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CONSULTATION REPORT: XXXXXXX XXXX

March 13, 2000

PURPOSE AND BACKGROUND OF CONSULTATION

My services were requested for the purpose of reviewing and analyzing the educational and behavior management plans and methods that have been designed and implemented for Ms. XXXXXXX.

I am a Professor of Special Education, with 25 years of experience working with individuals with significant disabilities, including severe behavior problems and severe intellectual disabilities. I have published numerous articles in refereed journals, chapters and three books in the areas of behavior management and curriculum; serve as associate editor of two major refereed journals in the field (*Journal of Positive Behavioral Interventions* and *Journal of the Association for Persons with Severe Handicaps);* am on the editorial board of 3 other refereed journals; consult with families; and speak at conferences and seminars across the country.

In order to prepare for writing this report, I conducted a one-hour observation of XXXXXXX on February 28, 2000; a one hour and 15 minute interview with Dr. XXX XXXXX and Mr. XXX XXXXXXX on February 28, 2000; a 50 minute interview with Dr. XXXX and Mr. XXX XXXXXXX on March 10, 2000; a comprehensive review of a variety of reports and records (e.g., ISP Priorities; records from May Institute; Proposed Behavior Modification Treatment Plans; Psychological Evaluations, Social Summaries; Vocational Report; Individual Service Plan, etc.). Unfortunately, there was also much information that I requested, and was informed that was available, that was not provided to me (e.g., Teacher classroom schedule; schedule of activities at XXXXXXX's residence; documentation of Functional Behavioral Assessment which was referred to in the March 2000 Behavior Modification Treatment Plan; written instructional plans; data regarding skill-building).

This consultation represents the third experience I have had observing the program at JRC, interviewing staff, and reviewing records. My previous (second) consultation resulted in a 22 page report (dated November 23, 1999). In this report I provide many pages of description of how the participant's program was neither educationally nor behaviorally representative of the standards of practice promoted by current research, literature, scholarly books, and other experts in the field. I include pages of references to such current research and literature. I hesitate to spend the many hours repeating the same information. This hesitation comes from my perception that the information and concerns contained in my prior report, and the many other reports written by many other highly-respected experts and scholars in the field of challenging behavior, were obviously not effective in influencing the court.

My conclusion is that it appears to be an expensive and fruitless endeavor for me to critically and comprehensively examine the practices of JRC as it relates to yet another individual, as I and so many others have already done. These reports do not seem to be considered with the seriousness with which they are written. This author does not intend any disrespect of the Court, but rather to highlight some pressing concerns that I have. It appears that, for reasons unknown to me, the process that has been followed to date has not provided the court with sufficient motivation to further question, challenge, or change the practices at JRC. It should be noted that (to the best of my knowledge) outside the confines of the JRC, and the "legal arena" within which this program is reviewed, there is little or no support for the program. This should be taken very seriously.

Because of the ineffectiveness of the prior attempts to inform the court that JRC is using practices that are not supported by the predominance of current research and experts of stature in the disability community, I am attempting a different path with this consultation. This report is comprised of three sections: (1) a list that briefly and concisely summarizes the same issues as I expressed with my prior report (most of which have been listed in many other reports by experts); (2) a list of a few new points that may not have been raised before; (3) a concise and brief summary of concerns that I have with the process of review as it currently is conducted; and (4) recommendations.

Ongoing issues

1. There is about 20 years of empirical research that demonstrates that even the most serious problem behavior can be effectively addressed without the use of severe punishment strategies when behavior support is based on functional behavioral assessment.

2. Functional Behavioral Assessments are not conducted with the rigor necessary to intervene with the types of challenging behaviors faced by JRC, and the information from Functional Behavioral Assessments are not used in educative and positive ways to support the individual.

3. Neither the educational nor behavioral program is individualized for XXXXXXX. Although there is some level of individualization *within* a goal, the treatment procedures and behavioral strategies identified for XXXXXXX are remarkably like the treatments identified for the other students who I have observed.

4. The environment at JRC is not age-appropriate for a woman of 34 years of age. The décor is replete with Disney characters and candy sculptures.

