

Habilitation Services at Southbury Training School

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Acknowledgments

Our thanks to the Honorable Judge Ellen Bree Burns, United States District Court for the District of Connecticut; David Ferleger, Special Master; Tom York, representing the State of Connecticut (Defendants) and Linda Keyser, representing the United States Department of Justice (Plaintiffs), for this opportunity to be of service to Connecticut's children and adults with developmental disabilities. We especially appreciated the assistance provided by Margaret Kailukaitis, Director of the Consent Decree Office, and her staff members, Karen Dunn, State School Teacher, Susan Cragin, State School Teacher, and Terri Ann Tilquist, Secretary. They were very professional, knowledgeable, and willing to be available at any time, day or night, to help us with our review of records and site visits. Our thanks as well to Kathy Hanewicz, STS Director of Family Support and Case Management; Donna Josephson, Director of the CQIR Office; Fritz Gorst, Director of Southbury; Eugene Harvey, Assistant Director; Larry Doran, Director of Day Services for the West Region, and other administrative staff for their help. Special thanks go to the direct care staff at STS and in the community for taking time away from their work to answer our questions regarding the class members and programs being provided to those being served. Last, but not least, our sincere appreciation is extended to all of the consumers who allowed us to meet with them in their residences and day programs. Your patience and graciousness were appreciated. We wish you happy and productive lives!

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I. Introduction

In the Case of United States of America v. State of Connecticut, et al., (Civil Action No. 3:86-cv-252 (EBB), on September 30, 2005 Senior Judge Ellen Bree Burns, of the United States District Court, District of Connecticut, issued the following order:

- 1) the Defendants and Plaintiff United States of America shall come to an agreement on an expert acceptable to all parties on or before October 7, 2005;
- 2) the parties shall forward the name and credentials of that expert to the Special Master and the Court, and;
- 3) such expert shall then expeditiously conduct the review of the outstanding Remedial Plan requirements related to Habilitation.

In a footnote to that ruling, Judge Burns added the following: “The Court reminds Defendants that they suggested ‘the parties could even be bound by the findings of such an expert’ and, furthermore, that ‘a new expert acceptable to everyone could be given a rebuttable presumption of reliability which would make the need for a hearing unlikely.’ Defendants’ Objection at 4.”

On October 7, 2005, Special Master David Ferleger issued the following order:

In response to the Court’s September 30, 2005 Ruling (Dkt. #1312), the parties have agreed that Edward Skarnulis, Ph.D., is ‘an appropriate candidate to conduct the habilitation review’ and that ‘he will provide a fair and informed evaluation of habilitation services at STS... Special Master Ferleger ordered the “...compliance review of the outstanding Remedial Plan as set forth in and under the Standard of Review established in the master’s Report to the Court No. 21 (Revised): Scope of Work for Consultant Review (May 21, 2001), approved by Order of May 24, 2001.”

In a footnote to that order it was noted that “Given the time constraints, it may be necessary ...to utilize appropriate assistance to conduct the review...” After reviewing qualifications outlined in a Curriculum Vita submitted for that purpose, and hearing no objections from the Parties, in email correspondence (followed by fax) to the Parties on October 11, 2005 Special Master Ferleger approved the appointment of Ms. Dorothy A. Skarnulis, LMSW, as Assistant to Dr. Skarnulis.

On September 21, 2005 (prior to the above orders and rulings) the Special Master issued an “Order on Habilitation Review” which included the following observations: “On July 21, 2005, the Court ordered the Special Master to ‘continue with the process envisioned under the Remedial Plan’ and ‘to expeditiously proceed toward making compliance determination recommendations to the Court and, if compliance is lacking, in ensuring effective corrective action so that compliance will be achieved by February 1, 2006.’...”The Special Master is obligated ‘to make compliance determinations and, where there is non-compliance, to recommend additional relief designed to secure sustained compliance as soon as practicable.’.... Release from active judicial oversight comes after a year of ‘sustained compliance.’.... “The parties are reminded, however, that the Court has repeatedly advised them that ‘there is no need for a battle of the experts at this stage of the litigation’ and that ‘the second-guessing’ of the expert consultants appointed by the Special Master’ is to be avoided.”....the Special Master is hopeful that a live evidentiary hearing will not be required.”

The Report is generally organized as follows:

- I. Introduction (Background, History)
- II. Methodology (How the Study was Conducted)
- III. Findings
- IV. Summary and Conclusions (Specific Recommendations Regarding Compliance)

It is submitted in response to the Orders of the Court and Special Master stated above., and attempts to adhere closely to the “Specific Questions to be Answered” contained in the Report to the Court No. 21 (Revised): Scope of Work for Consultant Review provided to this Consultant by the Special Master. In the Joint Meeting of the Parties at Southbury Training School on October 27, 2005, the Special Master emphasized that his Office “...wants clear answers to the questions: are they (the Defendants) in compliance? Have they been in compliance for at least a year? And, what would it take for them to be in compliance?” At that meeting, the Special Master emphasized that while suggestions or recommendations made by the Consultant and his Assistant to Southbury Training School Administrators or Staff may be included in this report, the focus should be on findings of Compliance with the Remedial Plan’s Court Requirements as articulated in the Special Master’s Scope of Work document

