post-discharge peer-oriented social network to provide on-going community reintegration, rehabilitation (e.g. help with housing, education, work and a social life) and support.

Mosher also outlined the "Essential Characteristics" of Soteria: 36

- 1) Small and home-like, sleeping no more than 10 persons including staff
- 2) Two staff on duty, a man and a woman, in 24 to 48 hour shifts
- 3) Ideologically uncommitted staff and program director(to avoid failures of "fit")
- 4) Peer/fraternal relationship orientation to mute authority
- 5) Preservation of personal power and with it, the maintenance of autonomy
- 6) Open social system to allow easy access, departure and return if needed
- 7) Everyone shares day to day running of the house to the extent they can
- 8) Minimal role differentiation to encourage flexibility
- 9) Minimal hierarchy to allow relatively structureless functioning
- 10) Integrated into the local community
- 11) Post-discharge continuity of relationships encouraged
- 12) No formal in-house "therapy" as traditionally defined

To better understand these cultural elements, all staff who work at Soteria-VT should read *Soteria: Through Madness to Deliverance*. If they have experiences working in or using traditional mental health services, they should be especially aware of how the Soteria model differs in ideological understanding of psychosis and health. As a starting point, consider this chart comparing conventional views of psychosis with alternative ones:<sup>37</sup>

	Conventional	Alternative
Framework	Essentially Biological	Essentially Contextual
Cause	Brain disease, inherited genes, epigenetics, neuro-developmental	Trauma, existential struggle, narrative events, socio-developmental
Nature	Toxic, non-sensible, dangerous, symptomatic	Purposeful, understandable, valid, experiential
Approach	Mental illness diagnosis, psychotropic medication indefinitely	Being with, attempts to understand, allying, meaning-making

<sup>37</sup> Rethinking Psychosis: The Soteria Model for First Break, Slide 26

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<sup>&</sup>lt;sup>36</sup> Soteria-California and Its Successors - Therapeutic Ingredients

Goal	Symptom elimination, illness acceptance	Completion of process, integration of experience		
Outlook	Chronic, maintenance therapies	Hopeful, Possibility of "Weller than Well"		

Also, the following analogy helps illustrate a way of thinking about psychosis differently from the medical model:<sup>38</sup>

Your body mounts a fever to kill off bad bacteria and viruses. You don't have agency over that process: in other words, you don't decide, I wanna go into a fever right now. It happens to you. The intelligence of your body drives this process. You are sick before the fever, and the fever is an attempt to make you better. So, fevers can rid you of bad guys and ultimately leave you better off, but they can also kill you. The central debate is: should we allow this process, or should we squelch it? Apparently the medical community generally errs on the side of reducing the fever, and thus interfering with the body's innate intelligence. Yet then the bad guys survive, and unless you're lucky, are likely to harm you until you find another way to get rid of them.

It's not difficult to see the analogy of this process with psychosis. Psychosis also happens to people; generally, no one decides to start being psychotic. Where does it come from? The overwhelming ideology has been "from disease," whatever that means, and thus the effort to squelch it. But what if, like a fever, psychosis is not the problem in itself, but is rather the solution being mounted by your body and mind's innate intelligence? Is it possible that psychosis could be an attempt to reorganize one's orientation toward the world, particularly an orientation that has been damaged by trauma, and that the reorganization – much like the effects of high temperature – look temporarily like illness? Of course, there can be no objective data proving or not proving such a subjective claim, but there is plenty of anecdotal. Stories abound of people recovered who believe the process of psychosis – while terrifying and even dangerous – was ultimately necessary and brought them to a more complete and integrated understanding of the world.

In addition to holding a wide understanding of psychosis, Soteria-VT culture should encourage staff to act within a broad range of boundaries that enable their roles to shift and adapt to the situations at hand. Traditional mental health boundaries will inhibit Soteria-VT by disallowing

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<sup>&</sup>lt;sup>38</sup> Rethinking Psychosis: The Soteria Model for First Break, Slide 27

the spontaneity and intuitive ingenuity necessary for responding to extraordinary circumstances. Mosher notes:<sup>39</sup>

The presence of multiple, shifting, and often ill-defined roles and relationships created an environment that could respond rapidly and flexibly to changing demands.

Indeed, formulaic procedures and protocols provide a sense of order and safety in crisis, but often get in the way of a natural human response, which may be exactly what is called for. Certainly, Soteria-CA relied upon the innate sensibilities of its staff to create solutions for problems at the house. Their ethos – "What you see is what you get, deal with it as best you can" – was not a naïve or dismissive attitude; it was a trust in the ability of good people to generate good ideas and act rightly when free to do so.

Above all else, Soteria-VT culture should establish a sense of community at the house. The following commentary is from Another Way, a daytime community center for psychiatric survivors, and talks about how boundaries look different when trying to create community as opposed to trying to "treat" people:<sup>40</sup>

Crucial to the creation of community is a shared understanding of personal boundaries. Traditional mental health services erect strong boundaries between staff and patients. Patients are ill; staff are experts on the illness. Personal disclosure of certain life experiences by staff – one's own problems, trauma or psychiatric history, even interests – is strongly discouraged or outlawed, as it is seen to negatively influence the patient's recovery by unnecessarily influencing his or her decision-making, by sending mixed messages, or by overwhelming him or her mentally and emotionally. These boundaries are put forth to "protect the patient." However, such boundaries often have the adverse effect of reinforcing to a person that he or she is "the sick one" and part of the "other group" and is incapable of handling stress or negotiating relationships. Besides being paternalistic, this approach essentially creates the opposite of community, as it disallows genuine connection between people because it segregates folks into two types – those who are expected to communicate openly and realistically about all the troubles of their lives, and those who are expected to stay quiet about such matters, or in some silly situations, talk about them in the third person.

Another Way is built on a different understanding of boundaries. Most staff persons also use Another Way as a resource center, and certainly staff and users have

<sup>40</sup> From author's presentation on Another Way, 2011

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<sup>&</sup>lt;sup>39</sup> From *Soteria: Through Madness to Deliverance* 

relationships that extend well beyond our community center. There are few top-down policies that curtail personalities – for instance, there is no dress code beyond wearing some kind of clothes to cover the body, and no rule about sharing a beer after work among staff and users. Issues such as excessive swearing are naturally curtailed by community norms, and people – whether paid or not – are free to be as open as they like about their lives.

Of course, ethical conflicts do not dissipate just because there is greater liberty: problems do arise about relations, and are often messy. The point is, we address them as a community, not because of policy. This approach encourages self-reflective learning and deepens moral responsibilities. Yet it also relies on strong leadership, and at the risk of sounding polemical: a striving for the common good.

Loose boundaries at Soteria-CA meant that relationships often extended well beyond the walls of the house. In fact, some people who were residents at Soteria-CA are still connected with some of the workers even now, decades later. It should be acceptable for workers at Soteria-VT to engage in some "dual relationships" with residents, meaning that residents and staff can become friends. Also, touch was valued at the original house and is valued at Soteria-AK, meaning massages, hand-holding, hugs, rubbing backs — these are regarded as expressions of affection and care and are not to be regulated at Soteria-VT. When sexual advances came up at Soteria-CA, staff demonstrated exceptional maturity in navigating them, and were able to say "No" with light-heartedness, then move on.

Any organization that operates by principles first and procedures second is more dependent upon integrity in leadership, so Soteria-VT will need to ensure that its endorsement of self-reliance in tending to matters is matched by ethical leadership. The best safeguard against loose boundaries becoming exploitation is to hire staff who have an innate concern for justice and morality.

<sup>&</sup>lt;sup>41</sup> Personal communication with Voyce Hendrix, 2010

## APPROACH<sup>42</sup>

Soteria-CA resisted falling into prescriptive modalities that would make their interactions rote and fail to appreciate the uniqueness of each resident's situation. Wisdom was acquired through hands-on experience, but never cast into stone. And since the paradigm is still experimental, Soteria-VT should expect to learn by doing and remain willfully open to changing course as differing residents come through.

One of Soteria-CA's original House Managers noted: "Every psychosis we start from scratch." This is a marked departure from the current mental health culture that implements evidenced-based practices *onto* people. Instead, Soteria calls for a needs-adapted framework that welcomes each situation as unique, and with unusual flexibility. The book reads, 44

No prescriptive rules governed Soteria staff's therapeutic approach. From this stance evolved, bottom-up, a number of techniques, which were neither imposed nor theoretically predetermined. Such techniques grew out of the repetitive interactions that took place...

Overtime, the most important technique that developed at Soteria-CA was *Being with* people in distressed states. Essentially, *Being with* meant openly attending to and following another's path without preconception or unnecessary interference. At Soteria-AK, I heard it referred to as "honoring the process of psychosis."

In *Being with* a person at Soteria-CA, "it was not uncommon for an individual staff member to spend entire shifts for weeks on end with one resident, often even sleeping in the same room." There were lots of all-nighters. Staff attended to regression and rebirth, unusual beliefs, experiences of death and dying, and they took it all seriously, assisting and facilitating people's processes and staying with one another until safe. "Unusual behavior was accepted and acceptable. Controlling such behavior was specifically forbidden unless a situation became dangerous."

Being with meant going with the flow, softening one's ideologies and reactions, and listening with a genuine curiosity towards another's expression – even and especially when it was hard

<sup>&</sup>lt;sup>42</sup> Material in this section is expounded upon in *Rethinking Psychosis: The Soteria Model for First Break* and *Soteria: Through Madness to Deliverance* 

<sup>&</sup>lt;sup>43</sup> Personal communication with Alma Menn, 2010

<sup>&</sup>lt;sup>44</sup> From Soteria: Through Madness to Deliverance

<sup>&</sup>lt;sup>45</sup> From *Soteria: Through Madness to Deliverance* 

<sup>&</sup>lt;sup>46</sup> From *Soteria: Through Madness to Deliverance* 

to relate. Risk-taking was common such that *Being with* required a substantial willingness to live with uncertainty.

What did this look like in practice? Since Soteria-CA was a residence, for the most part *Being with* involved a lot of ordinariness: morning meetings, cleaning, cooking, chess, watching TV, going out to the park, on walks, to movies, to jobs, to the beach, and so on. But in relating to extraordinary happenings, here are a few brief examples of *Being With* at Soteria-CA:<sup>47</sup>

- Staff would *be with* a resident's regression to infancy (a somewhat frequent experience that Soteria-VT should be prepared for) by rocking people back and forth, changing people's soiled clothes, reading stories by their bedside, providing diapers, even nursing folks with baby bottles. Such regression was never induced but was also not medicated away or denied when it happened. Instead, it was treated as the reality in front of them, and often became an important step in people's process of reintegration.
- At a small store, a woman resident suddenly knelt down in front of a greeting card with the Virgin Mary on it and started praying. The cashier eyed her, and the Soteria staff who was with her was anxious about it, not knowing where it was going. The Soteria staff was able to talk the woman into leaving, but on their way back home the woman kept kneeling down in public places and praying. So the staff person decided to be with her and prayed alongside, over and over, even though it lengthened a short trip into a couple of hours.
- A male resident told staff repeatedly that he needed to be reborn, so three staff ended up *Being with* his experience by laying around him to form a makeshift birth canal that he could push through. The man went through the canal repeatedly trying to "get it right." At one point he tried to go out the window (another canal), but staff interfered and pulled him back in. After a considerable amount of attempts over a period of weeks, he eventually got his birth ritual "right" and became free of the overwhelming need to experience it. Then he progressed forward.
- A resident kept speaking about a time and place when aliens were arriving to take him away. So, staff drove him there on that date and time, and much to his surprise, the aliens never arrived. He concluded, "I guess they're not coming after all" and let it all go.

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<sup>&</sup>lt;sup>47</sup> Adapted from *Soteria: Through Madness to Deliverance* 

At Soteria-VT, the success of *Being with* will depend on quality relationships built around trust. You cannot *be with* someone who does not want you there. To create connection, it is imperative that people at Soteria-VT are validated in their experiences. The current medical model approach is that the content of psychosis makes no sense and is inappropriate for interaction. In comparison, the Soteria model calls not only acknowledging that another's experience is real, but demonstrating a real interest in and care for its content. Says Mosher,

Within staff-resident relationships, an integrative context was created to promote understanding and the discovery of meaning within the subjective experience of psychosis. Residents were encouraged to acknowledge precipitating events and emotions and to discuss and eventually place them into perspective within the continuity of their life and social network.

