

**Contextual Essay**

**Involuntary Commitment and Recovery:  
An Innovative Mental Health Peer Support Program**

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## Table of Contents

Contextual Essay.....	i
Chapter I Introduction.....	1
Justification.....	2
Moving Ahead Project.....	4
Community Links.....	5
Critical Social Theory.....	5
Chapter II Literature Review.....	8
Involuntary Commitment.....	8
Values and Ethics of Mental Health Recovery and Peer Support.....	12
Defining Recovery.....	13
Research on Recovery.....	16
Peer Support.....	20
Relevant History of the Vermont State Hospital.....	22
Programs.....	29
Conclusion.....	38
Chapter III Methods.....	39
Methodology.....	41
Institutional Review Board process.....	43
Project Administration.....	45
Publicity Campaign.....	45

Advisory Boards .....	47
Informational Meetings/Focus Groups .....	49
Recruitment Strategies .....	51
Interviews.....	56
Interviews with Other Stakeholders.....	57
Data Analysis .....	58
Initial Review .....	59
Limitations .....	61
Conclusion .....	63
Chapter IV Findings.....	64
Involuntary Commitment Experience.....	64
Challenges.....	65
Losses and Traumas .....	67
Views on Diagnosis .....	68
Hopes and Dreams .....	69
Interests and Strengths .....	70
Self-Perception.....	71
Relationships.....	71
What Helps and What Does Not.....	72
Medications.....	73
Peer Support and Recovery Education .....	74
Vermont State Hospital Experience.....	75
Recommendations.....	79

Vermont State Department of Mental Health Questions and Responses .....	79
Core Elements of Pilot Project Design .....	85
Chapter V Pilot Project and Manual Development.....	87
Development of Pilot Project Design .....	87
Core Elements of Pilot Project Design .....	87
Training.....	92
Training Evaluation .....	94
Program Implementation .....	96
Evaluation .....	98
Chapter VI The Future of Community Links .....	101
Further Recommendations Based on Study Findings.....	103
In Conclusion .....	108
References.....	109
Appendix A Statutes Pertaining to Involuntary Commitment from.....	112
Appendix B Informed Consent Form .....	129
Appendix C Moving Ahead Press Release .....	131
Appendix D Moving Ahead Poster.....	132
Appendix E Semi-structured Interview Guide.....	133
Appendix F Community Links: Pathways to Reconnection and Recovery Implementation Manual.....	137

## Chapter I

### Introduction

The Vermont State Department of Health is concerned about the recovery and community integration prospects of people who have mental health related orders of involuntary in-patient or outpatient commitment. People in this group often have repeated restrictive orders and are reputed to have lives that are defined and limited by their mental health difficulties. In an effort to better meet the needs of these people and promote their recovery and reintegration into the community, the Vermont State Department of Mental Health funded principal investigator Mary Ellen Copeland, the author of this document, and coresearcher Shery Mead to:

1. Find out what recovery-oriented and peer support initiatives would help people who have these orders take back control of their lives;
  2. Design and implement a pilot program based on the findings of the study; and,
  3. Develop a manual that would allow for state and national program replication.
- (State of Vermont, 2001).

This essay describes the study, called the Moving Ahead Project, and the Community Links program that was developed and piloted based on the findings of that study, including the development of a manual to facilitate the replication of the Community Links program. It includes:

1. An overview of the project.

2. A literature review of the issues of involuntary commitment, mental health recovery, and peer support, including the established values and ethics of these initiatives, a historical perspective of past and current recovery efforts in Vermont and an overview of related mental health programs.
3. A description of the development of the proposal for the State of Vermont to fund the study (Moving Ahead Project) to determine those mental health recovery and peer support initiatives that might be helpful to people who have repeated involuntary mental health commitments.
4. An explanation of the implementation of the study.
5. The data analysis process, an overview of the findings, and the process of using the data as the basis for developing the Community Links program.
6. The design, implementation, and evaluation of the Community Links program.
7. Responses to specific questions posed by Vermont mental health officials and recommendations for future action based on the findings of the study.

### *Justification*

*Community Links: Pathways to Reconnection and Recovery* is a program designed to facilitate the recovery, independence, interdependence, and community integration of people who have had repeated court-ordered involuntary inpatient and outpatient mental health commitments. Typically people who have these court orders have a long history, often since childhood or adolescence, of dealing with a psychiatric illness that may involve distressing symptoms like hearing voices, anxiety, deep depression, bizarre behavior, repeated and long term institutionalization, on-going experiences of trauma and poverty, and ostracism from the community. In the past, when these people received

court orders, the orders dictated that they be institutionalized for long periods of time, often the rest of their lives, in facilities where they received minimal treatment and support. Current court orders can still force institutionalization, or they can define conditions that would allow a person with an involuntary commitment order to continue to live in the community. Further specific information on involuntary commitment statutes is included in Chapter II of this document.

According to Vermont State Department of Mental Health officials, there are about 200 people in Vermont who have these orders at any given time, 150 of them on outpatient commitment orders (meaning they can live in the community if they adhere to specific provisions or restrictions) and 50 who are patients at the Vermont State Hospital in Waterbury, Vermont. The Vermont State Department of Mental Health is seeking to reduce the number of people who have involuntary commitment orders. They funded principal investigator Mary Ellen Copeland, the author of this document, and coresearcher Shery Mead to conduct a study to:

1. Find out what kinds of mental health recovery-oriented and peer-support initiatives might be most helpful to people who have outpatient and inpatient involuntary commitment orders,
  2. Design and implement a pilot program based on the findings of the study, and
  3. Develop a manual that would allow for state and national program replication.
- (State of Vermont, 2001).

In the past decade, recovery-oriented and peer-support strategies have become much more common in the mental health field (Ralph & Corrigan, 2005). Prior to that time, people who had severe psychiatric symptoms were generally thought to be

incurable (Ralph & Corrigan, 2005). The only treatment options that might help to relieve symptoms were medications and electroshock therapy, along with maintenance and support services. Now, with impetus from a strong national mental health recovery movement, it is recognized that people can and do *recover*, that there are things they can do to help themselves feel better, that they can learn about these things and use them in their own lives, and that they often benefit from positive contact with others who have similar life issues (Ralph & Corrigan, 2005). Vermont wanted to develop a program to use this new focus to facilitate the recovery of those people who are often most difficult to reach—people who have orders of involuntary inpatient or outpatient commitment.

#### *Moving Ahead Project*

The initial study, known as the Moving Ahead Project, included: interviews with 28 volunteers who now have or have had these orders; meetings with others who either have these orders or who have an interest in this issue, like program administrators, care providers, and court personnel; examination of other programs across the country that have been designed to address this issue or similar issues; and a review of related literature. The findings indicated that people who have involuntary commitment orders want to recover, want to have connections outside of the mental health system, and want to be integrated back into their communities, and that there are aspects of other programs including a historic Vermont program (Chittick, Brooks, Irons, & Deane, 1961) that might be useful in planning and implementing a Vermont initiative (Copeland & Mead, 2004b).

### *Community Links*

Based on these findings, the coresearchers developed and implemented a three-day training called the Community Links training; the two-month pilot project, Community Links; and the *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual* (Copeland, 2005). Ten people from the community were trained in various aspects of developing mutually supportive relationships, assisting others in making connections, and personal resource development. Following the training, each person who took the Community Links training was matched with a person having an involuntary commitment order who had requested a “Link”. Then, in a series of mutually designed meetings and activities over a two-month period, the Community Link and the person who had asked to be in the program worked together to learn recovery skills and strategies, explore community resources, and connect with others. At the end of the pilot program, the researchers evaluated the effectiveness of the program based on feedback from both the people who took the Community Links training and the participants and revised the training manual based on the findings of this evaluation.

The writer, Mary Ellen Copeland, developed the manual *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual* based on the findings of the study and the evaluation of the pilot program. This manual describes how to implement every aspect of the Community Links program. As a result of this program it is expected that more people will have their orders rescinded, be able to manage their lives without an order, have more friends and connections in the community, and be able to work toward their own goals and dreams.

While working closely with Shery Mead on this project, the writer took full responsibility for development of the *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual* including organizing and composing the manual, and writing the Contextual Essay.

### *Critical Social Theory*

Both the Moving Ahead and Community Links Projects are based on the concept of Critical Social Theory:

Critical Social Theory is an attempt to understand, analyze, criticize and alter social, economic, cultural, technological, and psychological structures and phenomena that have features of oppression, domination, exploitation, injustice and misery. They do this with a view to changing or eliminating these structures and phenomena and expanding the scope of freedom, justice and happiness. The assumption is that this knowledge will be used in processes of social change by people to whom understanding their situation is crucial to changing it. (Bentz & Shapiro, 1998, p. 146)

People who “act differently” or have been diagnosed with a mental illness have been stigmatized for generations. They have often been the victims of violent attacks. Because they cannot advocate for their own needs, the resources expended to address this situation have been minimal. The Community Links project has the potential for beginning to provide assistance and support to people in these circumstances. The eventual goal will be to have people become integrated back into the community as fully participating members of that community.

Recovery-focused work like this project is effectively changing mental health service provision for people who have the most serious mental health issues from an antiquated system focused on force, coercion, institutionalization, and maintenance to an innovative and life-enhancing system focused on recovery and life transformation. People who have been struggling with mental health difficulties often accompanied by poverty and ostracism from the mainstream are finding new hope. They are learning that they can recover. They are using recovery-oriented self-help skills and strategies to manage and relieve pervasive symptoms. They are taking back responsibility for their own lives and are working toward meeting their own goals and dreams (Copeland, 2005).

The State of Vermont is integrating the Community Links Program into their statewide mental health program. Now, even before they leave the state hospital, people will be supported by a well-trained person from the community who will work with them as they leave the hospital, sometimes after years of confinement, and reenter their community.

## Chapter II

### Literature Review

This literature review provided essential data and helped set the context for the Moving Ahead Project and eventually the Community Links pilot project that resulted from it. It includes discussion of involuntary commitment, the values and ethics of mental health recovery and peer support, mental health recovery, peer support in mental health, pertinent historical information regarding Vermont interventions related to individuals who were involuntarily committed, programs that have been used elsewhere to address the needs of people with orders of involuntary commitment, and the social relevance of this project.

#### *Involuntary Commitment*

The Moving Ahead Project (Copeland & Mead, 2004b) was an attempt by Vermont State Department of Mental Health officials to reduce the number of people who have orders of involuntary commitment by supporting the development of initiatives that use recovery-oriented education and peer support initiatives to promote wellness and recovery. Their interest is to have fewer and fewer people who need these orders. The Vermont statutes that pertain to involuntary commitment are in Appendix A of this document.

The justification for both involuntary inpatient and outpatient commitment, as stated in the Vermont State Statutes (Legislative Council of the General Assembly for the State of Vermont), is the prevention of harm to self and others:

7611 “A person in need of treatment” means a person who is suffering from mental illness and, as a result of that mental illness, his capacity to exercise self-control, judgment or discretion in the conduct of his affairs and social relations is so lessened that he poses a danger of harm to himself or others;

(A) A danger of harm to others may be shown by establishing that:

- (i) he has inflicted or attempted to inflict bodily harm on another; or
- (ii) by his threats or actions he has placed others in reasonable fear of physical harm to themselves; or
- (iii) by his actions or inactions he has presented a danger to persons in his care.

(B) A danger of harm to himself may be shown by establishing that:

- (i) he has threatened or attempted suicide or serious bodily harm; or
- (ii) he has behaved in such a manner as to indicate that he is unable, without supervision and the assistance of others, to satisfy his need for nourishment, personal or medical care, shelter, or self-protection and safety, so that it is probable that death, substantial physical bodily injury, serious mental deterioration or serious physical debilitation or disease will ensue unless adequate treatment is afforded. (Legislative Council of the General Assembly for the State of Vermont, 2003)

In addition to reading the statutes, interviews with lawyers and other officials helped to clarify the involuntary commitment process. According to these accounts, involuntary commitment orders are orders given to people whom the court declares a

danger to self or others. These orders mandate loss of independence, restrict a person's activities, freedom, and choice, and may include adherence to a particular treatment regime such as medications, the use of case management services, and hospitalization or institutionalization (involuntary inpatient commitment). If the person is in an institution, the order will restrict their freedom when they are released, and allow for their expeditious return to the institution if provisions of the order are not followed. If a person has an involuntary outpatient commitment, they will live in the community while adhering to the specifications of the order. In most cases, people who receive these orders have been diagnosed with a severe and chronic mental illness. These orders are seen as a way to keep both the community and the person who has the order safe, and, in the case of outpatient commitment, to prevent hospitalization, although this is not specified in the statutes.

Discussions with various mental health officials and care providers showed that people who get these orders have either been arrested and held under observation or taken into custody at the request of family members, supporters, mental health professionals, or community members. They are ordered to appear in court, or are taken to court. The statutes do not specify who develops the order. The researchers found that officials of the court, who usually have not met the person receiving the order and are not expected to meet that person, develop the specifications of the order. The order is then given to the person or sent to the person by mail. It might be assumed that the order would be developed to support the recovery of the person receiving the order, but the researchers found that this was rarely the case. More often it was a document based on a template developed over time that had no personal relevance to the person receiving the order.

Most people involved in the implementation of these orders, including people who have or have had these orders, reported that they are not strictly enforced. This lack of enforcement makes the order confusing and stressful, sometimes exacerbating their symptoms. People who have these orders are often on them for long periods of time, or are on and off orders repeatedly over the years.

Through the statutes (Appendix, Section A), Vermont legislators have attempted to protect people who might receive orders of involuntary commitment. However, when they developed or when they revised these statutes, they were under tremendous pressure from people with various perspectives, including those who believe that these orders are unconstitutional and should never be allowed, and that if people are breaking the law they should be treated as criminals; others support these laws and believe they should be more stringent. Therefore the law is a compromise, trying to satisfy as many constituents as possible (Copeland, 1998).

Section 7613 of the statutes says, “The notice of hearing shall set forth the date and time of the hearing and shall contain a list of the proposed patient’s rights at the hearing” (Legislative Council of the General Assembly for the State of Vermont, 2003). The rights mentioned in this section were of particular interest to the researchers. Repeated attempts to obtain that list of rights were futile. Apparently that part of the statute is overlooked.

As with any statutes there are difficulties with interpretation. Interpretation varies from court to court and from person to person. Little consistency could be found in the application of these statutes, making an already difficult situation even more confusing for the person receiving the order and for family members and care providers. In addition,

several mental health constituency groups argue that the statutes are not sufficient and need to be more specific to adequately meet both the needs of people who might receive such an order and the community that these orders are designed to protect.

Although it is hoped that the conditions of the order might contribute to a person's recovery, there is nothing in the statutes that addresses this issue or that suggests the order might include recovery-oriented activities.

Study of the effectiveness of these orders in protecting people in the community and addressing contentious human rights issues around these orders is outside the scope of this project.

#### *Values and Ethics of Mental Health Recovery and Peer Support*

The State of Vermont, in accepting Mary Ellen Copeland and Shery Mead as the researchers in this study, knew that Copeland and Mead have collaborated for many years, have interviewed many people who experience mental health difficulties including those who have had involuntary commitments, and have developed, tested, and published a listing of values and ethics that informs all of their work and would inform every aspect of this project. These values and ethics are:

1. There is hope. A commonly held belief has been that people who experience certain kinds of "symptoms" can never get well, and will probably worsen over time. However, it is now known that people can and do get well and go on to do the things they want to do with their lives (Copeland, 1991; Ralph & Corrigan, 2005).
2. Self-determination, personal responsibility, empowerment, and self-advocacy are vital to recovery (Copeland, 1991).

3. Treating each other as equals with dignity, compassion, mutual respect, and unconditional high regard is essential.
4. We must afford all people unconditional acceptance as they are, as unique, special individuals, including acceptance of diversity with relation to cultural, ethnic, religious, racial, gender, age, disability, and sexual preference issues.
5. There are “no limits” to recovery.
6. Recovery and peer support are about choices and options, not final answers.
7. Participation in all activities is voluntary.
8. Each person is the expert on himself or herself.
9. Clinical, medical, and diagnostic language are avoided.
10. The focus is on working together to increase mutual understanding, knowledge, and wellness.
11. Peer support and recovery initiatives are adaptable to anyone’s personal philosophy.
12. The emphasis is on strategies that are simple and safe for anyone and away from strategies that may have harmful effects.
13. Responses to difficult situations need to be “normalized”.
14. The focus is on strengths and away from perceived deficits (Rapp, 1998).
15. The body of knowledge is always expanding and is infinite (Copeland & Mead, 2004a).

### *Defining Recovery*

For many years, it has been assumed that people who experience severe and persistent mental health difficulties do not recover, leading to low expectations that have

been seen to wear away hope and support chronicity (Harrison & Mason, 1993). In the introduction to *Mental Illness and Recovery*, Ralph and Corrigan (2005) stated that:

Prior to 1990, students of major mental health disciplines learned that the serious mental illnesses were defined as having poor prognoses with progressively downhill courses. Treatment was limited to custodial options. People with these diagnoses had to foster ideas of hope and recovery in a mental health system that viewed serious psychiatric disorders as harbingers of doom. According to the old school, people with serious mental illness needed to accept that normal life was impossible, that dreams of independence were unattainable, and that long-term institutionalization was inescapable. Recovery signaled a monumental revolution in the mental health paradigm. (p. 4)

Recovery is a common term that is generally equated with getting well or getting back to normal (Roberts & Wolfson, 2004). However, when this term is used with respect to mental illness, most people agree that it refers to a process rather than a steady state. Although a clear definition of recovery is elusive and seems to mean different things to different people, most people agree that a person “in recovery” is working to take back control of his or her life and is working toward achieving her or his own goals and dreams. It does not necessarily mean an absence of what might be considered “psychiatric symptoms”. It does mean learning to relieve difficult feelings and behaviors, and to live well in spite of these difficulties (Ralph & Corrigan, 2005; Roberts & Wolfson, 2004). As people who have a lived experience of mental health difficulties have attempted to define recovery, various themes have emerged (Ralph & Corrigan, 2005). These themes include:

1. Recovery is defined in terms of continual growth, increased control over one's life, and either a redefining or reestablishing of a sense of self in the recovery process.
2. Recovery is a highly individualized process rather than a universally defined end state, and requires methods of research that can capture or at least more accurately assess the dynamic and varied nature of the phenomenon.
3. Recovery is a nonlinear, ongoing process—people do not move through the recovery process in a predetermined, orderly manner.
4. People play an active role in their own recovery process.
5. People are the experts on the topic of their own experiences, needs, and their own recovery.
6. Hope is an essential ingredient.
7. Meaning and purpose in life are necessary to recovery.
8. Relapse is part of a process and not a failure. (Davidson & Strauss, 1992; Loveland, Randall, & Corrigan, 2005; Morse, 1997; Ralph, 2000; Strauss & Carpenter, 1981; Young & Ensing, 1999)

Ralph and Corrigan (2005) contend that recovery is concerned with a sense of meaning in life and personal comfort, and is focused on validation of personhood, recognition of common humanity, and tolerance for individual differences. Allott, Loganathan, and Fulford (2003) and Ralph, Lambert, and Kidder (2002) consider that the turning point in a person's life, when they begin to focus away from illness and toward recovery, is marked by the individual's active and responsible engagement with his or her distress and difficulties. Recovery is often described as having a defining moment or a

turning point (Allott et al., 2003). Sometimes it is a low turning point before which the person had a hard time moving forward, feeling that they would never be well, and dealing with the grief and anxiety that is commonly associated with loss of health and hope for the future. It is sometimes claimed that recovery is often further delayed by a state of learned helplessness encouraged by the low expectations of mental health professionals. Several authors suggested that a beginning of working toward recovery can often be attributed to talking to peers about mutual experiences and self-help strategies. People begin to regain their sense of self, taking back control and responsibility for their lives (Faulkner & Layzell, 2000; Leibrich, 2001).

