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Recommendations of the Special Master's Office
McCoy v. Belmont
May 17, 1999

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BACKGROUND

The June 19, 1998 Order of Reference appointing the Special Master in the McCoy v. Belmont case includes, in part, the following statement of duties and responsibilities:

- "4. This Special Master is directed to:
- (1) Conduct an immediate and thorough review of all aspects of the Defendants' care and treatment of the plaintiffs covered by the March 10, 1992 Consent Decree to determine the changes needed to meet the Decree's desired ends;
 - (2) formulate specific methods, strategies, and approaches to implement the March 10, 1992 Consent Decree as soon as possible,...
- "5. (1) To examine in detail and to evaluate defendants' compliance... and any barriers to full implementation of the Court Decree.
- (2) To develop within six (6) months of this appointment, with as much consensus of the parties as is possible, a comprehensive plan, using such input from consultants, experts, the parties and others as this Special Master deems appropriate, to assure the delivery of programs and services called for in the March 10, 1992 Consent Decree and subsequent orders of the Court, and to otherwise satisfy the requirements of such orders. At the Special Master's request, and for good cause shown, the date for the plan may be extended upon approval of the Court. In developing the comprehensive plan, the Special Master shall, to the extent possible, include but not limit his plan to the following:
- a. develop a managerial plan for implementation of the Consent Decree....
 - b. develop an internal plan for the management of Staff House II on a daily basis, including designating recommended positions and duties;
 - c. examine and review thoroughly the hiring process and staff turnover problem with proposed recommendations for hiring, training and retaining staff;
 - d. evaluate and make recommendations with respect to the plaintiffs' needs, including, but not limited to, staffing needs;
 - e. make recommendations for minimizing disputes and tensions between the parties.
- (3) To monitor implementation by defendants of the orders of the Court and make recommendations as to any supplemental remedial orders;
- (4) To report periodically, at least quarterly, to this Court regarding the status of implementation ..., to recommend to this Court such modifications and alterations in the remedial orders or plans as appear necessary and proper,...." (pgs. 2-4)

A written quarterly report was submitted in September. In addition to numerous telephone contacts and conference calls I have met with Magistrate Margolis and members of her staff on a monthly basis to keep her informed of the status of the

Special Master's work and the activities of the Parties. An extension for the six months report was requested in order to gain more information, and toward that end, as permitted under paragraph 5, Number 2 above, Ms. Rosemary Geraci, a State Employee, was temporarily assigned to assist my office in gathering additional information for this report.

The September Special Master's Report contained a number of recommendations and observations, some which continue to be valid in their entirety and some which require modification. I concluded in that report that the continued administration of this home by Southbury Training School was not producing the desired results and a new administration was needed. That continues to be accurate, and remains the most urgent and pressing action that needs to be taken.

It was recommended that a different house be located, one which would be wheelchair accessible, provide a bedroom for each man, and would be free of the negative relationship that has developed between Mr. and Mrs. McCoy and the employees of the Southbury Campus. That recommendation, while less urgent than the change in administration, is also one which needs to be implemented.

The Report also included the following conclusion:

"While meeting with people I was open to discussions about "who's to blame?", however I tried to move beyond that question to "where should we go from here?" I believe little is to be gained by continuing to dwell on what has happened and why (emphasis added). The court has had numerous hearings on the subject, and the parties have written extensively about their respective points of view. The McCoys continue to believe that there is an ongoing effort by some people to undermine the welfare of their sons and deprive them of what was promised in their consent decree.

Conversely, State administrative, professional, and union employees continue to believe that it has been interference by the McCoys in the operation of the home that has caused the problems that exist. Neither point of view is likely to change, and for that reason this report does not address those issues."

Not fixing responsibility for the problems which have developed was a mistake for the following reasons:

1) We are poised to try one more time to make the spirit of the Consent Decree become a reality. There is agreement that a new administration needs to take over. That administration must be given every chance to succeed. But, as the philosopher Santayana notes, "Those who do not learn from history are doomed to repeat it." If the new administrative team does not avoid the mistakes of their predecessors, and if they are interfered with in their work by others, as has occurred in the past, we will find ourselves having gone full circle and be back where we started.