II. Methodology

At the time this Review began, there were 564 people being served by the Southbury Training School. After consultation with research colleagues at Texas A&M University, Commerce, Texas, it was determined that a random sample of 5% (28) of that population would be sufficient to satisfy validity and reliability considerations, however, to assure even greater validity we doubled the number of people reviewed to 10% or 56 people. Seven people could not be included because they were ill or in the hospital unit. Forty nine people were seen at both their Day Programs and in their Residences. They are shown on Appendix B (attached). Their Records were carefully reviewed, with special emphasis on their Overall Plan of Service (OPS) and Person-Centered Plans. A “Consultant Record Review of Habilitation-2005” form and a “Consultant On-Site Review of Habilitation-2005” form (Appendix A attached) were completed on each person reviewed. The questions on those forms are taken from the Scope of Review questions prepared by the Special Master. They include the following:

1. CR 43, EC 3: “Are client’s individual and group training and programs being evaluated at least annually and recommendations made?”
2. CR 43, EC 4: “Are all clients provided those group training/education opportunities as defined in their OPSs?”

1. CR 44, EC 1: “Are all clients who need day programs in a day program?”
2. CR 44, EC 2: “Do all these day programs meet each client’s needs?”
3. CR 44, EC 3: “Are work opportunities provided to all individuals in need of such?”

Relating to habilitation programs provided to residents covered by Court Requirement 52 specifically:

1. CR 52, EC 3: “Do assessment of staff by interview or sample observation confirm that there is consistent implementation of programs?”
2. CR 52, EC 4: “Are training/education programs for clients available and are clients referred to those programs?”

We also looked at the following issues:

Is there evidence of individualization, i.e., programs to promote client growth & independence, coupled with necessary support to maintain and increase living skills?

Are programs structured to protect residents from risk to personal safety and unreasonable restraint?

As noted in the Scope Document, each of the Evaluation Criteria was evaluated according to the following questions:

2. Are Defendants currently in compliance with the requirements set forth above?
3. If yes, have Defendants been in compliance with these requirements over the past year?

4. 3. If no, what actions are necessary to bring Defendants into compliance with these requirements?

The compliance thresholds for these requirements were reviewed as described in the Scope Document, i.e., "...an examination of Defendants documentation and quarterly data, and...such other data, interviews and observations as the consultant deems necessary." (Scope, pg. 8)

Consultant Reports

We reviewed the following Consultant Reports:

1. Guy Caruso, Ph.D., Domenico Cavaiuolo, Ph.D., Karen Clay, MS Jaylon Fincannon, MA, and Amy Gerowitz, M.Ed., MA, MBA. "Impact of Staff Reductions on Habilitation and Case Management. June, 2003.
2. Jaylon Fincannon, MA. "Person-Focused Overall Plan of Service Enhancement Initiative. January, 2003.
3. Michael J. Kendrick, Ph.D. "The Report of an Independent Consultative Evaluation of the Habilitation Program at Southbury Training School December 2002. January, 2003.
4. Kevin K. Walsh, Ph.D. "Case Management and Habilitation at Southbury Training School: Rebuttal to Several Reports." July, 2003.
5. Ann Williams, RNC, MS. "Consultant Report STS: Habilitation Review and Review of Case Management Plan. June, 2003.

Our purpose in reviewing these reports was to try and ensure that we not overlook important aspects of habilitation noted by other colleagues in the field. However, we were also very sensitive to the need to avoid prejudging based on what we had read in their reports, or allowing their opinions to influence our own Review. It should be noted that their Reviews and Reports were written several years earlier, and focused not just on habilitation but on other issues such as case management, staff layoffs, etc. as well.

Definition of Habilitation:

In the October 27, 2005 meeting with the Special Master and the Parties, the Scope of Work was discussed as it relates to the term, habilitation. In the field of developmental disabilities the term "habilitation," is often synonymous with the term "day programs" ("day" is, of course, a misnomer since creative programs develop options that allow many people to work at night). Habilitation commonly refers to adult activity centers, work activity centers, sheltered workshops, supported employment, enclaves, work crews, client-owned-or operated businesses....the names differ from state to state. Such programs generally have higher staff-to-client ratios than do residential and recreation programs (except, of course, for people who are labeled medically fragile). They are assumed to provide teaching or instruction targeted to vocational outcomes for clients, i.e., performing work or getting a job.

However, Medicaid's introduction of the Title XIX concept of "active treatment" (a medical model term) came to be regarded as requiring a 24 hour a day, 7 day a week "therapeutic" regimen. It had its genesis in the original 19th, and early 20th-century institution/asylum/hospital, serving "sick" people who needed treatments administered by medical professionals to help them get "cured". Having testified at congressional hearings in the seventies and early eighties when the concept was introduced, I am familiar with the arguments for adoption of the "active treatment" paradigm...it was introduced in part as a way to assure Congress that it was okay to use federal funding to support this population, since Medicaid had previously been used for indigent populations in nursing homes and other medically focused settings. It was also a way to appease institution advocates who were concerned that community programs were displacing traditional institutions. "Active treatment" reinforced the belief that people who live in institutions are there because they have greater medical needs than do others living in the community.