5. XXXXXXX is not being provided with the skills necessary to function in natural environments or in an adult world outside of JRC; that is, even if XXXXXXX were to emit little or no problem behaviors, she would be left without a behavioral repertoire to assist her to live a life in which she may meaningfully participate in less restrictive environments or the social world of individuals with less significant disabilities or with no disabilities.

6. One of the most researched strategies for reducing problem behavior is *Functional Communication Training,* or teaching *functionally equivalent behavior,* which focuses on teaching students a response that serves the *same* function as their challenging behavior. The types of behaviors listed in the Proposed Behavior Modification Treatment Plan, while identified as "replacement or alternative" behaviors for XXXXXXX, are not actually replacements for the intent of her problem behaviors. Instead of giving her alternative ways to communicate, JRC's goals focus on compliance to staff demands.

7. Procedural reliability and inter-rater reliability measures are not conducted.

8. Speech and language evaluations are not conducted on a frequent enough basis, and do not inform program development. This is a critical omission as there are language skills that are identified as priorities (e.g., "Increase the use of complete sentences") and "Inappropriate Verbal Behavior" is one of the highest categories of problem behavior identified for XXXXXXX (i.e., 17,423 in a 6 month interval).

9. According to graphs provided by JRC, there appears to be extended periods of time that show no progress or desirable trends in the data without showing program changes. It is inappropriate to wait too long before changing an ineffective program.

10. The impact of XXXXXXX's curriculum, both in contributing to problem behaviors and in the resolution of problem behaviors, does not appear to be given much consideration or evaluation.

11. Skill acquisition objectives are not currently charted. Thus, it is impossible to determine if progress is being made on any of these skills, and if the individual is working on skills that he or she has already mastered.

12. My observations have revealed generally nonfunctional environments that would be humiliating for most people. For example, XXXXXXX was participating in a work task (i.e., placing earrings on their cards) that she clearly already knew how to do; further, once she completed the task, a staff person would take the work apart in front of her and request that she do the task again.

13. Critical skills such as choice-making and language skills, which are referred to in the Individual Support Plan, are not meaningfully or systematically taught.

14. Qualitative aspects of XXXXXXX's life are not evaluated. Evaluation must extend beyond the reduction of isolated problem behaviors and include measurement of variables that might effect her overall emotional well-being such as social relationships, time spent with peers without disabilities, participation in preferred work, school, home and leisure activities, and opportunities for self-determination.

15. There do not appear to be any planned contacts with students who are not disabled, prohibiting her from accessing the motivational opportunity and peer models that may increase social skills and relationships.

16. The verbal interactions initiated by the staff to the participants are inappropriate in terms of their negativity, the lack of affect, the absence of sociability and conversation, and their lack of constructive alternatives.

New issues

1. The auditory stimulus produced by a GED application appears to be a conditioned stimulus for some other individuals in the program. (I observed at least one student grimace and startle when another student received a shock). Thus, other individuals may be inadvertently and noncontingently punished. Noncontingent punishment is not an approved procedure.

2. The part-time clinician I interviewed (Dr. XXXX) did not agree with, collect, or use the type of data collected by JRC (i.e., semi-logarithmic charting), but preferred to use his own observations and recordings. This presents a serious threat to the integrity of the data collection, reliability, analysis and evaluation.

3. According to Dr. XXXX and Mr. XXXXXXX, XXXXXXX is being tethered by one wrist to the wall while bathing. This is not indicated in her Individual Support Plan or the Proposed Behavior Modification Treatment Plan. In the data provided to me, data collection of the use of this restraint varies from 16 times in a month to one per month (e.g., Sept. and Nov. 99), and even zero times in June 1999)—yet I was informed that this restraint is used daily.

4. The six components of an "Individual Vision" required by the Massachusetts Department of Mental Retardation (i.e., Rights & Dignity, Individual Control, Community Membership, Relationships, Personal Growth & Accomplishments, and Personal Well-Being) do not appear to drive the planning process, as intended. Rather, current JRC practices are merely slotted into each category.