2) There is a need for a healing process to begin. But human beings have difficulty putting real or imagined injuries behind them. It won't be easy to move from an adversarial relationship to a trusting one. Merely introducing new players into the

equation is not going to accomplish anything if everyone involved isn't willing to let down their defenses and begin trusting one another. That means that people on both sides have to be willing to accept responsibility for their role in creating the current impasse.

Given my thirty five years as a parent advocate, my personal experience living with a family member who had severe medical problems (my stepson Michael), and my knowledge as a former state official of how screwed up bureaucracies can be, I was initially inclined to see the Defendants as the sole source of many of the problems that have developed. This point of view was strengthened after meeting and talking with Mrs. McCoy and Leo McCoy and Staff at the house. They gave a seemingly endless list of examples of bad decisions (or worse, no decisions) that had been made by Southbury Administrators. They also cited innumerable examples of behavior exhibited by employees from Southbury that were evidence of an apparent disregard for the men and the staff who serve them. They told of repeated cases of what could only be described as orchestrated rudeness or outright hostility emanating from line level and supervisory staff at the facility. And what I found supported those allegations.

But, it would be simplistic to conclude that this is a battle being waged by one side only. There are numerous examples of equally bad decisions, hostility, and abusive behavior coming from Mr. and Mrs. McCoy. There must be a cessation of hostility if the quality of life for the two men is to be improved. When South Africa moved from the oppression of an apartheid system, its leaders....headed by President Nelson Mandela and Archbishop Desmond Tutu...created the Truth and Reconciliation Commission. A similar process is needed in this case. People need to own their responsibility for creating and perpetuating this destructive, adversarial condition.

Southbury Administration

I have concluded that a culture has developed among the employees at STS, both direct service staff and line level supervisors, that at best tolerates, and at worst encourages, undermining of the efforts to provide adequate numbers of competent, trained, staff. I have also concluded that there has been an abdication of responsibility by upper level administrators of their responsibility to assure quality services for these two men. That abdication of responsibility has also resulted in a failure to protect the rights of employees to enjoy a humane, civilized, respectful work environment. I find the argument that the McCoy's "usurped" authority of the administration to be less than compelling. It was given away, not taken. Nor is the excuse given by STS administrators to former employees who contacted me, that the Federal Court intervention "caused" administrators to take a hands off attitude, a compelling one.

There were actions that could be taken to safeguard the administrative integrity and authority of this program. Few, if any, were. Indeed, there is clear evidence that charges and counter-charges made by the McCoy's and the Staff at the home fell on

deaf ears. Employees who were ready to resign because of maltreatment were told that nothing could be done. Employees accused of misbehavior were not investigated. When I met with the Director of the Training School he told me that he had taken a "hands off" attitude toward the McCoy home, leaving the problem-solving to George Moore and others. While I understood his desire not to micro-manage, it struck me as incomprehensible that a problem as recalcitrant, costly, and high profile as this one would not demand the personal attention of administrators at every level, including the Commissioner himself. It was painfully obvious that it wasn't being solved by the people in charge at the time.

When Ms. Papale and Ms. Geraci began to develop a transition process we met for an hour with the STS administrators, and were given assurances that they would do everything in their power to keep the home adequately staffed and supervised until the transition was completed. They have failed to do so. There have been repeated shifts which were not adequately covered. Pull employees who arrived at the McCoy home coughing and wheezing were sent back to the administrator who sent them to the home. Instead of being relieved of their duties, they were allowed to resume work on the main campus (and infect many more people?). The response to these concerns by Mr. Moore was that "The McCoy's have generally used a higher standard than is used across the facility." But Mr. Moore did not become personally involved in an attempt to resolve the differences and the problem has continued to fester. The result, as Mr. McCoy noted in his memo regarding these incidents, is that the only ones hurt by these failures to resolve problems, are Bill and Leo.