So, we have two different models. One model based on normalization (or social role valorization), presumes people get training/habilitation to reduce dependency and increase skills so they can be productive members of society. The residential programs support what's being done in the day programs, speech therapy, physical therapy, etc., however, the intensity of the training in a residence is expected to be far less than that of day programs, "therapy" groups, etc. People enjoy a "normal rhythm of day," i.e., they can relax, watch TV, go to a movie, go out to a restaurant, take a nap, or do any of the things they'd do in their own home without an expectation that they're being "programmed" constantly. This is not to say, of course, that functional skill building such as eating, toileting, dressing, etc. are not taught at appropriate times throughout a 24 hour period.

The second model presumes people are ill and need the same level of therapeutic intervention around the clock to help them get better. Residential staff are expected to not only support, provide continuity and consistency, but to provide the same level of intensity of "...continuous active treatment...which includes aggressive, consistent implementation of a program (emphasis added) of specialized and generic training, treatment, health services...." (IAC 7/8/92, 12/11/02 US. Department of Health and Human Services' definition of "active treatment", Ch. 82, p.5) If so, should it receive equal weight with the day programs, i.e., should the same level of intensity of habilitation be expected as that of day programs? The ratios of staff to clients are quite different. How to reconcile the expectations given that difference?

The question of what constitutes Habilitation was raised earlier in this case. In his 2003 report to the Court on Habilitation, Michael J. Kendrick stated that: "the term 'habilitation' is generally construed to be measures taken to assist the individual to live a full and productive life on the assumption that the disability is largely irreversible" (p.4) Kevin K. Walsh, in his "Rebuttal" to Kendrick's report stated that: "in contrast to this, it appears that the term as used in the field and embodied in CMS regulations actually implies a *teaching* or *instructional* model of service, with this didactic function included

in order to enhance the skills and personal self-sufficiency of people with developmental disabilities. (p. 41)

Based on our discussion at the Parties Meeting on October 27, 2005, and the Special Master's reading of the concept of Habilitation as it pertains to this case, it was decided that Residential Reviews must be included in the overall Habilitation Assessment. As the Special Master pointed out in the meeting, the Overall Plan of Service is the foundation document and it must be ensured that its various skill goals are implemented, wherever the client is located.

Therefore, in every review the various skill goals were analyzed by the Reviewers to determine whether they were appropriate and whether they were being implemented by the staff assigned that responsibility, regardless of where the client was located. Furthermore, all reviews, while not "...second guessing the opinions made by the professionals at STS"...nevertheless attempted to determine whether professional judgments of STS staff met the standard defined as "A decision...that is not such a substantial departure from accepted professional opinion, practice, or standards as to demonstrate that the person responsible did not base the decisions on such professional opinion, practice, or standards." (Scope, pg. 8).

I agree with *both* Dr. Kendrick and Dr. Walsh that Habilitation means "...measures taken to assist the individual to live a full and productive life..." *and* it is a "... *teaching* or *instructional* model of service, with this didactic function included in order to enhance the skills and personal self-sufficiency of people with developmental disabilities."

Finally, in my initial meeting with STS staff I expressed the opinion that a prudent person looking at Habilitation Services would ask the following questions: 1) does it take into account a person's wants and needs, likes and dislikes? 2) would taxpayers in society see this as a positive situation? 3) is the person growing and developing...becoming more independent? 4) are they becoming less dependent on other people? Reduction of dependency can be defined in a myriad of ways, from reducing economic dependency on others by performing paid work, to developing functional skills such as feeding oneself or strengthening one's leg muscles such that the person can hold his/her body up when staff are transferring them from their wheelchair to the seat of a car. All of these would, it seems, be legitimate aspects of habilitation.

Study Design

This Review attempted to link both quantitative information and professional judgment in making evaluations. The sample consisted of 49 people. This sample was drawn randomly from the total population of 564 by selecting every tenth person from the facility's alphabetized list of current residents. The smaller final number (49 vs. 56) resulted from the fact that some people were ill or recuperating in the hospital unit or their living area. It was felt that the resultant sample size was still sufficient to yield the desired information necessary for this Report. In order to assure the maximum

consistency in data collection, only two individuals (the Consultant and his Assistant) collected all of the data. The same instruments were used with every individual and staff member observed. All 49 individuals were observed in their day programs, and their records reviewed. 45 people were visited in their homes. Three of the four people not seen in their living areas (Helen K. Ted M. and Mark R. reside in cottages that were visited previously) the residential visits were made whenever clients were in their homes, usually in the evening. In addition to observing/interviewing the 49 individuals and talking with their residential or day program staff members, the Reviewers also observed and made notes on services being provided to individuals outside the sample who were in the residential or day program sites at the time of the visit. Twenty six people were selected for a more intensive record review. A copy of the person's OPS and Personal Assessment was obtained from staff and evaluated upon our return home, the purpose being to do a more thorough analysis of the adequacy of the programs being provided.