Coleman (1999), who has a lived experience of mental distress including institutionalization and who is an advocate for recovery, emphasized that recovery depends far more on self-help and collaboration than on being treated.

Recovery is not a gift from doctors but the responsibility of us all... We must become confident in our own abilities to change our lives, we must give up being reliant on others doing everything for us. We need to start doing these things for ourselves. We must have the confidence to give up being ill so that we can start becoming recovered. (Coleman, 1999, p. 7)

### *Research on Recovery*

The notion that recovery from severe psychiatric disorder is impossible is now contradicted by impressive and well-known longitudinal studies and the anecdotal experience of many, many people.

In the Japanese Long Term Study (Ralph & Corrigan, 2005), follow-up evaluations were conducted for 105 people with the diagnosis of schizophrenia who had

been discharged from mental institutions between 1958 and 1962. Follow-up periods were from 21 to 27 years. Results indicated that 31% were *recovered*, 46% improved, and 23% were unimproved. Forty-seven percent were fully or partially self-supporting and 31% were again hospitalized. Early stages of the illness course were typically found to fluctuate with regard to social functioning, whereas later stages stabilized to either a stable self-supporting state or a chronic institutionalized state.

Roberts and Wolfson (2004) considered the International Study of Schizophrenia (Harrison et al., 2001) to be the most comprehensive long-term follow-up study of recovery. It included 1633 participants from 14 culturally diverse areas who were studied at 15 years and again at 25 years after diagnosis. The results were in line with previous studies. Outcomes at 15 years and 25 years were favorable for over half of the participants. However, the researchers in this study admit that their studies, like other similar studies, rely heavily on the presence or absence of symptoms and social disabilities as outcome indicators rather than indicators that might be defined by the study participants.

Of most relevance to this project is the Vermont Longitudinal Research study (Harding, Brooks, Ashikaga, Strauss, & Brier, 1987). In this study, 269 people were followed for about 32 years. On average, the people in this study had been ill 16 years, totally disabled for 10 years, and hospitalized in the back wards of the Vermont State Hospital for 6 years. Patients participated in a model rehabilitation program organized around the goal of self-sufficiency, residential and vocational placements in the community, and long term continuity of care. They had been released from the hospital with community supports already in place. At follow up one-half to two-thirds were

considered to have improved or recovered, depending on the criteria used. Sixty-eight percent did not display signs or symptoms of schizophrenia. Forty-five percent displayed no psychiatric symptoms at all. More than two-thirds were rated as having good functioning on tests that included both psychological and social criteria. This landmark study was hailed across the country and around the world as evidence that, given intensive education and support initiatives along with medical treatment, recovery from severe mental illness is possible. This finding had a great impact on the mental health field because it was in contrast to the longstanding view that people with mental health symptoms could not get better.

These findings were further supported by the Maine–Vermont Comparison Study (Desisto, Harding, McCormick, Ashikaga, & Brooks, 1995), which used a group-matching design. This study compared the outcomes of 269 people in Maine in similar circumstances with the 269 people in the Vermont Longitudinal Study. However, the Maine patients received standard inpatient treatment and aftercare. Vermont participants were found to be more productive and had fewer symptoms, better community adjustment, and better global functioning than Maine participants. Roughly one half of the Maine participants were rated as having good functioning. The researchers in these studies suggest that the model rehabilitation program utilized in the Vermont study (which will be discussed in the history section of this literature review) gave Vermont participants an earlier opportunity to adapt to life in the community and may explain the better outcomes for these participants.

Anecdotal evidence of recovery from severe mental health difficulties is growing at a rapid pace. Ralph and Corrigan (2005) state that as people have gained more voice

around issues that impact their lives, a new understanding of recovery has emerged based on their lived experience (Deegan, 1988). This understanding of recovery was introduced in the 1970s with the rise of the consumer/survivor/expatient movement (Chamberlin, 2002) and is not based on a disease model framework. This view has emanated from individuals who were living with and trying to recover from mental illness and the effects of institutional and other medically based treatment interventions (Chamberlin, 2002). Walsh (1996) suggest that mental illness changes lives irrevocably. She says, “We can never go back to our ‘premorbid’ selves. The experience of disability and stigma attached to it changes us forever. People would not want to go back. Recovery involves growth and an expansion of capacities.” (p. 87) For many people who write about this process, recovery is a personally meaningful goal rather than an abstract construct that is studied academically.

Although Roberts and Wolfson (2004) feel that there is a need to gather and strengthen the evidence base for recovery, they suggest that this can and needs to be a major area for collaboration between people who experience mental health difficulties and care providers. They contend that meta-analyses or randomized, controlled trials provide little guidance on what might make a difference to a person who is working on their recovery.

How does the medical model fit into all of this? Roberts and Wolfson (2004), well-known British psychiatrists, claim that the medical model is narrowly focused on disease, treatment, and biological reductionism, and contrast this with the broader person-centered focus of recovery models. Ralph et al. (2002), assert the validity of an evidence base largely composed of personal narrative, and the views of “experts by experience.”

At present there is significant tension between the medical model and recovery initiatives. Often their values and language stand in significant disjunction with one another. However, in this research project and in mental health recovery work around this country and around the world, this researcher has found that the medical community, while often unwilling to give up the notion that medical treatment is essential, is discovering that by supporting recovery initiatives and peer support, they experience more successful outcomes (Copeland, 2004c).

### *Peer Support*

Peer support in mental health is different from other kinds of peer support that grow out of shared experience. In mental health, historically, peer support grew out of a civil and human rights movement in which people gathered around their shared experience of negative mental health treatment, which included things like coercion, isolation, restraint, rights violations, overmedication, and ignored trauma histories (Mead & MacNeil, 2004).

Peer support is a system for giving and receiving help founded on the principles of respect, shared responsibility, and mutual agreement of what is helpful. It is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. It is based on the premise that when people find affiliation with others they feel are "like" them, they feel a sense of connection. "It is not about joining a club for the mentally ill" (Mead, Hilton, & Curtis, 2001, p. 135). In this context, a peer is person who is or was receiving mental health services and self identifies as such (Solomon & Draine, 2001). Others define it as social and emotional support that is mutual and provided by people

having similar mental health challenges in their lives with the purpose of bringing about desired social or personal change (Gartner & Riesman, 1982; Solomon, 2004).

Studies by George, Blazer, Hughes, and Fowler (1989), Walsh and Connelly (1996), and Salzer (2002) speak to the value of peer support for the person who is experiencing mental health difficulties. They support the notion that supportive relationships promote positive adjustment and assist people in dealing with difficult times. Peer support provides people who usually have few supportive friends and family members with people in their lives on whom they can rely, who clearly care about and value them, and who they can work with to meet their mutual needs (Sarason et al., 1983). Other benefits include information, guidance, feedback (including the unique knowledge that can come from people with similar experience), a sense of belonging, enhanced self-esteem, validation, and hope. Peer support promotes choice, self-determination, and empowerment, and increases confidence (Mead et al., 2001). People who are alienated from the mental health system and are opposed to using it are more likely to use peer support. Peers can more easily engage people who would be difficult to engage (Segal, Gormory, & Silverman, 1998). However, it must be recognized that peer support is of little value to people who feel that help is not valid if it is not delivered by highly trained health care professionals (Rappaport, 1993).

Peer support has been recognized as acceptable and beneficial since the development of community mental health systems in the 1970s. It can be financially compensated or voluntary (Solomon, 2004). It is nonmedical and often occurs in flexible informal settings that are nonhierarchical and nonmedical (Mead, 2004; Salzer, 2002; Solomon, 2004). It can happen informally when several people get together, and in

various contrived circumstances including self-help groups, peer-delivered services, warm lines, hot lines, peer programs, advocacy programs, outreach, mobile crisis teams, and respite (Mead et al., 2001). It may be free standing or sponsored by an agency or organization. In this project's Request for Proposals, Vermont asked the researchers to consider a peer support initiative as part of the pilot project. The options were to be restricted due to the funding and time restraints of this project. For instance, mobile crisis teams and respite would not be possible.

Studies of peer support initiatives are relatively recent. By their very nature they are difficult to study (Davidson et al., 2001). Though the studies are limited in number and scientific rigor, they have shown positive outcomes. For people specifically with a mental illness diagnosis, the findings are encouraging but tentative given the limitations of the research (Christensen & Jacobson, 1994). There is a lack of testing of peer support due to the culture of self-help groups that makes traditional methodologies more difficult to employ (Kingree & Ruback, 1994). The challenge in studying peer support is developing standards. It is difficult to find ways to translate practical knowledge into clear accounts of "what is the ideal" and why this is so. Mead and MacNeil (2004) felt that it would require narrative frameworks. However, this does not preclude outcome studies looking at easily measured outcomes such as employment, social participation, and hospitalizations.

### *Relevant History of the Vermont State Hospital*

In developing and implementing this study, it was helpful to look intensively at the history of the treatment provided at the Vermont State Hospital. Almost all of the study participants had spent months and often years of their lives committed to the

Vermont State Hospital, or less frequently, using state supported mental health services in one of the community mental health centers. If these people had lived before the beginning of deinstitutionalization and before the onset of a remarkable program in Vermont that, at least for a time, highly influenced care and services at the hospital facility, they would not have been given the option of having an involuntary commitment order that included living in the community. They would have been housed, and probably lived out their lives, at the Vermont State Hospital. *Empty Beds: A History of Vermont State Hospital* (Kincheloe & Hunt, 1988), though more journalistic than scholarly, provides insight into this issue by taking a close look at the Vermont State Hospital from its founding in 1891 to 1988. This fascinating book often reads like the history of a gala resort with depictions of social gatherings, hilarious activities, and outings for those that might be eligible, and even pictures of certificates for award winning Holstein cows on the hospital farm. But within the pages can be found the bleakness and horror of life in this state mental institution. Describing a visit in 1985, the authors say:

The elderly people were dressed in short, open-backed johnnies and lined up in a big circle of chairs around the walls of the day hall, and the place smelled of that typical overpowering hospital smell of urine, air freshener and disinfectant. The people in the day hall looked like hundreds (there were only 24) of little white birds all with broken wings, flopping and squawking, with staff stuttering about tending to them. We seemed to go through endless sets of locked doors before arriving at the inner reaches of the ward. Never having been in a prison, this did seem to match my image of one. We were immediately surrounded by male staff to escort us, and, because they were all taller than me, all I saw was backs and

chests and faces, and then we left, and I was thoroughly imbued with a sense of danger and control. Patients' fear, anger, defensive lashing out and even desire to die in the first few days cannot be solely attributed to mental illness, but rather to a very normal reaction to being forced into a terrifying situation. (Kincheloe & Hunt, 1988, p. 187)

Census at the hospital peaked at 1,172 in 1966. There were precipitous drops in inpatient census through the 1970s and 1980s. There were only 161 patients when *Empty Beds* (Kincheloe & Hunt, 1988) was written in 1988, and there are currently between 40 and 60 people at the hospital at any given time. What factors account for this drop in census, and how might that information be important to this study and the program that would be developed as a result of the study? Clearly these issues beg to be explored.

Dr. George Brooks, who began working at the hospital in 1947 and was superintendent from 1968 to 1984, was highly regarded as a strong advocate for improving mental health care and for people who experienced mental health difficulties. In 1957, he applied for a grant that was funded through the US Department of Health, Education, and Welfare, Office of Vocational Rehabilitation. It was called the Vermont Project. Its purpose was to develop and implement a rehabilitation program for people diagnosed as having chronic schizophrenia. *The Vermont Story* (Chittick et al., 1961) is a detailed description of this project. It not only changed the lives of hundreds of people who had lived at the Vermont State Hospital for many years, it became a guide for similar efforts that were occurring or being planned across the nation.

Brooks and his colleagues recognized that in cases of chronic illness and lengthy hospitalizations, the person would no longer have a place in a community. They might

have lost many of their employment and social skills. They might no longer have contact with friends and family. In order for the person to be independent, self-sufficient, and reinstated in the community, there must be active participation by both the person and the community in the rehabilitation program. To meet this need, Brooks and his colleagues developed and implemented a program that included the following components:

1. The use of drug treatment. “About 9 out of 10 of the patients in this program receive some neuroleptic medication” (the only kind of medication that was available at that time for psychosis (Chittick et al., 1961, p. 31). This was in the early days of medication availability and use. This may be why they had been taking these drugs for relatively short periods. The authors state that the “duration of treatment ranges from one month to over five years” (Chittick et al., p. 32) Currently long-term use of drugs to treat these illnesses is common, and people are often told that they will have to stay on these medications for the rest of their lives. Also, today a much broader spectrum of drugs that treat psychiatric symptoms is available.
2. Changes in ward care. Prior to implementation of this program, patients were typically confined in crowded institutional wards with little attention from staff, limited options for activities, and few opportunities for making choices. In this program, “We try to provide a more normal and home-like atmosphere...The atmosphere is relaxed and noncustodial. Attendants are included in discussions and planning groups. The wards are pleasantly decorated and furnished. They have television, laundering facilities, etc. The

patients have pets; they make popcorn and plan parties” (Chittick et al., 1961, p. 32).

3. Therapy groups. Patients participated in therapy groups. Group leaders were anyone who worked on the staff including attendants, nurses, social workers, physicians, and vocational counselors. The focus of these groups was reality problem solving in the areas of job training, job finding, living arrangements, social activities, and the relevance of hospital activities to the patients’ goals in these areas. Patients were encouraged to make choices.
4. Graded privileges. Patients could move rapidly from limited ground privileges to freedom of movement within the entire hospital, and then to freedom of movement in the community (Chittick et al., 1961).
5. Activity therapy. Patients were involved in occupational and recreational therapy groups designed to encourage or require group cooperation, first with each other, then toward the entire hospital, and then toward the community. Examples included making dinner for each other, putting on a hospital bazaar, and participating in the village Fourth of July parade (Chittick et al., 1961).
6. Industrial therapy. This part of the program used the hospital as a training facility. “Patients are assigned to jobs based on their expressed interest (a new concept for these people) and ability in light of their future plans” (Chittick et al., 1961, p. 33) They worked toward paid employment in the community.
7. Vocational counseling. People received intensified vocational counseling. Counselors worked with the patients realistically on planning for the future.

This continued even in the rehabilitation house or in the community until the person was well established.

8. Blurring. A variety of activities were planned and implemented to blur the boundaries between hospital and community. This included ongoing opportunities for connection between people who were just beginning the program and people who had progressed into rehabilitation houses or the community (Chittick et al., 1961).

In this program, leaving the hospital was considered a critical life transition. People were given instruction and rehearsed situations they were likely to encounter in the community. People lived in halfway houses or participated in a form of graduated return to the community. Supports and long-term follow-up contacts were established to continue after the person was settled in the community. A high incidence of relapse occurred when this was not in place. Of 298 cases, 83% were released from the hospital after one year or more of intensive effort to reintegrate them back into community life. In 1965 it was reported that more than 500 severely disabled chronic patients had been successfully returned to the community. This program was the beginning of a statewide system of community mental health centers to take over aftercare programs and to provide a wide range of outpatient, prevention, and support services (Kincheloe, 1988).

This program was studied by both the Vermont Longitudinal Research study (Harding et al., 1987) and the Maine-Vermont Comparison study (Desisto et al., 1995). These landmark studies were hailed across the country and around the world as evidence that, given intensive education and support initiatives along with medical treatment, recovery from severe mental illness is possible. This finding had a great impact on the

mental health field because it was in opposition to the longstanding view that people with mental health symptoms could not get better, and could even expect to get worse as they aged (Copeland, 1991).

This research convinced people across the country and around the world that recovery from mental health difficulties is possible and even probable. The state of Vermont probably would never have funded the current project to study which recovery and peer support strategies might be helpful to people with orders of involuntary commitment were it not for the findings of these studies and this historic exemplary “recovery” program.

Unfortunately, the Vermont State Hospital is no longer the avant garde institution that it once was. Through the late 1980s and 1990s and on into the new century, funding was reduced and attention was focused on community mental health centers. With changes in key personnel and government officials, the phenomenal *Vermont Story* (Chittick et al., 1961) was forgotten and the programs that meant life to so many people were forgotten as well. The hospital has recently been decertified by Medicaid, following an investigation by the United States Department of Justice in July, 2005 (Beiner, 2005). Their findings contain allegations that VSH is violating the federal statutory and constitutional rights of patients. This was a stunning blow and a huge embarrassment. Officials are struggling to correct these insufficiencies. However, they are not looking to *The Vermont Story* (Chittick et al., 1961) for answers. Linda Corey, Executive Director of Vermont Psychiatric Survivors, reports that there is currently no rehabilitation program at the Vermont State Hospital (personal communication, March 5, 2005). Recently a hospital official found copies of *The Vermont Story* and was going to discard them until

they were rescued by Corey. There are three private facilities in Vermont that provide rehabilitation services modeled after the Vermont program that worked so well; but these programs are generally not available to people with limited resources, as is usually the case for people on orders of involuntary commitment.

To its credit, Vermont has an exemplary recovery network that was developed by a group of key stakeholders, people who experience mental health difficulties. Vermont Psychiatric Survivors, an organization of people with experience in the mental health system, is well known across the country for its ability to raise money through federal, state, and private grants and for its popular statewide network of mental health recovery and Wellness Recovery Action Planning programs that are available without charge to anyone who wants to attend. Although supported by the state department of mental health, Vermont Psychiatric Survivors is a nonprofit organization administered by people who have used the mental health system. The Executive Director reports that it has been difficult to get people who have orders of involuntary commitment to take advantage of these programs (Linda Corey, personal communication, March 5, 2005).

### *Programs*

The researchers conducted a nationwide search to find programs that had been developed to meet the needs of people who have repeated involuntary commitments. They began by contacting the state Departments of Mental Health and following up on their leads. It was a frustrating task. Very little has been done to address the specific needs of people in this category. However, many mental health recovery and peer support programs designed to serve a broader base of people with mental health difficulties were reviewed and helped inform development of the pilot project. Of particular interest to the

researchers were those that were developed by people who had been or are currently users of mental health services, including people who have had involuntary commitments.

Wellness Recovery Action Planning (WRAP), a program that was developed at one of the author's seminars in Vermont in 1997 by people who have a lived experience of mental distress including involuntary commitment, is now offered in every state and in many other countries. WRAP programs, which can be led by anyone but are most often led by others with similar issues, help people design and use a personal recovery plan (Copeland, 2002). From the onset of this project, it was clear that the State of Vermont Department of Mental Health and the people interviewed in the study wanted to include some form of individualized recovery planning like WRAP in the pilot project. The following quote from an interview illustrates the point (the interviewer's comments are in italics):

*Are you familiar with Mary Ellen's WRAP stuff?* I am. I used her program, actually, at the hospital. *What was useful and not useful about WRAP?* I think it was really useful, because it made me look at symptoms. It made me look at warning signs. It made me put those into reality.

WRAP is a program in which participants identify internal and external resources for facilitating recovery, and then use these tools to create their own individualized plan for successful living (Copeland, 2002b). The creation of a WRAP plan generally begins with the development of a personal Wellness Toolbox, consisting of simple, safe, and free or low-cost self-management strategies such as a healthy diet, exercise, sleep patterns, and pursuit of adult life roles (Copeland, 2002b). Using this Toolbox, the person

creates an individualized plan for engaging each strategy to obtain and maintain their recovery. The plan also includes identification of “early warning signs” of symptom exacerbation or crisis, and how the Toolbox can help people to manage and feel better. WRAP also encourages development of a crisis plan, which states how the person would like to be treated in times of crisis (similar to an advance directive for inpatient psychiatric care), as well as a post-crisis plan for getting back on the road to recovery (Copeland, 2002b).