Employees working without current CPR certification, highly paid registered nurses being expected to do custodial work, the case management supervisor having to cover a shift because Mrs. McCoy wouldn't accept the assigned staff, lack of staff training and a training program for Leo, little or no data collection.....these are not just the responsibility of the McCoy's.

There are six basic responsibilities in personnel administration:

1. Recruit
2. Screen, interview and hire
3. Train and educate
4. Support, monitor, evaluate and reinforce appropriate behavior
5. Promote or discipline
6. Terminate

Few of these responsibilities are being carried out by Southbury Administrators. Certainly the most critical ones, hiring and firing, are perceived to be the prerogative of Mrs. McCoy. Employees are almost never given regular evaluations. Training is virtually non-existent. Employees who have felt that their rights were abrogated have found no one willing to advocate on their behalf.

McCoy Administration

If these functions, for whatever reason, have been abdicated by Southbury, what has happened? The McCoys have argued that they constantly filled voids left by STS because their sons' safety and well-being was at stake. Thus, if sufficient staff were not available to work a shift, there was no one but them to perform that function. If no one else would do the personnel administration, what else was there for them to do but step in and do it? The end result has been that Mrs. McCoy is viewed as the administrator of the home. Leo McCoy has said that "My attorney refers to this as chaos but it isn't chaos. When Esther took it over it was a mess, but now it runs like a fine-tuned watch."

Mrs. McCoy has written ads to recruit people, and, given the number of people who applied, they must have been reasonably well written. Bill Ale is reported to have said that Mrs. McCoy does a good job helping to screen and interview candidates. Even those who have subsequently resigned because of disagreements with her were impressed with how warm and gracious Mrs. McCoy was in the interview session, seeking their opinions and thoughts on problems. Several people said it was her charm and sensitivity that convinced them to take the job.

There is certainly a supportive response from the "core" staff who have been at the home for some time. When meeting with the McCoys at the house it was commonplace for them to be called into the room by the McCoys to support a particular position. Letters of support have been received by the Court from Rosemary Strauss, Pauline Polozhani, and Doreen DePaiva. Ms. Polozhaniania requested a meeting with the Special Master to share her views regarding the McCoys. It was held on January 12th in the main lobby of the Heritage Inn. She brought Ms. DePaiva with her. Both women fiercely defended the McCoys and were very critical of ex-employees who were unhappy with the McCoy's actions. The meeting lasted nearly two hours and it struck me as strange that during that entire time, while both women could recount numerous examples of misbehavior on the part of others, neither mentioned anything the McCoy's might have done that could have caused the problems. I shared that observation with them, and asked if Mrs. McCoy or her husband had ever made a mistake of any kind. They seemed genuinely perplexed that I would even ask the question. Their response was a resounding "no, never!"

So, what's the problem? If the home runs like a fine-tuned watch why have over 80 people resigned or been terminated since 1995? Why, if Ms. Geraci's figures are correct, is there an 800% turnover rate? Why have some former employees characterized the way in which they were treated as "dehumanizing," "All of the people who resigned were themselves at fault?"

Why, in all of the meetings I've attended at which the McCoys were present, and in all of the correspondence generated by them, has there never been a single admission by them of responsibility for any of the problems? While one applauds the loyalty of their core staff and, perhaps, their desire to protect Mr. and Mrs. McCoy, it nevertheless strains credibility to believe that no mistake was ever made. Conversely, while I cannot

recall a single example of the McCoys admitting errors in their judgment or behavior, and accepting responsibility for the same, there have been many instances of state representatives (Linda Goldfarb, Tom Harris, Jim Welsh, and Bill Ale come to mine) admitting that mistakes were made from time to time.