There is an honest attempt to understand the actual experience of psychosis from the point of view of the person experiencing it, and a want to relate instead of judge or categorize. First and foremost, however, staff should act genuinely: one should not fake consideration while actually believing there is a disease and irrational fodder, for people in acute states are often highly perceptive and will read the incongruence.

#### **RULES**

Psychiatrist RD Laing ran an experimental and virtually rule-less facility in London during the mid-60s called Kingsley Hall<sup>48</sup> that Mosher visited and found on-the-right-track, though a bit too structureless and freewheeling. When opening Soteria-CA, he was conscious of power dynamics inherent in rules – especially institutional rules – and wanted to create the least restrictive environment possible for safety.

Mosher comments on the rules for Soteria-CA:<sup>49</sup>

- 1) No violence to self or others
- 2) No unknown, unannounced visitors (family and friends had easy access, but as a home its boundaries to outsiders were like those of usual families)
- 3) No illegal drugs (there was enough community noted deviance at Soteria already)
- 4) No sex between staff and clients (an intergenerational incest taboo). Note, sex between clients or staff was not forbidden.

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<sup>48</sup> http://www.guardian.co.uk/books/2012/sep/02/rd-laing-mental-health-sanity

<sup>&</sup>lt;sup>49</sup> See Soteria-California and Its Successors - Therapeutic Ingredients

The project director introduced the first three rules. The fourth was put in place by staff and clients in a house meeting after the second month of the project's operation.

Notice that Soteria-CA did not prohibit alcohol. There is an illuminating story in the book in which a resident was drinking wildly and negatively affecting the house. Instead of implementing a ban on all alcohol, the other residents decided to quit drinking for two weeks as a community and asked this individual to join them. Remarkably, he did, and never went back to drinking for the rest of his stay, demonstrating the power of grass-roots decision-making and community agreements.

Soteria-AK does not allow alcohol or illegal drugs at the house. While the Soteria approach is designed to be as unrestrictive as possible, allowing alcohol would seem to increase the chances of violence or destructive behavior. As such, alcohol should be banned from Soteria-VT for at least the first two years while the program establishes itself and learns the bounds of its abilities.

Otherwise, Soteria-VT should open using the same rules as the original house. It is important to note that Soteria-CA went through phases which called for temporary rules, and these were always made with resident input. Likewise, Soteria-VT should ensure that any additional rules are made with resident involvement and are carefully considered so as to not to create an excess of top-down structure that interferes with the ability for people to "be with" each other.

# **BUDGET**

Soteria-VT has \$1 million appropriated annually from the Department of Mental Health budget. The following budget includes start-up costs separately.

SOTERIA VERMONT ANNUAL	BUDGET		
Personnel	FTE	Salary	Total
Administrative Assistant	0.5	\$32,000	\$16,000
Aftercare Coordinator	1	\$35,000	\$35,000
Bookkeeper	0.4	\$40,000	\$16,000
House Manager	1	\$40,000	\$40,000
Project Director	1	\$55,000	\$55,000
	2 @		
Residential Assistants	24hrs/day	\$15/hr	\$262,800
Residential Assistants (Extra	1 @ 20bro/wk	Ф4 <i>Е/</i> Ьг	<b>\$45.600</b>
Support)	1 @ 20hrs/wk	\$15/hr	\$15,600
Total Gross Salaries			\$440,400
Fringe		29%	\$127,716
Total Salaries & Fringe			\$568,116
Contractors			
House Keeper	0.2	\$18,720	\$3,744
Naturopathic Doctor	0.2	\$80,000	\$16,000
Psychiatrist	14 hrs/wk	\$120/hr	\$87,360
Total Contractors			\$107,104
Rent and Utilities			
Cell Phone Expense	12 mos	\$350	\$4,200
House Rent	12 mos	\$4,000	\$48,000
House Renter's Insurance	12 mos	\$200	\$2,400
Internet - Office	12 mos	\$95	\$1,140
Internet/Phone/Cable House	12 mos	\$220	\$2,640
Office Rent/Utilities	12 mos	\$900	\$10,800
Phone/Fax	12 mos	\$40	\$480
Snow Removal	12 11100	Ψίο	\$500
Total Rent and Utilities			\$70,160
Operating Expenses			
Car Insurance	12 mos	\$100	\$1,200
Client Emergency			\$5,000
Food for Meals	5 residents	\$20/day	\$36,500
Fuel for Company Vehicle	12 mos	\$200	\$2,400
House Repairs			\$15,000
House Supplies (Art,			
Gardening, etc).			\$18,250

IT Support	7 hrs/wk	\$75	\$27,300
Legal Fees			\$5,000
Office Supplies	12 mos	\$100	\$1,200
Postage	12 mos	\$25	\$300
Printing/Copying			\$1,000
Program Activities	12 mos	\$1,000	\$12,000
Publicity/Publication			\$1,000
Staff Mileage	150 miles/wk	\$0.51/mi	\$3,978
Staff training			\$25,000
Total Operating Expenses			\$155,128
Total Expenses:			\$900,508
Admin/Overhead		18%	\$162,091
		GT	\$1,062,599
Start-Up	Units	Cost / Unit	
All-in-One Printer/Copier			
(office/house)	2	\$500	\$1,000
Wellness supplies (guitars,			
yoga mats, easels)	10	\$400	\$4,000
Bathroom	3	\$100	\$300
Bedroom (\$1000/room)	5	\$1,000	\$5,000
Computers	10	\$650	\$6,500
House - ReHab (accessibility)			\$30,000
iPads	6	\$500	\$3,000
Job Advertising			\$500
Kitchen/Dining/Living			\$10,000
Office Furniture (home and office)	5	\$400	\$2,000
Other Computer (headsets,			<del></del> /
etc.)	10	\$60	\$600
Vehicle Purchase			\$20,000
Total Startup			\$82,900

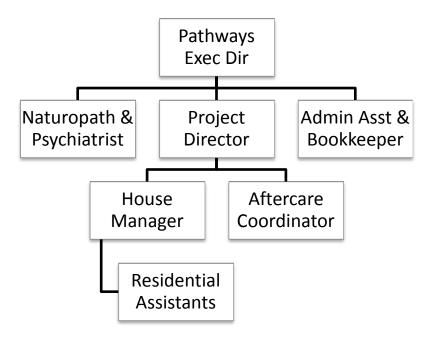
## **STAFFING**

Soteria-VT should include the following staff:

Position	FTEs
Administrative Assistant	0.5
Aftercare Coordinator	1.0
Bookkeeper	0.4
House Manager	1.0
Naturopath*	0.2
Project Director	1.0
Psychiatrist*	0.2
Residential Assistants	9.3
(2 people @ 24hrs/day)	(@ 36 hrs = 1 FTE)
Residential Assistants	0.5
(Extra Support)	

<sup>\*</sup> The Psychiatrist and Naturopath should be hired as consultants – not on staff, so they carry less liability and the house and organization are not under their direction.

An organizational chart with hierarchy based on supervisory role:



Residential Assistants at Soteria-CA house worked long shifts, often 24 - 48 hours. Mosher felt the length was important for relational continuity so that a resident undergoing an intense process could stay connected with the same person and avoid disruption. There were always at least two RAs at any given time, preferably a man and woman.

Soteria-AK staff work 8 hour shifts (so does Alyssum staff), but are considering longer shifts to realize the benefits of continuity. Some staff at Soteria-CA did burn out from such arduous periods of work, but some found it convenient to complete a week's worth of work in two days, as it freed up time for other activities such as college classes.

For Soteria-VT, it seems 8-hour shifts will create too much turnover in a day, yet 24-hour shifts setup the possibility of adversely affecting an RA's health from lack of sleep such that s/he may become edgy and reactive. Soteria-VT should thus experiment with at least 12-hour RA shifts. However, everyone has a different sleep tolerance, and if folks can be effective for back-to-back shifts that total 24-hour shifts or longer, it seems this longer length of time is ideal.

Broken into 12-hour shifts, Soteria-VT will have 28 shifts available per week. If each RA works 36 hours (3 shifts) per week, Soteria will need to hire 9 RAs @ 36 hours per week and 1 RA @ 12 hours per week.

### A sample weekly schedule:

RAs on staff: Laura, Hilary, Steven, Rebeca, Pat, Sam, Devan, Nicola, Mandy, Nick (part-time)

	Sun	Mon	Tues	Weds	Thurs	Fri	Sat
8 AM – 8 PM	Steven	Steven	Pat	Hilary	Steven	Laura	Pat
	Sam	Hilary	Sam	Nicola	Sam	Hilary	Nicola
8 PM – 8 AM	Rebeca	Pat	Rebeca	Mandy	Mandy	Laura	Rebeca
	Laura	Devan	Devan	Devan	Nick	Nicola	Mandy

It is possible for the House Manager to cover shifts, though when Soteria-VT is a full-house, there will likely be a need for his or her presence in addition to the two RAs available. Mosher thought the correct composition of the house to be (in unfortunate terms) "50% sane / 50% insane." Thus, the House Manager's position should work shifts only when needed as backup or emergency fill-in. Instead, Soteria-VT should budget for a half-time "Extra Support RA" who can add additional people power when needed.

Like Soteria-CA, Soteria-AK employs RAs who are young, intuitive, open-minded, flexible, compassionate, artistic and/or creative, and mostly without traditional mental health

backgrounds. High-quality staff is crucial to the program's success and may be the most important determinant in whether the unique Soteria culture is sustained.

On the importance of staff, Mosher comments:50

Probably the single most important part of why [Soteria] worked were the kinds of relationships established between the participants-staff, clients, volunteers, students-anyone that spent a significant amount of time in the facility... The Soteria staff was characterized as psychologically strong, independent, mature, warm, and empathic. They shared these traits with the staff of the control facilities. However, Soteria staff was significantly more intuitive, introverted, flexible, and tolerant of altered states of consciousness than the general hospital psychiatric ward staff... Because they worked 24 or 48-hour shifts they were afforded the opportunity to "be with" residents (their term for clients/patients) for periods of time that staff of ordinary psychiatric facilities could not. Thus, they were able to experience, first hand, complete "disordered" biological cycles. [Overtime], many clients were able to be "helpers" during the latter part of their stays.

Volunteers can also play a key role at Soteria-VT by adding support, as well as benefitting Soteria-VT's aim at educating the public by bringing what they learn back into their communities and possibly schools (for instance, a Soteria-AK volunteer I met was also a psychology student at a local college and was bringing his unique experience to his professor). Both Soteria-CA and Soteria-AK made and make use of volunteers from local colleges. Soteria-VT should explore accessing volunteers from Burlington College, UVM, and St. Michael's, as well as the myriad of other youth epicenters outside of educational centers in the area.

It is vital that volunteers be a natural ally with Soteria-VT's values and are supervised by seasoned staff. Expectations of their responsibilities should be clearly spelled out in policy.<sup>51</sup>

#### **PSYCHIATRY**

Soteria-VT will need to contract with a psychiatrist; however, as outlined in the original book, psychiatry is practiced unconventionally in the model. The general philosophy is that antipsychotic drugs have high risks — particularly if taken long-term, and that most people can recover from psychosis without using them. Soteria-CA tried to wait at least six weeks before prescribed any antipsychotic drugs, although their data shows that about 1 in 8 people did take them continuously throughout their stay. Overall, the majority of residents never took

<sup>&</sup>lt;sup>50</sup> See Soteria-California and Its Successors -Therapeutic Ingredients

<sup>&</sup>lt;sup>51</sup> See Soteria-AK Volunteer Policy for reference

antipsychotic drugs, and when they did, the average length of time was for 7 days.<sup>52</sup> However, at Soteria-CA many people were given benzodiazepines to help restore sleep, especially if they entered the house having not slept for a sustained period of time. The benzos were discontinued shortly thereafter.