It needs to be clear what this Review is not. This Review did not utilize an elaborate research design employing numerous staff, collecting voluminous data over an extended time frame. It is not intended to be an empirical research document, using extensive quantitative data, collected by teams of academically trained researchers, with an eye toward submitting the results to a learned, scholarly, juried journal. The author has done such research as a university professor, and has taught same to students at the graduate and undergraduate level, has served as an editor of juried journals, and has served as a member of numerous doctoral defense committees over the past three decades. While every effort was made to use appropriate research design where it was felt necessary (e.g., a randomly selected sample of sufficient size to draw valid, reliable conclusions, consistency in questions asked and forms used) this report does include opinions, judgments and conclusions based on experience and observation, and a knowledge of what are considered to be contemporary practices in the field of developmental disabilities.

It is impossible to avoid ideological and philosophical judgments when doing a review such as this. Those who claim to be totally objective are probably not being completely objective about their own human limitations. For example, without understanding the history of this field, and the quality of life previously experienced by class members, it is impossible to appreciate the need for litigation such as this. However, to the extent that our ideological beliefs are reflected in this report, they are not reflected in our recommendations of compliance or non-compliance, which are defined in legal terms.

III. Findings

Environmental Observations

Approximately 75% of the population at Southbury Training School is classified in the severe or profound range of disability. Individuals at that level of ability require a great deal of assistance with activities of daily living, e.g., dressing, toileting, shaving, bathing, mealtimes, etc. Every person we saw was clean, dressed appropriately, clean shaven, and appeared to be in good health and well-nourished. For anyone who has lived or worked with people who are as dependent as this population, the task of providing decent physical care on a daily basis is a major challenge. Employees were attentive to their needs. In every unit staff (including supervisors) were actively interacting with people, as opposed to congregating together or occupying themselves with administrative tasks.

The physical environment was also a reflection of attitude about the way in which people are served. The day program areas and living sites are clean (some are spotless) and furnished appropriately for the purpose served (e.g., comfortable furniture, window coverings in residences, lots of training materials/equipment in day programs). There are none of the odors historically associated with congregate living...urine, feces, or bleach and Lysol. Although many of the buildings are old, having been constructed thirty or more years ago, they are well maintained, with good lighting, fresh paint, and good ventilation systems. There were no conditions observed which might have constituted a safety hazard for people.

Staff

One of the most difficult administrative challenges in delivering services to people with developmental disabilities is that of recruiting, training, and, especially, retaining quality staff. The turnover rates throughout the country for this population are very high. Since consistency is critical in training of any kind, but particularly with this population, staff turnover is an obstacle to individual skill development and physical well-being. For example, while this Review wasn't charged with looking at medical issues, the literature describing medically fragile individuals who were found to be at risk is replete with examples of a failure by administrators to provide continuity of care. If nursing staff can't quickly recognize symptoms of stress, their patients are in trouble (See, for example, the Florida Hodges Report).

That same continuity is necessary in habilitation. We were pleasantly surprised at the number of staff at Southbury who have been working there for many, many years. It was not unusual to find employees who have 10, 20 or more years of longevity, many working all of that time at the line level...hands on...with clients. The result is that they know the people in their area. If our conversations and observations of the interaction between clients and staff is accurate, there are genuinely strong, caring relationships between those who serve and the consumers. They could tell stories of events involving their clients which occurred many years ago. There are staff who have for years been taking clients with little or no family involvement to their homes for holidays or weekend visits, of staff volunteering at STS as teenagers and getting to know the people they now serve as employees, of close relationships between staff and the parents or siblings of STS residents, and of staff who are now second and third generation STS employees.

Every staff member interviewed was familiar with the Overall Plan of Service (OPS). Directives on how to carry out the individual plans were explicitly detailed in the (huge) notebooks containing the Person Centered Plans, OPS, professional team member evaluations, and implementation (strategy) plans. Responsibility was fixed at the individual and group level...it was clear as to who would be expected to do what. The habilitation plans were measurable and objective. All files were current and complete. Case managers have a clear responsibility to assure follow through on team directives, and documentation of same.

Client Characteristics and Reviews Conducted

As noted earlier, 49 people were reviewed and observed. Twenty three were females, twenty-six were males. The youngest person in our sample (Robin B. dob 10/30/65) was forty years old. The oldest person (Helen K. dob 10/23/23) was eighty two years old. The median age of the sample population was 56 and the mean was 58.49. The majority (18) of individuals in the sample were people 50-59 years of age. Only 11 of the 49 were in their 40's. (Appendix C attached) The sample mirrored the STS population as a whole. For example, the youngest person at STS is 38 years old and the oldest is 97. The age of the population correlates directly with issues involving habilitation, both currently and in the future. With advancing age, health becomes more central to program planning. The ability to do strenuous physical labor is reduced. Reduced stamina, vision and hearing need to be considered in individual plans. OPS documents reflect team consideration of these issues. Some clients have chosen to retire and some have a reduced number of hours of day programs provided by staff that go to their residential settings.

The OPS's and Personal Assessments of the 26 people chosen for extra attention resulted from questions which arose after meeting those individuals and observing them in their homes or day programs. For example, individuals may have talked about their wants and needs and were curious to see if those were documented in their Service Plans. Some people had difficulty communicating verbally but used other communication methods, e.g., gesturing, taking people by the hand, etc. We wanted to know if that was reflected in their Service Plans. Some individuals were unable to communicate verbally or non-verbally about abstract feelings and desires. We were concerned that their OPS's reflected individuality and uniqueness rather than all having been prepared in ways that made them indistinguishable from one another. What we found was that the level of cognitive or physical ability didn't translate into "cookie cutter" Plans. Each was unique and reflected individual strengths, abilities, needs and wants, which in turn were translated into individualized goals for the coming year.