What has been the response of the McCoys when told that current or former employees have expressed concern about dehumanizing conditions? Was there acknowledgment that there might be some legitimacy to the person's concerns? That they might be responsible for causing the problems? Was there a willingness to sit down in a sincere and respectful way, as equals with those who criticize, and try to get at the root of the problem to avoid its recurrence? Too often the response when told that current or former employees expressed feelings of anger, disappointment, or hurt at the way that they were treated was to attack the accusers. Attack the validity of those feelings, or question the truthfulness and sincerity of the person, or challenge their professional competency or willingness to work. Or, at the extreme end of the spectrum, to threaten lawsuits or exposure in the media.

Such responses defy common sense. We live in an imperfect world. People make mistakes and, if we're lucky, we learn from mistakes.

"It is interesting that this particular approach--admitting a mistake--usually provokes an important discussion among supervisors. Many say they have felt that to be effective, they should not admit to having faults. They view it as exposing a weakness that would lower their status in the eyes of workers. But when asked to think about important authority figures in their lives, most realize that this kind of honesty made these people seem more real, less like cardboard figures, more vulnerable, and less threatening. In fact, workers are relieved when supervisors make and admit mistakes. Indeed, it is the supervisor who always seems to be perfect, in control, and never flustered who is hard to live with."

(Shulman, Lawrence, Interactional Supervision, pg. 55
4th edition, 1998, NASW Press)

What has been commented on by many of the people who are involved in this undertaking is the lack of laughter in the house, an absence of good-natured joking, a feeling of high morale among all staff. People are deadly serious, intense. Why? Because they work harder than the employees across the street and don't have time to enjoy themselves? Because they're more dedicated than others doing similar work? Ms. Geraci and others have described an "us and them" mentality. The McCoys and the core group versus new staff who haven't proven themselves yet, pulls from across the street, the union, administrators at STS or others. It has been argued that this defensiveness, this "circling the wagons" reaction came from years of abuse of the McCoys and their sons. Perhaps. But developing a program for Bill and Leo is a human undertaking involving ordinary human beings. While it is true that Bill and Leo have been the victims of physical and emotional abuse, and thus deserve special consideration, it is no less true that employees who serve them have a right to freedom from emotional abuse. There have been too many reports of employees in tears or

claiming to be scarred because of the way they have been treated not to believe that there is some validity to their concerns. Just as there is a culture of negativism among the STS employees and administrators, there is a culture of denial among the core staff and the McCoys. Freedom to speak is felt only as freedom to agree with the McCoys. There is "selective sharing" of information among staff. Certain staff are told what's going on, others aren't. This is unfortunate in that productivity increases with increased interaction between staff. It is not true that what people don't know won't hurt them. They can't perform effectively if they don't know what's going on.

Recommendations

There are two categories of recommendations, as follows:

- A) Recommendations which require immediate action and are, in my opinion, absolutely essential for the successful transition of administration from STS to the new administrative group, but which do not require the Court's modification of the Consent Decree;
- B) Recommendations which involve either a re-wording of the Consent Decree or the Court's clarification as to its intent;

A) Recommendations which do not require modification of the Decree

1) A line item budget for the program which clearly identifies the level of funding required to implement the proposed program must be provided to the court. Commissioner O'Meara must make it clear that Ms. Papale and the Manager of the home have authority to administer those funds.

2) The Department of Mental Retardation's Quality Assurance Division must begin immediately to include the home as one which they are responsible for monitoring. The Consent Decree (p. 2) clearly requires this but it has not been done.

3) In order to assure that the program is being implemented as envisioned the Commissioner should provide the Court with regular written quarterly reports until such time as the new management is in place and operating properly and the men are settled in a new home appropriate to their requirements.

4) The Manager needs three other supervisory level staff, one for each shift. These three supervisors and the Manager will provide coverage for each other during vacations, sickness, training, etc. The Manager must report directly to Ms. Papale.