When used, prescription medications should be prescribed at the lowest possible effective dose and monitored closely for adverse effects. Most importantly, Soteria-VT should never propagate the idea to individuals that they are "mentally ill" or taking medications to fix a chemical imbalance.

The Soteria-VT psychiatrist should visit the house one day per week and meet with each resident, and also be available on-call for consulting with challenging situations. Staff meetings should be scheduled on the day the psychiatrist is present so that s/he can attend. All prescribed medications must be voluntarily taken, and full informed consent wherein all significant risks are discussed must be obtained. It is telling that the legislative language for creating a Soteria-VT specifically outlines that the program be "non-coercive," a necessary directive only because so many mental health services rely upon coercion to influence client decision-making.

Psychiatrists generally have power in mental health workplaces through which their guidance and directives are followed and trump dissenting opinions. Since the Soteria-VT psychiatrist will be hired as a consultant, the program and psychiatrist carry less (or zero) liability in ignoring this dynamic. It is important that the psychiatrist serve as a collaborative member of the Soteria community, and be aligned with the principles of the program from the outset. Spending time at the house hanging out, sharing meals, and interacting with residents on a person-to-person basis will be important in establishing the desired relational atmosphere.

#### **NATUROPATH**

Soteria-VT is taking an innovative approach to mental health by hiring a Naturopath as part of the support team. Naturopathic doctors "work with their patients to prevent and treat acute and chronic illness and disease, restore health and establish optimal fitness by supporting the person's inherent self-healing process." In Vermont, Naturopaths can be primary care physicians and their services are Medicaid-reimbursable.

Ideally, residents entering Soteria-VT will agree to an initial urine and blood test to produce a comprehensive health profile, which should include checking for hormonal imbalances, vitamin

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<sup>&</sup>lt;sup>52</sup> From *Soteria: Through Madness to Deliverance* 

http://www.naturopathic.org/content.asp?pl=16&sl=59&contentid=59

deficiencies, thyroid and adrenal functioning, and food allergies and intolerances. These tests can be run and interpreted by the Naturopath.

Like the psychiatrist, the Naturopath should plan to spend one day per week at Soteria meeting with each resident, and likewise should serve as a collaborative member of the Soteria community. S/he should schedule his or her visitation day to align with the meal planning so that s/he can be a voice in that conversation. Again, spending time at the house hanging out, sharing meals, and interacting with residents on a person-to-person basis will be important in establishing the desired relational atmosphere. The Naturopath can also be involved in designing and tending gardens, offering informal classes on healing modalities, cooking, and any other skills that s/he brings from experience.

Of course, it is imperative that the Naturopath and Psychiatrist converse regularly to avoid prescribing drugs or herbs that interfere with each other.

#### SAMPLE JOB DESCRIPTION – RESIDENTIAL ASSISTANT

Title: Residential Assistant
Supervisor: House Manager
Employment Status: Full-Time

#### Description

The Residential Assistant works 36 hours per week, including some evenings and weekends as needed. The primary responsibilities are to connect and be with residents at Soteria-VT in a way that promotes trust, respect, and support in a non-coercive environment.

#### Responsibilities

- Uses active listening, compassionate communication, and intuitive skills to engage with and be with residents
- Validates and interacts with unusual expressions and experiences
- Collaborates with wishes and desires of residents to help facilitate their expression
- Explores with residents ways to connect current experiences into the continuity of their lives
- Maintains expectations of learning and growth
- Shares skill-building knowledge
- Helps to prepare meals
- Administrative duties, such as answering the house phone and completing required documentation
- Coordinates with and advocates for residents to access resources

• Provides support to volunteers

### Requirements

- Excellent interpersonal skills
- Insightfulness, intuitiveness, and a strong ability to self-reflect
- Ability to tolerate uncertainty
- Personal qualities of integrity, credibility, and commitment to the mission
- Conflict resolution and mediation skills
- Knowledge of psychiatric alternatives and psychosocial approaches to mental health and wellbeing

### **TRAININGS**

Soteria-CA trained staff through apprenticeships at the house. To get the house up and running, staff apprenticed at an experimental local hospital ward.

Aside from general safety trainings, the goal of training Soteria-VT staff should be to increase people's ability to:

- Tolerate uncertainty
- Connect with distressing and unusual experiences
- Appreciate the potential growth process inherent in psychosis
- Self-reflect
- Communicate honestly and effectively, sometimes non-verbally
- Think contextually and understand the impact of trauma upon lives
- Identify and reduce power dynamics

There are no Soteria-specific trainings currently available, but there are several trainings that cover the above goals. Potential trainings to explore:

## Intentional Peer Support<sup>54</sup>

"Intentional Peer Support (IPS) is a way of thinking about and intentionally inviting powerfully transformative relationships among peers. Participants learn to use relationships to see things from new angles, develop greater awareness of personal and relational patterns, and to support and challenge each other as we try new things."

IPS is generally a five-day training. While it is grounded in peer-to-peer relationships, it is also a valuable framework for people involved in any service or community role. IPS trainers have trained staff at several peer-run crisis respite houses (including Alyssum), and would be able to tailor a training specifically for Soteria's goals.

## Non-Violent Communication<sup>55</sup>

"NVC begins by assuming that we are all compassionate by nature and that violent strategies—whether verbal or physical—are learned behaviors taught and supported by the prevailing culture. NVC also assumes that we all share the same, basic human needs, and that each of our actions are a strategy to meet one or more of these needs. People who

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<sup>54</sup> http://www.intentionalpeersupport.org/

http://www.cnvc.org/

practice NVC have found greater authenticity in their communication, increased understanding, deepening connection and conflict resolution."

NVC can be a powerful framework for communication and for re-interpreting why people act in particular ways. It has particular use in mental health in that it is anti-psychiatric diagnosis and believes that people all operate from the same needs, even if those actions seem highly unusual or unrelatable. NVC Trainers can be found on their website and contracted individually to provide staff trainings.

### Hearing Voices<sup>56</sup>

The Hearing Voices Network is a growing international network "for people who hear voices, see visions or have other unusual perceptions." HVN links to peer support groups and also has participants who train health workers in understanding and working with voices in non-traditional ways. Spring Lake Ranch<sup>58</sup> organized a training in 2011 with Jacqui Dillon – national chair of the Hearing Voices Network in England, and Gail Hornstein – psychology professor at Mount Holyoke College. Both Jacqui and Gail are potential trainers for Soteria-VT, as is Sera Davidow, <sup>59</sup> who is the Director of the Western Massachusetts Recovery Learning Community.

## Alyssum's Dialogue with Voices<sup>60</sup>

Gloria van den Berg, the Executive Director of Alyssum, has created a three-day training that covers the following ground:

"Dialogue with Voices is designed as a three-day training. It can also be attended as separate days. Rather than providing a step by step model for "success," this training is focused on self-awareness, realizing insights and shifting worldviews so as to generate and expand awareness and comfort around Voice hearing.

Day One of training includes an exploration of self "reality" and worldview, how this is interrelated with the impact of trauma, and the development of a grounded and clear sense of self. It examines dialogue and the components of authenticity so as to create the ability to connect in a non-judgmental and meaningful way.

http://www.hearing-voices.org/

<sup>56</sup> http://www.cnvc.org/

<sup>58</sup> www.springlakeranch.org

<sup>&</sup>lt;sup>59</sup> sera@westernmassrlc.org

<sup>60</sup> alyssum.ed@gmail.com

In the following two days, Voice hearing is explored as a healing and transformative process through role plays and an informative breakdown of progress through the stages of Voice hearing.

Day Two explores Class I Voices from trauma-related impact such as dissociative identity, post-traumatic stress and multiple personalities.

Day Three explores Class II Voices generated by a spiritual or energetic shifts, also being voices which lead to a disconnect from this reality. This part of the training includes discussion and examination of spirituality and the human energy system."

## • Non-Abusive Psychological and Physical Intervention (NAPPI)<sup>61</sup>

"NAPPI teaches safe and humane resolutions to conflict, moving individuals away from a paradigm of control toward a paradigm of cooperation and trust."

NAPPI training is useful for recognizing and responding to signs of crisis before they erupt. It also teaches safety strategies should violence occur. Pathways Vermont has an internal NAPPI trainer.

There are upcoming trainings available to "train the trainer." Here's an email from Becky Mitchell at NAPPI: "As I mentioned, NAPPI will be holding our Standard Certification course starting Monday, January 28<sup>th</sup> until Friday, February 1<sup>st</sup>, 2013 if your team at Pathways Vermont makes a decision to send an individual to our event to become a trainer. The 2013 Boston Training Event will take place at the Wyndam Boston Chelsea Hotel, 201 Everett Avenue in Chelsea, MA. As we discussed, this certification course offers NAPPI's curriculum in safe and humane psychological and physical interventions in behavior management. The course covers all of NAPPI's standard training modules and the skills to teach those modules to fellow staff members. Upon successful completion of the 5-day course, you (or the person who will be your designated trainer) will be qualified to teach up to 16 hours of content and the course includes a Trainer Kit with Instructor Manual and all you need to teach your first class. The cost of this course is \$1299.00 per person."

#### Food and Mood

Soteria-VT should have a basic training on how food and nutrition affect mood, including an overview of food allergies and intolerances, and the relationship between digestive health and mental health. The outcome is not to create prescriptiveness about how folks "should" eat, but rather to create awareness and dialogue around such matters. This training should

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<sup>61</sup> http://nappi-training.com/

also introduce staff to the Naturopathic approach and provide an understanding of the Naturopath's function at the house.

Erica Koch, ND<sup>62</sup> is a naturopathic doctor who has extensive experience designing and presenting workshops on food, health, and exercise. She is available to create the following half-day workshop for Soteria-VT's needs:

"Our mood can be affected by both our internal and external environment. Nutrition, food intolerances, digestion, assimilation, and elimination effect how we think and feel. In addition, the way we move our body, breathe, and exercise can encourage healthy mood regulation. In this 4-hour workshop, we will discuss nutrition and lifestyle and learn practical measures that can be applied in daily life to encourage healthy moods and emotional resilience."

The following trainings are standard at many Designated Agencies and with Alyssum, either of whom could be contacted to make arrangements:

- CPR
- Blood borne pathogens/HIV awareness
- Bio hazardous waste disposal

Because of its unique approach and philosophy, Soteria-VT should ultimately seek to develop in-house trainings and apprenticeships. The goal should be for new staff to receive hands-on experience by shadowing other seasoned workers, participating in community dialogues, and learning by doing. It will be imperative to build in all-staff meetings at least once a week to discuss and reflect on happenings at the house. In addition, informal, daily community & house meetings held with staff and residents present will be important to creating solidarity and generating dialogue that helps facilitate solutions to problems.

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<sup>&</sup>lt;sup>62</sup> erica.koch.nd@gmail.com

### **NUTRITION**

At the outset, Soteria-VT staff should try and establish food and nutrition as topics of conversation around the house so that they naturally become part of the community tenor. No better way of encouraging this process is to hire staff or volunteers who have a passion for cooking. Licensing regulations will require Soteria-VT to create weekly meal plans — and these should of course be led by resident input, but it will also be a good use of the Naturopath's time to join these discussions as a resource and voice.

Soteria-VT should ensure that adequate money is budgeted to purchase whole, healthy, organic food for every meal. Particular consideration should be given to potential food intolerances and allergies (most common are: milk, eggs, peanuts, tree nuts, fish, shellfish, soy, wheat), and to ensuring that sugars are minimized. Given some research demonstrating a connection between gluten intolerance and psychosis, it is tempting to consider eliminating gluten from the household as a rule instead of exception. However, food is of such cultural importance that its social value may outweigh its nutritional. Thus, Soteria-VT should seek first to purchase foods that are not known to be highly allergenic, but always weigh this approach against resident's desires, which should in most cases take priority. Also, obviously a resident can use his or her own money to buy whichever food s/he would like.

In researching food and mental health, I spoke with Mary Strickland Kreider, who is the Integrative Health Director at a farm-based North Carolina healing community for people with psychiatric diagnoses called Cooper Riis. I had heard that Cooper Riis was focusing intensely on diet. Mary informed me that Cooper Riis uses mostly a plant-based diet with some fish. Cooper Riis is working towards becoming gluten-free, and residents are currently tested for gluten allergies, though Mary emphasizes that many of the tests currently available do not detect allergies and intolerances with 100% accuracy.