The following are a few comments taken from Plans which reflect the previous observations. All of the individuals either participated in their OPS or were invited and declined to participate.

Stephanie A. 40 years old "enjoys having her hair styled and things with soft textures."

Annie D., 62, “communicates her dislikes through tone of voice and flailing. She likes lightweight clothes, chocolate, and visits from her sister.”

Robin B., 40, “enjoys one on one time with staff, beauty sessions. She makes her needs known by vocalizations and facial expressions.”

Sheddric J., 46, “rarely expresses himself verbally...answers yes and no questions. He has the ability to complete multi-step tasks in sequence...strength and stamina.”

Carolyn O., 56, “lets you know what she wants by gesturing, pointing, and shaking her head yes. She has fine and gross motor skills, counting skills, collating and packaging.”

Robert T., 69, “asks staff for what he wants, likes to be busy on the van, and enjoys a variety of duties.”

Sandra S., 64, “usually tells you what she needs. Likes being home during the day when there are few others there.”

Virginia L., 72, “has to ask for what I need. She likes helping Liza water plants and give them to customers.”

Mary C., 64, “I tell staff what I need. She’s good at relaying facts and needs, likes making ravioli, eating hot lunches, and waiting on customers.”

A comparison was done between Continuous Quality Improvement Reviews (CQIR’s) and Intermediate Care Facility (ICF) reviews completed by the State Health Department. The CQIR group did a minimum of one residence review each month between October of 2004 and September of 2005 (two were done in the months of May and September of 2005)...a total of 14 Reviews. There were also 12 ICF Surveys done during that same time period. The number of ICF citations found were minimal (0-2, with one 3 and one 4).

IV. Summary and Conclusions:

Using the “Scope of Work for Consultant Review Habilitation (CRs 43, 44 and 52*)” as delineated according to Purpose and Specific Questions to be Answered, the following are this Consultant’s findings in relation to Compliance or Non-Compliance:

Court Requirement 43. Training Programs (EC 3, 4)

- A. Purpose: “Procedures for periodic evaluation shall exist and be implemented regarding training program needs, including habilitation, and sufficient hours of training programs shall be provided.”
- B. Specific Questions to be Answered: CR 43, EC 3: *“Are client’s individual and group training and programs being evaluated at least annually and recommendations made?”*
- C. Recommended Finding: Compliance. In my opinion, every client is being evaluated at least annually (or more often) and reasonable recommendations are being made. It was this consultant’s opinion that the evaluations and recommendations were prepared in a thoughtful manner, were individualized, were professionally completed and the recommendations made were appropriate for the individual being evaluated.
- D. General Questions to be Answered: 1. *“Are Defendants currently in compliance with the requirements set forth above?”* Yes. 2. *“If yes, have Defendants been in compliance with these requirements over the past year?”* Yes. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.
- E. Specific Questions to be Answered: CR 43, EC 4: *“Are all clients provided those group training/education opportunities as defined in the OPSs?”*
- F. Recommended Finding: Compliance. In my opinion, all clients are being provided with group training or educational opportunities as defined in their Overall Plans of Services.
- G.** General Questions to be Answered: 1. *“Are Defendants currently in compliance with the requirements set forth above?”* Yes. 2. *“If yes, have Defendants been in compliance with these requirements over the past year?”* Yes. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.

Court Requirement 44, Day/Vocational Programs (EC 1-3)

- A. Purpose: “The availability of day programs for persons who are mentally retarded is a vital component of the department’s mission. Like residential settings, day programs must be developed to meet individual client needs. Therefore, the department is committed to the development of programs designed to promote client growth and independence and to provide an array of day program opportunities, emphasizing employment, coupled with the necessary support to increase and maintain living skills.”
- B. Specific Questions to be Answered: CR 44, EC 1: *“Are all clients who need day programs in a day program?”*

- C. Recommended Finding: Compliance. Every client needing a day program was in a day program. The only exceptions found were people who were medically/physically unable to attend such programs, with or without assistance. Some very elderly individuals had made a choice to retire and not attend day programs. When interviewed/observed, the decision appeared to be an appropriate one.
- D. General Questions to be Answered: 1. *“Are Defendants currently in compliance with the requirements set forth above?”* Yes. 2. *“If yes, have Defendants been in compliance with these requirements over the past year?”* Yes. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.
- E. Specific Questions to be Answered: CR 44, EC 2: *“Do all these day programs meet each client’s needs?”*
- F. Recommended Finding: Compliance. This question, and the next (EC 3), were difficult questions to answer. Had the population been a younger one (see the “Brief Discussion of Vocational Expectations” below) the recommended finding might not have been compliance. Similarly, the number of individuals with severe or profound levels of mental retardation or physical disability has an impact on the type of individual planning that is created (see “Southbury Compared to Other Programs Nationwide” below). However, given the age of the individuals being served and their level of ability it is the opinion of this Reviewer that the person’s Team has developed programs that are designed to meet their individual needs.
- G. General Questions to be Answered: 1. *“Are Defendants currently in compliance with the requirements set forth above?”* Yes. 2. *“If yes, have Defendants been in compliance with these requirements over the past year?”* Yes. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.
- H. Specific Questions to be Answered: CR 44, EC 3: *“Are work opportunities provided to all individuals in need of such?”*
- I. Recommended Finding: Compliance. (see the “Brief Discussion of Vocational Expectations” below)
- J. General Questions to be Answered: 1. *“Are Defendants currently in compliance with the requirements set forth above?”* Yes. 2. *“If yes, have Defendants been in compliance with these requirements over the past year?”* Yes. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.