The Manager and Ms. Papale need positive, constructive assistance from all levels of the Department. Commissioner O'Meara must make it clear to central office staff that this project has his personal support, and that he expects every employee to do everything they can to expedite requests for assistance. I recently learned that, despite explicit instructions by then Deputy Commissioner Linda Goldfarb to establish a petty cash fund for the home, that fund has still not been established. It has been at least six months since this reasonable request was made. I can think of no other

reason for this failure than that someone is engaged in bureaucratic obstructionism. The Commissioner needs to make it clear that such behavior is unacceptable.

5) A residence supported by shift staff is not the same as "in home support" in a person's natural home. Under the current arrangement the level of involvement by the parents makes it impossible for a manager to operate and run this program. It is essential for a new administrative team to be successful that a clear, unambiguous message is sent to all employees that a different management team is now in charge. As long as the McCoys continue to reside in the current residence such a message will not be sent. It is imperative that they move back to their own home immediately. Further, if staff are to be clear about the new chain of command, there must be a clear understanding that the McCoys do not supervise staff and that must be reinforced by the words and behavior of the McCoys themselves. There will be a natural tendency for existing employees to turn to the McCoys for direction, however they need to be instructed to talk to the Manager or the person supervising their shift. Similarly, if the McCoys have concerns they too must direct those to the Manager or the person designated by the Manager to be in charge of the home at the time.

6) The new management team must have not only the responsibility, but the authority, to Recruit, Screen, Interview, Hire, Train, Support, Evaluate, Monitor, Discipline, Promote, and, if necessary, Terminate. The most basic element of such authority is the ability to control how employee time is used. The authority to decide how staff time will be used must rest with the Manager and no one else. If the McCoys, for example, want to take their sons home, it is imperative that the Manager be told as far in advance as possible so staff can be scheduled efficiently. If the McCoys need help from a staff person during a home visit, or want to schedule staff to support a clinic or hospital visit, the Manager must give the final approval. Hopefully such arrangements can be worked out in an informal, uncomplicated manner, but it is important that the final control over staff time be clearly in the hands of the Manager.

6) Open systems are healthier than closed ones. There must be an opening up of this home if the program is to be successful. All employee meetings should be held weekly, and staff should both be expected to be there and be given time off or other compensation to make their attendance possible. The meetings should be open and people should feel free to criticize or praise what goes on in the home, without fear of recrimination. New employees, in particular, should be encouraged to express their views, to make suggestions for improving the way that things are done. Often they are the ones with a fresh way of looking at things that have become routine for everyone else but are not working well. Ms. Geraci's note regarding Leo being given warm tea just before bedtime while programs are developed to try and help Leo stop wetting the bed at night is a good example of how established routines can work at cross-purposes. All Employees should know what's going on. Employees were not given a copy of the Order appointing the Special Master and therefore had no idea what his function was. Some of the statements made by employees who wrote letters of support clearly indicate they do not understand the role of the Special Master. They

were not given a copy of the Master's Quarterly Report, nor was it discussed with them. I am convinced that if Ms. Geraci, Ms. Papale, and I had not brought copies of the Order appointing the Transition Manager, they would not have received copies of that document as well. There needs to be free, open, undefended, communication between all who work in the home if a true sense of teamwork is to develop.

While there is evidence that pulls from STS have often behaved inappropriately, there is also evidence that the existing staff have not been as welcoming to new people as they should have been. The new administration must meet with each existing staff member and be very clear with them about how new employees are to be treated in the future. Staff who cannot accept the importance of treating others respectfully should be encouraged to look for other employment opportunities.

7) One of the conspicuous things lacking in the past has been clear accountability for getting things done. The meetings that were held previously with Ms. Goldfarb were productive because follow up meetings were scheduled to review progress, and no action step was proposed without someone being assigned specific responsibility for its completion. While I support the recommendations outlined by Ms. Geraci, I would be remiss if I did not make the point that each of them needs to be re-stated in a way in which it is clear: 1) who will do it?; 2) when will it be done?; 3) how will it be done (what should it look like)?; 4) where?; 5) what resources are needed to get it done and who will obtain them?; and 6) who will monitor to see that the objective was met, and met satisfactorily? Too often in this case there have been meetings in which many things were discussed but they never got done. Similarly, there have been no consequences for failure to complete assigned tasks.