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<sup>63</sup> http://www.mayoclinic.com/health/food-allergies/AA00057

<sup>64</sup> http://www.journals.elsevierhealth.com/periodicals/bps/article/PIIS0006322310002507/abstract?rss=yes

<sup>&</sup>lt;sup>65</sup> For example, when I was at Soteria-AK, I went grocery shopping with a few of the young guys. We bought raw materials to make pizza, and one of the gentleman grabbed a sugar-loaded drink. Making and eating pizza at the house is a weekly ritual that brings people together, and pizza is obviously a food that many young people enjoy and that is hard to replace (gluten-free pizza is, well, not the same). I could have commented to the young man that the drink he was buying is sugar-loaded (and has he considered an alternative?), but that could have potentially interfered with his own determination and choices at that moment and setup the expert/patient dynamic that Soteria-VT must avoid. A more Soteria-friendly approach would be to talk – at the right moment – about the effects of sugar-loaded drinks from my own experience, but to ensure that I am not being preachy, and that I am still open-minded enough to be thinking about it all wrong.

# **SUPPLEMENTS**

At a conference in Maine in September 2012 called *Innovative Solutions for Building Recovery Using Alternative to Psychotropic Medication*,<sup>67</sup> two integrative psychiatrists presented about nutritional supports for people in psychiatric crisis. James Greenblatt, MD<sup>68</sup> in Boston spoke about food intolerances, the importance of Omega 3 fatty acids, and correlations between low cholesterol and suicidality, vitamin B3 (Niacin) and schizophrenia, and vitamin D3 and depression. The other integrative psychiatrist – Miles Simmons, MD of True North<sup>69</sup> in Maine – stressed the importance of creating individualized nutritional plans, and emphasized that nutrition is only one of many components of health. However, he did talk about EMPowerplus from True Hope,<sup>70</sup> which is a micronutrient supplement used for so-called mental illness and also for supporting people in coming off psychiatric drugs. EMPowerplus has been clinically studied in multiple trials, and apparently has good results. Dr. Charles Popper of Harvard<sup>71</sup> is a leading proponent.

Also, the Vermont Center for Integrated Herbalism<sup>72</sup> is a potential ally and support. VCIH provides consultations and homegrown herbal remedies for folks, and they are sliding-scale. They also have a traveling clinic that could come on-site to Soteria-VT.

While Soteria-VT should be skeptical of falling into believing that a pill can cleanly fix an ail, there is certainly a case that nutritional deficiencies are contributing to stressful and difficult experiences. In addition to a thorough understanding of food and mood, the Naturopath and Psychiatrist for Soteria-VT should be familiar with a range of supplemental options, including True Hope's formulas. There are also many books<sup>73</sup> written on the subject of "natural healing" in schizophrenia and psychosis – including orthomolecular approaches, though of course any panacea should be met with skepticism. For mostly political reasons, comparatively little research has been conducted to study the impact of food and nutrition on psychosis/schizophrenia and gut disorders on mental health, so it can be difficult to assess the integrity of treatment approaches based on such; however, stories abound of people finding significant health recovery through nutrition.

<sup>&</sup>lt;sup>67</sup> Materials are here: <a href="http://www.ccsme.org/info.php?id=208">http://www.ccsme.org/info.php?id=208</a>

<sup>&</sup>lt;sup>68</sup> www.jamesgreenblattmd.com

<sup>69</sup> http://www.truenorthhealthcenter.org/miles simmons.asp

<sup>70</sup> http://www.truehope.com/empowerplus/

http://www.mmhforum.org/speaker charles.html

http://www.vtherbcenter.org/

<sup>&</sup>lt;sup>73</sup> For example, see *Gut and Psychology Syndrome* by Campbell-McBride; *Nutrition and Mental Illness* by Pfeifer; *Natural Healing for Schizophrenia and Other Common Mental Disorders* by Edelman

Finally, a note about environmental toxins: for the same reasons that Soteria-VT should focus on having "clean" food in its kitchen, it should use only "green" cleaners, detergents, and sprays, and even then, at a minimum. Many people have chemical sensitivities — often unknown — that are exacerbated by common household cleaners.

# INTAKE, EXIT, AFTERCARE

Soteria-VT should welcome referrals from any source, but only accept residents who voluntarily want the services offered. Soteria-VT should ensure that referral sources understand that Soteria-VT should not be offered as a coercive option: in other words, if a person is given the option of an inpatient stay or Soteria, and wants neither, but chooses the latter because it sounds like the least restrictive.

Referrals of potential residents will be made primarily from:

- 1. Self, family, friends
- 2. Emergency screeners
- 3. Emergency rooms
- 4. Other mental health workers

# INTAKE

Individuals can be accepted to Soteria-VT who are:

- 1. 18 years or older
- 2. Voluntary
- 3. Experiencing an acute psychotic episode for the first time that might otherwise be treated in a hospital, crisis respite center, or other high intensive program
- 4. Antipsychotic-naïve for the past twelve months, or taking antipsychotic medication for no more than one consistent month at intake
- 5. Not yet entrenched in the mental health system
- 6. Not such a danger to self or others that they cannot remain safe in an unlocked, community-based facility that relies upon relational supports

Intake Procedures to determine eligibility, necessity and appropriateness for services at Soteria-VT will include:

- 1. Initial contact and screening by trained Soteria-VT staff at referral source
- 2. Visit to Soteria-VT house and interaction with residents and staff
- 3. Psychiatric assessment
- 4. Medical testing to rule out physiological causes of psychosis, including testing for nutritional deficiencies, food allergies, and hormone functioning
- 5. Collateral information and other assessments previously completed from other sources
- 6. TB testing

#### **EXIT**

Criteria for exiting the program include:

- 1. Resident no longer desires services
- 2. Presenting treatment issues are resolved, and the resident no longer needs the service, or maximum benefit has been gained within available resources and services
- 3. A resident may be discharged if he or she threatens violence to another resident or staff member in a verbal or physical manner that presents significant danger; and/or significantly interferes with service programs
- 4. Individuals discharged for lack of participation or interruption of services due to institutionalization or some other valid reason may be readmitted in an accelerated fashion at the discretion of the Soteria House Manager and Project Director.

## **AFTERCARE**

Soteria-CA provided no formal support to residents after they left, though many returned to volunteer, hang out, and receive informal support. Soteria-AK does provide some aftercare supports, such as peer supports and service coordination.

Pathways Vermont specializes in Housing First services, and as such, is in a uniquely qualified position to design and provide aftercare services to former residents of Soteria. Their teambased approach is designed to work with individuals in independent apartments who have significant challenges staying housed. If Pathways has available housing vouchers and capacity in a region, it may be able to offer supportive housing services for interested residents. Pathways also operates The Wellness Co-Op,<sup>74</sup> a peer-run community center in Burlington that is open during the daytime and offers peer supports, including help finding jobs. Residents at Soteria-VT may wish to visit there some days, or connect with them after moving out.

Additionally, Soteria-VT should hire a full-time position dedicated to aftercare coordination. Given the data that most original Soteria residents were rehospitalized within two years, it makes sense to setup Soteria-VT with a broader-based approach as opposed to a one-stop shop. The Aftercare Coordinator can help link folks to available services, find jobs, connect with community supports, or just spend time with people. Also, Soteria-VT should provide opportunities for past residents to come back to the house to hang out, volunteer, work, or be of service.

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<sup>&</sup>lt;sup>74</sup> http://www.pathwaystohousingvermont.org/Wellness-Co-op.html

# LICENSURE

The Department of Disability, Aging and Independent Living (DAIL) licenses mental health residences of three or more beds who provide services to three or more individuals unrelated to the operator.<sup>75</sup>

Regulations for licensure are found on the DAIL website,<sup>76</sup> and they are governed by Chapter 71 in Title 33 of the Vermont Statutes Annotated.<sup>77</sup> It appears that our licensure options are as a:

- Therapeutic Community Residence (TCR),
- Level III or Level IV Residential Care Home, or
- Assisted Living facility

It is important to note that the Therapeutic Community Residence regulations are currently being rewritten.<sup>78</sup>

### From the statutes:

Title 33: Human Services

Chapter 71: REGULATION OF LONG-TERM CARE FACILITIES

33 V.S.A. § 7102. Definitions

- (1) "Assisted living residence" means a program which combines housing, health, and supportive services for the support of resident independence and aging in place. Within a homelike setting, assisted living units offer, at a minimum, a private bedroom, private bath, living space, kitchen capacity, and a lockable door. Assisted living promotes resident self-direction and active participation in decision-making while emphasizing individuality, privacy, and dignity.
- (10)"Residential care home" means a place, however named, excluding a licensed foster home, which provides, for profit or otherwise, room, board, and personal care to three or more residents unrelated to the home operator. Residential care homes shall be divided into two groups, depending upon the level of care they provide, as follows:

<sup>&</sup>lt;sup>75</sup> One way to skirt around licensure is to have multiple one- or two- bedroom buildings on a property.

<sup>&</sup>lt;sup>76</sup> http://dail.vermont.gov/dail-statutes/dail-statutes-default-page#regulations

<sup>77</sup> http://www.leg.state.vt.us/statutes/sections.cfm?Title=33&Chapter=071

<sup>&</sup>lt;sup>78</sup> A work-in-progress copy is included in the "Licensing and Regulations" folder

- (A) Level III, which provides personal care, defined as assistance with meals, dressing, movement, bathing, grooming, or other personal needs, or general supervision of physical or mental well-being, including nursing overview and medication management as defined by the licensing agency by rule, but not full-time nursing care; and
- (B) Level IV, which provides personal care, as described in subdivision (A) of this subdivision (10), or general supervision of the physical or mental well-being of residents, including medication management as defined by the licensing agency by rule, but not other nursing care.
- (11)"Therapeutic community residence" means a place, however named, excluding hospitals as defined by statute which provides, for profit or otherwise, transitional individualized treatment to three or more residents with major life adjustment problems, such as alcoholism, drug abuse, mental illness, or delinquency.

All four sets of regulations spell out requirements for meal planning, medication dispensement, building setup, progress notes, resident rights, and so on. They also specify that the facility will only serve adults eighteen and over unless special permission from the licensing agency is granted on a person-by-person basis.

Level III Residential Care Home requires nursing, so is not a feasible nor desirable option for Soteria-VT.<sup>79</sup> All regulations pertaining to Level III also apply to an "Assisted Living" designation, so the latter should be ruled out as well.

It appears to me from reading the regulations that there is little pragmatic difference between opening a facility as a Level IV Residential Care Home versus a Therapeutic Community Residence. I spoke with Pam Cota<sup>80</sup> – Licensing Chief from Licensing and Protection, and she said the Level IV designation is intended for more long-term stays, and thinks a TCR will be the best designation for Soteria-VT. Also, the philosophy spelled out in "General Provisions" of the TCR regulations speaks closely to the purpose of Soteria-VT. For this reason, I recommend that Soteria-VT seek licensure as a TCR.81

<sup>&</sup>lt;sup>79</sup> Second Spring, for instance is a Level III; http://www.secondspring.org/

<sup>&</sup>lt;sup>80</sup> Pamela.Cota@state.vt.us; 802-871-3317

<sup>&</sup>lt;sup>81</sup> While restrictive regulatory frameworks can be limiting and damaging to Soteria's unique approach, the TCR regulations appear, on the whole, to be flexible and allow for variances. Nothing in them seems to compromise the program's mission.

## CERTIFICATE OF APPROVAL VERSUS CERTIFICATE OF NEED

Most new healthcare projects must obtain a Certificate of Need<sup>82</sup> (CON) from the Department of Financial Regulation. Selected Service Agencies (SSA), which include the Designated Agencies in mental health, are excluded from needing a CON when creating a new program and can instead obtain a Certificate of Approval<sup>83</sup> (COA) from the Department of Mental Health.