Court Requirement 52, Implementation of Training Programs

- A. Purpose: To evaluate compliance with Court Requirement 52, which reads: “Consistently implement programs to protect residents from risks to personal safety and unreasonable restraint. This applies both to habilitation programs under the OPS generally and to behavior programs.”
- B. Specific Questions to be Answered: 1. CR 52, EC 3: “*Do assessment of staff by interview and/or sample observations confirm that there is consistent implementation? If implementation is not acceptable, have corrective steps occurred?*”
- C. Recommended Finding: Compliance.
- D. General Questions to be Answered: 1. “*Are Defendants currently in compliance with the requirements set forth above?*” Yes. 2. “*If yes, have Defendants been in compliance with these requirements over the past year?*” Yes. As it relates to habilitation, there were no conditions observed that could be characterized as potential risks to personal safety or unreasonable restraint. In fact the direct care staff and their supervisors expressed concern for the safety and well being of the people they serve and were observed taking steps to protect their clients from risks. In addition, the STS service delivery system has several layers of quality assurance oversight, including the Continuous Quality Improvement Reviews (CQIR) Process, Case Management services, Intermediate Care Facilities for the Mentally Retarded (ICF/MR) surveys, mandated Training requirements, and the Consent Decree Office. These functions are intended to, among other things, protect client safety. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.
- E. Specific Questions to be Answered: 2. CR 52, EC4: *Are training/education programs for clients available and are clients referred to those programs?*”
- F. Recommended Finding: Compliance
- G. General Questions to be Answered: 1. “*Are Defendants currently in compliance with the requirements set forth above?*” Yes. 2. “*If yes, have Defendants been in compliance with these requirements over the past year?*” Yes. Based on review of the defendant’s data measuring compliance, and observations made of programs provided, I believe the Defendants meet the compliance threshold set for this requirement.

Product

“This expert review will include, when appropriate under a given Evaluation Criterion, a determination of whether the professional judgment of STS staff meets standards; defined as:

A decision...that is not such a substantial departure from accepted professional opinion, practice, or standards as to demonstrate that the person responsible did not base the decisions on such professional opinion, practice, or standards.”

(See Below: “Southbury Programs as Compared to Other Accepted Professional Opinion, Practice, Standards” for further Discussion of this directive)

Recommended Finding: Compliance. In this Reviewer’s opinion all of the professional judgments of STS staff meet the standards defined above.

“In addition to a site visit(s) at STS, the review will begin with an examination of Defendants’ documentation and quarterly data, and continue with review of other such data, interviews and observations as the consultant deems necessary. A written report will be delivered to the Special Master within three weeks of the completion of the review.

Response: This review has been ongoing since first receiving written materials from the Special Master in early October. The last site visit was completed November 1, 2005. The report was submitted to the Special Master by E-mail November 15, 2005, with accompanying appendices next day mailed that same date.

“The consultant will assist the Special Master to ‘verify the sustained compliance reported by Defendants,’ and is ‘charged with evaluating sustained compliance [defined in the Remedial Plan as compliance for one year], and must conduct reviews specifically tailored to the relevant CRs [Court Requirements].”

Response: The forms used for individual reviews (Appendix A1 and A2) were taken directly from the Scope Document. In addition, the Review Methodology (Section 2) was shared with the Special Master and the Parties. In correspondence with the Parties, the Special Master encouraged the Parties to share any material or other information that might be of value in this Review.

In his mailing dated October 7, 2005, the Special Master sent the order of appointment, recent orders on the habilitation review, a copy of the habilitation section of the Scope of Work, and he requested that Margaret Kailukaitis provide me with the Remedial Plan, and related materials which were subsequently delivered to me. No other materials, except those requested by us during the site visits, were provided by the Parties. There were no objections or suggestions made by the Special Master or the Parties which were not accepted and incorporated into the Review Process. For example, questions regarding the scope of review of CR 52, and the inclusion of Residential Services as part of the Review were discussed with the Special Master and the Parties at the Meeting on October 27, 2005. That discussion was incorporated into the Methodology used in this Review.

***Note:**

CR 52 was addressed only as it dealt with habilitation issues defined throughout this document. While our Review included people who may or may not have severe behavioral problems, we did not assess the adequacy of their behavioral programming as such. It is our understanding that those aspects of CR 52 either are, or have been addressed separately.

Similarly, while we noted communication needs, e.g., use or lack of communication boards, use of sign with individuals who had hearing problems, etc., as a part of the overall Review of habilitation, education, and training, we did not address communication services per se as a speech pathologist might.