For example, "All positions must be filled..." Who is responsible for doing this? By what date? Who will monitor to see that it gets done? "Immediate training of all current staff..." Who is responsible for assuring that this be done? The Manager? Ms. Papale? Someone at Central Office? By what date certain must it be done? Who will provide staff coverage so employees can be released?

8) Many of the problems which exist are related to supervision of nursing staff. The following recommendations must be implemented immediately by state administrators:

- nurses must be held accountable for training staff in the proper practice of Infection Control/Universal Precautions, and must use those practices themselves;
- nurses must take medically-related orders only from licensed medical practitioners, must follow those orders as prescribed, and must assure that all medical records are current and maintained in a manner consistent with good medical practice;
- the Manager of the home and the McCoy's must meet regularly and the two must communicate information regarding the status of health-related matters with each other. Diagnostic information provided by consultants must be recorded in the medical records of each man and be maintained at the home.

9) Statements like "this is Billy and Leo's home" have been used as a justification for a double standard in the way that employees are treated as contrasted with the way in which the McCoy men are treated. Thus, employees are not allowed to sit at the dining room table at mealtime and be treated as part of the family, take their break in the house....perhaps enjoying a cup of coffee in the living room while watching television, or feel as though they can relax in the home. I cannot believe that when such tension exists, when some employees are treated simply as indentured servants and not as part of a family, that Bill and Leo don't sense it. If this is to be a warm, inviting, comfortable, home, the artificial distinctions between "trusted" staff and new ones, have to be eliminated. Ideally, staff and Bill and Leo should have meals together. At the very least, staff must be allowed to use the dining room and living room for meals and breaks.

10) The McCoy's have said that their vision of the future when the Consent Decree was signed was one that allowed them to feel that their sons' needs were being met, but also one that included their own ability to enjoy a more normal life. That has not happened. However, in order for them to experience the kind of lives they had hoped for, certain support services are going to have to be put in place. One reality that we all face is that none of us will live forever. And when we have sons or daughters who have severe medical needs, we have to figure out how those needs can be met when we're gone. Who will coordinate the health care for Leo and Bill when Mrs. McCoy and Leo are no longer able to do so? Dr. McDonald is currently the primary care physician but he is contemplating retirement himself. Who will replace him when he decides he can't continue in that capacity? Dr. Rubin attempted to raise this question. The nursing staff in the home, the Manager, and someone designated to be the primary care physician for the men needs to be identified, if not now, soon. This should be a high priority when the new management team is in place.

In the meantime, it must be clear that if Dr. McDonald is to continue to coordinate health care, he needs to have full authority to do so and his costs should be reflected in the program's budget. And, as noted above, the nurses at the McCoy home need to be able to relate directly to Dr. McDonald for their supervision. Similarly, Dr. McDonald and the Parents need to communicate all changes in the medical status of the men to the residence Manager in order to assure appropriate documentation. As the Manager and his staff increase in their understanding of the men's' needs, the Parents need to increasingly allow the Manager and nursing staff the authority to make decisions and provide the care they are trained and licensed to provide.

11) In addition to Dr. McDonald, what other services can/should be continued with the new administrative structure? To begin with, it must be noted that community services have been successfully provided for individuals whose needs are as severe as Bill's or Leo's for more than thirty years now. The field has grown and developed in ways we never envisioned so that virtually any service that could be provided in an institution can and is being provided every bit as well in community programs. The

future of large institutions like STS is not bright. It would be a mistake to maintain dependency on that facility.

Ms. Papale's transition plan will allow a level of independence from the institution that will enable this program to be self-standing. Again, if we are genuinely concerned with the ability of this program to exist long after the rest of us are no longer around, it must be self-sustaining. I support her proposed transfer process and assume that she will monitor those activities to assure specific people are assigned responsibilities for its implementation, and that things happen within the time frames stated.

12) An individualized day program must be initiated immediately for each man.