Currently, Pathways-Vermont is not an SSA, but should that change, Soteria-VT can directly apply for a COA. Instead, as it stands, Soteria-VT has the option of either applying for a CON or partnering with a local SSA to apply for a COA. The CON process is apparently cumbersome and difficult, and should be avoided if possible. It may also be challenging for an unconventional program like Soteria-VT to win approval. The COA process is much simpler and should be sought by Soteria-VT.

There are two local SSA's in Burlington: HowardCenter and Northeastern Family Institute (NFI), either of which can act as a "sponsoring" SSA so that Soteria-VT can receive a COA. Both Howard and NFI are interested. A concern for Soteria-VT is whether and how affiliating with either of these organizations will affect its ability to provide unconventional services (i.e. Will their liability dictate how psychiatry is practiced at Soteria-VT? Will their personnel policies affect how people at Soteria-VT have relationships?). It appears from conversations with DMH that either SSA can act simply as a pass-through of funds to Soteria-VT, thus eliminating their involvement in any operational matters. Soteria-VT can create a Memorandum of Understanding to clarify this relationship, which can also release HowardCenter and NFI from any liability or responsibility for the program.

Thus, ideally, Soteria-VT will seek a COA by partnering with either Howard or NFI, whose involvement in its affairs will be limited through an MOU to a financial pass-through.

<sup>82</sup> http://www.dfr.vermont.gov/health-care/hospitals-health-care-practitioners/certificate-need

<sup>83</sup> http://mentalhealth.vermont.gov/coa

# LOCATION & ZONING

Soteria-CA was and Soteria-AK is a part of a neighborhood, and as such indistinguishable from residential households. It is important that Soteria-VT have easy access on a busline or walking route to town so that residents are not isolated from everyday community life. It will be ideal to have a small yard and some separation from neighbors as well. Soteria-VT should expect to be loud sometimes and should consider the impact that will have on neighbors.

Soteria-VT is intended to be sited in the greater Burlington area for the following reasons:

- Burlington has the highest population of young persons in Vermont, thus will have the highest population of people experiencing first-break psychosis who are eligible for Soteria-VT. The local screeners said they are seeing about five people experiencing a first-break per month in the area.<sup>84</sup>
- It is desirable to hire young persons to work at Soteria-VT, and there are several colleges and other young adult communities from which to draw attractive staff.
- Potential research opportunities with St. Michael's College and/or the University of Vermont.
- Burlington is a progressive community with an array of social services, arts communities, and open-minded individuals that can help Soteria-VT be successful.
- The local mental health agency is supportive of a Soteria approach, which makes it more likely that Soteria-VT will receive referrals.

Soteria-VT is likely to meet opposition in any neighborhood where it tries to settle. Some social services have faced big challenges – sometimes insurmountable – in trying to open programs in Burlington proper.<sup>85</sup> It appears that some Burlingtonians perceive the city as too saturated with social programs, and some mental health programs have been unable to open in the area because of citizen opposition. Local zoning regulations also make renovating a building and operating a program in the downtown area expensive.

Given these potential conflicts, it may be wise to consider surrounding areas. Winooski is just north of Burlington but on the busline and has a less expensive housing stock (some with significant yard space). It is also experiencing a downtown revival and is a progressive

<sup>&</sup>lt;sup>84</sup> Sheryl Bellman, Director of Crisis Services with HowardCenter

<sup>&</sup>lt;sup>85</sup> I met with Sheryl Bellman, Director of Crisis Services with Howard, and Maria, Director of ASSIST (a hospital diversion program with Howard), to talk about siting a program in Burlington. Sheryl said it took close to four years to get ASSIST up and running in downtown Burlington, and that there was "huge opposition" to opening it.

community. Other areas to consider: South Burlington, Williston, Essex Junction, and Colchester.

The Burlington Housing Authority<sup>86</sup> (BHA) has worked collaboratively with social service agencies to open programs in the past (i.e. Oxford House, Northern Lights), mostly by purchasing a house then leasing or renting it to the agencies. In these scenarios, BHA does the work of finding a property and "fighting the battle" with zoning and oppositional neighborhoods. While their experience in this area is alluring, it is important to consider how landlording will impact the Soteria-VT program. Soteria-VT should expect to experience property damage, and needs to have landlords who appreciate and endorse the program's mission.

### **ZONING**

Zoning laws vary from community to community. The house for Soteria-VT will have to obtain an appropriate zoning designation to operate, which will likely involve filing for a change of zoning on a pre-existing property, thus triggering a process of local review, community input, and potential appeals.

Soteria-VT should consult with a lawyer to review the zoning regulations of Burlington and surrounding communities in order to determine which type of zoning designation the project should seek, and to identify potential zoning barriers across communities. This review should be completed before or early on into the housing search.

<sup>&</sup>lt;sup>86</sup> I met with Mike Ohler<sup>86</sup> mohler@burlingtonhousing.org and Paul Dettman<sup>86</sup> pdettman@burlingtonhousing.org of the Burlington Housing Authority (BHA)

# **RESEARCHING & INTERNSHIPS**

Soteria-CA had a large-scale, expensive research component, in no small measure because Loren Mosher was the Director of Schizophrenia Studies with the National Institute of Mental Health at the time. While it would be the "gold standard" to replicate a randomized, cross-comparison study with other first-break approaches, it would be expensive, time-consuming, subject to regulatory approval, and potentially distracting and interfering. Instead, Soteria-VT should seek from the outset to develop a small-scale research component, not only to demonstrate to funding sources that the Soteria model is efficacious (though DMH will likely require its own data collection), but to publish in the peer-reviewed journal world, which will help expose and promote this first-break approach.

One potential financial sponsor is the Foundation for Excellence in Mental Health Care,<sup>87</sup> a new and exciting organization providing grants to innovative efforts and research in mental health. Their mission:

To promote better mental health outcomes. We do so by identifying, developing, and sharing knowledge with the public about mental health care that best helps people recover and live well in society. We promote improvements in mental health care by sponsoring research and the development of programs designed to help people thrive-physically, mentally, socially and spiritually.

As for local researchers, Ron Miller<sup>88</sup> from the Department of Psychology at St. Michael's College has been interested in Soteria for years and teaches the material to his students. He has a history of bringing influential, non-traditional speakers (Thomas Szasz, Dan Fisher, Robert Whitaker) to the area. Ron is tentatively interested in creating an internship program at Soteria-VT wherein students can also perform research.<sup>89</sup> He favors "action research" and specializes in "Comprehensive Case Study Research," which involves interviewing people over time and capturing their story, then corroborating it to more objective measures of change. It is essentially narrative-based while also demonstrating outcomes. Also, if Soteria-VT has

<sup>&</sup>lt;sup>87</sup> http://femhc.org/

<sup>88</sup> rmiller@smcvt.edu

First-year practicum students can intern eight hours per week. Second-year practicum students can intern twenty hours per week, but must be supervised by a licensed psychologist (unlike first-year interns). Some organizations who work with St. Michael's second-year interns will hire a psychologist for a couple of hours per week to provide that supervision, but that can be costly. Both first-year and second-year students are generally unpaid at their internships.

<sup>&</sup>lt;sup>90</sup> Meaning researchers work within the community being researched to develop the protocols and kinds of questions they want to ask, as opposed to researchers being brought in "from the outside."

specific needs and areas of interest they wish to explore, it is possible those needs and interests can be brought to graduate students to take on as theses. It may be possible to obtain a grant from the Foundation for Excellence in Mental Health Care in the \$20k - \$50k range to pay for St. Michael's to study Soteria-VT in these capacities.

UVM's Social Work department has a good reputation and is another possible research partner. However, any collaboration with UVM's Depts. of Psychology or Psychiatry should first assess their ideological stances on mental health matters and ensure they align with Soteria's.

# ADVISORY COMMITTEE

People were invited to join the Soteria-VT Advisory Committee based on their interest in the model, potential contribution to its success, proximity to location, and representative constituency (trying to bring in diverse interests around a common cause, and for public education). The Committee has met once, in late November.

The Committee serves right now in an advisory-only capacity as opposed to a more directive steering committee or governing board. Should Soteria-VT seek to become its own non-profit, the Advisory Committee would be a natural place to start for a Board of Directors.

The following Logistics and Intentions were spelled out in an invitation letter:

### LOGISTICS

The Advisory Committee will consist of up to twelve people and meet once a month for an hour and a half. We will meet in-person in Burlington, with availability for a call-in option and video-conferencing. Ideally, members will commit for a year to these monthly meetings and to occasional readings that will be necessary to stay informed. To accommodate schedules as best as possible, we will be using a Meeting Wizard each month to set the date and time. Our first meeting will be in late November / early December.

### **INTENTION**

The success of a Soteria-VT will depend on a clear vision, competent and creative staff, supportive community, and collaboration across the system of care. My hope is that the composition of the Advisory Committee will reflect the diversity of skills and perspectives necessary to ensure this development. On a pragmatic level, your knowledge will help us complete the aforementioned tasks. But I also believe a larger goal of Soteria is to create a cultural climate where we can start thinking about mental health in new ways, and I look forward to these Committee meetings as an opportunity to share ideas that push the conversation forward.

The current Advisory Committee Members are:

#### **Amanda Back**

Amanda has earned credentials as an ex-patient and a background and education in legal work and research. She worked as a lawyer's apprentice after receiving her BS in legal studies and left to pursue more meaningful work. She worked as a residential

counselor in community mental health for the past two years, and will be working for the State of Vermont DMH as a mental health recovery specialist at Green Mountain Psychiatric Care Center when it opens in late December 2012.

# **Rick DeAngelis**

Rick DeAngelis has been on the Another Way Board of Directors since October , 2010. He has many years' experience developing community based affordable housing and is currently the Associate Housing Director of the Vermont Housing and Conservation Board. Rick also serves as the chairman of the Washington County Continuum of Care which coordinates services for the homelessness in the region. He has an active interest in mindfulness meditation and convenes the Montpelier Mindfulness Community, Rick lives in Montpelier.

#### **Nick Emlen**

Nick Emlen coordinates mental health services for Vermont's designated provider agencies. He is a resident of Calais.

#### Erica Koch

Erica Koch, ND, MEd, FABNO, RMT is a licensed Naturopathic Physician with a focus on Family Health. She earned her Doctor of Naturopathic Medicine degree (2003) from National College of Natural Medicine and a Master of Education from Rutgers University (1999). Dr. Koch enjoys teaching people of all ages about food as medicine and growing herbs/foods to encourage health. In addition to her private practice, for three years she designed health promotion curriculum and practiced at Nike in Oregon as an integral part of their Employee Health program. For several years, she practiced integrative oncology and developed patient and nurse education curriculum at Cancer Treatment Centers of America in Philadelphia. She is a traditional Usui Shiki Ryoho Reiki Master, practicing Reiki since 2000. Erica is an advocate for whole systems healing and teaches Reiki as one way to tangibly integrate spirituality and health. Through treating many people with chronic disease, she has seen the far-reaching benefits of incorporating a daily healing practice into life. She is currently credentialed at Gifford Medical Center and practices at Integrative Health in Randolph, VT.

# **Hilary Melton**

Current Executive Director of Pathways Vermont, Hilary was the Program Director on the first Housing First project in New York City in 1992. Hilary has over 18 years' experience with program administration and is a published poet.

## **Chuck Myers**

Chuck Myers, Ph.D. is a Licensed Psychologist – Doctorate and the Executive Director of Northeastern Family Institute, NFI Vermont. His interests include the integration of complex trauma prevention, diagnosis, and services into systems of care, and families. NFI is a non-profit Specialized Services Agency in Vermont providing trauma informed, evidence based, mental health services to adolescents and young adults intense needs throughout Vermont.

### Laura-Nicole Sisson

Laura-Nicole hails from Burlington and has been with Pathways Vermont since September 2011, serving in a variety of roles. She currently serves as Project Assistant to the Soteria Development Project and to Pathways Vermont as a whole. Laura has a passionate interest in the development of alternative approaches within Community Mental Health. In the past, Laura had been tagged with a variety of labels by the Mental Health system and has happily been living label free for the past 2.5 years.

# **Ed Paquin**

Of Barre, Vermont, is a former builder and state legislator who is the director of Disability Rights Vermont, our state's designated protection & advocacy system for people with disabilities. He advocates for a system free from coercion that honors our civil rights, offering alternatives that encourage people to meet our potential.