Judith Cook, a mental health researcher at the University of Illinois in Chicago, established the evidence base for WRAP. “There is an evidence base for WRAP due, in part, to the availability and widespread use of a pretest/posttest instrument developed by the model’s creator (Copeland, 2003) and widely used by its facilitators. A number of pretest/posttest design studies have examined the impact of WRAP on consumers’ well being, use of WRAP techniques, and recommendation of WRAP to other peers” (Cook, 2004, p. 3).

Cook corroborated the findings of the study conducted by Copeland (2003) with those of two other studies, Corey (2001) and a study by the State of Minnesota (Buffington, 2003). Findings from these studies showed significant increases in people gaining a sense of hope that they could and would recover, as well as the ability to recognize early warning signs of mental health difficulties. People learned to use tools, skills, and strategies for coping with and relieving symptoms. These studies showed that people prefer natural supports instead of using the mental health system as their support, and that they benefit from support groups and from close connection with other people with similar life challenges. There were significant increases in their ability to develop

daily plans that support wellness and recovery and to create crisis plans or advance directives that others could use to assist them in an emergency. Finally, following WRAP training, people reported being more comfortable obtaining information about community services and engaging in self-advocacy.

In 2003, the federal Center for Mental Services contracted with the author to develop a recovery curriculum called Taking Action that would be piloted, revised according to the findings of the pilot, and then distributed for national use in mental health agencies, organizations, and institutions. In developing this intensive curriculum, the author worked with a steering committee of 15 people who represented federal, state, and local agencies, as well as people with lived experience. These included representatives of various cultural groups including Hispanics, Native Americans, and African Americans from various economic and educational backgrounds. The pilot programs in three locations began in January 2006. Because the author developed this curriculum, the information she gathered in this process also informed the development of the Community Links Program. Of particular import to this program was the focus on cultural diversity, learning difficulties (making information more easily accessible to people who may have difficulty learning), flexibility in program implementation, values and ethics of mental health recovery, adaptation for use in various settings, a wellness rather than an illness orientation, working toward achieving personal life goals and dreams, community integration, and using action planning to achieve that integration.

Dr. Abraham Low can be credited with pioneer recovery thinking and the earliest mental health recovery-based program on record, Recovery, Inc. Low started an organization to disseminate his methods in 1937. This organization continues to grow and

be strongly influential in the mental health field. Although Dr. Low is now deceased, other family members and staff continue to carry on his important work. The following description of his work appears at Recovery Inc's website.

A worldwide organization with headquarters on Chicago's near north side, Recovery is a cornucopia of self-help methods and techniques that parallel those used in cognitive therapy. The program uses surprisingly simple methods to help people dislodge themselves from emotional ruts. The process begins by learning to modify thoughts and behavior. Patients meet in small groups to examine the distressing trivialities of everyday life—an inconsiderate driver, a noisy co-worker—to show how symptoms can be triggered by anger and how to strengthen one's nervous system against them. The goal is to translate success in dealing with these trivial incidents into mechanisms for handling life's bigger challenges. Following a structured framework, the program uses practical coping techniques and methods developed by Dr. Low as well as cognitive/behavioral therapies that can be used individually and in conjunction with professional help. The program avoids use of diagnostic terms. The Recovery framework of observing behavior eliminates complexes, childhood memories, dream experiences and subconscious thought. Everyone is simply considered a "nervous patient" or "nervous person." (Sidney, n.d.)

In 1950 Dr. Low wrote a book, *Mental Health through Will-Training*, that has been in continuous publication since that time. Although many of the examples are dated, Dr. Low's emphasis on self-help and wellness are remarkable. People who have used this program as their primary recovery tool were espousing it at a national mental health

conference in 1992. They described the horrific life circumstances that had previously characterized their lives including continuing episodes of psychosis, delusional thinking, and bizarre behavior. They attributed their high level of functioning, wellness, and competence to Low's recovery program. Although this program has never gotten the credit it deserves, it can be a valuable guide to recovery. It can also be easily incorporated into other recovery-focused programs. Although numerous articles have been written that support this valuable work, supportive research is lacking. People who have involuntary commitments might use the skills and strategies of Recovery, Inc. to improve their life circumstances.

*Peer to Peer* (McNulty, 2002), is an experiential learning program for people with serious mental health difficulties that was developed by Kathryn McNulty under the auspices of the National Alliance for the Mentally Ill. McNulty is a user of mental health services, a former provider and manager in the mental health field, and a longtime mutual support group member and facilitator. This program consists of nine 2-hour units and is taught by a team of three trained people who are personally experienced at living well with mental health difficulties. In discussing this program with McNulty, she said that each class contains a combination of lecture and interactive exercise material and closes with mindfulness practice (techniques offered to develop and expand awareness). Each class builds on the one before: attendance each week is therefore required. Participants come away from the course with a binder of hand-out materials as well as with many other tangible resources: an advance directive; a "relapse prevention plan" to help identify tell-tale feelings, thoughts, behavior, or events that may warn of impending

relapse and to organize for intervention; mindfulness exercises to help focus and calm thinking; and survival skills for working with providers and the general public.

Although this curriculum contains many exercises that are validating, the aspects of mandatory attendance, the focus on diagnosis, and the lack of flexibility in implementation made this curriculum less useful as a model for those who have had orders of involuntary commitment, for whom self-determination is critical.

*BRIDGES: Building Recovery & Individual Dreams & Goals through Education & Support* is a mental health recovery curriculum that was developed by the Tennessee Mental Health Consumers' Association (n.d.), consumers being people who have experienced psychiatric symptoms. Developed in the early 1990's, it has been adapted for widespread use by mental health systems in several states. While the researchers found much useful information in this curriculum, particularly the descriptions of self help tools and strategies, they felt that people who have involuntary commitments might find this program offensive because of its heavy emphasis on the medical model and its use of medical language. In addition, being a scripted curriculum, it lacks the flexibility needed by people who have different learning styles, needs, and preferences. (Tennessee Mental Health Consumers Association, n.d.)

The *Peer Bridger Program* in New York State has been in existence for many years and may be one of the earliest attempts to reintegrate people who were in state hospitals back into the community. They are currently focusing on work with adult homes, building community resources and connections, and training peers to support people in developing advance directives. Peer Bridger has been successful in helping peers develop mutually supportive and beneficial relationships that allow for new role

development and healthier community relationships. “Bridgers” (people who provide assistance and support) have maintained connections with people in the community and offered informal support to avoid crises. Not only has this program been helpful to people who have been “bridged,” it has also had a tremendous influence on hospital and community support staff attitudes. Hospital staff members have moved from skepticism to unconditional support of this peer program (Matthew Matai, personal communication, February 23, 2005). The effectiveness of this program has been studied by several rigorous research projects (MacNeil, 2001, 2004).

The ComPeer program matches people with involuntary commitment orders with community volunteers who share similar interests. However, in this program, the ComPeer is considered part of the clinical team and reports back to the team. This might make it difficult for the person who is being supported to feel that the relationship is mutual and to be trusting of the ComPeer. Volunteers for ComPeer are trained in a medical approach to mental health and so potentially come with some assumptions that may be inaccurate about the people they mentor. This program has been helpful in connecting people with resources outside the mental health community. Also the relationship with someone outside the treatment arena potentially allows for a more reciprocal relationship (see [www.compeer.org](http://www.compeer.org)). A qualitative assessment of this program that studied differences between volunteers who have a psychiatric diagnosis and those who do not found that people who were assigned to ComPeer who had a psychiatric diagnosis were more comfortable in the relationship, but everyone benefited from the program in some ways regardless of the volunteer’s status (Davidson et al., 2001).

*Intentional Peer Support: An Alternative Approach* is a comprehensive curriculum developed by Shery Mead that effectively deals with all aspects of peer support from a relational perspective (Mead, 2005). Although other peer support curriculums tend to focus on peers in service provision and have little applicability to the people in this study, this curriculum addresses in depth all aspects of a topic that is difficult for everyone, developing and maintaining relationships. Mead defines peer support and discusses its applicability to addressing mental health issues and recovery. She takes learners into uncharted territory by encouraging them to explore “how they have learned what they have learned,” how they can develop new, enriching ways of knowing. She moves them away from service-based relationships to mutually supportive, nonhierarchical relationships, and discusses why peer support needs to be “trauma informed”. Topics include subjects that are commonly overlooked, like how to make first contact, language that helps and language that hurts, listening in ways that raise consciousness and encourage self reflection, negotiating relationships, setting limits, dealing with power related issues, issues related to internalized oppressions and learned helplessness, redefining safety, negotiating risk, and dealing with conflict. She includes specific information on peer support within the mental health system, peer-run warm lines, and peers running a crisis alternative respite program (Mead, 2005).

The author and Shery Mead discovered in their trainings that people were combining Wellness Recovery Action Planning and peer support methodologies, sometimes well and sometimes not well, and were sometimes violating the values and ethics that are intended to guide these initiatives. They worked together to develop a manual, *Wellness Recovery Action Plan & Peer Support: Personal, Group, and Program*

*Development* (Copeland & Mead, 2004a) and a training protocol to address these issues.

This comprehensive work describes a flexible approach that is easily adapted to meet specific needs. It provides an in-depth review of the WRAP process in a peer support context.

### *Conclusion*

This chapter reviewed pertinent aspects of involuntary commitment, the values and ethics of mental health recovery and peer support, definitions of mental health recovery, recovery-related research, peer support in mental health, the history of recovery interventions in Vermont related to individuals who were involuntarily committed, and programs that have been used to address the needs of people with orders of involuntary commitment. The following chapters describe how the literature that was reviewed prior to and during this study informed the Moving Ahead Project and the development of the Community Links Program.

## Chapter III

### Methods

In 2003, the Vermont State Department of Mental Health distributed a Request for Proposals (RFP). They were searching for researchers who would address the question: “What kinds of recovery-oriented education and peer support strategies will be most helpful to people in reducing court-ordered control of their lives?” Mary Ellen Copeland, Principal Investigator (the author of the present work), and researcher Shery Mead, both well known for their work in mental health recovery and peer support, developed a proposal and applied for funds to implement this project. The final proposal, submitted to the State of Vermont in March 2003, was the result of months of collaboration, study of various research methods and similar research projects, consultation with other mental health researchers including Boston University’s Center for Psychiatric Rehabilitation, and review of similar initiatives. The proposal, titled *Moving Ahead*, was accepted in May 2003.

In developing the proposal and program design, and in implementing the project, the funders and researchers were cognizant of the following issues:

1. As described in the RFP, funding for this project was limited to \$125,000 to cover all expenses of the study and the pilot project, and the project time line was one year from start to project completion. These parameters clearly restricted project activities.
2. The program was defined by the values and ethics of peer support and recovery (Copeland & Mead, 2004a). Of particular relevance to this project is the belief that each person is the expert on her- or himself. Therefore, to be

consistent with these values the data came primarily from people who have had or currently have orders of involuntary commitment. These people were difficult to engage as they often did not trust the system or anything sponsored by the system (Mead, 2005). In a recent Vermont study of people who have been involuntarily medicated, the researchers were not able to get any volunteers to participate in the study.

3. It was acknowledged from the outset that people who have mental health difficulties, even those that are most severe and chronic, can and do recover (Ralph & Corrigan, 2005; Roberts & Wolfson, 2004). Each person in every interaction was treated as a recovering person.
4. The focus was on working together with all stakeholders to increase mutual understanding and knowledge, and to promote wellness. Therefore the lived experience of the researchers was significant, and opportunities for people who were interested in this project to meet and work together were included in all aspects of the project.
5. The language used in the study was nonmedical, nonclinical, and nondiagnostic. Responses were normalized in the context of a person's life and lived experience (Copeland & Mead, 2004a).
6. The focus was on strengths and away from perceived deficits (Rapp, 1998).
7. It was understood that participants in this project may have histories of trauma and abuse, and that sensitivity to this issue was supported through all parts of the research process (Mead, 2005).

8. Participants were treated with dignity, compassion, respect, and unconditional high regard at all times (Copeland & Mead, 2004a).
9. Participation in all activities related to this project was voluntary (Copeland, 1991).
10. The body of knowledge concerning mental health recovery and peer support is constantly expanding. The findings of this study and the resulting program are contributing to that body of knowledge. They are not considered to be the final answer.

The findings from this study were used to develop a program rather than to find out how an existing program is working. Prior to this study and the Community Links program, there was no program in Vermont to specifically address the needs of people who have orders of involuntary commitment and to facilitate their recovery and independence.

### *Methodology*

Qualitative research methods were used for this study because the project was clearly concerned with identifying a process rather than defining an end point or outcomes as would be expected in a quantitative study. Creswell (1994, pp. 2–3) describes qualitative research as “an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words reporting detailed views of informants, and conducted in a natural setting.”

As stated by Morse (1997), the project clearly fit within the parameters of qualitative research because (a) there was a lack of theory and previous research on the issue of using mental health recovery-oriented practices and peer support in addressing

the needs of people with orders of involuntary commitment, (b) there was a need to study, explore, and describe issues related to this topic to better meet the needs of people in this group, and (c) this problem was not suited to quantitative study because there was not sufficient information to establish precise response categories in advance.

Of the many qualitative models of study, an action research process was chosen for this study because it focuses on resolving a problem or addressing an issue (Patton, 2002)., in this case using recovery-oriented education and peer support to meet the needs of Vermonters who have orders of inpatient or outpatient involuntary commitment. As described by Lewin (1948), action research is a three-step spiral process of (a) planning, which involves reconnaissance; (b) taking action; and (c) fact-finding about the results of the action. In this project, the researchers intensively studied issues related to the recovery needs of people who had orders of involuntary commitment, developed and implemented a pilot project based on the findings, and then evaluated the pilot project. The researchers have recommended that this action research process be repeated over time to continue to refine this program and develop other effective strategies to promote the recovery of people in this group.

The research model allowed the study to be accomplished within the one year allotted timeframe and the \$125,000 budget even though it included a literature review, interviews, focus groups, and data analysis, and then the development, implementation, and evaluation of a pilot project. Other research models that were considered, such as narrative research (Polkinghorne, 1988), ethnography (Denzin, 1997), and life story models (Hertz, 1997), would have taken more time and been more costly.

In this action research process, people who have these orders, people who have had similar experiences, and people who work closely with people with these orders were involved in every aspect of the study process, making it most relevant to the actual lived experience of people who have involuntary commitment orders (Rogers & Palmer-Ebbs, 1994). The research became part of the process of change by engaging the people, in this case people who have orders of involuntary commitment, in the process of studying and solving their own problems. As is often the case with action research, the research, the resulting program, and the evaluation became blurred as the project proceeded, and the research process became less formal even as it was generating useful information. Through the study process, it was noted that the participants began to feel a sense of hope, to understand that they have value, and to believe that what they have to say about their own lives is important and significant (Patton, 2002). The researchers found themselves in multiple challenging roles that included facilitator, collaborator, instructor, counselor, and friend in support of the people involved in the study.

Although in most action research the findings are seldom disseminated beyond the program within which the study takes place, in this particular case the findings of the study will be written into a full report for use by the Vermont State Department of Mental Health and may be the subject of several articles that will appear in mental health journals.

#### *Institutional Review Board Process*

Before beginning the research process, the Moving Ahead Project had to be approved by both the Vermont State Department of Mental Health Institutional Review Board (IRB) as the project funders and the Union Institute & University IRB because the principal investigator is a doctoral candidate at that school. Although each board had

specific and differing areas of concern, both boards agreed that people who have had repeated involuntary commitments are a vulnerable population and that extra precautions and care were necessary to protect their interests and rights. Comprehensive applications were developed that described every aspect of the process of interviewing study participants. Initial applications were returned and needed extensive revision in order to be approved. Coming to agreement with both of these boards on how to handle issues related to vulnerability was challenging, took more time than anticipated, and delayed the interviews. However, it did help to assure that this project would be carried out in a rigorous manner, paying close attention to the needs of each project participant.

There was also a discrepancy between the two IRB boards. The Vermont Board wanted interviews to be limited to an hour. The Union Board felt that longer interviews would be needed; however, they acceded to the requirements of the Vermont Board. In retrospect, the hour-long interviews worked well, and longer interviews might have been difficult for some of the participants. If there had been more time for the project, additional interviews with these participants might have produced even more enlightening data.

The researchers had planned to train a cadre of people who have had mental health difficulties and a history of involuntary commitments to interview the study participants. Through the IRB process, it became clear that this would not be possible. The training and intensive oversight that would have been needed if inexperienced people conducted the interviews did not fit within the parameters of this grant. Therefore the principal investigator and coresearcher did all of the interviewing in the study.

The IRB process took much longer than anticipated because the boards did not respond promptly to the applications. In future projects, more time needs to be allowed in the project timeline for this process. Because of this delay, timelines had to be revised repeatedly; and it was necessary to work more intensively when the applications were approved to keep within the project timeline.

### *Project Administration*

The principal investigator (the writer) hired a part-time project administrator who was responsible for administrative tasks such as project promotion activities, setting up focus group/informational meetings, copying, mailing, and making initial contacts with people responsible for other programs that address the issue of recovery and involuntary commitment. A bookkeeper was also hired to distribute funds and develop financial reports.

All direct contact with participants and potential participants was carried out by the principal investigator and the coresearcher to assure adherence to the requirements of the Institutional Review Boards. A toll free confidential phone line was set up to receive calls from possible study participants. The researchers responded to these calls.

### *Publicity Campaign*

An intensive publicity campaign at the beginning of the project was effective and successful. The purpose of this campaign was to:

1. Inform people about the study. In a small state like Vermont where many people have an investment in the mental health system, people like to know what is going on. They tend to be distrustful and unsupportive if they are not fully informed.

2. Invite people to attend the informational and focus groups meetings.
3. Recruit volunteers to serve on the Moving Ahead Advisory Board.
4. Recruit participants for the study.

The following recruitment strategies:

1. Articles describing the project were published in the quarterly newspaper of Vermont Psychiatric Survivors (a peer-run mental health education and support organization) and in other newspapers across the state.
2. Descriptive posters were posted in key locations around the state including bulletin boards at community mental health centers, drop-in centers, churches, grocery stores, and other public places.
3. The principal investigator and the coresearcher described the project at a meeting of administrators of community rehabilitation teams, gave them information to distribute, and asked them to talk to people who might be interested in attending the focus groups or the interviews.
4. Staff from Vermont Psychiatric Survivors networked information through their statewide system of support groups.
5. The principal investigator and the coresearcher made personal calls to key contacts around the state.

As a result of this campaign, people in the mental health system statewide learned about and supported the project. The informational and focus groups were well attended. Many people inquired about the study. Twenty-eight people were interviewed, almost twice as many as had been planned. It is hoped that articles about the study and networking activities had some informational benefits in the greater community that

cannot be monitored or measured. Although this campaign was time consuming, it was well worth the effort and would be advisable for future similar projects.

### *Advisory Boards*

The researchers set up and worked with two advisory boards. In addition to advising the researchers, people on these boards recruited participants, collected data, gave feedback on the study and pilot project design, assisted with implementation of the pilot project, and coordinated efforts to continue project activities after the pilot project was complete. They offered differing perspectives and were essential to the research process. Both advisory boards presented challenges that took patience, consideration, and consultation to resolve.

The Vermont State Department of Mental Health Advisory Board included the state project officer, several state officials, the executive director of Vermont Psychiatric Survivors, and the state coordinator of the mental health recovery education program. At least two of the people on this board were people who have had mental health difficulties and have been users of the mental health system. Contact with this board was through an initial face-to-face meeting, followed by monthly conference calls. Board members were available for consultation as needed.

