# CONSUMER STAFF IN PSYCHIATRIC INPATIENT FACILITIES

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"Self-help" and "recovery" are difficult concepts to convey to staff and patients in an inpatient facility. When a mental health consumer was hired to work as a full-time permanent staff member, patients and staff began to understand the real meaning of recovery. This narrative describes the process of building staff trust in the concept, educating patients and staff about the role of the consumer advocate, and the startling successes of the program.

#### **Forward**

As Administrator of the State of Wisconsin Division of Supportive Living and former Director of the Bureau of Community Mental Health, I am thankful to Larry Schomer, Joann O'Connor, and the staff of the Winnebago Mental Health Institute for implementing this project. Thanks also to Barry Blackwell, a retired psychiatrist, for interviewing the people involved and helping to bring the manuscript to completion.

Wisconsin and several other states have recognized the importance of consumer involvement at all levels of planning and implementation of mental health services. The presence of a consumer as an employee in an inpatient facility is another step forward that can have an important influence by encouraging hope, role-modeling recovery, and reducing stigma. This paper provides enough detail that others in Wisconsin and elsewhere may be encouraged to develop similar projects

#### Introduction

The purpose of this narrative is to describe a successful project that I have the pleasure of enjoying in sufficient detail that others may be encouraged and enabled to replicate it with whatever modifications meet local needs. The ability of persons with severe and persistent mental illness to lead functional independent lives continues to evolve. It is fueled by courageous consumers, creative men-

tal health administrators, changes in public policy, and improvements in medical, social, and psychological therapies. Progress is also shaped by bold experiments that demonstrate innovative ways to improve the path towards full independence for all consumers. The ability to replicate such projects is often frustratingly difficult because of the perception that they seem to evolve from a unique set of human and environmental forces that are poorly understood or defined. This project was a significant step forward in care of patients who suffer from mental illness, by a person with mental illness. The project occurred because of synergy between parallel forces, followed by careful planning and bold leadership and a consumer with courage.

#### The Recovery Concept.

The half-century leading up to the millennium witnessed a profound change in society's response to people with severe forms of mental illness. The civil rights sentiments of the post World War II era, coupled with discoveries in the medical treatment of mental disorders, led to a switch from custodial care in large state institutions to community-based services. We have found that persons with mental illness can recover and return to their previous state of health. Many people with mental illness feel it is more accurate to endorse the concept of "procovery," meaning obtaining a new level of meaning and being in



a persons life. Unfortunately, when deinstitutionalization began, it was in many cases, done in advance of the resources, philosophy, and technology needed to assure its success. Neither recovery nor procovery had a chance. Now, with emphasis on consumer empowerment, the concept of recovery and recovery concept offers new hope.

As hospital beds closed, the inability of the community to accommodate consumers was demonstrated by rising re-admission rates, often called the revolving door. Patients discharged from Rockland State Hospital in New York banded together in the early fifties to form Fountain House, a community clubhouse, and initiated a rapidly growing national and international movement in which individuals encouraged one another to provide mutual support and seek employment independent of professional oversight.

Supported by a slim body of empirical research (Corrigan & Gorman, 1997), consumer empowerment has increased in force, fed by a growing consensus that political and professional paternalism may have unwittingly stifled people's innate capacity to adapt and thrive despite their disorders. The concept that illness and disability are related, but independent variables, is now well accepted in the domain of physical illness. Self-help consumer guides have proliferated to assist individuals cope with chronic pain, arthritis, cancer, chronic fatigue, irritable bowel syndrome, and other disorders (Blackwell, 1992). In addition, discrimination between physical and mental illness is dwindling as demonstrated by the move toward insurance parity and inclusion of both in the Americans with Disabilities Act.

The Recovery concept asserts that all individuals, however severe or persistent their mental illness, have the capacity to lead a productive and fulfilling life as they choose to define it, despite their disabilities. It is a rehabilitative model that seeks to eliminate learned helplessness or dependency by strengthening

a person's coping or adaptive capabilities. Recovery defines success in ways that build self-esteem, encourage hope, and erode stigma and discrimination (Anthony, 1993; Fisher, 1994). Recovery is enhanced by clinicians and consumers forming a partnership in which the consumer is actively involved in his or her own treatment planning. Recovery is the very personal process of personal growth and life-long learning.