## **Annie Ramniceanu**

Annie Ramniceanu is a Licensed Clinical Mental Health Counselor and Licensed Alcohol and Drug Counselor in the State of Vermont. Currently she is the Associate Executive Director of Clinical Programs at Spectrum Youth & Family Services in Burlington, VT. Annie is also the Chair of the State of Vermont Alcohol and Drug Certification Board.

# **Sandy Steingard**

Sandra Steingard, M.D. is Medical Director, Howard Center, Burlington, Vermont, and Clinical Associate Professor of Psychiatry at the University Of Vermont College Of Medicine. For over 20 years her clinical practice has primarily included patients with schizophrenia and other psychotic illnesses. She is a past Medical Advisor to NAMI-VT from whom she received an Exemplary Psychiatrist Award in 1996. She was named to Best Doctors in America in 2003. She is on the Board of Directors for the Foundation for Excellence in Mental Health Care and she writes a blog called *Anatomy of a Psychiatrist* on the website "Mad in America Science Psychiatry and Community".

## Gloria van den Berg

Gloria is the Executive Director of Alyssum, a peer-run crisis respite house operating in Rochester, VT. She is a person with lived experience with Voices, both the kind from psychosis and from trauma, and she has a background of recovery without use of the Mental Health system and without medication. She is familiar with alternative methods of healing, and her interest in Soteria is based on personal lived experience.

# Laura Ziegler

Laura Ziegler was involuntarily institutionalized, diagnosed and forcibly drugged at age 17. She has been involved with the organized mad civil rights movement since 1983. While in NY she worked as a paralegal for a regional Protection & Advocacy office and was a member of Project Release, one of the early mutual support and advocacy groups run for and by psychiatric survivors. In Vermont she has spent many years at the Statehouse advocating for the rights of people with disabilities or in state custody. She is a former board member and longtime participant in the National Association for Rights Protection and Advocacy.

# OTHER SOTERIA-LIKE FACILITIES

• Two other "madness sanctuaries" for people experiencing first-break psychosis operated in the San Francisco Bay area during the Soteria-CA era. All three obtained funding partly through results of studies<sup>91,92</sup> which had demonstrated that over the long-term people experiencing psychosis who did not take medications were far less likely to relapse than people experiencing psychosis who did take medications. All three lost funding when the psychiatric landscape changed towards a more biopsychiatric worldview that embraced Neo-Kraepelin principles.<sup>93</sup>

The first of these sanctuaries was a small residence designed and directed by Dr. John Weir Perry called Diabasis. Details of the program are found in his books, *Trials of the Visionary Mind*<sup>94</sup> and *The Far Side of Madness*<sup>95,96</sup> Diabasis was entirely medication-free and required residents to engage in Jungian-based therapy, but otherwise was similar to Soteria-CA in milieu, philosophy, and staffing. Unlike Soteria-CA, Diabasis had a room called the "Rage Room," which had padding on the walls, objects to hit, and Styrofoam swords that people could swing around. Staff oftentimes went into the room with residents, who utilized this space to scream and rage and safely hit things. Soteria-Vermont should create such a space as well. Diabasis was not independently studied, though Perry said 85% of residents emerged from the program "weller than well."

The other sanctuary was called I-Ward, and operated in a building on the campus of a traditional hospital. I-Ward had close to 20 beds, making it much larger than both Diabasis and Soteria. Their approach was mostly medication-free, and apparently they would work with anyone in early crisis, including people who were known to be violent. They did not independently study outcomes either. Information about I-Ward is difficult to come by; Michael Cornwall, PhD<sup>97</sup>, who used to work there, is a good resource.

• Today, there are several Soteria-like facilities operating in Europe, but it appears that none are adhering strictly to the original model. In particular, they are admitting residents who are not first-break and who have had substantial prior exposure to antipsychotics. 98

<sup>91</sup> http://www.madinamerica.com/wp-content/uploads/2010/04/Schooler3.pdf

http://www.madinamerica.com/wp-content/uploads/2011/12/Rappaport.pdf

http://kadi.myweb.uga.edu/Kraepelin and the Neo-Kraepelinians.html

http://www.amazon.com/Trials-Visionary-Transpersonal-Humanistic-Psychology/dp/0791439887

<sup>95</sup> http://www.amazon.com/Side-Madness-John-Weir-Perry/dp/0882145576

<sup>&</sup>lt;sup>96</sup> http://www.madinamerica.com/wp-content/uploads/2011/12/Cornwall-2002-PhD.pdf

<sup>97</sup> http://www.madinamerica.com/author/mcornwall/

<sup>98</sup> http://www.ncbi.nlm.nih.gov/pubmed/10086470

- Peer-run crisis respite houses<sup>99</sup> are emerging across the country, including Alyssum<sup>100</sup> in Rochester, VT. A lot of these programs are similar to Soteria in theoretical approach "Being with" people in crisis instead of "Doing to," lessening of hierarchy, skepticism about biopsychiatry, pro-choice on medications, focus on community building, genuine relationships with loose boundaries, homelike environments but are different in their lengths of stay (generally up to 2 weeks), and in their intake criteria (many will not admit people in acute psychotic crisis).
- At \$17 million dollars, the Parachute Project<sup>101</sup> is just getting underway in New York City and will create four crisis respite homes for people experiencing first-break psychosis. They are training all of their staff in Intentional Peer Support and are focusing on "Needs-adapted treatment," a critical component of Open Dialogue and of Soteria (though not specifically named as such by Mosher).
- The Hilltop Recovery Residence in southeastern Vermont is operated by HCRS and is seeking
  to work with first-break folks in a mostly medication-free environment, though they are also
  helping people reduce and come off psychiatric drugs. Hilltop has eight beds and opened in
  Fall 2012; Emily Mastaler<sup>102</sup> is the Program Director.
- Another Way<sup>103</sup> in Montpelier is a community center for psychiatric survivors. Though only open during the daytime, it incorporates many of the tenets being with, mutual aid, adiagnositic, acceptance of altered states, social networks of Soteria, and has been around for decades such that these ways of interacting with one another are steeped into the culture. Also, food, art, and community play prominent roles at Another Way and have naturally become integrated into so-called services, which could be helpful at Soteria-VT as well. See also The Wellness Co-Op<sup>104</sup> in Burlington, a recently opened peer-run community center.
- Finally, it appears at the time of this writing that a two-bed Soteria-New Mexico is about to open. It is privately-operated and will seek self-paying residents for the time being.

<sup>99</sup> http://www.power2u.org/crisis-alternatives.html

<sup>100</sup> http://alyssum.org/

http://www.communityaccess.org/component/content/article/279

emastale@hcrs.org

www.anotherwayvt.org

http://www.pathwaystohousingvermont.org/Wellness-Co-op.html

# OPEN DIALOGUE

Open Dialogue is a systems-wide approach used in Western Lapland, Finland to work with people in crisis. It has been extensively studied, and currently has the highest recovery rates from first-episode psychosis in the Western world. 105

I attended the first session of four on Open Dialogue at the Institute for Dialogic Practice<sup>106</sup> in Massachusetts. Three workers from HowardCenter's START outreach team in Burlington are also participating in the training and integrating the material into their work. The Director, Mary Olson<sup>107</sup>, came to Vermont in December 2012 to present on Open Dialogue for interested mental health workers.

The description below is from the Institute's website, and one of the founders, Jaakko Seikkula, has written a book about it called *Dialogic Meetings in Social Networks*<sup>108</sup>:

Open Dialogue is an innovative approach to acute psychiatric crises developed by Jaakko Seikkula, Markku Sutela, and their multidisciplinary team at Keropudas Hospital in Tornio, Finland.

Starting in the eighties, there have been a variety of research studies of Open Dialogue and its outcomes with early psychosis. Garnering widespread international attention, the results consistently show that this approach reduces hospitalization, the use of medication, and recidivism when compared with treatment as usual. For example, in a five-year study, 83% of patients had returned to their jobs or studies or were looking for a job (Seikkula et al. 2006), In the same study, 77% did not have any residual symptoms. Such outcomes led the Finnish National Research and Development Center for Welfare and Health to award a prize recognizing the Keropudas group for "the ongoing development of psychiatric care over a period of ten years."

With strong foundations in philosophy and science, its principles are:

- 1. congruent with our knowledge of the best practices for treating early psychosis;
- rooted in systems and communication theories that have become widely accepted; and

http://www.iarecovery.org/documents/open-dialogue-finland-outcomes.pdf

http://www.dialogicpractice.net/

<sup>&</sup>lt;sup>107</sup> maryo@dialogicpractice.net

http://www.amazon.com/Dialogical-Meetings-Networks-Systemic-

Thinking/dp/185575410X/ref=sr 1 1?s=books&ie=UTF8&qid=1355859414&sr=1-1&keywords=Jaakko+Seikkula

3. are consistent with the recovery perspective of consumer advocacy groups and the system-of-care initiatives.

Open Dialogue can be thought of as a double helix that meshes a dialogic process, or new style of psychotherapy, with an integrated treatment system that delivers care primarily in the community. The basic vehicle of Open Dialogue is its radically altered version of the treatment meeting. As soon as possible in a given situation, the team, which consists of at least two clinicians, gathers everyone connected to the crisis, including the person at the center, their family and social network, all professional helpers, and anyone else closely involved. There are no separate staff meetings to talk about the "case." Rather all discussion and any decisions about medication and hospitalization take place with everyone present.

The aim of the treatment meeting is to generate dialogue that leads to common understandings, which become the basis of care. It begins first by eliciting the point of view of the person who has the overt symptoms. Often there is a special kind of meticulous, back-and-forth exchange between this person and the therapists to develop a more lucid way of expressing the situation and create a shared language. Building on this interaction, the therapists weave a common understanding of the crisis by bringing forward the voice of each of the participants. The exchange of voices creates a new fabric of meaning and engagement to which everyone has contributed important threads. This process can take one meeting or many meetings.

Fundamental to the approach is the shift away from an immediate emphasis on trying to eradicate symptoms. The conversation, or dialogue, is not "about" the person, but a way of "being with" them and living through the crisis together. "Withness practices," to quote Tom Andersen M.D., mitigate the sense of isolation and distance a frightening episode can produce. As the person at the center acquires greater voice and agency, they can participate meaningfully in both the conversation and the resulting decisions about their own lives, thus becoming more empowered. The perspective at work in Open Dialogue is that recovery from psychosis and other severe crises happens between people and with the help of important others. The result is that the open dialogue approach has achieved unique success in assisting people to navigate first time psychosis and other crises while relying much less on medication and hospitalization.

Soteria-VT and Open Dialogue share many values and theoretical orientations, especially the idea of "being with" people in crisis instead of "doing to." However, it is clear that the Open Dialogue approach is structurally different, and includes processes – such as reflective dialogue

between team members – that are unique. There are many elements in Open Dialogue that could be of value to Soteria-VT. For instance, the approach towards elevating voices and finding solutions in a polyphony of perspectives could orient the Soteria staff and residents towards focusing on the health of the community instead of any one identified individual.

Also, Open Dialogue practitioners generally do not talk about clients without their presence and instead keep supervision focused on how the practitioner is feeling as opposed to discussing a client's behavior. It may be useful to experiment with such an approach, though in a small community setting like Soteria-VT, it could also be self-limiting should staff feel the need to expand their understanding of a resident's process by discussing its specifics privately (i.e. understanding that a resident's wanting to wear diapers may be part of an experience of being a baby again, and therefore the person may need to be treated with responses appropriate to such age). In Open Dialogue, such discussions happen with the client present.

A possible collaboration around Open Dialogue could involve Soteria-VT staff being part of "Open Meetings" with HowardCenter's START team, especially when responding to crises involving psychosis. Since Open Dialogue in western Finland overarches *all* public mental health services (instead of being just the specialty of one group), it would follow in their success to collaborate across service providers beneath its principles.