Recommendations

1. One way to check the validity and professional acceptance of the behavioral paradigm used at JRC is to determine if there are any *experts* who would support the model. I have long noted that JRC does not provide testimony from experts

outside of their current employees (or Board) to testify in support of their educational and behavioral program? The court should attempt to discover if there are indeed experts in the field of *applied behavior analysis specifically related to individuals with severe behavior problems,* that support the behavioral program used at JRC. In this case, an expert can be defined as a professional who:

a. Currently publishes in peer-reviewed, refereed behavioral journals of national recognition (e.g., Journal of Applied Behavior Analysis, American Journal on Mental Retardation, Journal of Positive Behavior Interventions), Journal of Autism and Developmental Disabilities, Mental Retardation);

b. Has written or edited scholarly books in the field of applied behavior analysis published by recognized publishing companies, or contributed chapters to such books; and

c. Serves leadership roles in national long-standing professional organizations (e.g., ABA, AAMR)

The difficulty (I predict) in finding such experts would testify to the lack of support for JRC's practices in the professional community.

2. Determine if there are any experts in the field of severe disabilities that support the *educational* program used at JRC. In this case, an expert can be defined as a professional who:

a. Currently publishes in peer-reviewed, refereed special education, habilitation, or vocational journals of national recognition (e.g., American Journal on Mental Retardation, Journal of Positive Behavior Interventions, Journal of Autism and Developmental Disabilities, Journal of the Association for Persons with Severe Handicaps, Exceptional Children).

b. Has written or edited scholarly books in the field of severe disabilities published by recognized publishing companies, or contributed chapters to such books;

c. Serves leadership roles in national organizations (e.g., TASH, AAMR)

The difficulty (I predict) in finding such experts would testify to the lack of support for JRC's educational practices in the professional community.

3. The special needs of staff who design and implement painful contingent electric shock to people must be acknowledged and addressed. This can be accomplished in several ways:

a. Each person who is responsible for administering shock should experience the shock prior to its implementation.

b. Follow-up counseling should occur because the pain of the shock (which I personally experienced) is extremely intense and staff must emotionally deal with the fact that they are administering such severe pain to another person--a person who is under their care.

c. Ongoing guidance from a trained counselor should be required to assist staff to reflect on their actions that create pain in another human being. This counselor should be a professional not associated with JRC so that staff would feel free to express themselves about their experiences without the fear of reprisal or impact on their job.

d. If staff indicate that they have no emotional reaction to personally administering pain to another person, then employment in a setting where they are in a position of control with individuals with disabilities should be questioned, as they likely do not see the individual with disabilities as a real person.

4. The professionals who are involved in making decisions regarding the use of contingent electric shock should experience it. This should include all attorneys as well as the Honorable presiding judge and the Master. It is only in this way that the people responsible for making the "substituted judgment" can truly understand the seriousness of the treatment that they are considering. To hear that an individual's rate of GEDs have reduced from 150 times a month to only 20 times per month for instance, sounds like great progress. It is not until *a single* shock is personally experienced that one can understand what 20 really means.

5. Videotapes of each and every individual receiving each aversive consequence used in his or her program should be provided to the court and to consultants. This would include videos of individuals as they are in the process of receiving:

    a. GED applications
    b. Any DMR level II or III intervention (e.g., time-out, positive practice and restitutional overcorrection, water spray)
    c. Partial or full physical restraints

JRC already has the technology to easily record this information. It is only in this way that we can truly understand the seriousness of the treatment that individuals are receiving, and the only way we can prevent ourselves from responding to watered-down and benign labels for intrusive and painful treatment rather than seeing what implementation of the treatment really entails. This would allow the court to see the details of the treatment proposed for each individual— this would include, for example, how the person looks when in anticipation of the treatment, the vocalizations and

verbalizations of the individual before and during treatment, possible physical resistance, and the ease or difficulty with which the staff can carry out each of the procedures. Further, this visual demonstration might also help us gain some insight into the individual's treatment preferences (XXXXXXX's Proposed Treatment Plan states, "XXXXXXX has not expressed a preference for treatment).

I have reflected deeply and for some time before writing this report. My words are intended to support the legal process that protects XXXXXXX. I implore the court to seriously consider these recommendations. The court is charged with making decisions concerning XXXXXXX's treatment because XXXXXXX is deemed unable to make decisions or express preference concerning her treatment. The court, however, has the capacity and interest to avail itself of opportunities to more fully understand the nature of the treatment and the alternatives that are proposed. My recommendations are an effort to assist the court to do so.

Respectfully submitted by:

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