# **The State Planning Process**

In May 1996, Wisconsins' Governor Thompson appointed a Blue Ribbon Commission on Mental Health to redesign the mental health delivery system so that it would emphasize wellness and recovery. The Commission met with over 700 persons and had broad consumer and family input at all stages (Executive Summary, 1997). The report strongly endorsed a Recovery-oriented system and recommended consumer involvement at every level of planning and service delivery. Its conclusion noted that, "the remarkable aspect of this report is that all stakeholder groups represented on the Commission agreed to these key approaches" (p. 13).

In a briefing paper prepared for the Commission (Jacobsen, May 1998), a dozen other states are also noted to be incorporating the Recovery concept into their re-designed mental health delivery systems. In addition to Wisconsin, at least six other states are planning to involve consumers as paid employees in service delivery: Massachusetts, California, Nebraska, New Hampshire, South Carolina and Vermont.

To begin implementing the Recovery Concept, Wisconsin has adopted several strategies, including allocating almost 10% of the Federal Mental Health Block Grant to consumer/family self-help and peer-support

activities. In addition, progressive facilities and counties have invested local resources to support similar projects. For example, Milwaukee County has hired a consumer as Director of Consumer Affairs for the Mental Health Division and has established consumer satisfaction teams to assess service-provider agencies, including group homes.

#### Director

Prior to 1996, while working in the California Mental Health system, I had the opportunity to be involved with the preliminary steps of organizing a consumer self-help group in one of the state hospitals where I witnessed the profound effects of consumers helping consumers. I saw first hand renewed hope within the most severely ill patients, and increasing strength in recovering consumers who were part of the self-help mentor group. In January 1997, I accepted appointment as Director of Winnebago Mental Health Institute in Wisconsin.

#### The Facility

Winnebago Mental Health Institute is one of two state psychiatric hospitals that serve a population of 5.1 million people. The Institute, situated close to the town of Oshkosh in central Wisconsin on the shores of Lake Winnebago, celebrated 125 years of service in 1998. The current Institute has 14 units and an average daily census of 290 patients. It provides services to civil-and forensic-committed adults, adolescents, and children from all 72 Wisconsin counties. Patients stay for variable time periods, from many months to years.

Shortly after arriving, I began attending a "Recovery" subcommittee of the Blue Ribbon Commission. The committee members included consumers who had worked many years in recovery and self-help programs, and others who had little experience beyond the inpatient experience. One person who lived close to the Institute approached me about

spending some volunteer hours at the Institute meeting with patients and starting a self-help program. That person was Larry, who will introduce himself to you now.

#### The Consumer

I am Larry. I grew up in Wisconsin and am 48 years old. My mother developed a mental illness and was hospitalized when I was a toddler. I grew up in an emotionally withholding and abusive home where I learned not to expect success. I graduated from high school and attended college at University of Wisconsin - Oshkosh. During my senior year I experienced my first major psychiatric breakdown and because of that, I failed to graduate.

I lost the entire decade of my twenties to a recurrent paranoid psychosis and spent almost one and a half years on inpatient units during fifteen admissions. I was diagnosed as suffering from schizophrenia. My first psychiatric hospital admission lasted seven weeks during which time I received twelve ECT treatments and 1000 mgs of Thorazine daily. In the early eighties, my wife divorced me and I became homeless for three months, living in the back of my car. Following this I spent ten months in a halfway house where I gave up alcohol, developed a new routine to life, and began a remission that has lasted 13 years. I still take a major tranquilizer and I see my psychiatrist for regular checks. I feel fairly stable, but I am well aware that I still suffer from a major mental illness. I pace my life, and I am careful to get enough sleep. Once in a while I wonder if I should stop my medication, but I feel it is not worth the risk.

Since my recovery began, I have become increasingly active as a consumer advocate. I served four three-year terms on the Governor's Mental Health Council, and have been its Vice-Chair and Chair. I was also an active member of the Blue Ribbon Commission. For several years, I have been available as a speaker to lay and professional audi-

ences, and I have talked about my own recovery on over 250 occasions throughout Wisconsin and the nation. As an active consumer, I became a close acquaintance of the Director of Bureau of Community Mental Health, and it was she who introduced me to the Director of Winnebago Mental Health Institute early in 1997 when all three of us served on the Blue Ribbon Commission.