Finally, a few of my notes from the first session training stick out:

- "Flowing with conversation instead of going through a pre-planned set of questions"
- "In a crisis, everyone is disoriented, and you find a solution through a polyphony of voices"
- "If you treat the living world with non-living ideas (i.e. chemical imbalance), you make huge mistakes, so we need a language that is consonant with the living world"
- "In the absence of having a voice, the body speaks (i.e. hallucinations)"
- "It's impossible to follow a plan because every meeting generates a new plan"
- "Giving up the clinical gaze and assessment and embodiment of such actually makes things safer and produces much more information"
- "Every situation generates its own language; there is no linguistic stability"
- "Less interested in family dynamics and more interested in ensuring that everyone is heard"
- "Meetings are for creating new words for experiences that do not have words, not for removing symptoms"
- "It is best to meet when you're *most* in crisis"
- "Needs-adapted is the approach; wonder how this contrasts with the increasingly popular 'person-centered approaches'"

# **SOTERIA-ALASKA**

I visited Soteria-AK in early November for one week, and the following report documents what I learned.

Soteria-AK is part of a larger non-profit organization called Choices-AK, both of which are located in Anchorage, Alaska. They act as partners, share the same Board of Directors, and have the same Executive Director. Soteria-AK operates on an annual budget of about a half million dollars, which they believe to be inadequate to support their services. For the last several years, independent researchers have been studying outcomes for Soteria-AK and have demonstrated favorable progress for many folks.

Operating since 2009, Soteria-AK itself is located a couple of miles from downtown in a residential neighborhood. The five-bedroom, one-story house used to be a bed and breakfast and was zoned for such when leased several years ago. Soteria-AK is currently seeking to purchase the building and expand it to host more bedrooms. It is licensed as an Assisted Living facility.

The house has close neighbors but an enclosed yard, which is ideal so that residents can spend time outside but not always in public view. Soteria-AK has had some problems with neighbors who have been upset by late-night noise, obscenities (like folks shouting or running around naked), and police response to incidents at the house. Outreach to neighbors to explain the nature of the program and hear their concerns has been important in maintaining good relations.

Inside, the kitchen is centrally located and part of a large open space where people gather around an island bar, dinner table, and futon. This spacious setup allows for all residents and staff to be present at the same time and encourages lots of interactions. Homemade art hangs on the walls, musical instruments abound, and the overall décor is homey and relaxed. You would never get the idea that you were at a "mental health" facility.

Each resident has his or her own bedroom. There are no locks on the bedroom or bathroom doors. The front entrances are unlocked from the inside but always locked from the outside, a decision made in response to outside threats. Residents are asked to sign in and out when they leave the house, and this log helps staff know when to be concerned if people are gone for unexpectedly long periods of time. Though not a secured facility, if a resident leaves the house in distress, staff will usually follow and try to stay connected with him or her.

The residence is for adults only and is technically a dry house, though residents are not immediately evicted for using substances. People living at Soteria-AK become tenants, and as such are entitled to rights of tenancy. This presents a difficult barrier when an unwilling resident is asked to leave because they must be properly evicted, which can take considerable time. When legally viable, Soteria-AK has solved this problem by obtaining a restraining order against a resident so that s/he could not return to the property and be around other residents who were involved in a confrontation.

Potential residents are referred through local social services, mental health agencies, and the local Emergency Room. Though Soteria-AK is strictly voluntary, sometimes people at the ER are given the choice between its services *or* the hospital's. In the past, some out-of-state referrals made by parents were accepted, but Soteria-AK found their program does not work well for such situations. Additionally, to keep their beds full and to be helpful for people in the most difficult situations, Soteria-AK used to accept residents who had histories of institutionalization and long-term psychiatric drug use. Through trial and error, they learned that the Soteria model is generally not well-suited for these complicated situations either, which in turn caused a lot of distress on the house. Therefore, they advise Soteria-VT against accepting referrals other than first or second break and with minimal psychiatric drug use. Soteria-AK has lately been working with the ER to receive more first-break referrals, and when I visited in early November, the three residents at the time were first-break young men who were not taking psychiatric drugs.

There are always two staff (called RA's) working at any one time at Soteria-AK, and they work 8-hour shifts. This is a noticeable departure from Soteria-CA model, in which staff worked 24 – 48 hour shifts based on the premise that continuity was important for working with people in a psychotic process. Soteria-AK is currently reviewing whether they want to experiment with longer shifts in order to keep that continuity. Overnight staff can doze off on the couch, but oftentimes this is impossible because of intensity in the house. Also, Soteria-AK includes on-call RAs in their staffing patterns in case someone must suddenly miss a shift.

Direct service staff at Soteria-AK are young in age, which helps to connect with residents, who are also young in age. At this point, many of the staff are being referred and recruited through word-of-mouth networks, but there also folks from local colleges who work and volunteer there, too. Many of the staff and volunteers have lived experience with mental health challenges and/or as a psychiatric survivor, making their passion for the work palpable.

The psychiatrist is not on staff with Soteria-AK and is instead a consultant. The residents that he sees are not "his patients," but rather clients of Soteria-AK. This is an important distinction

that allows for him to carry less liability, and for the house to be able to say "No" to his recommendations if there is strong disagreement in approach.

The psychiatrist meets with each resident once a week, and is on-call otherwise as needed. All psychiatric drugs are taken voluntarily, and the general philosophy is to try to withhold using them entirely, but in low doses for short periods of time otherwise. He prescribes benzodiazepines or Lunesta for helping restore sleep, and occasionally Haloperidol or Geodon for short periods of time to help blunt acute crises. Also, less harmful substances — such as Melatonin, Benadryl, Sleepy Time Tea — are generally recommended first in lieu of psychiatric drugs. Because of the specific license that Soteria-AK holds, staff cannot hand medicine to residents. They must dispense it into trays, and residents can pick it up from there. They keep medications locked up in a safe alongside a written log off all medicines dispensed.

Soteria-AK is required by their licensing agency to create weekly meal plans, and they try to encourage residents to participate in making these. Due to limited funds, they allocate \$100 per week for food, which is inadequate for buying solely nutritious foods. They use the Foodbank regularly to stock their pantry, and host a weekly homemade pizza dinner.

The current Executive Director stressed that the most important task is to have quality staff working in the house, people who have the ability to think contextually and who can "honor the process of psychosis." Other staff feel is crucial to ensure the right residents are brought in, that working with people having an early experience of psychosis and who are mostly antipsychotic naïve is the best fit for their services. All staff at Soteria-AK are re-reading the original book and meet once a week to discuss it. They are talking about how to respond to specific presentations of psychosis – such as regression into infantile states – that have sometimes left them feeling perplexed.

Staff and residents hold voluntary community meetings at each meal. Here they discuss what's happening for the day, incidents or concerns, and any relevant matters happening in anyone's lives. Sometimes they just laugh together. All meetings and interactions at Soteria-AK have an air of informality and casualness, more like folks living together in a commune than in a program. This dynamic is important to the spirit of the house, which tries hard to foster genuine relationships as opposed to service relationships based on expert-patient dynamics. In this regard, boundaries are looser: people touch one another affectionately, give massages, rub backs, dress as they wish, and in general act "as themselves" as much as possible. True to the original model, I could not discern in my first hours there who was a resident and who was a staff member.

If an incident of concern happens, staff write an Incident Report, which is then read by staff coming onto the next shift, and by the "Leadership Team" (a group of three staff who have managerial duties) at their weekly meeting held in the open kitchen. Daily Logs are also recorded by each staff person regarding the content of their shift. Soteria-AK is reimbursed by Medicaid, and as such must keep notes about residents, which they call Resident Services Log. These are basic records about a Resident's daily life. Soteria-AK recognizes that such notes can compromise the non-clinical nature of the program, so they have devised a form for recording notes that poses lay questions and expects lay answers, which is then translated by a designated staff member into clinically-based, Medicaid-reimbursable language. All notes are available for residents to read.

There is a house rule of "No Violence," but in reality each situation is worked with on an individual basis. Sometimes folks are asked to leave permanently, sometimes a plan is drawn up under which residents can stay. The procedure for responding to violent situations is as follows: when there is a threat or instance of violence, staff notifies On-Call (which consists of one of the Leadership Team members), who may come to the house or consult with the ED or psychiatrist, and then an Incident Report is created and a house meeting is held as soon as possible to discuss what happened. The police are notified when necessary. In general, the house is intentionally setup to avoid easy access to potential weapons (i.e. knives are locked up depending on the makeup of the current house).

Violence is understandably a major concern and factor in programmatic structuring. Staff are trained in Non-Violence Crisis Intervention<sup>109</sup>, which (from the website) "not only teaches staff to respond effectively to the warning signs that someone is beginning to lose control, it also addresses how staff can deal with their own stress, anxieties, and emotions when confronted with these challenging situations." As a group, staff continue to explore ways that relational dynamics lead to individuals acting violently, and they are committed to figuring out ways to lessen violent incidents. For example, Soteria-AK is working on an "Early Warning System" to help improve communication between staff when it seems as though a resident is struggling. They are also moving towards doing one-on-one Vigils with people in acute crisis, which is a way of "being with" used in the original model that involved staying with a resident non-stop for long periods of time.

Soteria-AK keeps money available in the budget for household repairs. Property damage by residents is not uncommon, and there is also a need to remove bio hazardous waste (such as feces) sometimes, so it is important to have procedures for this.

<sup>100</sup> 

http://www.crisisprevention.com/Specialties/Nonviolent-Crisis-Intervention

Choices-Alaska has "Peer Bridgers" on staff, who serve as an advocate for individuals receiving services. These individuals do not keep records on people, and are not part of a treatment team. At Soteria-AK, they will meet with residents and be an advocate with them, sometimes against Soteria-AK if needed and requested. When residents leave Soteria-AK, they can choose to stay connected with Choices-Alaska, which has multiple other services available (including peer supports) to help support people in independent living environments. Also, Soteria-AK is planning to have a Vocational Rehabilitation Counselor available soon for folks who want to get jobs.

# **OTHER**

# **PERSONNEL POLICIES**

While Soteria-VT remains a subsidiary of Pathways Vermont, all Soteria-VT employees with be subject to Pathways Vermont's Personnel Policies.

# **WEBSITE & MAILING LIST**

The Soteria-VT website<sup>110</sup> contains a link to a Mailing List setup through Google Groups. There are currently over 150 people signed up to receive news on the project, a hodgepodge of out-of-state people with interest and local stakeholders, including folks at DMH. There's a lot of diverse interest in this project, and it's helpful to have a central place where folks can stay connected, thus I am always encouraging people I meet to sign up. I updated the group once a month and encourage the continuance of this effort. Also, I used the group to make important announcements and distribute information, such as that regarding the Coming Off Psych Drugs and the Open Dialogue trainings.

# **ETHICS**

There is no specific code of ethics or core values devised for the Soteria model. In policy, Soteria-AK has adopted the United States Psychiatric Rehabilitation Association's code<sup>111</sup> and values<sup>112</sup>. While the USPRA's materials are mostly Soteria-friendly, it would be ideal for Soteria-VT to share in a code of ethics and core values that are agency-wide within Pathways Vermont.

http://pathwaysvermont.org/Soteria.html

https://uspra.ipower.com/Certification/Practitioner Code of Ethics.pdf

http://uspra.ipower.com/Board/Governing Documents/USPRA CORE PRINCIPLES2009.pdf

# APPENDIX A: ORIGINAL SOTERIA-VT PROPOSAL

August 19<sup>th</sup>, 2011

To Christine Oliver:

We are writing to recommend the creation of a Soteria–Vermont as part of the effort to create community services that can replace or reduce the need for Vermont State Hospital. While this brief letter will give an overview of the concept of Soteria, attached is a much more thorough report prepared for stakeholders in Alaska before opening a Soteria-Alaska in 2009. It contains vital information that Vermont could adapt and use towards creating its own version.

Soteria-CA project was created by the late psychiatrist Dr. Loren Mosher in the early 1970s and funded by a National Institute of Mental Health grant. It involved an unlocked residence in a California community where up to eight individuals having an initial psychotic break received voluntary support. What made Soteria different from traditional hospitalization was its focus on "being with" instead of "doing to" individuals, its tolerance and flexibility to adapt to one's psychotic process, its cautious use of antipsychotic medications, its creative and nonprofessionalized environment, and most importantly, its belief that psychosis could be a temporary experience that one could work through as opposed to a mental illness that needed to be managed.