At the first meeting, the board reviewed the project design and related research, and discussed anticipated problems in recruiting volunteers. After this face-to-face meeting there were monthly conference calls, members of the committee reviewed documents on an on-going basis, and there was e-mail correspondence to address timely issues. Although much of this input was helpful and facilitated connection with Vermont Legal Aid and the Vermont Agency of Protection and Advocacy, inconsistent

participation by members who then challenged decisions made in their absence hampered this mutual work. Key to the success of this committee was the consistent dedication of the state project officer who often cleared the way for progress when others seemed intent on an agenda that was less than supportive. Several state officials attempted to micromanage the project from time to time. This was frustrating, and the researchers had to use patience and negotiation skills to resolve these issues.

The Moving Ahead Project Advisory Board consisted of eight people who were selected by the researchers because they had expertise and experience that was expected to be helpful to the project. The board membership included a person representing the Vermont State Agency of Protection and Advocacy and the director of a regional acute care facility. The rest of the board members were people who have used mental health services and who have either had current experience with or have histories of involuntary commitment.

Meetings were held with this group every other month. The researchers consulted with board members between meetings. This board was primarily validating and supportive, giving suggestions that broadened perspectives and helped in defining the Community Links Project. Inconsistent attendance and failure to review the interim reports that were used to keep them updated hampered the process. In addition, one person was very contentious, trying (and sometimes succeeding) to use the meeting to meet her personal needs, and making it difficult to get our agenda done. It became apparent that it is important to get references for people serving on boards to keep energy from being needlessly wasted. Board members worked together well, using a negotiation and problem-solving process to resolve this difficulty.

### *Informational Meetings/Focus Groups*

Three focus groups/informational meetings were held, one in the southeastern part of the state in Springfield, one in the central part of the state in Berlin and one in the northwest corner of the state in Burlington. The purpose of these gatherings was to inform people about the project, to recruit people to serve on the advisory boards and volunteer for the study, and to ask for input on:

1. All aspects of involuntary commitment;
2. Questions that can be asked of people on involuntary commitment to build a better understanding of what will be helpful to them;
3. Recruitment of study volunteers.

These meetings were recorded, and the information was used to guide the study and develop the semistructured interview guide.

Although it would have been preferable to have separate focus groups and informational meetings, the timeline of the project would have made this difficult. However, given the power of the focus group, it was important to include this strategy, even in a less than perfect context. According to Patton, “Focus group interviewing was developed in recognition that many consumer decisions are made in a social context, often growing out of discussions with other people” (Patton, 2002, p. 385). He goes on to say:

In a focus group, participants get to hear each other’s responses and to make additional comments beyond their own original responses as they hear what other people have to say. However, participants need not agree with each other or reach any kind of consensus. Nor is it necessary for people to disagree. The object is to

get high-quality data in a social context where people can consider their own views in the context of the views of others. (Patton, 2002, p. 386)

An average of 10 people attended each of these group meetings. Reminder phone calls to key people made it possible for some people who would not otherwise have transportation to attend. Several mental health workers brought van loads of people. Participants included people on involuntary commitment orders, people who had been on these orders in the past, people who had been in the mental health system but who had not been on orders, clinicians, administrators, and family members.

The researchers began the meetings by describing the project and the need to recruit people to serve on a project advisory board and people who would be willing to be interviewed. This was followed by a rich discussion of the issues. These meetings began to give the researchers perspective on how people feel about involuntary commitment orders and possibilities about the kind of initiative that might be helpful. Suggestions from the participants were helpful in developing the semi-structured interview guide to use in the interviews.

The researchers facilitated these recorded meetings. Specific information and lists of concerns were written on a newsprint pad. In addition the researchers wrote field notes after each meeting. Some of the concerns identified by the various stakeholder groups at these meetings included:

1. lack of enforcement of involuntary commitment orders causing them to be ineffective and causing confusion;
2. lack of personal involvement in the development of the public safety aspects of the orders;

3. lack of exposure to mental health recovery and peer support initiatives, and recovery-based proactive and preventive crisis planning programs;
4. lack of family and community supports and exclusion from the community;
5. lack of validation, focus, and assessment on the effects of trauma and abuse;
6. “maintenance” as a definition of recovery for many people;
7. general poverty and lack of resources;
8. coercion;
9. over-use of medication as well as issues related to medication noncompliance;
10. internalized and external stigma and oppression.

### *Recruitment Strategies*

It was hoped that at least 15 people would be interviewed in this study. However, there were two major issues that the researchers felt might hamper recruitment efforts.

1. Because this tends to be a group of people who have been treated badly in society and in the mental health system, it was assumed that they might have issues that would keep them from volunteering, such as trusting others and trusting the mental health system.
2. People who had these orders cannot be contacted directly due to confidentiality issues.

The following recruitment strategies were used to overcome these barriers:

1. People were informed in advance that they would be paid \$30 for each one-hour interview.
2. A confidential, private toll-free number was set up so people could call and leave messages. One of the researchers called them back, described the project, and answered any questions. If they agreed to be interviewed and fit the requirements of the project, a time and place for the interview was arranged.
3. Project announcements that included project specifics and information about the stipend were posted in the state hospital and other psychiatric hospital facilities, institutions, community care homes, group homes, mental health programs and agencies, peer support projects, and drop-in centers.
4. An announcement about the study, including contact information, was published in the Vermont Psychiatric Survivor newsletter and in local and regional newspapers.
5. Information about the study was networked around the state by Vermont Psychiatric Survivors staff.
6. The researchers addressed the directors of Community Rehabilitation Teams at their monthly meeting so these directors could tell people about the program and suggest they call the toll-free number.
7. A confidential letter was sent out through Vermont Legal Aid to each person who has an involuntary commitment order. (Lawyers at Vermont Legal Aid have contact information on people who have these orders and agreed to contact them about the study.)

8. Three well-publicized public informational meetings and focus groups were held to inform people of the project, encourage participation, gather data on perspectives on involuntary treatment and possible helpful strategies, and seek out information on the kinds of questions people thought should be asked in the study.
9. People who have experience as users of the mental health system and involuntary commitment were primarily responsible for all aspects of the study including direct contact with the study participants.

These efforts to recruit people who had orders of involuntary commitment were extraordinarily successful. Because, as previously stated, people who have these orders tend to be distrustful, people on the advisory boards warned the researchers that recruitment would be difficult and that the sample size of 15 people would not be reached. Actually, 40 people volunteered to be interviewed. Only 28 people were interviewed due to funding and timing constraints. Feedback from people who agreed to be interviewed suggests that the stipend was very important to them and was probably the primary factor that encouraged them to participate. The letters from Vermont Legal Aid and contacts by staff on the Community Rehabilitation Teams also seemed to be key factors in this successful recruitment effort. Study participants noted that they appreciated the confidential toll-free line and knowing that the people who did the interviews had experience as users of the mental health system.

There were 16 men and 12 women in the sample, representing proportionally the usual number of people in the state who have these orders. Male ages ranged from mid-20s to mid-60's with a mean age of 40. Women's ages ranged from early 20s to late-60's with a mean age of 36. Sixty-six percent of the participants had one order, and 33% had

more than one order. Twenty-six percent of the participants had been on their current order one year or less, 13% had been on the order for 2 years, while others ranged between 3 to 10 years with the mean length of 5 years for people in this group.

Participants included people from all areas of Vermont with 30% from Chittenden County, the most populous county in the state which includes Burlington, the state's only large city (148,000 population). The population of Vermont is 625,000.

The sample was extremely diverse. Common characteristics are difficult to identify. Some participants came from extreme poverty. Others came from backgrounds of wealth and privilege. The advantage that those people who came from wealth and privilege had was that they could hire lawyers so they had more input into their orders and had more choice in care options. Several people had been wealthy at one time and their funds had been "cut off" by family members. A few had less than a high school education, but most had at least graduated from high school. Some were obviously intellectually gifted. Several had advanced degrees and had been proficient in their fields prior to their involvement with the mental health system. Only one person was currently employed. Another was planning to go back to college. All of the participants had been involved with the mental health system for many years. The shortest time was two years and the longest more than 25 years.

Each person had a tumultuous and trauma-filled history that often included severe loss. Although most of this occurred prior to their involvement with the mental health system, some severe trauma and loss occurred within the mental health system and was related to mental health treatment (e.g., forced medication, restraint and/or seclusion, abuse from other patients or staff, and institutionalization).

With several notable exceptions, the physical health of the participants was poor. People were overweight, had various movement disabilities, and had serious chronic illnesses like heart disease and diabetes. Although they knew they had these conditions, they had little information about anything they could do to help themselves other than medical interventions. Only one person talked about trying to maintain a healthy diet and work on weight loss.

The study participants had little insight or knowledge about the possible causes of mental health difficulties and knew little about their own treatment, alternative treatments, and self-help strategies for addressing mental health difficulties. They were accustomed to having things done to them rather than taking the initiative to help themselves.

People also had notably limited systems of connection. Some couldn't name anyone they felt close to. Others had only several supportive people in their lives. Some could only name care providers as people in their circle of support. Most had lost connection with family members and did not feel part of any community.

All of the people in the sample had a history of being perceived as dangerous, either to themselves, family members, or the community. The researchers were warned in advance that they were potentially dangerous. Prior to the interviews, the researchers expressed some anxiety about safety. Consultants from Vermont Protection and Advocacy taught them how to deescalate difficult situations and how to quickly leave a situation that had the potential to be dangerous. However, the researchers did not experience any situations in which they felt they were in danger.

## *Interviews*

The participants were interviewed by either the principal investigator or the coresearcher in one-hour interviews. The researchers worked with the participant to arrange a place for the interview that was most comfortable and convenient for the interviewee. Interviews were held in people's homes, restaurants, drop-in centers, or private space at a mental health agency.

Before beginning the interviews, the researchers, using data gathered in the focus group meetings, developed an interview guide.

The interview guide is prepared to ensure that the same basic lines of inquiry are pursued with each person interviewed. It will provide topic or subject areas within which the interviewer is free to explore, probe, and ask questions that will elucidate and illuminate that particular subject. Thus, the interviewer remains free to build a conversation within particular subject areas, to word questions spontaneously, and to establish a conversational style but with the focus on a particular subject that has been predetermined (Patton, 2002, p. 343).

Qualitative inquiry, strategically, philosophically, and therefore methodologically, aims to minimize the imposition of predetermined responses when gathering data. It follows that questions should be asked in a truly open-ended fashion so people can respond in their own words (Patton, 2002, p. 353).

Open-ended questions were designed to avoid predetermined responses. The researchers noted that after the first few questions, they tended to follow tangents addressed by the interviewee that they felt might lead them to the most helpful information. The Semi-structured Interview Guide is included in Appendix E

A flexible approach was used in the interviews, adapting styles and strategies to best meet the needs of the study participants and to facilitate collection of pertinent data.

Although this guide was far too extensive for most of the one-hour interviews, it provided a helpful structure. In retrospect, it might have been preferable to interview each person several times. In subsequent interviews, participants might have been more trusting, and more open to sharing at a deeper level.

In spite of their initial distrust, after the participants learned about the interviewer and the focus of the study, they opened up, some slowly, others more quickly, often escalating into an unexpected intensity. They seemed to relax when they understood that the interviewer was not part of the mental health system, but a person like them who had mental difficulties for many years and had attained a level of recovery. They were openly surprised that anyone would want to spend time with them, to hear what they had to say, and that anything they had to say might be useful. The time passed quickly. Both researchers reported that they wished for more time and further connection. They left the interviews with mixed feelings, frustration at not being able to spend more time and delve more deeply, and satisfaction that they had ventured into territory that few have been privileged to enter.

#### *Interviews with Other Stakeholders*

In addition, using an informal narrative interview process, the researchers talked to Vermont State Hospital personnel, court officials, community mental health center administrators and care providers, law enforcement officials, and other community members who have experience with or an interest in this issue. These people were not directly connected to the people that were interviewed, nor did they or anyone know who

was interviewed. The researchers recorded information from these interviews with field notes.

These interviews were not as helpful as had been anticipated. Those that were most helpful were interviews with people who work directly with individuals who have orders of involuntary commitment, including program administrators and case managers. They talked of their frustration with inadequate funding to provide needed supports and resources that would allow for a recovery-oriented focus. They currently feel that much of what they do simply “maintains” people. They supported the possible implementation of a program that would include a system of mentors. Because court personnel did not personally know the people who have involuntary commitment orders, they seemed to be unable to consider other options for people. Family members, many of whom had little or no contact with the person who has the involuntary commitment order, held views that seemed inflexible. They had already decided what “these people” needed and thought things would be better if they would just be “compliant.” Some of them talked in support of the involuntary commitment process and said it was needed. If the study time period had been longer, the researchers would have tried to reach out to more people in the community to see if they could find some with helpful insight.

### *Data Analysis*

In addition to the literature review, the data from the field notes of the focus groups and informal interviews with stakeholders, along with the hundreds of pages of transcriptions from the interviews with people who have had involuntary commitments, were analyzed to find out what strategies should be included in a program or project that

would be helpful and useful to people who have orders of involuntary commitment. Finding answers to questions posed by Vermont state mental health officials also informed the learning process. It was not the intention of the project to analyze the individual participants, but rather to hear them and learn from their experiences.

### *Initial Review*

The researchers began the analysis process by reading and rereading the field notes and transcripts. From the initial readings, the researchers developed a list of 27 domains. These domains were entered into the software program HyperResearch. HyperResearch was chosen for this process because it was highly recommended by Cheryl MacNeil, one of the consultants on the project, and because further study of this topic indicated that “associations and links within data can be made more easily using this program” (Miles & Huberman, 1994, p. 44). In addition, one of the researchers had used this program successfully on other projects.

To facilitate the analysis process, the researchers developed a list of codes that they felt would most effectively meet the needs of studying the data. Significant phrases, statements, and sections of each transcript were coded and entered into the software program. This coding was an intensive, extensive, and powerful process. It required ongoing revision as the researchers discussed the data and discovered new meaning. “The best advice I ever received about coding was to read the data over and over and over. The more I interacted with the data, the more patterns and categories began to “jump out” at me” (Patton, 2002, p. 446).

The close scrutiny of this potent information was frustrating, draining, and exhilarating: frustrating because it felt like the system has done such a poor job, draining

because the researchers were affected by the traumatic experience of each of these disenfranchised people, and exhilarating because this is a project that has the potential for ending the suffering for at least some of the people that were interviewed while creating change in the mental health system.

As the data were being analyzed, the researchers continually referred to the literature studied in developing the research proposal, in designing the project, and as the project proceeded. A sense of hopelessness and disenfranchisement seemed to permeate the data, making it often feel heavy, dark, and incredibly sad. Were it not for the occasional words of wisdom that allowed a glimpse into a different way of knowing, a glimpse that showed the brilliance, the creativity, and the courage of many of these people, the data analysis would have been a dreary task.

After careful consideration, continued review, and discussion of the data, patterns emerged and the codes were collapsed into each other. The resulting themes were::

- Involuntary commitment experience
- Challenges
- Losses and traumas
- Views on diagnosis
- Hopes and dreams
- Interests and strengths
- Self-definition
- Relationships (including peer, intimate, family, mental health, and community relationships)
- What helps and what doesn't help

- Medication
- Peer support and recovery education
- Experience at Vermont State Hospital (Waterbury)
- Recommendations

Again, the researchers read and reread the transcripts and the theme reports from the Moving Ahead project. They studied the field notes on the focus groups and the informal interviews. They had meetings, phone calls, and strings of e-mails. They discussed the theme reports and shared various ideas with both of the advisory boards and project consultants. They talked again with some of the people who had orders that were interviewed. Although they continually referred back to the literature, field notes, transcripts, and theme reports, compiling the following summary of each theme helped the researchers clarify possible core elements of the pilot project.

### *Limitations*

This study would have benefited from additional time and funding. The Vermont State Department of Health allowed one year from the date of project implementation to the project conclusion and \$125,000 for project expenses. This project as designed would have been more appropriate to a three-year time frame and \$375,000 in funding.

Additional time and money would have allowed interviews with all of the people who volunteered to participate and second interviews with some participants. Only 28 people could be studied due to the financial and time constraints of the project, the limited number of people that fit the study criteria and the difficulties inherent in getting

people in this group to volunteer for such a study. Interviewing more people would have increased the amount of data to be analyzed and might have impacted the study findings. In addition, people who were not willing to volunteer to participate in the study are a specific subset of this group and might have had different perspectives to share that would have further informed the study findings and program development.

Inherent in a qualitative study is the problem of interpretation of the data. It is necessarily influenced by the background and life experience of the researchers and other people involved in the study. Different interpreters coming from different perspectives might have come to different conclusions. If more funding had been available, the researchers could have involved people who had been interviewed and other key stakeholders in the data analysis process.

Focus groups that only included people who have involuntary commitments rather than groups that included other stakeholders and had to meet several disparate purposes (publicizing the study, getting mental health agency support, and securing participants) would have provided valuable data. Additional outreach to stakeholders such as court and law enforcement officials, health care providers and administrators, family members and interested members of the community would have also been helpful.

A longer pilot project (four to six months) would have allowed for further refinement of Community Links prior to developing the manual and turning the program over to the state of Vermont for further implementation.

Again due to financial and time constraints, additional methods of study such as observation and surveys that might have enhanced the data and provided a check on what was reported in the interviews could not be used.

The quality of the information obtained during an interview is largely dependent on the interviewers, on how much people are willing to share, and on their perception of specific events. Distortion of the data may be a problem as well. According to Patton (2002, p. 563), “By their nature, qualitative findings are highly context and case dependent.” Loveland (2005, p. 21) states that, “There are multiple realities and the truth is based on consensus rather than on immutable laws”.

### *Conclusion*

This chapter provided an in-depth description of the process that was used to gather the data to use in program development, including the methodology, the Institutional Review Board process, project administration, publicity, advisory boards, informational meetings and focus groups, recruitment of respondents, and interviews. The next chapter will describe the process of analyzing the data from this study.

## Chapter IV

### Findings

#### *Involuntary Commitment Experience*

Interviewees as a group reported negative experiences with the involuntary commitment process. Key problems that people had with these orders was lack of understanding of why they have the order, what constitutes a violation of the order, the stigma of being on the order, the lack of choice, feeling like it is a punishment, and the lack of consistency about protocol for getting the order rescinded. They said orders dictated things like where you can live, what you do with your time, and the specifics of your treatment including medications. They contend that these issues increase frustration and stress levels that make their lives even more difficult and make it more likely that they would have difficult times and continue to need the order. For example (the interviewer's words, where needed for clarification, are in italics):

They've taken it upon themselves to be in charge of my involuntary commitment order, which is something I had to sign to get out of the hospital so it's basically an extorted agreement. Although it is better than living in the hospital, it's worse than living free on the outside. I'm not a free person.

This involuntary commitment order that Dr. [name] did—It was like being punished. He was punishing me.

I'm only allowed out a few hours a day. Yeah. I feel like I'm trapped. I want my life back.

*So, why are you on an order of involuntary commitment?* I don't know. Am I supposed to be a dangerous man? Am I supposed to have done something terribly wrong? *Why do you think you have this order of involuntary commitment?* I don't know. Am I supposed to be a danger? Am I supposed to--? *What--?* No threatening behavior, it says. Don't use alcohol. I don't know. I don't know. Did I ever threaten anybody? No, no, no. And I was never drunk. *So, how could it be you have an order of involuntary commitment?* I...DON'T...KNOW.