# Developing the Project Step one: Assembling the Key Players

The synergy that gave birth to the project is now apparent. A state director of mental health was committed to developing and implementing the Recovery concept, and myself, a new director of a large state institute, looking for a way to implement it. Larry, a consumer advocate, was living in the nearby community, and all three were on the state Commission planning the next innovative steps for the state to pursue. And finally, an evolving and growing national consensus favored the role of consumers as paid participants in service delivery (Fisher, 1994). As Director of Winnebago Mental Health Institute, I became excited about the possibilities that seemed to be presenting themselves to me.

### Step Two: Planning and Staff Buy-In

At the same time, I was aware of the need for caution and careful planning. Three years earlier, McCabe and Unzinger (1995) had cited the concerns voiced by others (Besio & Mahler, 1993), including issues of confidentiality, role confusion, employment stresses, reasonable accommodations, and stigmatization and distrust by non-consumer staff.

I met with Larry for the first time in early March 1997. At this time, our goal was simply to explore ways of helping current in-patients make contact with 'outside' consumers who were living successful lives in their home communities. Larry would be the bridge for this purpose. Over the next few days, Larry

and I met with several key staff to discuss the project, raise enthusiasm, and identify barriers. I also met with executive staff and clinical, and administrative leadership in order to obtain support and endorsement. I explained the importance of the project and how I felt it would help the recovery process for patients in the Institute. In mid-March, Larry made a formal (and well publicized) presentation to patients and staff on "Personal Perspectives on Mental Illness," which was well attended and enthusiastically discussed. Larry and I spoke to many staff and patient groups seeking support for Larry's new role.

# Step Three: Start Small, Build on Success

Larry was now officially oriented as an unpaid volunteer and assigned a formal supervisor who was the Institute's Client Rights Facilitator. Together they toured the facility and met with line staff and patients. I chose this particular supervisor because she had been a strong, supportive influence, and is well respected in the Institute. This has been a very



significant factor in Larry's subsequent success.

In early April 1997, 2 of the 13 units expressed an interest in hearing Larry's presentation. I considered this a turning point in the success of the program because the unit staff and patients had requested the presentation. When Larry presented to these two groups, his words were well received. This became the model we followed: speak to groups about the concept, act quickly when there is a pocket of interest, and lastly, work closely with people within those pockets of interest to develop the relationships. Shortly after the

presentations, another significant event occurred. Staff was considering the use of a new form of restraint, "the body wrap." The patient is completely enfolded in a blanket secured with Velcro flaps for safe transportation to a seclusion room when necessary. Larry asked to be placed in the device, measuring its impact against old memories of having been placed in full leather straps for five days after staff found him engaged in the "dangerous" activity of throwing a paper ball against the seclusion room wall. Larry survived the ordeal and endorsed the new device. Staff members were impressed with Larry's capacity to become an active participant in the decision-making process and were increasingly willing to ask for his advice.

By late April, Larry had met again with staff on the two interested units, and they endorsed his idea to begin holding weekly meetings with interested patients. News of Larry's work began to spread: a staff member on another unit asked for help with a patient anxious about discharge, and another patient talked openly about how much he had been helped by Larry's visits.

# Step Four: Formalizing the Arrangement

By early May, Larry and I decided that there was ample scope for a full-time, paid staff position. We began to put together the outline for a job description, modestly titled as an entry level "Client Services Assistant." By early in August, we had completed the job description and developed standards with which to evaluate candidates. Meanwhile Larry continued his volunteer activities, and by the time he became a formal applicant for the job, he had logged 700 hours of volunteer service.

Developing justification for a salary level that exceeded the minimum entry level pay proved to be difficult because Larry did not have any degrees or any recent work history. As a result, the pay I could offer was scarcely

more than what he received in disability payments. The standard state contract had no health benefits for the first six months of employment. In the past, this was a serious obstacle to any consumer seeking work because Medicare coverage lapsed as soon as employment began. Larry discovered that there is now a nine-month grace period so that he did not have to forgo health benefits in order to work. Nonetheless, when the state health coverage policy became available, Larry was forced to give up his regular psychiatrist who was not covered under the plan. He was lucky enough to find that the psychiatrist who had treated him twenty years earlier was available and in the provider network of his new health care provider. Finally, like most new jobs, this one had minimal vacation or sick time as a buffer against stress or a minor relapse.