Finally, although both of us have had extensive experience working with individuals who are physically involved and/or complex in terms of their need for appropriate positioning

or adaptive equipment required for mobility, we noted only situations in which it was obvious that the person was not receiving such support. We did not attempt to second guess the medical diagnoses and prescription of such service or devices.

We did, however, carefully review all records of the sample population to assure that those records contained evaluations and recommendations in cases where clients were identified as having behavioral, medical, mobility or communication needs.

Southbury Programs As Compared to Other Accepted Professional Opinion,

Practice:

The congregate residential and day program models at STS are organized and operated in the same manner as those observed and/or reviewed by this Consultant in other states and communities. The living units and day programs are organized according to level of cognitive and physical ability, with people who have the most severe disabilities placed together in living units and day programs typically referred to as “adult activity” or “day activity” centers. The more capable one is (“higher functioning” is a term some people use), the greater the likelihood s/he will have employment involving real work. On campus that might include shredding paper, collecting vending machine soda cans, or picking up trash from containers. Others might work at the farm or in one of the two café’s (Leonardo’s Bistro, or the Gatehouse). The majority of the sample group (33) have their programs provided on campus, while 16 are in the community (Appendix D). Because their work includes regular contact with community citizens the employees in the Greenhouse, Leonardo’s, and the Gatehouse are included in the 16 as well. Most of the 33 are served at Roselle School Building. For the most part, their activities include various “therapies” (music, art, sensory, etc.), going to the “physical fitness” room, being positioned, toileting, walking on the track, and occasional community visits to the park, Dunkin’ Donuts, etc. The ratio of staff to clients was approximately 2 staff to 5 clients while I was there. The groupings in Roselle School Building (day activity programs), as well as those in the community such as Project Act run by the Kennedy Center in New Britain or the CDP Danbury Turn it Around Program, are similar to programs found throughout the country. It is important to note, however, that at STS everyone deemed to need one, is in a program of some sort. In the rest of the country there are often long waiting lists to get into services of any kind.

None of the campus-based programs observed is what might be considered “cutting edge” or innovative. Workers at the Farm are doing pretty much what was being done during the early years of institutions (circa 1860-present). Similarly, restaurants such as Leonardo’s and the Gatehouse, were being operated in Kentucky, Oklahoma, Pennsylvania, Nebraska and other states as early as the 1970’s. It should be noted, however, that there is one significant difference between the examples noted above and STS. Historically, farms, restaurants, work crews, work stations in industry and other places of employment employed people who were classified as mild, or “borderline” intelligence (a classification level abandoned by the AAMD in the mid-1970’s)). In other words, they were very capable individuals who required relatively little

supervision. However, many of the individuals employed in such settings by STS fall into the moderate to severe ranges of mental retardation and receive much more supervision by STS and community agency staff. And, there is an effort made to have the food service programs serve a broad range of people, e.g., lunches prepared for clients and staff in day programs, food provided for community concerts, the Gatehouse open to the public for lunch.

We visited a variety of programs provided off-campus. Some were operated directly by STS and some served clients through contracts with STS. We visited CRI-Oakville and Middlebury, the Kennedy Center, “Turn it Around” in Danbury, the Waterbury Arc site, and Prime Care, to name a few. In addition, there are a variety of other alternatives being operated directly or indirectly by STS, including “Breads Unlimited”, Dust Busters, a bottle recycling program, lawn mowing and trash pickup service. It is worthwhile to note that, according to Larry Doran, Director of Day Programs, there are currently 200 people getting paid for their work. While we didn’t count the number of work related programs, it was impressive how many have been developed, and the variety of creative options is significant.

A Brief Discussion of Vocational Expectations As it Relates to CR44, EC 3: “Are work opportunities provided to people in need of such?”

As noted above, like most programs throughout the United States, Southbury Training School is organized according to cognitive and physical levels of ability. All of the people who were felt to be physically and cognitively able, were being provided with “real” work opportunities, in farm work, food service, or other work settings.

Over the past three decades some educators and experts in work training for people with disabilities, (notably Dr. Lou Brown from the University of Wisconsin at Madison, Dr. Jennifer York-Barr of the University of Minnesota, and the late Dr. Marc Gold), have demonstrated that even people with the most severe or profound disabilities can be helped to develop work related skills. Through intensive, one-on-one support, advancing concepts like the principle of “partial participation, training “job coaches” in supported employment, and other methods they have encouraged many programs to test the limits of what is considered possible with people who have very severe disabilities. And the results have been encouraging. Through their efforts many programs have been able to reduce the level of dependency historically assumed to be immutable among individuals who are severely or profoundly cognitively or physically disabled. Professionals in the field of vocational services have pushed the envelope in terms of raising our expectation of what may be possible now and in the future for adults with profound levels of disability. (It should be noted that Brown and York-Barr worked primarily with school-age individuals living in the community, and Gold worked with people in institutional settings but they were primarily young adults.)

In addition to the skills training approach used by Brown *et al*, a more values embedded school of thought has emerged which is sometimes seen in “person-centered planning” (PCP) approaches. This view places primary importance on a person’s “wants, dreams, and desires.” Dr. Kevin Walsh has addressed these PCP approaches in his Rebuttal

Report on pages 43-45, citing experts such as Wolf Wolfensberger, and arguing that such approaches are inconsistent with the needs of many of the people at STS, whom he sees as “having a need for pervasive levels of support” and as “not having a robust potential for growth.”