I pretty much do what I want as far as the order of involuntary commitment goes. The only part of it that I have to go into is I go in for meetings once every three months, and my injection, once every three weeks. Aside from that, I pretty much ignore it, because just reading it makes me upset. It's like a nasty letter that's written to you. It's like saying you're a second-class citizen, basically. My opinion is you were in the hospital to get better supposedly. So when you get discharged, you're better. That's it. You're out. You don't need an order of involuntary commitment.

Several people said they asked to have the order renewed because they had become convinced through the process that they can't control their own lives. In effect they were using the order as a safety net. One person described this as "institutionalization."

Because it is already known from the research that people who experience mental health difficulties can and do recover (Ralph & Corrigan, 2005), the pilot project needed to support people in the recovery process so that they could take back control of their lives and be personally responsible for their own behavior, eliminating the need for the

involuntary commitment order. Recovery education, developing a personal WRAP (Copeland, 2002), and peer support (Mead, 2001) facilitated this process. In addition, it helped people understand how they can deal with or avoid crisis situations. Programs like the Peer Bridger Program and ComPeer served as guides (see Chapter II). Certainly, the Vermont Project (Chittick et al., 1961), with its record of success and intensive focus on education, was emulated where possible.

### *Challenges*

People reported that they have difficulty meeting the challenges in their lives, especially those that are unique to their circumstances. Some of the most common challenges reported by the interviewees included:

- Feeling powerless

They sometimes just make me feel like I should just be in the hospital.

They make me feel like if I don't show up for this appointment or do what they say, they're going to put me away. But it's not my choice that I want to do these things.

- Loss of control

People spoke of feeling controlled by others including their psychiatrist, the courts, specific family members, and the mental health system. Intrusive symptoms over which they felt they had little or no control increased their feelings of impotence.

I feel like a baby again. I'm living with them. I have to live with them, because they are my guardians.

- Lack of freedom

They restrict me—I'm only allowed out a few hours a day. That's the only part I don't like. It's weird. I want to get out of the mental health system, but I can't. And I can't get out of the involuntary commitment order. I can't leave the state. They have all my money. It's hard to make friends. Joking around and socializing is hard.

- Financial difficulties including extreme poverty
- Medication side effects interfering with quality of life including weight gain, “sluggishness,” and lack of sex drive
- Too much responsibility and lack of supports when they get home from the hospital

It seems the weight of responsibility falls on a patient when they get home and there's not too much help in that area, or not much support.

In the pilot, people were assisted and supported as they worked to meet these challenges in their lives. Identifying these challenges and having them validated in a peer relationship was often a first step (Mead, 2001). Then a peer or mentor supported them and worked with them to address and relieve these issues, and introduced them to skills that would assist them in addressing life challenges in the future. Programs that focus on one-on-one mentoring like ComPeer and Peer Bridger (see Chapter II) are respected for their success in helping people to address their life challenges and move forward with their lives. The Vermont Project (Chittick et al., 1961) also provided people with support in addressing life challenges. Some of their methods, which included practice and role modeling, were included in this project.

## *Losses and Traumas*

All those who were interviewed reported multiple traumas and losses in their lives. They spoke of loss from:

- Physical injury and disability
- Loss of relationship with their own children

I had another baby after I left the hospital. Parental custody was removed for all my children and they were adopted.

- Sexual and physical abuse
- Banishment from housing and family

And she kicked me out of the house when I was 12. I was on the streets for a year? Then I got sent to this Camp for troubled teenagers. I didn't like that place. Their approach was totally drugs. No therapy, no nothing. Before I left there, I tried suicide just a couple times, but nothing real serious. When I was up there at ... Camp, I went over to ... and took a bunch of wooden chairs and paper towels and all that stuff and put it in a circle and tried to kill myself. Set them all on fire. The only thing that saved me is one of the handymen there saw the smoke, and pulled me out of it. Otherwise, I'd be dead.

- Loss of relationships

So I tried to get a hold of my wife. She wouldn't respond. She didn't show up to see me, not even ....

Clearly the pilot program needed to validate the loss and trauma people have experienced, give them opportunities to talk about it, and discuss the role of trauma in their mental health difficulties. People involved in the project as mentors or peers needed to receive instruction in trauma-informed methods and use them to guide their relationships with people who have orders of involuntary commitment (Mead, 2004).

### *Views on Diagnosis*

Participants' views on diagnosis varied. A few people found diagnosis to be minimally helpful. Others did not and often found it to be harmful. Many people did not understand what the diagnosis meant. It was clear from these responses that the pilot project, in order to be most inclusive and to be respectful of all views, needed to avoid a diagnosis basis. This meant that, in order to take part in this program, a person did not have to be specifically diagnosed with an illness like schizophrenia or bipolar disorder, or accept that they have a mental illness, but rather it was a program for people who have mental health difficulties, have an order of involuntary commitment, and wanted to work toward their recovery and independence. However, activities in the pilot helped people to understand any diagnosis they have been given and to make decisions regarding what role they want that diagnosis to play in their recovery and their life. The program was clearly and intentionally complementary to medical treatment and not designed to take the place of medical treatment.

### *Hopes and Dreams*

The dream of recovery as defined in the research seemed to have passed by people who have involuntary commitments (Ralph & Corrigan, 2005). They hardly knew enough about recovery even to dream of it. They seemed almost afraid to dream of any

positive change in their lives. In responding to questions regarding their hopes and dreams, they said they were told what their hopes and dreams should be, and were not supported in having hopes and dreams of their own. Most said they had given up on or forgotten their dreams and had little or no hope. With further interviewing, they shared hopes and dreams that included things like independence and recovering parts of their previous lives that they had lost, like their home life, custody of their children, and certain relationships. They talked about helping others, going back to school, having a family, making enough money to live comfortably, pursuing a career, regaining their health, and doing normal things in the community like shopping and going to the movies.

The literature clearly shows that people who live with even the most severe mental health difficulties can get well, stay well, and successfully do the things they want to do with their lives (Desisto et al. , 1995; Harding et al., 1987; Ralph & Corrigan, 2005) and that they benefit from having a sense of hope and dreams or goals (Ralph & Corrigan, 2005) The pilot program and the peer or mentor attempted to renew people's sense of hope and assist and support them in working toward making their dreams reality.

### *Interests and Strengths*

People shared a multitude of strengths, abilities, and interests. However, many of them noted that they no longer have opportunities to use their strengths and do the things they can and like to do. It seemed obvious that creating opportunities for people to pursue their interests and strengths might renew their passion for life, enhance their quality of life, and help them to feel better (Rapp, 1998). Some people found it hard to identify interests and strengths. When asked what their strengths and interests are they responded

with statements like the following quote from a study participant: “I don’t know. I don’t know. I really don’t know. Honestly ... I don’t know.”

A successful program would build on people’s strengths and interests and focus away from their perceived weaknesses (Rapp, 1998). It could also lead them to discover new interests as well as explore things they used to enjoy and try them again (Copeland, 1991).

### *Self-Perception*

Among the interviewees, there was a general sense of despair around the conditions of their lives. Many of them saw their lives as a result of conditions outside of themselves—that the problems and the “illness” were something that happened to them. They made little connection between their life circumstances and the various life traumas they had experienced or specific actions they had taken. This clearly affected their self-perception. Low self-esteem, lack of ability to self-advocate, lack of ambition and motivation, and feeling that other people don’t like them seemed to be an endemic condition in this group of people. The pilot project included activities that help people develop self-esteem, learn how to self-advocate, and practice self-advocacy (Copeland, 1991). As they developed these skills and felt better about themselves, they felt more ambitious and motivated and began to take on recovery-related tasks.

### *Relationships*

The common thread that ran through much of the data was that people wanted to feel close to others, to have relationships, and to feel connected to their natural community. Most also thought that they would benefit from peer support and recovery

education in their efforts to reach that goal. People want connection with others and a strong sense of community outside of the mental health system.

In analyzing the data, it became clear that in all kinds of relationships (peer, family, intimate, mental health system, and community), the qualities that people felt would be most helpful in others included many that are the same as for peer support (Mead, 2001). People said their relationships with family were not good and that they want them to be good. They craved strong connection with their own children, many of whom had been taken from them long ago. They spoke of abusive spouses and parents, but did not mention any possible connections between this abuse and their mental health difficulties. Almost all of the interviewees spoke of their lack of intimate relationships and their wish for intimacy in their lives. And many emphasized a strong desire to be in close connection with their community. Some of the words and phrases that they used to define close relationships that guided pilot project relationships include: mutuality, accepting of each other's reality, working together on decision making, compassion, understanding, listening, sharing, paying attention, not being judgmental, patience, trust, adaptability, normalizing of symptoms, and avoiding of personal analysis.

Although it was expected that people would want more connection with their peers in the mental health system, that was not a finding of this study. Rather people said they want to know how to sustain close relationships with the people in their lives, meet and become friends with people outside of the mental health system, and be involved in their community. Therefore the pilot program helped people develop interpersonal skills, create opportunities to meet potential friends, and feel more closely connected to their community.

### *What Helps and What Does Not*

People shared extensive lists of things they know they can do to stay as well as possible and that help when they are having a hard time. People said it would help them to recover and get off the involuntary commitment order to: have hope, have a social place to be with friends, be busy, take care of children (especially your own children), help others, be listened to without judgment, write poetry, write journals, play music, exercise, be with people who have confidence in you and give you hope, be out of the mental health system, remain positive when life is really hard and seems unbearable, be able to work, and/or have transportation or have their own car. Other important ideas included:

- Education about mental health difficulties and medications;
- Peer relationships where nobody is the professional, nobody is getting paid, and it's a mutual experience;
- Feeling cared about, respected, and trusted;
- Being reminded of good times and that the person has gotten through difficult situations before;
- Having more community involvement, more friends that are stable, and more friends that are in normal jobs;
- Having people explaining to the person what was going on.

These lists are similar to the lists that people put forth when they develop the Wellness Tools section of a Wellness Recovery Action Plan (Copeland, 2002b). In the pilot project, people had an opportunity to develop long lists of tools and develop plans that would guide them in using these tools.

People eschewed the following values, which would not be a part of the pilot project, were not helpful, and were often harmful: lack of control, coercion, restraint, seclusion, isolation, threats, shaming, blaming, bullying, judgments, teasing, and not being heard.

### *Medications*

People in this group seemed to have little knowledge about their medications. Typical responses to questions about medications included statements that indicate that in some cases they don't understand why they are taking them; they are told they must take them; they hate the side effects of the medications, which they say seriously affect the quality of their lives; and they find forced medications to be a demeaning process. In several cases people reported that they willfully stopped taking their medications to get back into the hospital, as their living circumstances had become intolerable, such as living on the street in winter, being forced to share living space with people who treat them badly, or not having enough money to buy food.

People who facilitated the pilot project did not have the expertise to advise people about medications (the project did not have enough funds to hire such a person). However, a part of recovery education and the peer relationship, when it seemed necessary and appropriate, was to learn together about the medications and medication management, and help people find the information they need to make medication decisions. People who took part in this program as mentors were told that they could not and must not advise people about taking or not taking medications, but could suggest the person talk with their doctor when these issues arise. They were advised of the liability issues related to advocating that a person stop taking their medications.

### *Peer Support and Recovery Education*

Most of the people who were interviewed had never heard of Recovery Education, Wellness Recovery Action Planning (Copeland, 2002b), or Peer Support (Mead, 2001). This was an interesting finding given that the Vermont State Department of Mental Health through Vermont Psychiatric Survivors supports an exemplary peer-run program that sets up peer support groups across the state and offers on-going, free recovery education and Wellness Recovery Action Planning seminars that are open to anyone. It seems that information on the availability of these initiatives is not reaching people who have involuntary commitments, or they are not willing to participate in these activities.

One of the people who had recently learned about these opportunities said, “I’m just learning it now. The two classes I’ve been in I could tell there’s definitely a lot of support from other people. That feels good because I’m not used to anybody else understanding exactly how I felt.” Another person said that if she had known about these programs she would have gone sooner. Several people said that they thought these programs would be useful to them.

Given this feedback, the State of Vermont’s interest in these programs, and the research that supports the effectiveness of these kinds of initiatives, the researchers felt that recovery education, Wellness Recovery Action Planning, and peer support should be included in the pilot project. By incorporating these approaches in the pilot, this project had the potential for demonstrating how these initiatives would work for people who have or have had involuntary commitments. The interviews show that these initiatives needed to be modified to best meet the needs of people in this group, be easily accessible,

and voluntary. Also, people's interest in community integration initiatives, not generally addressed in recovery education or peer support, would need to be addressed in the pilot program. As an end goal, the people who were interviewed felt that becoming fully integrated into the community was more important than peer support. Peer support might allow people to practice skills they needed to become more fully integrated into their community.

### *Vermont State Hospital Experience*

In developing the pilot project, it was useful to look at the common experiences that the interviewees shared. Each person had, at some time, been hospitalized at the Vermont State Hospital. Several were currently patients in that facility. The following quotes from people who were interviewed in the study describe what they found to be helpful about the hospital experience.

It was an escape from a difficult situation, a rescue.

It gives me a place that's warm where there is food and a place to sleep.

Some of the staff are patient with me.

Specific staff were really great.

I appreciated the individual attention from volunteers, something I'm not used to.

Being around people, caretakers, workers, who care about you. They're friendly.

They offer programs. Good change of pace from sitting there alone, feeling depressed, feeling rather desperate about a situation.

The pilot project did what it could to emulate the positive aspects of the hospital experience that were noted by these study participants.

Although several people reported there was plenty to do, things like going to the canteen, woodworking, groups, crafts, and spending time in the gym, others complained that there were long periods of time when there was nothing to do, especially on the weekends. One person said, “Weekends is a big down time. They don’t have the staff. Weekends are really, really slow. I listen to my walkman, watch a little TV, exercise. I eat. I smoke. They’ll let you go out and smoke every couple of hours.” Several people reported that they started smoking so they could go outside with the smokers. The pilot project introduced people to activities that they can engage in either alone or with others when they are living in the community (Copeland, 2001).

Most people reported a negative hospital experience, Quotes from them include:

It’s a question of recovering from the hospitalization. Usually, it will take me about a year to recover from the hospitalization.

Cooped up like this is horrible. It’s stagnating. The air is stagnant. And this is such an old building—Vermont State Hospital has to be the worst place as far as air, and I’m a smoker.

I think the hospitalization, in large part, represents the sadism of the human character. ’Cause really it is people setting traps for other people to fall into, basically, just intimidating them into the hospital.

I think the staff there was really horrible. At least one in particular was very disrespectful, and sexually inappropriate. When people who were very sick would

do strange things he would laugh. The emphasis was on disciplining people and not really on helping them.

I was also being treated lousy. I couldn't make phone calls. I was allowed only one phone call an hour, because I still wasn't taking the pills. I couldn't do activities.

In the project that resulted from this study, careful attention was paid to the values and ethics that guide mental health recovery and peer support to insure that circumstances like these are avoided (Copeland & Mead, 2004a).

People complained about a lack of transitioning from the hospital to the community. For instance, one person said:

They didn't do anything to get you ready to get out. Not one thing. They just sent you to court and if you got out, you got out.

Another person made the following recommendation:

They should have had a psychologist there working with you, talking to you about adjusting to your new environment, which is a shocker when you get out. How to adjust and giving you ideas and really laying the groundwork for you. There wasn't any of that. They just let you out, and you're .... There you go! You're on your own, and I had no idea what to expect when I got out. It was awful. I had to adjust on my own.

A key facet of the Vermont project that made Vermont State Hospital famous for a time was a process called "blurring" (Chittick et al., 1961). It was a highly sophisticated transitioning program that could easily be replicated by the hospital at this time. As

happened in the Vermont project, the pilot project included mentors who could go into the hospital as people were preparing to leave and work with them on developing plans for how they could manage when they got out. This person could also be an advocate and could provide education, support, and companionship while introducing the person to a variety of activities and community resources.

### *Recommendations*

Study participants were not accustomed to being asked for recommendations. However, when they realized that their ideas would be heard and validated, they were willing to talk about their ideas. Most of these ideas are incorporated in the other theme summaries.

However, several people suggested the option of trained peer mentors, people who would listen and provide a bridge back into the community. These would be people who could be trusted and who would help people make choices and who might serve as a role model. They could attend events and share activities. These nonjudgmental, caring people would be like natural friends and would have nothing to do with mental illness.

### *Vermont State Department of Mental Health Questions and Responses*

The data analysis process was further enhanced by responding to the questions posed by the Vermont State Department of Mental Health in their request for proposals. Those responses were included in the final report to the Vermont State Department of Mental Health.

Question 1: How are people who have involuntary commitments currently interacting with professional and peer organizations and the community?

Very few people had a sense of, or connection to, their larger community. Many people felt isolated due to their lack of transportation, limits on personal freedom, stigma, and the loss of old friends. It was also not uncommon for people to identify their residential program or even the state hospital as their community.

When people had internalized the message that they are different from others they often felt shame just walking around in the community, felt that people judged them unfairly, or were worried that they might have an embarrassing incident while in the community. Many people identified recovery as having friends outside the mental health field.

Because of this lack of connection, mental health workers were often cited as either sole supporters or as controlling parental figures. Either way, they were a large part of people's self-defined community.

When people had had good experiences with mental health professionals, the qualities they cited as helpful were: nonjudgmental listening, easy access, providing basic necessities, compassion, easy to talk to, and professionalism (Copeland & Mead, 2004b).

Many people were anxious to break off their connection with mental health services. They spoke about the over-controlling nature of the relationships, the lack of collaboration around medications, and the perceived use of orders of involuntary commitment as punishment. It was also quite clear that some of the incidents resulting in hospitalization were perceived differently by mental health workers and the recipient.

Question 2: What are the treatment and support needs of people who have orders of involuntary commitment that are not being provided by the current professional and peer support systems?

Participants had many treatment and support needs that went beyond the scope of their current services or connections with peer support. For example, many people felt that they had little connection with the larger community, that friends were hard to make, and there were few places where people could get together.

Although some people used the local clubhouse, most did not find it particularly stimulating; and no one identified it as a place to build connections. One person was interested in a peer-run “clubhouse” where activities could be held and where people could “hang out.” Others spoke about peer-controlled and peer-operated alternatives to hospitalization (Chamberlin, 2002).

Mentoring or one -to-one peer support came up frequently. However, “peers” (in many cases) were described as “people having nothing to do with mental health.” Particular qualities in these mentors included affirming conversations, nonjudgmental listening (including nonmedical interpretation of experience), capacity to build hope and confidence in others, being genuinely interested, connecting to resources, and advocacy skills (Mead, 2001).

Interestingly, many people also wanted to be on the other end of the helping relationship. People commented that they were “natural helpers,” and that it felt really good to know you made a difference in someone else’s life. When asked about becoming peer mentors themselves, many people thought that would be a great idea (Chittick et al., 1961).

Exercise was an important component in many people's recovery. While some people were already working out, many others felt bogged down by too much medication, weight problems, or limited physical ability. They also felt that there were not sufficient resources or programs that could address their individual needs.

Almost all of those interviewed had never heard of WRAP or the concept of Recovery Education. Most people said they were not interested in going to groups; they had been forced to go to groups in treatment settings and felt certain this would be the same. Specific WRAP programs tailored to the individual might allow people to do it in their own way and to avoid groups.

Finally, many people felt frustrated by the lack of information about their medications and the lack of collaboration on medication related issues. They were frightened of telling the psychiatrist that their medication wasn't working or that they wanted less of it. For those people who found their medication helpful, this was not an issue, but for those that didn't it seemed to be a constant source of stress with the perception that medication and the involuntary commitment order are inextricably linked (Roberts & Wolfson, 2004).

Question 3: How do these people perceive their own mental illness and the mental health system?