13) The Draft Stipulation prepared by the State's Attorney should be reviewed by the Parties, finalized and presented to the Court for consideration. It contains the plan for development of a new home for the men.

B. Recommendations which may require modification of the Consent Decree:

1) The Consent Decree gives the McCoys the authority to approve the hiring of line level staff. As noted earlier, Mrs. McCoy has been described by Bill Ale and Tom Harris as very helpful in the interview process. It is anticipated that the McCoys will continue to cooperate with the new Manager in this work, however if that cooperation does not continue, and the manager's ability to hire is interfered with, the Consent Decree should be modified to allow the Administration to do their job.

2) The requirement that a home be within 5 minutes driving distance from the home (p. 8) may severely limit the ability of the State to locate a lot for a home, or an existing home which meets the requirements of the men. I assume the objective of that requirement was to assure that the McCoys have regular and frequent contact with their sons not only now, but when they themselves become aged and, perhaps, medically fragile. A more reasonable requirement might be to require that the home be located in the same city in which the Parents reside and, if the Parents are unable to drive to visit their sons, the state be required to provide transportation for them.

3) Page 9 of the Decree should be re-worded to assure life use of the home for the men and the requirement that other residents be allowed should be dropped.

4) The allocation of \$10,000 (p. 10) for hiring of consultants needs to be a specific line item in the Budget for the home. It is understood that this was an element of the Decree that guaranteed the Parents would have resources to enhance their Sons' lives. This is in no way intended to change the intent of the Decree or limit the McCoys free access to those funds. However, by including it in the Budget for the home as a specific line item, it assures that those resources will be available if the men outlive their parents.

Summary

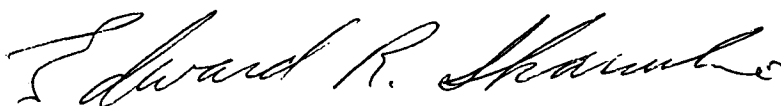
This is a pivotal moment in the lives of Bill and Leo McCoy. A new group of people are being put together to form a team who will build on the past work of Mr. and Mrs. McCoy and the existing staff members. The result could be a home of their own which they can enjoy for the rest of their lives. It can be a full complement of dedicated and trained employees who are committed to helping each man achieve his potential at the highest level possible.

It is also a pivotal moment for their Parents, Mr. and Mrs. McCoy. They have an opportunity to begin to experience the security of knowing that no matter what happens to them their sons will be taken care of by people who are dedicated to providing the best possible care. This is what all parents want, regardless of whether their children have a disability or not. They can be involved in the process of creating that future.

But, as happens with the life cycle of all human beings, there comes a time when parents need to allow their offspring to develop other relationships, to allow their children to be dependent on significant people other than their parents---friends, partners, co-workers, and others. One of the most important roles as a parent is to help your children transition from dependency on parental safety and security to allowing others to provide that support and security. With the current arrangement the McCoy's are the center of their sons' universe. While the core staff care deeply for the men it is the parents who currently make virtually all decisions affecting the welfare of these men. Unless the circle of people who are responsible for overseeing the welfare of these men is expanded, at the time of the parents incapacitation or death, their sons will be totally devastated, not knowing who to look to for their needs. Now is the time to begin to gradually establish other relationships with a team of people who can provide continuity of care over time.

This will require making other adjustments as well. It means that Mr. and Mrs. McCoy will need to begin to find other interests to focus on, to spend less time in close proximity to their sons. With more time available to spend together their own relationship with one another will change. Trusting others to carry out what has been done by you alone involves risk. There will be moments of doubt and anxiety. There will be comparisons made about the way others do things versus one's own way of doing things. All of this will be unsettling, but is a normal part of life. I would strongly recommend that Mr. and Mrs. McCoy get professional assistance during this time. They need someone they can talk to, a family therapist or counselor, who will give them opportunities to express their feelings and move beyond the past.

Respectfully submitted,



Edward R. Skarnulis, Ph.D.