I agree with much of what Walsh and Wolfensberger say on this subject. Many of the claims made by leaders in the PCP movement are exaggerated, and raise false hope among parents and staff. We simply have no idea at this stage of our understanding of disabilities how to apply concepts such as empowerment, rights, choices, self-determination and self-advocacy with people who have severe or profound levels of cognitive disability. We don't really know what their dreams and vision for the future are, and Walsh is correct when he says that at the end of the day, family and staff have to use their best judgment in deciding what a person might want or desire.

The Principle of Normalization was first articulated in Europe by its author, Bank Mikkelsen and later translated into English by Bengt Nirje. Subsequently, Wolf Wolfensberger became its leading advocate in the U.S. Its premise was essentially that in addition to training and skill development we needed to look at the environment and its impact on people with mental retardation. All three of these pioneers found themselves having to defend the concept from distortions, including accusations that they were trying to “make these people normal.” They were accused of being idealists, of refusing to accept the reality of mental retardation, of giving parents and others false hope. On the one hand it is true that exaggerating what is possible by person centered planning (given our current level of ignorance) isn't helpful in advancing our knowledge base, and can engender feelings of guilt when parents and staff don't accomplish the “miracles” claimed by some. It is equally true, however, as the advocates for Normalization demonstrated, that idealism and hope aren't bad either.

How does this apply at STS? While healthy skepticism as articulated by Walsh and others is worthwhile, it would be doing people with severe disabilities a disservice if they were written off based on I.Q. as incapable of engaging in real work. Brown and others have made an important contribution in developing skill-based training methodologies that seem to work with people who have severe disabilities. Connecticut undoubtedly has vocational settings which are building on those contributions in service to people with severe developmental disabilities. And they should be encouraged in their work.

But, there are “Seasons of Life.” While it is important to continue to push the envelope in helping young people with severe disabilities maximize their potential there comes a point when one has to acknowledge the limitations of both clients and those who serve them. At some point common sense dictates that one has to stop teaching people their “ABC's”, or tying shoes, or performing a job skill. That point has been reached with most of the people living at Southbury who have severe cognitive and physical disabilities. Thus, I want to be clear that the recommendation that STS be found in compliance with CR 44, EC 3 is not based on a belief that this population is incapable of learning to perform real work in real work settings. Rather, it is based on the recognition that what they might have been capable of doing as young adults is simply not possible

today. With people in their 50's and 60's it is, in this author's view, unrealistic to continue to set goals and objectives that don't improve, and may actually hinder, their quality of life.

People who have severe or profound physical or cognitive disabilities, have day programs provided either on campus in the former school building or at their residence, and off-campus in adult activity centers. This is also true for people whose team has decided that advancing age makes continued employment unreasonable. The activities for these two groups are generally not vocational or ("real") work-related...most of what they do each day would accurately be described as recreational or leisure, e.g. finger painting, watching television ("Wizard of Oz", Marx Brothers, Animal Planet), decorating for Halloween, etc. Many of the programs in the Roselle School building and some of the community sites visited are labeled as a form of "therapy", e.g., "Music Therapy," "Art Therapy," "Pet Therapy," "Equine Therapy," "Aroma Therapy," "Snoezlen" (a commercial package combining lighting and soothing music marketed as a form of "Sensory" Therapy), etc. To a lay person the word therapy is a medical term connoting rehabilitation or treatment for an illness. It's presumed the therapy will help the "patient" get better---will "cure" their illness. We don't have a cure for developmental disabilities at this time. Further, by the time people are in their 50's or 60's their sensory systems have long since reached the point of maximum development.

The hands on staff that run these programs are faithfully carrying out what the professionals and administrators at STS have directed them to do. Almost everyone enjoys music, art, nice aromas, pets, riding horses, etc. Kids and adults with mental retardation, cerebral palsy, epilepsy or other developmental disability are no different in that regard. This Report is not intended to suggest that those programs be stopped. But, it would be worthwhile to have a frank discussion with staff to clarify what the purpose of these activities is and what outcomes are expected. They provide opportunities for staff to interact in an enjoyable activity with the people they serve. That personal contact is invaluable. We certainly don't want to return to the days when staff congregated in nursing stations while clients languished on wards watching television or sleeping.

Final Thoughts

At the risk of being redundant, STS is blessed with some fabulous people serving their clients. Every single staff person was positive, engaging with the people they serve, and having fun. Maybe because of the number of experts/consultants these folks have dealt with they are absolutely not intimidated or threatened by the likes of Dorothy or myself. We saw lots of little displays of caring that were unexpected. Liz at the Kennedy Center; Bonnie, working with people to make "horse treats;" Chris at the "Turn it Around Program;" Adonna at Leonardo's; Karen who works with Annie D. and Robin B.; Joe who works with Harry G.; the residential supervisor and her staff member who were giving three guys much appreciated "water foot massages;" and we could go on and on.

Our thanks again for the opportunity to assist in the work of the Court and for the opportunity to be of service to the people of Connecticut.

APPENDIX