In the sample of people who were interviewed there were people who feel they have a biological brain disorder that is dependent on medications and medical treatment for control, and others who believe they don't have a "mental illness" and that their involvement in the system is the result of unfortunate life circumstances over which they

have little or no control. About one third of the people interviewed felt that treatment had been very helpful, and two thirds felt limited and trapped by the system.

Question 4: What factors have contributed to instances in which these individuals have accepted or sought out support?

Most of the people who were interviewed are solitary. Few have sought out or accepted support when it was offered; they only sought out support when they were forced to by the system and when they were placed in circumstances, like the state hospital, where there is on-going contact with others. A few attended groups and programs that were mandated or strongly suggested through the mental health center. Several people reported positive involvement with support-related programs in specific locations. Almost all of the interviewees reported a yearning for close connection with others.

Question 5: What factors have contributed to instances in which individuals who had been receiving a high level of involuntary treatment were able to no longer require involuntary treatment?

In talking to people who have had involuntary treatment in the past, the key factors that seemed to make it possible for them to move on included a change in their perception of what they can do to help themselves (a more positive outlook), mutual support, use of self-help techniques and strategies, and adequate housing and financial resources.

Question 6: What external and internal pressures (legal, community, financial, and ethical) do mental health providers face when serving (or not serving) these people?

In talking with Community Rehabilitation Team directors and other mental health providers, it is clear that they have a dilemma. They need to be concerned with both the needs and rights of the person they are serving, and the protection of the community. Although they are ethically committed to the least invasive and restrictive options for everyone, their decision-making is often driven by concerns of liability and responsibility to the larger community.

Financial concerns limit possibilities. Cost is always an issue. The focus often needs to be on giving the person the best possible service for as little money as possible. With more adequate financial resources, mentoring, educational, and peer support programs could be implemented—programs that might better meet the needs of people who have orders of involuntary commitment. However, funding for these kinds of initiatives continues to be cut.

Anything that can be done to reduce the need for involuntary treatment of any kind will relieve the pressure on mental health providers, allowing them to provide higher quality service to all who need it (Copeland, 1998).

Question 7: To what extent have recovery education and peer support been accessible and helpful in supporting these individuals?

People in the study reported little access to recovery education and peer support initiatives. Almost all of them knew nothing about these kinds of programs. When they understood what they were, they thought these programs sounded like a good idea.

Question 8: In what ways should recovery education and peer support be expanded, improved, and/or modified to reduce the need for involuntary treatment of these individuals?

Anyone on an involuntary commitment order needs to be informed about recovery education and peer support opportunities and how they can access these services. The availability of these services needs to be expanded. In addition, the programs need to be presented in diverse formats and venues to make them most available to people with varying needs (Copeland, 2004c). This means that they could be offered one-to-one, in small groups, or in larger groups. Materials could be available to be read, on tape, or described by someone else. Programs and materials could be modified to meet individual needs. A key place to offer recovery education and peer support is in the state hospital and in community treatment centers. A next step might be making them more readily available in the community. Because people on involuntary commitment orders often have issues with trust and relating to others, it is suggested that the first experience with mental health recovery initiatives and peer support be in a one-to-one situation with a peer mentor.

Question 9: What new and innovative approaches for working with individuals with severe and persistent mental illness exist that could be incorporated into recovery and peer support approaches to help reduce the need for involuntary treatment?

Several innovative programs were identified as helpful in relation to the development of the pilot project. Included in these were The NY Peer Bridger Program, The ComPeer program, Wellness Recovery Action Planning (Copeland, 2002b), recovery

education (Copeland, 2002a), and peer support programs (Mead, 2005). Further information on these programs is included in Chapter II.

### *Core Elements of Pilot Project Design*

From this assessment and the literature review, the core elements of the pilot project were developed. These elements are:

- People who have orders of involuntary commitment will benefit from having a mutual and/or peer relationship with a nonjudgmental, caring, well-trained person.
- The pilot project will be guided by defined values (Copeland & Mead, 2004a).
- Elements of recovery education including Wellness Recovery Action Planning (Copeland, 2002b), and peer support (Mead, 2001), specially adapted to meet personal needs, will be made available to project participants on a voluntary basis.
- Community integration will be emphasized.
- The Community Links program will be focused on assisting people in taking back control and being responsible for their own lives, regaining a sense of hope and rebuilding their self-esteem.
- The program will feature an on-going participatory action evaluation process that allows for on-going program refinement to best meet the needs of the people who are taking part in this program.

Chapter V describes how each of these core elements was incorporated into the pilot project.

## Chapter V

### Pilot Project and Manual Development

This chapter describes the development and implementation of the pilot project which resulted from the analysis of the data of the Moving Ahead Project and the development of *Community Links: Pathways to Reconnection and Recovery Implementation Manual*,.

#### *Development of Pilot Project Design*

The researchers and the advisory boards worked collaboratively to develop the Community Links program. Some of the interviewees also provided input into the pilot project design.

Project development was guided by the core elements, which were discovered through the data analysis of the Moving Ahead Project including the literature review, interviews with people who have or have had orders of involuntary commitment, and interviews with other stakeholders. These analyses revealed core elements that the principal investigator felt would be critical to the success of the pilot project. The detailed training format that was used for the initial training is described in the *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual*.

#### *Core Elements of Pilot Project Design*

This section lists the core elements and describes how each element is reflected in the pilot project and the pilot project training.

*Peer Relationship.* People who have orders of involuntary commitment will benefit from having a mutual and/or peer relationship with a nonjudgmental, caring, well-trained person.

The pilot project, Community Links, connected people who have orders of involuntary commitment (participants) and who chose to be in this program with people who had been recruited from the community to serve in this capacity (Community Link).

People who volunteered to be Community Links attended a three-day training where they were given information about the involuntary commitment process and the issues, needs, and goals of the people who have these orders, and were trained to provide mutual peer support, community reintegration assistance, and recovery education.

Following the training the Community Link was matched with a participant. People who qualified for the program learned about the program through a publicity campaign similar to the one used to recruit people to be interviewed in the Moving Ahead Study. In the pilot project, the Community Link worked with the participant for two months. Officials of the State Department of Mental Health supported those Community Link partnerships that benefited from continuing past the end of the pilot project.

The Community Link and the participant met one or more times a week when it was mutually convenient. Participation in the program was voluntary. The participant worked with the Community Link to decide how they would use their time together. However, neither person in the Community Links relationship was expected to do anything that felt uncomfortable to them or that they did not want to do (Copeland & Mead, 2004a).

The Community Link assisted the participants to identify strengths and interests that may have been forgotten, learn self-help techniques that enhance wellness, and develop a more holistic view of herself or himself. They worked together to develop a relationship that would provide a model for future relationship building. Together they visited places of interest in the community, attended community events, and attended support groups. The training clarified for the Community Link the kinds of activities that are possible within the Community Links relationship and those that should be avoided (see Chapter II, Programs).

Some of the mentors went into the hospital as participants were preparing to leave and worked with them on developing plans for how they could manage when they got out. The Community Link worked with the participant through this transition and continued to provide support and advocacy in the community while introducing the participant to a variety of activities and community resources. Others were linked with participants who had involuntary outpatient commitment orders and who requested a link to work on recovery and community integration issues (Chittick et al., 1961; Kincheloe & Hunt, 1988).

*Values.* The pilot project was guided by defined values that were adapted from the mental health recovery and peer support values and ethics as described by Mary Ellen Copeland and Shery Mead in *Wellness Recovery Action Plan Peer Support: Personal, Group, and Program Development* (Copeland & Mead, 2004a).

The training facilitators worked with the trainees to insure their adherence to the Community Links values. Although various activities throughout the training referred to these values, they were specifically addressed in Module 2 on Day 3 of the training when

each value was discussed, indicators of adherence were developed, trainees took part in activities that gave them practice in recognizing and adhering to values, and values that may be difficult to follow were discussed (Copeland & Mead, 2004a).

*Recovery Education.* Elements of recovery education, including Wellness Recovery Action Planning and peer support specially adapted to meet personal needs, were made available to participants on a voluntary basis.

Trainees were introduced to the Wellness Recovery Action Plan (Copeland, 2002b) process on the first day of the training to use as a tool in building and sustaining the Community Links relationship. They were also instructed in how they can work with another person on developing a personal Wellness Recovery Action Plan and the kinds of simple, safe, free, and effective skills and strategies (known as Wellness tools in the WRAP process) that can be built into a WRAP. They learned how people can use such a plan to stay well and to respond to difficult times and feelings, and how it can instruct others in their response in the most difficult times. This was one of many optional activities that people could choose to include in their Community Links relationship.

The Community Links program is a peer support project. Therefore the entire training modeled peer support by beginning the training with the development of participant guidelines, and refining and using those guidelines throughout the training (Copeland, 2001). In addition, all of the modules of the training included reference to peer support methods (Copeland, 2004c; Mead, 2004). Specific modules that addressed peer support through instruction, discussion, and activities included introductory sessions that defined the issue, and sessions that addressed

1. building trusting and mutually supportive relationships

2. negotiating the relationship
3. language issues
4. listening skills
5. first contact
6. boundary issues
7. using a Wellness Recovery Action Plan to maintain and sustain the  
Community Links relationship
8. working with the values of peer support
9. helping in the Community Links relationship
10. building nonhierarchical relationships, and
11. problem solving.

Trainees learned how the community links relationship differs from traditional mental health services by being collaborative, avoiding clinical language and expectations, using trauma-informed strategies, and helping people regain their power.

*Community integration.* Community integration was emphasized. Assisting and supporting people with community integration was reinforced throughout the training and the program. Between training sessions, people were asked to identify resources in their communities and to share the resources they discovered with other training participants. These were recorded and developed into a handout. Specific sessions focused on issues that people might face in the community regarding advocacy, rights, and responsibilities. Discussion focused on helping others define their own community and how they can be supported in reconnecting with that community. This part of the program emulates the facet of the Vermont Project (Chittick et al., 1961) known as “blurring”, a highly

sophisticated program for transitioning people from the state hospital back into the community developed in the 1950s and 1960s.

*Personal Responsibility.* The Community Links program focused on assisting people in taking back control and being responsible for their own lives, regaining a sense of hope, and rebuilding their self-esteem.

The Community Links, when requested, helped participants understand their orders of involuntary commitment and the steps they needed to take to have these orders rescinded, and supported them in taking these steps. Within the Community Links relationship, participants had the opportunity to discover new interests and rediscover things they used to enjoy and to try these things again. They were supported in identifying and working toward their personal life goals, and they had the opportunity to learn how to deal with or avoid crisis situations.

*Evaluation.* The program featured an on-going participatory action-evaluation process that allowed for on-going program refinement to best meet the needs of the participants and the Community Links.

At the training Community Link trainees were introduced to the specifics of the evaluation process. The project administrator collected qualitative data on a regular basis from both the Community Link and the participant. The data were analyzed and used to refine the program so that it more effectively meets the needs of everyone in the project. At the conclusion of the pilot project, and as this program was implemented in Vermont, provision was made for the continuation of this evaluation and program refinement component.

## *Training*

Ten people volunteered to attend the initial Community Links training and be paired with a person who requested a link. These people had learned about the program through networking by the advisory boards, state hospital personnel, and the statewide system of recovery educators. The principal investigator developed a draft implementation manual to guide the training. Although most of the volunteers had personal experience as users of the mental health system, several were connected to the system through having family members who used the mental health system. Several volunteers had orders of involuntary commitment in the past. One had recently had his order rescinded. There were five men and five women volunteers who had diverse interests and came from diverse backgrounds. References were checked to help assure that people were suited to this kind of program. People who volunteered to be a Community Link were paid \$500 for their participation in this project.

The training was held in August 2004 at the Three Stallions Inn, a beautiful country inn in central Vermont. It was held one day a week for three weeks from 9:00 AM to 4:30 PM. This site for the training was chosen in preference to a mental health facility because everyone involved in the project was clear that, although this program was funded by the State Department of Mental Health, it could only achieve success if it was as divorced from that system as possible. In addition, as much as funding would allow, everyone involved in the planning felt that these volunteers deserved to be well treated and that a day at an inn with fine food and space for outdoor breaks in an idyllic setting was warranted.

Each day was divided into four training modules. Each module covered one or several of the various training topics described in the core elements. In addition there was an opening welcome and housekeeping session and an ending session for reflections on the day. The training agenda is described in detail in the *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual*. Activities to support learning included the use of a series of specially designed slides included in the manual, instruction, discussion, role modeling, and small group work. The training was facilitated by the principal investigator and the coresearcher.

The volunteers quickly coalesced into a mutually supportive and sometimes contentious working group. They were passionate about the project and openly shared their ideas and concerns. Breaks and lunch were filled with animated conversation. It was a rich learning time for the volunteers and the facilitators.

### *Training Evaluation*

Evaluation of the training through surveys and personal interviews revealed the following positive aspects of the training (Danley & Ellison, 1999; Patton, 2002; Whyte, 1991).

1. The training was well received by the volunteers.
2. The trainees learned information, skills, and tools that will help them as Community Links and will be valuable to them in other situations as well.
3. The small group work was powerful and effective.
4. Trainees had an opportunity to explore values and ethics that were new to them, especially related to mental health.

5. The Participant Guidelines, developed at the beginning of the training, helped people feel safe in the group, and helped the group to negotiate several difficult situations.
6. Trainees came to an understanding of how Wellness Recovery Action Planning can be used to support the personal recovery journey, and as a tool in keeping the Community Links relationship strong.
7. The training leaders (the researchers) successfully modeled mutuality and negotiation in relationship.

However, these evaluations also showed that the following concerns must be addressed in the training section of the revision of the draft Community Links manual:

1. There was too much theory and not enough practice. As a result, the Community Links may not have sufficiently learned the skills they will need to work effectively with a participant.
2. The training leaders did not adhere as closely as needed to the timelines. Therefore, some important issues that needed to be expressed and discussed got less time than needed.
3. There was a need for more clarity around key points. Some of them were hidden in “wordy hand-outs.”
4. There were too many observers. Representatives from the Vermont State Department of Mental Health, people from several health care centers, and both the head of Vermont Psychiatric Survivors and the person in charge of their recovery education program wanted to attend and observe.

Everyone wanted to participate in everything. This diluted the effectiveness of the program.

Changes in the training are reflected in the revised *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual*.

### *Program Implementation*

Before, during and immediately following the training, the researchers disseminated information about the availability of this program and encouraged people to request a Community Link. In this task they were assisted by the advisory boards, Vermont Psychiatric Survivors staff, and staff at the Vermont State Hospital. This was more difficult than had been anticipated. Slowly people volunteered and were matched by the principal investigator with people who had been trained. The new manual addresses the issues of encouraging people to volunteer for the program, making the actual match, and introducing people to each other for the first time.

The researchers provided the Community Links with on-going assistance and support as they developed relationships and worked with participants. They were available by phone so that Community Links could reach out for guidance and support. This is an essential component of the program. The Links reached out for support throughout the program.

On-going reports throughout the pilot and discussion at a follow-up meeting indicated that, although there were several matches that did not work, there were many, many positive things that happened for both the participants and for the Community Links.

In the situations where the match did not work, contributing factors were age and life focus differences, confusion about expectations, and an unwillingness to work through difficult situations. Those people who have been trained to be Community Links continue to be committed to the program and are willing to be involved as Vermont Psychiatric Survivors works with the State Department of Mental Health to take responsibility for the program. It must be made clear to the Community Link that the match may not work, even with the best of efforts and intentions.

From the author's notes, some of the high points described at the final meeting with Community Links are the following:

Mike is Roy's Community Link. I met Roy recently. He is a patient at the Vermont State Hospital. I was doing a presentation on Wellness Recovery Action Planning. As the session proceeded, Roy shared bits and pieces of his life. He told of being sent to an institution when he was very young. He said he had been at "Waterbury" (the patient's name for Vermont State Hospital) many times. At one point he was sharing and suddenly put his head on his chest and began to sob. I reached out and gently touched his shoulder. I wanted him to know that I was there, and that I cared. After a few minutes, he regained his composure and became a full participant in the group again. Staff from the hospital told me that Roy's relationship with Mike is making a huge difference in Roy's life. "Where there was no hope, now there is hope."

Marty positively glowed as she described her experience with her participant, a woman her age who has been in the Vermont State Hospital repeatedly for many years. These two women have developed a close friendship that Marty feels will

“last a lifetime.” They have gone together to visit the participant’s childhood vacation home, and Marty supported her as she reestablished contact with a brother she had not seen in 11 years.

Mary Liz tells of delightful times with her participant, introducing her to a new community to replace the one she has lost through difficult episodes in her life. Because of this loss, this woman has developed strong connections with a tenuous program that may soon be eliminated. Together, she and Mary Liz are exploring options that will hopefully mitigate another potential loss.

Charlie, a Community Link, is spending long and enjoyable hours discussing spiritual transformation with a participant who has been hungering for this kind of discourse.

One after another people shared success stories, stories that may be only a small part of a much longer journey. But at least the journey has begun.

In most cases, two months was not enough time with a Community Link. Most people need months and even years with a Community Link. The State Department of Mental Health and Vermont Psychiatric Survivors have taken over the program, and relationships started in the pilot can be continued at the discretion of the participants. At least six of them will be continued.

### *Evaluation*

The following key points learned in the pilot project are reflected in the *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual*.

1. There was not enough time in the funding period to implement this pilot well. It took much longer than anticipated to recruit the Community Links and arrange the training. Then it took a long time to recruit participants who would like a Community Link.
2. The program needs a coordinator who will match people with Community Links and who will provide on-going support to Community Links throughout the program.
3. Some people who volunteer to be Community Links may not be able to work effectively with people who have serious mental health difficulties. It is the responsibility of the program coordinator to let people know they are not eligible to participate as soon as that becomes apparent.
4. Community Links need to understand that the person they are matched with may end the relationship at any time. That does not mean the connection, however brief, was not worthwhile. It may be another step in a person's search for recovery.
5. Relationships develop slowly, so the time people will usually work together will be much longer than two months.
6. Maintaining the voluntary and confidential aspects of the program is essential. If a mental health agency makes a referral to this program, they may have expectations about reporting that are not acceptable in this program. Therefore, it will be important to have this program sponsored by a peer run organization or a mental health agency that understands and respects these aspects of the program.

7. In order to be successful, this program must be completely voluntary. People need to ask for their own Community Link. That means promotional efforts need to be focused on the person who will benefit from having a Community Link.
8. This program will be helpful to anyone who is dependent on the mental health system and wants to work on his or her independence, recovery, and connection to the community, not only those who have orders of involuntary commitment.
9. There is a need for further discussion to develop values and ethics to guide this program (See Values and Ethics, Chapter II).

These findings are reflected in the latest revision of *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual*, which is the final product of this Project Demonstrating Excellence. The final chapter of this essay explores the future of the Community Links Project and recommendations from the principal investigator to the Vermont State Department of Mental Health based on the findings of the Moving Ahead project.

## Chapter VI

### The Future of Community Links

The principal investigator, Mary Ellen Copeland, is convinced of the value of the Community Links program, not only for people who have orders of involuntary commitment, but for anyone who is trying to recover from serious mental health difficulties. She believes that broad-based implementation of this program and other recovery-oriented, peer-based programs would reduce the stigma and oppression that have been the hallmark of the mental health system for generations (Chamberlin, 2002; Ralph & Corrigan, 2005). In addition, she predicts there would be:

1. A significant reduction in the number of people who have orders of involuntary commitment and a reduction in the time involuntary commitment orders are needed for people who have them,
2. Increased levels of wellness, stability, personal responsibility, empowerment, confidence, self-esteem, and improved quality of life for people who have or have had serious mental health difficulties,
3. An increased ability for people in this group to meet life and vocational goals and become valued members of the community,
4. A decrease in the incidence of mental health difficulties and in the traumatic life events and stigma associated with these difficulties,
5. An increase in the use of natural supports in addition to or instead of the mental health system,
6. A shift of focus in mental health care from symptom control to prevention and recovery, and

7. A significant reduction in the need for costly mental health and emergency services.

The Vermont State Department of Mental Health is now funding Community Links as a project of the nonprofit Vermont Psychiatric Survivors. In making this commitment, the state will serve in an advisory capacity only, with only general reporting required (number of training sessions, number of people trained as Community Links, and numbers of people in the Community Links program), and no specific reporting on any individual, in keeping with the values of the Community Links project.