# Step Five: Selecting and Supporting Consumer Staff

Larry had not held a full time job in five years, and he had serious misgivings about the risk he would incur by giving up the security and predictability of life on disability for the stress and uncertainty of the workplace. I felt the risk was very serious. We discussed my level of commitment and set him up for success by arranging for close supervision, frequent meetings, and lots of faith. In Larry's own words:

I wondered if I should give up the security of disability income for a job in which I didn't know if I would succeed. The salary offered was very near to the same amount as my disability income. Maybe if I worked part time and stayed on disability I would be protected. I had a fear that I would fail and then not be able to get back on disability income. I still struggle with paranoia and feel sometimes that people are talking about me or laughing at me. Would this interfere with my work? I wor-

ried that I might be just a token at the Institute for PR purposes, and not actually a staff member. I learned that when people heard my story and my qualifications, they respected me. We built up trusting relationships and staff did support my work with patients. I also knew that I had built up several important relationships with doctors and nurses. I had learned that when my symptoms were troubling me, I could go talk to these key people.

Larry finally took the plunge and began his new job in May 1998, one year after he first began his volunteer work. In retrospect, I have a clearer view of the qualities that have made Larry a success but which were not part of the job description. Understanding these qualities may assist other programs in screening for these attitudes and skills among consumer candidates. In the same light, it should be clear that consumers have many different attributes that will make them successful as a self-help staff member. A consumer very different from Larry will be just as successful if time and energy is spent making the program suited to the consumer-staff persons' special talents.

Several aspects of Larry's life as a consumer are important. He was seriously and persistently psychotic for several years, and had extensive experiences in inpatient and outpatient settings with a variety of providers. For a time, he was homeless and spent ten months in a halfway house. This provides Larry with a broad range of experiences to share with other consumers. At the same time, Larry has been in remission for a long period. He has learned how to manage his life and his illness without placing himself at risk of relapse. This includes the fact that he recognizes and accepts the value of medication although he is not at all complacent about the risk of side effects or over medication. At those times when his symptoms reappear, Larry knows the value of having others to confide in, including his supervisor, with whom he has a close relationship as well as ready and frequent access. Larry also knows that rest, relaxation, and sleep are important. Every Thursday he takes a half-day off, and after lunch, drives the eight miles to the home he shares with his two cats. He remains abstinent from alcohol. Larry is rediscovering interests outside of work, including ice and trout fishing. All this means that he is an excellent role model to other consumers in how to maximize recovery.

Larry has several skills that are powerful assets. He is an accomplished speaker who enjoys teaching. Illness apart, he has had varied life experiences. He is a keen observer, knows how to mingle and has an excellent sense of humor. But Larry's most powerful personal asset is that he is even-tempered and never abrasive; Sir William Osler considered equanimity the most vital attribute of a good physician. Additionally, Larry displays a strong sense of humility. Despite the success that attends his work, he is never boastful. On the contrary - he is fearful that the staff may overinflate his skills and come to expect miracles. Larry considers his job to be the best blessing of his life, and worries that he may become a workaholic. But he has taken a vacation with friends that he has made among the staff at the Institute.

# The Role and Effectiveness of Consumer Staff

It is difficult to find a name or title that best fits what Larry does. It is easier to call him a consumer employee than it is to describe the multiple roles he fills. To a large extent, these have evolved to match his skills with emerging consumer needs.

Larry works a five-day, 40-hour week, usually beginning at 8:00 a.m. and ending at 4.30 p.m. except on Wednesdays, when he runs a group until 7:00 p.m., and Thursdays, when he takes the afternoon off. Larry spends the first hour of the day reading correspon-

dence, literature, and e-mail in his office. Then he moves onto the units where he fills multiple functions. He has chosen to have a continuing long-term presence on one of the adult forensic units but also attends two or three staff-patient groups at random. On the adult forensic unit he participates in the weekly staffing attended by a dozen or more nurses, occupational therapists, and psychologist. The meeting is chaired by the unit psychiatrist. Each staff person identifies patients or problems about which they have a particular concern.