The Soteria project lasted for eleven years and was rigorously studied. Compared with controls at a traditional hospital, residents of Soteria fared as well or better on every measure. These results were striking because – contrary to standards of care at hospitals – the vast majority of Soteria residents were never exposed to antipsychotic medications. Instead, Soteria proved that interpersonal and psychosocial approaches alone could facilitate recovery for persons on course to schizophrenia.

Soteria-CA closed in 1983, mostly due to political reasons. Said Mosher:

Its message was difficult for the field to acknowledge, assimilate, and use. It did not fit into the emerging scientific, descriptive, biomedical character of American psychiatry, and, in fact, called nearly every one of its tenets into question. In particular, it demedicalized, dehospitalized, deprofessionalized, and deantipsychoticized what Szasz has called "psychiatry's sacred cow"—[schizophrenia]

However, the message of Soteria never died. Several adapted versions of Soteria later emerged in Europe, and today we have a Soteria house in Alaska.

Indeed, the climate for creating a new Soteria has changed. There is now growing recognition and a solid evidence base that antipsychotic medications can cause considerable harm and impede an individual's recovery. In light of this, alternative approaches for people experiencing psychosis are springing up internationally, and much attention has been drawn to the Open Dialogue Approach in Finland and to the Soteria models.

A Soteria-Vermont would specifically reduce the need for Vermont State Hospital by providing support to five individuals at a time who would otherwise be using VSH services. It would ideally work with people having a first or second psychotic break who have not had substantial prior exposure to antipsychotic medication. Within the focus of interpersonal relationship-building, Soteria-Vermont will offer residents:

- A safe, non-coercive, flexible, self-determining, and homelike environment
- Techniques for stress reduction such as bodywork, yoga, and meditation
- Trauma-informed peer supports
- Access to creative tools, such as art supplies and musical instruments
- Voluntary medication in selective instances
- Healthy food
- Naturopathic consultation
- Access to farm animals
- The ability to continue social roles (such as working, family, leisure) when appropriate
- Linkages to the community
- Aftercare, including the opportunity to volunteer
- Skill development, including basic life skills such as cooking, budgeting, gardening, and cleaning

Staffing will include a Program Director, House Manager, part-time psychiatrist as Medical Director, Residential Assistants, Administrative Assistant, Consultants and Volunteers.

Based on conversations with Soteria-Alaska, we expect that residents will stay on average three to four months. Thus, at full capacity Soteria-Vermont will serve roughly fifteen to twenty individuals per year, and at significant economic savings to the state of Vermont. Currently, Soteria-Alaska costs about \$330 per bed per day (\$600,000 annual operating budget). On a similar budget, Soteria-Vermont would cost four times less than the Vermont State Hospital's \$1400 per bed per day, and three times less than Second Spring or Meadowview's roughly \$900 per bed per day. Annually, this amounts to two million dollars in savings.

The development of a Soteria-Vermont would involve creating a new non-profit organization. To begin this process, a host organization would likely need to provide financial and technical assistance. Another Way, Alyssum, Pathways to Housing, and Vermont Psychiatric Survivors have all tentatively expressed interest. Additionally, from years of conversations and meetings about a potential Soteria-Vermont, there appears to be strong support from a range of stakeholders, which indicates that a competent and committed Board of Directors would emerge quickly. A Soteria-Vermont could reasonably be operating within a year thereafter.

Thank you for your consideration of this proposal, and we look forward to future dialogue.

# Sincerely,

Steven Morgan Executive Director	Sandra Steingard, MD Psychiatrist	Law Project for Psychiatric Rights
Another Way Inc.	Burlington, VT	Cham, Mand MCM
Gloria van den Berg Executive Director	Steve Sobel, MD Psychiatrist	Shery Mead, MSW Intentional Peer Support
Alyssum Inc.	St Albans, VT	Seth Collins Montpelier, VT
Linda J. Corey Executive Director VT Psychiatric Survivors	Alice Silverman, MD Psychiatrist St Albans, VT	Laura Ziegler Plainfield, VT
Hilary Melton Executive Director Pathways to Housing VT	Joe Lasek, MD Psychiatrist Burlington, VT	Laurie Curtis, MA, CPRP Middlesex, VT
Floyd Nease, MA Executive Director VT Assoc for Mental Health	Ronald B. Miller, PhD Professor of Psychology Director, Graduate Program	Michael Sabourin Marshfield, VT
Ed Paquin	in Clinical Psychology	Michael Pearson, PhD Norwich, VT
Executive Director Disability Rights Vermont Inc.	Dr. Sam Tsemberis CEO and Founder	Xenia Williams, MS, LCMHC
Lauren Spiro Executive Director National Coalition for Mental Health Recovery	Pathways to Housing Inc.  James B. Gottstein, ESQ  President & CEO	Barre Town, VT  Deborah Shell, MA, LCMHC St Albans, VT
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## **APPENDIX B: PROMOTIONAL MATERIALS**

# One Page Description:

In early 2012, the Vermont legislature passed Act 79 to enhance community mental health services. Among other initiatives, this legislation calls for the creation of:

...a voluntary five-bed residence for individuals seeking to avoid or reduce reliance on medication or having an initial episode of psychosis. The residence shall be peer supported and noncoercive, and treatment shall be focused on a nontraditional, interpersonal, and psychosocial approach, with minimal use of psychotropic medications to facilitate recovery in individuals seeking an alternative to traditional hospitalization.

Pathways Vermont was recently awarded a contract to develop this residence in the greater Burlington area utilizing principles from Soteria, a successful program from the 1970s that was started with a National Institute of Mental Health grant. The Soteria model differs from traditional hospitalization in its focus on "being with" instead of "doing to" individuals, its tolerance and flexibility to adapt to one's process, its cautious use of antipsychotic medications, its creative and non-professionalized environment, and most importantly, its belief that psychosis can be a temporary experience that one can work through as opposed to a chronic mental illness that needs to be managed.

Soteria-CA project lasted for eleven years and was rigorously studied. Compared with controls at a traditional hospital, residents fared as well or better on every measure. In effect, it proved that interpersonal and psychosocial approaches alone can facilitate recovery for many persons on course to being diagnosed with schizophrenia.

Ideally, Soteria-VT will work with people having a first or second experience with psychosis who have not had substantial exposure to antipsychotic medication. Its primary service will be interpersonal relationship-building in a safe, flexible, empowering, and homelike environment. Additionally, Soteria-VT will offer trauma-informed peer supports, Naturopathic consultation, voluntary medication in selective instances, techniques for stress reduction, access to creative tools, skill development, gardening, healthy food, and the ability for folks to continue social roles. Based on data available, stays at Soteria-VT are expected to average three to four months.

Soteria-VT is targeted to open in mid to late 2013.

# One Paragraph Description:

Soteria-VT is a project currently being developed in Chittenden County by Pathways Vermont. Based on a successful model from the 1970s, it will provide a residence where folks having an early experience of psychosis can give and receive support. What makes Soteria different from traditional hospitalization is its focus on "being with" instead of "doing to" individuals, its tolerance and flexibility to adapt to one's process, its cautious use of antipsychotic medications, its creative and nonprofessionalized environment, and most importantly, its belief that psychosis can be a temporary experience that one can work through as opposed to a chronic mental illness that needs to be managed. Soteria-VT is scheduled to open in mid to late 2013.

# One Sentence Description:

Soteria-VT will be a residence for folks having an early experience of psychosis that facilitates recovery by "being with" people through their experiences.

# **APPENDIX C: ARTICLES & STUDIES ABOUT SOTERIA**

See also for an exhaustive list of articles: Soteria in the Literature: A Chronological Survey

- A non-antipsychotic treatment for schizophrenia: analysis of the two-year postdischarge risk of relapse. Matthews SM, Roper MT, Mosher LR, Menn AZ. Schizophr Bull. 1979;5(2):322-33.
- A systematic review of the Soteria paradigm for the treatment of people diagnosed with schizophrenia. Calton T, Ferriter M, Huband N, Spandler H. Schizophr Bull. 2008 Jan;34(1):181-92.
- At issue: predicting drug-free treatment response in acute psychosis from the Soteria project. Bola JR, Mosher LR. Schizophr Bull. 2002;28(4):559-75.
- <u>Commentary on the Soteria project: misguided therapeutics.</u> Carpenter WT Jr, Buchanan RW. Schizophr Bull. 2002;28(4):577-81; discussion 583-8.
- <u>Community residential treatment for schizophrenia: two-year follow-up.</u> Mosher LR, Menn AZ. Hosp Community Psychiatry. 1978 Nov;29(11):715-23.
- Deinstitutionalized Residential Care for the Mentally Disordered The Soteria Approach
- Long-term outcomes of psychodynamic residential treatment for severely disturbed young adults: a naturalistic study at a Swedish therapeutic community. Werbart A, Forsström D, Jeanneau M. Nord J Psychiatry. 2012 Dec;66(6):367-75.
- Mental health crisis services: What do service users need when in crisis? Dr Kirsty Agar-Jacomb and John Read. 2009, Vol. 18, No. 2, Pages 99-110.
- <u>Minimal-medication approaches to treating schizophrenia.</u> Calton T, Spandler H. Advances in Psychiatric Treatment (2009) 15: 209-217.
- Outpatient vs. comprehensive first-episode psychosis services, a 5-year follow-up of Soteria Nacka. Lindgren I, Falk Hogstedt M, Cullberg J. Nord J Psychiatry. 2006;60(5):405-9.
- <u>Psychosocial interventions in people with severe mental illness: a Bleulerian perspective.</u> Becker T, Kösters M. Neuropsychobiology. 2012;66(1):70-5.

- Residential alternatives to acute psychiatric hospital admission: systematic review. Lloyd-Evans B, Slade M, Jagielska D, Johnson S. Br J Psychiatry. 2009 Aug;195(2):109-17.
- <u>Soteria and other alternatives to acute psychiatric hospitalization: a personal and professional review.</u> Mosher LR. J Nerv Ment Dis. 1999 Mar;187(3):142-9.
- <u>Soteria Berne: an innovative milieu therapeutic approach to acute schizophrenia based on the concept of affect-logic.</u> Ciompi L, Hoffmann H. World Psychiatry. 2004 Oct;3(3):140-6.
- <u>Soteria-California and its Successors: Therapeutic Ingredients.</u> Mosher LR. In Ciompi L, Hoffmann H, & Broccard M (Eds.) Wie wirkt Soteria? Ein atypische Pssychosenbehandlung kritisch durchleuchtet (Why does Soteria work? An unusual schizophrenia therapy under examination) Huber: New York and Bonn pp. 13-43, 2001.
- Soteria Project Final Progress Report. Mosher LR, Vallone B. Submitted to NIMH. Mar 1992.
- <u>Soteria a treatment model and a reform movement in psychiatry.</u> Aderhold V. Translated by Peter Stastny. Sept 2006.
- <u>The Myth of Schizophrenia as a Progressive Brain Disease.</u> Zipursky RB, Reilly TJ, Murray RM. Schizophr Bull. 2012 Dec 7.
- The Soteria-concept. Theoretical bases and practical 13-year experience with a milieutherapeutic approach of acute schizophrenia. Ciompi, L. Special lecture given at the 93 Annual Meeting of the Japanese Society of Psychiatry and Neurology, Tokyo, May 29th-31th, 1997, published in Psychiatria et Neurologia Japonica 99: 634-650, 1997
- The Soteria Project 25 Years of Swimming Upriver by Mosher L, Bola J.
- Treatment costs and clinical outcome for first episode schizophrenia patients: a 3-year follow-up of the Swedish "Parachute Project" and two comparison groups. Cullberg J, Mattsson M, Levander S, Holmqvist R, Tomsmark L, Elingfors C, Wieselgren IM. Acta Psychiatr Scand. 2006 Oct;114(4):274-81.
- <u>Treatment of acute psychosis without antipsychotics: two-year outcomes from the Soteria project.</u> Bola JR, Mosher LR. J Nerv Ment Dis. 2003 Apr;191(4):219-29.