Vermont Psychiatric Survivors has hired a Community Links program coordinator. This person is administering the program as directed in the most recently revised edition of *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual* (April, 2005). A Community Links training was held in August 2005 using the revised manual as a guide. There are currently 20 Community Links working with people in Vermont who have orders of involuntary commitment. An on-going training schedule calls for training every six months.

In addition, the revised *Community Links: Pathways to Reconnection and Recovery Program Implementation Manual* (April 2005) will be published and made available nationally through the mental health recovery network and the Copeland Center for Wellness and Recovery. Specific information on the program will be available through the Copeland Center website, <http://www.mentalhealthrecovery.com>.

The principal investigator will work with the Copeland Center for Wellness and Recovery to find funding for an on-going national Community Links program evaluation

that would provide data for program refinement and biannual revision of the Community Links Manual, continuing the action research process (Whyte, 1991).

*Further Recommendations Based on Study Findings*

Based on the findings of the Moving Ahead study and the initial phases of Community Links, the writer believes that the need for involuntary commitment orders could be significantly reduced over time. In addition to implementation of the Community Links program, she recommends consideration of the following actions.

1. This project marks the beginning of an important process, listening to and responding to the experiences and needs of people who have orders of involuntary commitment. Recruitment and interviewing was difficult in this project because people who have these orders are not accustomed to being asked for information or to feeling heard. In many instances they are accustomed to being treated badly at best and at worst coerced and punished for what they are told is a biological illness. It is time now to begin the process of building trusting relationships with these oppressed people. The state of Vermont, working closely with Vermont Psychiatric Survivors and the mental health system, needs to find a way to continue building these relationships, gathering the important information these people have to share, and using that information for on-going improvement in the mental health system.
2. There is broad-based agreement that the current involuntary commitment process does not work (Campbell & Schraiber, 1989; Swartz et al., 1999). In the instances where such an order might be necessary due to possible danger,

the person who receives the order needs to be involved in designing the order to best meet their needs and goals as well as the needs of the community. A well-trained personal advocate or mentor could work with the person to develop their order, and support them in their recovery when they have the order so the order can be rescinded at the earliest possible date. Others who might be involved in the development and oversight of an involuntary commitment order are, as requested by the person receiving the order, local care and service providers, family members, legal counsel, and other supporters. The involuntary commitment order needs to be designed so it can work and so it promotes rather than impedes progress toward independence and interdependence in the community.

3. Regional alternatives to the Vermont State Hospital need to be available. A provider stated that some community-based treatment centers have “no admit” lists for people they feel they can’t serve, the people with the greatest need. These community-based facilities need to be upgraded, or new ones added, so they *can* meet needs on a local and regional level, and so that the state hospital can be phased out. These new facilities would be integrated with community mental health centers and with medical hospitals to effectively meet all of a person’s needs. This localized system will help assure that people remain connected to their supporters and their communities when they require the specialized treatment they can receive in a hospital facility.
4. The mental health system needs to support people in the most difficult times—financially, with housing and food, and with care in a comfortable and

supportive place, preferably in their homes or in peer-run crisis respite centers, or when necessary, a regional care facility. The focus would be to assist people as they regain their independence as quickly as possible and become interdependent with natural supports and the community. This could be accomplished by using trained peers as supports (Mead, 2005) and diverting funds from long-term institutionalized care.

5. People who have involuntary commitment orders need to be introduced to and supported in involvement in peer support groups and activities based on mental health recovery values and ethics while they are in a treatment facility, and they need to be introduced to similar opportunities in the community when they leave the hospital. These activities and groups must be tailored to meet their individual needs.
6. The current Recovery Education approach in Vermont is an exemplary program that has changed the lives of many people (Corey, 2001). However, it may not be effective in meeting the needs of people who have involuntary commitment orders because they may have issues with lack of trust, low self-esteem, and transportation that make group participation difficult, and because they may have difficulty relating to people whose life experience is different from their own. Recovery education may need to be one-to-one and might happen more easily through the statewide Community Links program. In addition, any recovery-based curriculum needs to be modified so that it is presented in small steps that build on each other, includes examples that are specific to people who have orders of involuntary commitment, and makes

suggestions for using recovery strategies in difficult circumstances, like the hospital, a group home, living in a shelter, or living on the streets.

7. Treatment in mental health facilities needs to include on-going opportunities for intellectual development, creative expression, and physical exercise. This could include opportunities for people to work toward educational goals or degrees. Hospitals and treatment centers must become a “beehive” of positive recovery focused activities to promote recovery, counteract reported boredom, and to support personal growth.
8. Peer-run crisis respite centers (Mead, 2004) need to be available as an option for people who are having a difficult time. A beginning step in this process might involve reinterviewing participants in the Moving Ahead Study for their ideas on what would be most helpful.
9. People who have serious mental health difficulties need to have easy access to alternative and complementary treatment choices at all times. Education could be included in Community Links and the mental health recovery programs about the availability of these options. Funding needs to be secured to provide payment for these services.
10. Peers need to be specially trained using peer support methodologies and their services utilized throughout the mental health system, especially in support roles with people who are having severe mental health difficulties. In taking this step it is hoped that those people who have not been interested in mental health support will be able to make meaningful, more reciprocal connections that increase trust and motivation.

11. All treatment needs to be provided in a respectful and compassionate manner. Recovery-focused supervision and evaluation in which care providers assess themselves and offer each other feedback are needed. Care providers who are not treating people with respect and compassion should not be allowed to interact with people who are experiencing serious mental health difficulties.
12. All treatment and programming must be trauma informed. Many programs and trainings are available that work with systems, providers, and administrators on the use of trauma-informed services (Mead, 2004).
13. Insurance and parity issues need to be resolved so that everyone who needs help and support can get it.
14. People in treatment facilities need to leave the facility with knowledge and a clear plan of where they will live, how their needs will be met, and a support person. This may include provision of housing, money, food, clothing, and transportation. As the person worked on their recovery, they would take over responsibility for meeting their own needs. Again, this could be facilitated through the Community Links program.
15. All treatment including medications needs to be voluntary and explained in detail to the person who is receiving the treatment.
16. The use of coercion and restraint needs to be abolished using the guidelines in the new training curriculum that has been developed by Buffington, Geisler, and Jorgenson (2003).
17. Community education programs need to be implemented to reduce stigma and facilitate community reintegration. Following these guidelines for future

work will facilitate the on-going recovery process for people with orders of involuntary commitment.

*In conclusion*

It is hoped that this study marks the beginning of an important long-term and on-going process of action research supported by other kinds of qualitative and quantitative studies that will continue to refine the Community Links program and contribute to the improvement of other similar programs. In addition, further research could lead to the development of other innovative strategies and programs that will help to restore the independence and enhance the lives of people with involuntary mental health commitments and people who are living with serious mental health difficulties.

## References

- Allott, P., Loganathan, L., & Fulford, K. (2003). Discovering hope for recovery. *Canadian Journal of Community Mental Health, 21*(2), 13–34.
- Beiner, W. (2005). *Memorandum to legislative Mental Health Oversight Committee regarding United States Department of Justice Investigation 7/05.*
- Bentz, V., & Shapiro, J. (1998). *Mindful inquiry in social research.* Thousand Oaks, CA: Sage.
- Brown, C. (Ed.). (2001). *Recovery and wellness: Models of hope and empowerment for people with mental illness: Vol. 17.* New York: Haworth Press.
- Buffington, E. (2003). *Wellness recovery action plan: WRAP evaluation, State of Minnesota.* Minneapolis, MN: Mental Health Consumer/Survivor Network of Minnesota.
- Buffington, E., Geisler, C., & Jorgenson, J. (2003). *Roadmap to a restraint free environment for persons of all ages.* Washington, DC: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S Department of Health and Human Services.
- Campbell, J., & Schraiber, R. (1989). *In pursuit of wellness: The well-being project.* Sacramento, CA: Department of Mental Health.
- Chamberlin, J. (2002). *On our own* (Rev. ed.). Lawrence, MA: National Empowerment Center.
- Chittick, R., Brooks, G., Irons, F., & Deane, W. (1961). *The Vermont story: Rehabilitation of chronic schizophrenic patients.* Burlington, VT: Queen City Printers.

- Christensen, A., & Jacobson, N. S. (1994). Who (or what) can do psychotherapy: The challenge of nonprofessional therapies. *Psychological Science*, 5, 8–14.
- Coleman R. (1999) *Recovery: An alien concept*. Gloucester: Hansell Publishing.
- Cook, J. (2004). Mental illness self-management through wellness recovery action planning. *Mental Health Recovery Newsletter*, 5(3), 6-7.
- Copeland, M. (1991). *Learning to cope with depression and manic depression*. Brattleboro, VT: Peach Press.
- Copeland, M. (1998, October). Testimony before the Vermont State Legislative committee.
- Copeland, M. (2001). *The depression workbook: A guide to living with depression and manic depression*. Oakland, CA: New Harbinger.
- Copeland, M. (2002a). *Facilitator training manual: Mental health recovery including wellness recovery action planning*. Dummerston, VT: Peach Press.
- Copeland, M. (2002b). *Wellness recovery action plan*. Dummerston, VT: Peach Press.
- Copeland, M. (2003) *Mental health recovery and wellness recovery action plan survey*. Unpublished.
- Copeland, M. (2004a). *Reflective practice and human transformation*. Unpublished.
- Copeland, M. (2004b). Self-determination in mental health recovery: Taking back our lives. In J. Jonikas & J. Cook (Ed.), *UIC NRTC's National Self-Determination and Psychiatric Disability Invitational Conference: Conference papers* (pp. 68–82). Chicago: UIC National Research and Training Center on Psychiatric Disability.

- Copeland, M. (2004c). *Taking action: A mental health recovery self-help educational program*. Rockville, MD: Center for Mental Health Services.
- Copeland, M. (2005). *Community links: Pathways to reconnection and recovery program implementation manual*. Waterbury, VT: Vermont State Department of Mental Health and Mental Retardation.
- Copeland, M., & Mead, S. (2004a). *Wellness Recovery Action Plan and peer support: Personal, group and program development*. Dummerston, VT: Peach Press.
- Copeland, M., & Mead, S. (2004b). *Report of the Moving Ahead study*. Waterbury, VT: State Department of Mental Health and Mental Retardation.
- Corey, L. (2001). *Vermont Recovery Education Project*. Retrieved June 21, 2004, from <http://www.mentalhealthrecovery.com/vtrecovery.html>
- Creswell, J. W. (1994). *Qualitative & quantitative approaches*. Thousand Oaks, CA: Sage.
- Danley, K. E., & Ellison, M. L. (1999). *A handbook for participatory action researchers*. Boston, MA: Center for Psychiatric Rehabilitation.
- Davidson, L., Haglund, K., Stayner, D., Rakfeldt, J., Chinman, M., & Tebest, J. (2001). "I was just realizing ... that life isn't one big horror": A qualitative study of supported socialization. *Psychiatric Rehabilitation Journal*, 24, 275–292.
- Davidson, L., & Strauss, J. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, 65, 131–145.
- Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 11(4), 11–19.

- Denzin, N. (1997). *Interpretive ethnography: Ethnographic practices for the 21st century*. Thousand Oaks, CA: Sage.
- Desisto, M., Harding, C., McCormick, R., Ashikaga, T., & Brooks, G. (1995). The Maine and Vermont three-decade studies of serious mental illness. *British Journal of Psychiatry, 167*, 331–341.
- Faulkner, A., & Layzell, S. (2000). *Strategies for living: A summary report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation. Retrieved January 24, 2005 from <http://www.mentalhealth.org.uk/html/content/s4lreportsum.pdf>
- Gartner, A., & Riesmann, F. (1982). Self help and mental health. *Hospital and Community Psychiatry, 154*, 478–485.
- George, L., Blazer, D., Hughes, D., & Fowler, N. (1989). Social support and the outcome of major depression. *British Journal of Psychiatry, 154*, 478–485.
- Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S., & Brier, A. (1987). The Vermont longitudinal study of persons with severe mental illness: I. Methodology, study sample, and overall status 32 years later, *American Journal of Psychiatry, 144*, 718–735.
- Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., & Wanderling, J. (2001). Recovery from psychotic illness: A 15- and 25-year international follow-up study. *British Journal of Psychiatry, 178*, 506–517.
- Harrison, G., & Mason, P. (1993). Schizophrenia: Falling incidence and better outcome? *British Journal of Psychiatry, 144*, 718–726.
- Hertz, R. (1997). *Reflexivity and Voice*. Thousand Oaks, CA: Sage.

- Kincheloe, M., & Hunt, H. (1988). *Empty beds: A history of Vermont State Hospital*.  
Barre VT: Kincheloe.
- Kingree, J., & Ruback, R. (1994). Understanding self help groups. In T. Powell (Ed.),  
*Understanding the self-help organization*. Thousand Oaks, CA: Sage.
- Legislative Council of the General Assembly for the State of Vermont. (2003). Vermont  
statutes annotated. LexisNexis.
- Leibrich, J. (2001). Making space: Spirituality and mental health. The Mary Hemingway  
Rees Memorial Lecture, World Assembly for Mental Health, Vancouver, 2001.  
Article no. 333978. Retrieved March 12, 2005, from  
<http://mhcweb.org/Articles?worldCongress2001Jleibrich.htm>
- Lewin, K. (1948) *Resolving social conflicts; selected papers on group dynamics*.  
Gertrude W. Lewin (ed.). New York: Harper & Row.
- Loveland, D., Randall, K., & Corrigan, P. (2005). Research methods for exploring and  
assessing recovery. In R. Ralph & P. Corrigan (Ed.), *Recovery in mental illness:  
Broadening our understanding of wellness* (pp. 19–55). Washington DC:  
American Psychological Association.
- Low, A. (1950). *Mental health through will-training*. Glencoe, IL: Willett.
- McNulty, K. (2002). *Peer to peer*. Alexandria, VA: National Alliance for the Mentally  
Ill.
- MacNeil, C. (2001). *Working in partnership*. Albany, NY: The New York  
Association of Psychiatric Rehabilitation Services.
- MacNeil. (2004). *Getting the hospital out of us*. Albany, NY: The New York  
Association of Psychiatric Rehabilitation Services.

- Mead, S. (2001). *Peer support and a social-political response to trauma and abuse*.  
Unpublished manuscript.
- Mead, S. (2004). *Trauma informed peer support and crisis respite: A training manual*.  
Plainfield, NH: Mead.
- Mead, S. (2005). *Intentional peer support: An alternative approach*. Plainfield, NH:  
Mead.
- Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective.  
*Psychiatric Rehabilitation Journal*, 25, 134–141.
- Mead, S., & MacNeil, C. (2004). *Peer support: What makes it unique*. Unpublished  
manuscript.
- Miles, M., & Huberman, A. (1994). *Qualitative data analysis*. Thousand Oaks, CA: Sage.
- Morse, J. (1997). Responding to threats to integrity of self. *Advances in Nursing Science*,  
19(4), 21–36.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA:  
Sage.
- Polkinghorne, D. (1988) *Narrative knowing and the human sciences*. Albany, NY: State  
Univeristy of New York Press.
- Ralph, R. (2000). Recovery. *Psychiatric Rehabilitation Skills*, 4, 480–517.
- Ralph, R., & Corrigan, P. (Ed.). (2005). *Recovery in mental illness: Broadening our  
understanding of wellness*. Washington DC: American Psychological Association.

- Ralph, R. O., Lambert, D., & Kidder, K. (2002, June). *The recovery perspective and evidence-based practice for people with serious mental illness: A guideline developed for the Behavioral Health Recovery Management Project*. Portland, ME: University of Southern Maine, Edmund S. Muskie School of Public Service, Institute for Health Policy.
- Rapp, C. (1998). *The strengths model: Case management with people suffering from severe and persistent mental illness*. New York: Oxford University Press.
- Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in mutual help context. *Journal of Applied Behavioral Science*, 29, 239–256.
- Roberts, G., & Wolfson, P. (2004). The rediscovery of recovery: open to all. *Advances in Psychiatric Treatment*, 10, 37–48.
- Rogers, E., & Palmer-Erbs, V. (1994). Participatory action research: Implications for research and evaluation in psychiatric rehabilitation. *Psychosocial Rehabilitation Journal*, 18(2), 3-12.
- Salzer, M., & Mental Health Association of Southeastern Pennsylvania Best Practices Team. (2002). *Best practice guidelines for consumer-delivered services*. Peoria, IL: Behavioral Health Recovery Management Project.
- Sarason, I., Levine, H., Basham, R., & Sarason, B. (1983). Assessing social support: The social support questionnaire. *Journal of Personality and Social Psychology*, 44, 127–139.
- Segal, S., Gormory, T., & Silverman, C. (1998). Health status of homeless and marginally housed users of mental health self-help agencies. *Health and Social Work*, 23, 45–52.

- Sidney, L. (n.d.). *The legacy of Chicago's Abraham A. Low, M.D.: Recovery, Inc., an affordable mental health resource for patients*. Chicago: Recovery, Inc. Retrieved February 16, 2005, from <http://www.recovery-inc.org/resources/low2.html>
- Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, 27, 392–401.
- Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal*, 25, 20–27.
- State of Vermont. (2001). *Request for Proposals*. Montpelier, VT: Departments of Developmental and Mental Health Services (DDMHS) and Aging and Disabilities (DAD), Federal Real Choices Systems Change grant from the Center for Medicare and Medicaid Services (CMS).
- Strauss, J., & Carpenter, W. (1981). *Schizophrenia*. New York: Plenum Press.
- Swartz, M., Swanson, J., Wagner, H., Burns, B., Hiday, V., & Bourum, R. (1999). Can involuntary outpatient commitment reduce hospital recidivism? Findings from a randomized trial with severely mentally ill individuals. *American Journal of Psychiatry*, 156, 1968–1975.
- Tennessee Mental Health Consumers' Association. (n.d.). *BRIDGES: Building recovery & individual dreams & goals through education & support*. Retrieved February 16, 2005 from [http://www.tmhca-tn.org/About\\_Bridges.html](http://www.tmhca-tn.org/About_Bridges.html).
- Walsh, D. (1996). A journey toward recovery: From the inside out. *Psychiatric Rehabilitation Journal*, 20, 87.
- Walsh, J., & Connelly, P. (1996). Supportive behaviors in natural support networks of people with serious mental illness. *Health & Social Work*, 21, 296–303.

Whyte, W. F. (1991). *Participatory action research*. Newbury Park, CA: Sage.

Young, S., & Ensing, D. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22, 219–239.

## Appendix A

### Statutes Pertaining to Involuntary Commitment from

The Legislative Council of the General Assembly for the State of Vermont (2003)  
Vermont Statutes Annotated. LexisNexis.

#### **§ 7611. Involuntary treatment**

No person may be made subject to involuntary treatment unless he is found to be a person in need of treatment or a patient in need of further treatment.