Larry knows all the patients well; they not only attend the groups he runs but also frequently talk to him alone. During a recent staff meeting, his contributions included noting one patient's increasing difficulty with anger and another's reluctance to attend groups because he disliked talking about his illness. He knew that one patient was particularly interested in gardening, and staff arranged to accommodate this. The previous evening, staffhad been particularly concerned about a patient who refused oral medication. The psychiatrist was about to resort to intramuscular injections and asked Larry to talk to the patient. In doing so, Larry shared his own experiences with delusions in a way that allowed the patient to accept medication as a way to control his own intrusive thoughts. After learning that the patient was now taking oral medications, Larry spent additional time exploring his response and reassuring him about side effects. Larry has recently started a "voices" group in which patients can feel free to talk about the voices they hear. Larry tells members that it helped him to focus on only one voice; that it became much easier to read or listen to music when there was only one voice.

When asked about the outcomes of Larry's contributions, the staff are enthusiastic. They feel his presence breaks down a "we-they" dynamic between staff and patients. He is often able to provide new information about problems, strengths, and de-

sires of people who are withdrawn or have poor inter-personal relationships. He is also able to influence people who are reluctant to take medications. Staff noted that by role modeling and sharing his own experiences, Larry is able to influence patient self-care behaviors in ways they could not. A psychiatrist notes the significance of Larry's filling a paid position; he was accepted as an equal by staff, and patients saw the possibility of recovery, no longer feeling ashamed of their illness. There were also examples of contributions that only a consumer could make. Larry had noted that staff-patient bulletins typed in black on white paper were difficult for people to read when vision was blurred by anti-cholinergic side effects. They are now typed against a tan background. One unit had posted named photographs of staff to assist in the orientation of new patients. Recently, these disappeared because some staff disliked being photographed. Larry intends to gently intervene.

One very meaningful comment that I heard during the first year of Larry's employment was a staff member who said to me: "You know, you think different when Larry is in the room." I believe the staff member was referring to the fact that when Larry is sitting right there with us making decisions, you begin to think of all the patients as people with lives and hearts and issues, instead of just as "patients."

In any given day Larry may have from ten to twenty informal chats with patients in the dining area, around the grounds, or on the units. Although he has the authority to document in the patients' charts, patients know that he does so very rarely and only in two situations: (1) if there is a concern about patient or staff safety; or (2) if the patient has experienced the kind of success that both Larry and the patient agree should be drawn to the attention of staff.

In addition to weekly unit staffing, Larry participates in or runs six or more groups.



Participation is always voluntary. The purpose of these groups is therapeutic with the exception of the Apollo group, which seeks to improve services by identifying patient concerns and encouraging the facility to take corrective action. Examples include poor ventilation in bathrooms, patient privacy, and the practice of handcuffing patients when they are transported by police to court hearings in Milwaukee, 80 miles away. This last issue has been a major concern, leading a few individuals to waive their right to a legal hearing. As a result of this group's action, the Institute has gained court agreement to video conferencing, and funding has been obtained to purchase equipment. Larry notes with pride that people attending this group are seldom re-admitted to the facility, perhaps because of the healthy assertive behaviors learned and their effect on self-esteem.

Other groups address members who have a spectrum of difficulties, from young adults of both genders in a behavioral program to withdrawn older patients with hospital stays lasting several years. These groups usually include another staff person, either an occupational therapist or a social worker. Larry's role is to share experiences and role model behaviors that increase self-esteem and reduce shame or stigma.

His favorite group, and the one in which he has the leadership role, is on the adult forensic unit. It is highly popular and well attended. Larry uses Abraham Low's book *Mental Health Through Training* as a guide. Patients read excerpts, including case vignettes, and Larry and group members relate their own experiences in identifying feelings and learning new ways to control them.

Larry also participates in administrative committees at the Institute. His input is widely sought and appreciated at the organizational level. For example, he is a member of a task force that is reviewing the Institute's policy and procedures regarding anger management in general, and seclusion and restraint in par-

ticular. The goal is to develop a restraint-free environment, adopting new methods for anger de-escalation. With Larry's advice, the task force has begun to seek input from patients with a history of trauma concerning their experiences with de-escalation and restraint procedures. The implementation of new procedures will be accompanied by a continuous quality improvement project that measures specific outcomes, including consumer response.

Larry has three special longer term projects which add to his work environment. He realizes that visibility, understanding, and acceptance are key ingredients to success. For this reason, Larry meets with all incoming groups of new employees (about every six weeks) to explain his role. He regularly attends staff continuing education conferences and contributes to them. Staff sees Larry in the valued role of teacher, changing their perception about what consumers can do and their approach to patients. They also learn how and when to use his advice and assistance.

Secondly, Larry has set up a consumer information and resource section at the Institute Library, which provides patients with information about the local mental health services, about the Wisconsin Consumer Network, and about specific services, including free dental care, how to obtain low cost medications, and access to multi-lingual services. The goal is to better connect consumers with follow-up services in the community and so reduce the likelihood of re-admission.

The third and possibly most important project is to develop linkages between the Institute and the county system of outpatient services so that consumers who leave can immediately feel supported in their home community. With assistance from the State Bureau of Community Mental Health, Larry is compiling a Community Resource Manual that documents the services and consumer support groups in all 72 counties. We have

developed resources to pay local consumer activists for time and travel to visit people at the Institute who are about to be discharged back into their communities. The hope is that widening the scope of peer support will encourage Recovery.

After a year of planning and another year of implementation, there is no doubt about the success of this innovative project. That this is due in part to the unique attributes of the individuals involved is very likely. As other states initiate and report their own experiences, it will become possible to analyze and identify how to further develop the role of consumer staff in the mental health delivery system. Meanwhile, there are some observations arising from this project that may assist others as they attempt to replicate it.

# Planning and Implementing Institutional Change.

To produce change in organizations is difficult. People prefer the status quo to the unfamiliar or to change that challenges their experience or beliefs. Consumer empowerment and the Recovery concept require much explanation, working through, and support before staff can be expected to embrace them. I carefully worked through some of the steps of the change process with Senior management and professional groups before Larry even started his volunteer assignment. I identified supporters and personally attended department meetings to inform staff and enlist their support for the Recovery concept before hiring a consumer. The year-long introduction of Larry as a volunteer, his presentations to staff, and top management's endorsement of them were important precursors to his acceptance and success as a full-time employee. Another vital ingredient was the selection of a supervisor for Larry who was respected and excited and who viewed herself as a change agent.

# Selection and Training of Consumer Staff

The role of the first consumer employed in a psychiatric facility is a demanding one. The fact that it can be accurately described based on this experience will be helpful in finding other individuals willing to undertake the task. It is very important to develop ways of identifying, training, and supporting individuals ready to take on paid positions in servicedelivery systems. Psychosocial club houses and other consumer-operated programs may be natural seed beds since they have members with experiences, both in the work force and as board members, who can help prepare them. A period of mentoring with an already employed consumer, like Larry would be ideal but is not often available.

## Support and Supervision of Consumer Staff

Even the best-prepared and most stabilized individuals may have reservations about transition to a full-time, paid position. Employment accommodations are important, including quality health benefits, adequate vacation time, sick days, and flexible work hours. It is unreasonable to expect consumers with a lifelong history of illness to have obtained university degrees, professional training or lengthy work histories. When consumer positions are developed, there needs to be a flexible and equitable way to credit life experiences so that salary ranges are consistent with the considerable responsibilities and above what a person receives from entitlements.

Once a consumer is employed, there is need for a clearly defined and supportive supervisory relationship with ready access to senior administration. This is particularly true early in the project, before facility staff begin to recognize and appreciate the value of the role with the subsequent changes in their own perceptions of mental illness and Recovery. Even after this, there will be boundary issues

as the consumer struggles to define his/her own role both as a staff person and as a consumer advocate. Larry and I have focused on sustaining the consumer perspective so that neither staff nor patients feel the consumer has been co-opted by administration. Individual staff persons and units should be allowed to proceed at their own pace in developing a new working relationship with the consumer employee. There are still units here with very little involvement with Larry and others who are begging for his time. It is too early to anticipate the burnout potential of this new role. Larry has said:

I feel totally fulfilled and hopefully other consumers will too.

But there is always the risk that a person's own expectations or those of others will insidiously increase beyond that which is reasonable or sustainable. There is a need to employ more than one consumer in any organization to provide mutual support and help sustain the consumer perspective as well as to provide cross coverage during vacations or brief relapses, should they occur.

Consumers can clearly play an important part as full-time employees in service delivery systems. We look forward to the evolution of this role as other organizations and states seek to advance and improve upon our early experience.

Special Thanks to Barry Blackwell, M.D.

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