Chapter 171 in the Vermont State Book of Statutes describes the criteria for involuntary treatment, here referred to as being in need of treatment or in need of further treatment:

(16) "A patient in need of further treatment" means:

(A) A person in need of treatment, or

(B) A patient who is receiving adequate treatment, and who, if such treatment is discontinued, presents a substantial probability that in the near future his condition will deteriorate and he will become a person in need of treatment;

(17) "A person in need of treatment" means a person who is suffering from mental illness and, as a result of that mental illness, his capacity to exercise self-control, judgment or discretion in the conduct of his affairs and social relations is so lessened that he poses a danger of harm to himself or others;

(A) A danger of harm to others may be shown by establishing that:

(i) he has inflicted or attempted to inflict bodily harm on another; or

(ii) by his threats or actions he has placed others in reasonable fear of physical harm to themselves; or

(iii) by his actions or inactions he has presented a danger to persons in his care.

(B) A danger of harm to himself may be shown by establishing that:

(i) he has threatened or attempted suicide or serious bodily harm; or

(ii) he has behaved in such a manner as to indicate that he is unable, without supervision and the assistance of others, to satisfy his need for nourishment, personal or medical care, shelter, or self-protection and safety, so that it is probable that death, substantial physical bodily injury, serious mental deterioration or serious physical debilitation or disease will ensue unless adequate treatment is afforded;

**§ 7612. Application for involuntary treatment**

(A) An interested party may, by filing a written application, commence proceedings for the involuntary treatment of an individual by judicial process.

(B) The application shall be filed in the district court of the proposed patient's residence or, in the case of a nonresident, in any district court.

(C) If the application is filed under sections 7508 or 7620 of this title, it shall be filed in the district court in which the hospital is located.

(D) The application shall contain:

(1) The name and address of the applicant;

(2) A statement of the current and relevant facts upon which the allegation of mental illness and need for treatment is based. The application shall be signed by the applicant under penalty of perjury.

(E) The application shall be accompanied by:

(1) A certificate of a licensed physician, which shall be executed under penalty of perjury stating that he has examined the proposed patient within five days of the date the petition is filed, and is of the opinion that the proposed patient is a person in need of treatment, including the current and relevant facts and circumstances upon which the physician's opinion is based; or

(2) A written statement by the applicant that the proposed patient refused to submit to an examination by a licensed physician.

(F) Before an examining physician completes the certificate of examination, he shall consider available alternative forms of care and treatment that might be adequate to provide for the person's needs, without requiring hospitalization

**§ 7613. Notice-Appointment of counsel**

(A) When the application is filed, the court shall appoint counsel for the proposed patient, and transmit a copy of the application, the physician's certificate, if any, and a notice of hearing to the proposed patient, his attorney, guardian, or any person having custody and control of the proposed patient, the state's attorney, or the attorney general, and any other person the court believes has a concern for the proposed patient's welfare. A copy of the notice of hearing shall also be transmitted to the applicant and certifying physician.

(B) The notice of hearing shall set forth the date and time of the hearing and shall contain a list of the proposed patient's rights at the hearing.

(C) If the court has reason to believe that notice to the proposed patient will be likely to cause injury to the proposed patient or others, it shall direct the proposed patient's counsel to give the proposed patient oral notice prior to written notice under circumstances most likely to reduce likelihood of injury.

**§ 7614. Psychiatric examination**

As soon as practicable after notice of the commencement of proceedings is given, the court on its own motion or upon the motion of the proposed patient or his attorney or the state of Vermont shall authorize examination of the proposed patient by a psychiatrist other than the physician making the original certification. The examination and subsequent report or reports shall be paid for by the state of Vermont. The physician shall report his finding to the party requesting the report or to the court if it requested the examination.

**§ 7615. Hearing**

(A) Upon receipt of the application, the court shall set a date for the hearing to be held within ten days from the date of the receipt of the application or 20 days from the date of the receipt of the application if a psychiatric examination is ordered under section 7614 unless the hearing is continued by the court.

(B) The court may grant either party an extension of time of up to seven days for good cause.

(C) The hearing shall be conducted according to the rules of evidence applicable in civil actions in the district courts of the state, and to an extent not

inconsistent with this part, the rules of civil procedure of the state shall be applicable.

(D) The applicant and the proposed patient shall have a right to appear at the hearing to testify. The attorney for the state and the proposed patient shall have the right to subpoena, present and cross-examine witnesses, and present oral arguments. The court may, at its discretion, receive the testimony of any other person.

(E) The proposed patient may at his election attend the hearing, subject to reasonable rules of conduct, and the court may exclude all persons not necessary for the conduct of the hearing.

**§ 7616. Appearance by state; burden of proof**

(A) The state shall appear and be represented by the state's attorney for the county in which the hearing takes place or by the attorney general at his discretion.

(B) The state shall have the burden of proving its case by clear and convincing evidence.

(C) The attorney for the state shall have the authority to dismiss the application at any stage of the proceeding.

**§ 7617. Findings; order**

(A) If the court finds that the proposed patient was not a person in need of treatment at the time of admission or application or is not a patient in need of further treatment at the time of the hearing, the court shall enter a finding to that effect and shall dismiss the application.

(B) If the proposed patient is found to have been a person in need of treatment at the time of admission or application and a patient in need of further treatment at the time of the hearing, the court may order the person:

- (1) hospitalized in a designated hospital;
- (2) hospitalized in any other public or private hospital if he and the hospital agree; or
- (3) to undergo a program of treatment other than hospitalization.

(C) Prior to ordering any course of treatment, the court shall determine whether there exists an available program of treatment for the person which is an appropriate alternative to hospitalization. The court shall not order hospitalization without a thorough consideration of available alternatives.

(D) Before making its decision, the court shall order testimony by an appropriate representative of a hospital, a community mental health agency, public or private entity or agency or a suitable person, who shall assess the availability and appropriateness for the individual of treatment programs other than hospitalization.

(E) Prior to ordering the hospitalization of a person, the court shall inquire into the adequacy of treatment to be provided to the person by the hospital. Hospitalization shall not be ordered unless the hospital in which the person is to be hospitalized can provide him with treatment which is adequate and appropriate to his condition.

(F) Preference between available hospitals shall be given to the hospital which is located nearest to the person's residence except when the person requests

otherwise or there are other compelling reasons for not following the preference.

**§ 7618. Order; non-hospitalization**

(A) If the court finds that a treatment program other than hospitalization is adequate to meet the person's treatment needs, the court shall order the person to receive whatever treatment other than hospitalization is appropriate for a period of 90 days.

(B) If at any time during the specified period it comes to the attention of the court, either that the patient is not complying with the order, or that the alternative treatment has not been adequate to meet the patient's treatment needs, the court may, after proper hearing:

(1) Consider other alternatives, modify its original order and direct the patient to undergo another program of alternative treatment for the remainder of the 90-day period; or

(2) Enter a new order directing that the patient be hospitalized for the remainder of the 90-day period.

**§ 7619. Order; hospitalization**

An initial order of hospitalization shall be for a period of 90 days from the date of the hearing.

**§ 7620. Application for continued treatment**

(A) If, prior to the expiration of any order issued in accordance with section 7623 of this title, the commissioner believes that the condition of the patient is such that the patient continues to require treatment, the commissioner shall

apply to the court for a determination that the patient is a patient in need of further treatment and for an order of continued treatment.

(B) An application for an order authorizing continuing treatment shall contain a statement setting forth the reasons for the commissioner's determination that the patient is a patient in need of further treatment, a statement describing the treatment program provided to the patient and the results of that course of treatment.

(C) Any order of treatment issued in accordance with section 7623 of this title shall remain in force pending the court's decision on the application.

**§ 7621. Hearing on application for continued treatment; orders**

(A) The hearing on the application for continued treatment shall be held in accordance with the procedures set forth in sections 7613, 7614, 7615 and 7616 of this title.

(B) If the court finds that the patient is a patient in need of further treatment and requires hospitalization it shall order hospitalization for up to one year.

(C) If the court finds that the patient is a patient in need of further treatment but does not require hospitalization, it shall order non-hospitalization for up to one year.

(D) If at any time during the period of non-hospitalization ordered under subsection (C) of this section, it comes to the attention of the court, that the person is not complying with the order, or that the alternative treatment has not been adequate to meet the patient's treatment needs, the court may, after proper hearing:

(1) Consider other treatments not involving hospitalization, modify its original order, and direct the patient to undergo another program of alternative treatment for an indeterminate period, up to the expiration date of the original order; or

(2) Order that the patient be hospitalized, up to the expiration date of the original order.

(E) If the court finds that the patient is not a patient in need of further treatment, it shall order the patient discharged.

(F) This section shall not be construed to prohibit the court from issuing subsequent orders after a new application is filed pursuant to section 7620 of this title.

**§ 7622. Expert testimony**

(A) A mental health professional testifying at hearings conducted under this part may, if appropriately qualified, give opinion testimony and, notwithstanding section 1612 of Title 12, describe any information which he acquired in attending the patient.

(B) The facts or data in the particular case, upon which an expert bases an opinion or inference, may be those perceived by or made known to him at or before the hearing. If of a type reasonably relied upon by experts in the particular field in forming opinions or inferences upon the subject, the facts or data need not be admissible in evidence.

**§ 7623. Orders; custody**

All court orders of hospitalization, non-hospitalization and continued treatment shall be directed to the commissioner and shall admit the patient to his care and custody for the period specified.

From chapter 171. the following sections of the law are also pertinent to this issue.

**§ 7110. Certification of mental illness**

A certification of mental illness by a licensed physician required by section 7504 of this title shall be made by a board eligible psychiatrist, a board certified psychiatrist or a resident in psychiatry, under penalty of perjury. In areas of the state where board eligible psychiatrists, board certified psychiatrists or residents in psychiatry are not available to complete admission certifications to the Vermont state hospital, the commissioner may designate other licensed physicians as appropriate to complete certification for purposes of section 7504 of this title.

**§ 7111. Right to legal counsel**

In any proceeding before, or notice to, a court of this state involving a patient or student, or a proposed patient or student, that person shall be afforded counsel, and if the patient or student or proposed patient or student is unable to pay for counsel, compensation shall be paid by the state to counsel assigned by the court; however, this section shall not apply to a proceeding under section 7505 of this title.

**§ 7112. Appeals**

A patient or student may appeal any decision of the board. The appeal shall be to the superior court of the county wherein the hospital or school is located. The appeal shall

be taken in such manner as the supreme court may by rule provide, except that there shall not be any stay of execution of the decision appealed from.

**§ 7113. Independent examination: payment**

Whenever a court orders an independent examination by a mental health professional or a qualified mental retardation professional pursuant to this title or 13 V.S.A. § 4822, the cost of the examination shall be paid by the department of developmental and mental health services. The mental health professional or qualified mental retardation professional may be selected by the court but the commissioner of developmental and mental health services may adopt a reasonable fee schedule for examination, reports and testimony.

## Appendix B

### Informed Consent Form

## **Moving Ahead Project**

### **Statement of Volunteer Consent**

**Introduction:** I \_\_\_\_\_, hereby agree to participate in research for developing new recovery and peer support strategies for people who are either on involuntary community status or on orders of non-hospitalization (people who have orders that limit their choices, and make provision that they can be returned to in-patient treatment status in specific circumstances). I understand that this project will be under the supervision of the Principal Investigators, Mary Ellen Copeland and Shery Mead.

**Purpose:** The purpose of this research is to study the complex recovery needs of people who have been, or are currently on involuntary community status or on orders of non-hospitalization. This study will focus on recovery education and peer support as possible strategies that will facilitate recovery.

**Procedures:** The principal investigators will work with key stakeholders as an on-going group. They will interview volunteers through individual interviews and focus groups, asking participants to offer their own reflections on “what’s working and what’s not”, and “what helps and doesn’t help”. They will also be interviewing people who 1.) have had such orders in the past, 2.) people who been involved in making decisions for or about them, and 3.) treatment providers. In addition, information will be collected from programs around the country who are working on this issue.

After this information is collected, it will be studied by a committee of people who have first hand experience in the mental health system. The analysis will be used to develop a new program or project that will then be tested to see how well people feel that it works. The program will then be revised to reflect these findings. The investigators will develop a manual that describes the project so that it can be easily replicated.

It is hoped that, because of this study, this program or project will be more helpful than those that have been used in the past.

I wish to limit my participation as a subject in the investigation as follows (time commitments, etc.) \_\_\_\_\_ I also understand that I may withdraw from the study at any time.

**Risks:** I have been informed of the risks that I may reasonably expect as part of the study. These include sharing personal and potentially emotional stories and hearing difficult stories from others, but I understand that every precaution will be taken to assure my personal safety and comfort. In addition, if I feel my rights have been violated in any

way, I can contact Vermont Protection and Advocacy for assistance and support (802) 229-1355. If I have any questions about my rights I can also contact, can also contact Pat House of the Institutional Review Board at (802) 241-2624

**Benefits:** I understand that the information that is obtained may be useful to others. The potential benefits to me include having more input into mental health policy and practice, to learn more about research and evaluation, and to support my personal recovery. I also understand there may be no benefit to me.

**Confidentiality:** I have been assured that any and all information identifying me will remain confidential, or will be disclosed only with my written permission. However, I am in agreement that information that does not uniquely identify me may be presented at meetings and reported so that the information can be useful to others. I understand that the co-principal investigators will make available to me on request the audio taped version of the interview. I also understand at the conclusion of the project, October 1, 2004, the tapes will be destroyed. We will try to contact you before the tapes are destroyed in case you want to review them. The researchers will not be contacting or sharing information with your family members, friends or care providers.

**No Prejudice:** I have been informed that my decision about whether to participate will not prejudice my present or future relationship with any mental health services; nor will it influence the quantity or quality of care, which is otherwise available to me. If I participate, I understand that I am free to withdraw at any time, and that withdrawal would not in any way affect the nature of the care or treatment otherwise available to me. I understand that I may contact the Chairman of the Human Research Review Committee for further information related to the research and my rights as a subject in this study.

**Further Information:** If I have further questions concerning this project at any time, I understand that I am free to ask them of Mary Ellen Copeland (802-254-2092) or Shery Mead (603-469-3577. If I have complaints about how I have been treated, I can address them to Vermont Protection and Advocacy at (802) 229-1355.

I agree to participate in this project

Signature \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Witness \_\_\_\_\_ Date: \_\_\_\_\_

I have defined and fully explained the study as described herein to the subject.

Signature of interviewer: \_\_\_\_\_ Date \_\_\_\_\_

## Appendix C

### Moving Ahead Press Release

## Press Release

### Moving Ahead: A Project to Reduce Involuntary Commitments

The Vermont State Department of Mental Health has a strong commitment to programs that support recovery and wellness. In recent years, working with Vermont Psychiatric Survivors, an organization of people who have used mental health services, it has promoted various educational and peer support programs including Wellness Recovery Action Planning. These programs have helped numerous people work their way out of difficult times, moving on to do the things they wanted to do with their lives.

However, there is still a small group of people who continue to need intensive hospital services from time to time, and who remain on orders of non hospitalization, which means they have some supervision when they are not hospitalized. The state would like to find out what specific kind of initiatives would help these people to recover. Moving Ahead: A Project to Reduce Involuntary Commitments is designed to meet this need.

Over the next six months, Shery Mead and Mary Ellen Copeland will be interviewing volunteers—people who have repeated orders of non hospitalization, people who have had them in the past, family members, those who have provided them with care and others who have been involved in their lives such as judges, attorneys and advocates. Their goal is to find out what might help these people feel better, support their recovery, empower them, and help them stay out of the hospital. They will use the information they have gathered to develop a pilot project and eventually a curriculum designed to better meet the needs of these people.

To begin this process, there will be two public informational meetings, November 6, from 2-4 PM at Central Vermont Hospital in Berlin and November 11 from 2-4 PM at the Black River Center, Springfield. Anyone who would like to learn about or take part in this project is encouraged to attend. For more information, directions or assistance with transportation call 866-220-7538 Pin # 2008

#### *Community Calendar Notice*

***Moving Ahead: A Project to Reduce Involuntary Commitments* information meetings**  
November 6 2-4 PM Central Vermont Hospital, Berlin  
November 11 2-4 PM Black River Center, Springfield  
Anyone who would like to learn about or take part in this project is encouraged to attend. For more information, directions or assistance with transportation call 866-220-7538 Pin # 2008.

Appendix D

Moving Ahead Poster

Please Post

# Moving Ahead: Involuntary Commitment and Recovery

Moving Ahead is a study to learn from people who have repeated psychiatric hospitalizations as well as orders of non-hospitalization:

- what helps them feel better,
- supports their recovery,
- empowers them, and
- helps them stay out of the hospital

and to use what we have learned to design a program that will help people move on with their lives.

To do this, Shery Mead and Mary Ellen Copeland will interview people who are on, or have been on, orders of non-hospitalization and those people who have provided them with services and/or support.

As we begin this important project, we want input from anyone who might have something to offer. Please join us at one of the following information sharing meetings to help us begin this important project.

November 6, 2003 2 - 4 PM Central Vermont Hospital, Berlin

November 12, 2003, 2 - 4 PM SRS Office, Springfield

For more information or for assistance with transportation call:

Marty Roberts at this toll free number:

1-866-220-7538. You will be asked to punch in a pin #, this # is 2008

## Appendix E

### *Semi-structured Interview Guide*

#### Introduction

Perhaps you could start by telling me a little about yourself.

What are your strengths/gifts?

What are your hopes and dreams?

Do you think you can achieve your hopes and dreams? Why or why not?

What are your interests? What skills do you have that allow you to accomplish your interests?

What keeps you from doing the things you like to do?

#### Self perception/Other's perceptions

How do you think others would describe you? Do you agree with that description?

Do you think that other people understand you?

What is it about you that you they don't understand?

#### Support networks

What does your support network look like? What would you like it to look like?

Describe your relationship with the person or people you like to be with the most. Why do you like being with them?

If you find yourself getting into difficulties with someone you're close to, what do you generally do about it?

Do you ever feel isolated? Why do you think that is? Is that something that you want to change in your life?

If you were to invite others into your support circle, who would they be and what would you be doing with them?

Do you feel connected to the people in your community, why or why not?

If you wanted to, how do you think you could build stronger relationships with people in your community?

### Respect/Trust

How and where do you get respect in your life?

Where do you feel disrespected? What does that look like? Why is that so?

Where do you feel most safe? Can you describe the kind of situation in which you feel safe?

Where do you feel unsafe?

How do you build trusting relationships with people?

Who are the people that you're most uncomfortable with? Why?

### Coping Strategies

What are the things (circumstances, situations, etc.) that make you feel uncomfortable or upset?

Describe what that's like for you.

What are the things that you do during those times to help yourself feel better?

When you feel good, what's going on? Where are you? What sorts of things are you doing and with whom?

What are your current strategies for staying well or avoiding problems?

## Experience with the mental health system

What did it feel like to be told that you have a mental illness?

Has it been helpful to you to have a diagnosis? Why or why not?

How does being told you have a mental illness and being given a diagnosis affect your life?

Describe your experience with the mental health system. What's worked and what hasn't? Why do you think that's so?

How do you think that's helped you move ahead with your life?

Describe your experience with hospitalization. What's been helpful and what's not?

Describe your relationships with people in the mental health system.

Do you know about Peer Support programs? If so, what has been your experience with Peer Support?

Do you know about the Vermont Recovery Education Program and Wellness Recovery Action Planning? If so, what has been your experience with it?

## Experience with involuntary commitment

How many times have you had an involuntary commitment order? When were they? How long were you on?

Why do you think you were on an involuntary commitment order? How did you feel about being on it?

What difference did it make in your life?

Were you involved in planning your involuntary commitment order? If so, how was that helpful? If you weren't what was the result of that?

Other

Is there anything else you'd like to tell me?

Is there anything you'd like to ask me?