Deterioration of Care in Private Homes

From a Professional

Nursing - - Limited time for each individual, inexperienced nursing staff (not properly trained), not person centered. Leaving too much to chance or sending out individuals unnecessarily to the emergency room. Where is cost effectiveness?

Impartial advocacy for individuals and their families does not occur when all services are under one roof. No different from family sitting at a PPT table with just school personnel. Who do they go to, who pushes for better quality of services?

Follow up on recommendations, "informal promises" made by team members of day/residential programs. At times DDS is mediator for better communication. Private providers leave the managers of the home to complete redeterminations for benefits. Multiple mistakes and redos. Private agency typically contacts DDS for assistance.

Staffing issues are ongoing. Frequently the quality of staff and commitment is lacking. This is not subjective - - It is observed on a weekly basis.

Last week a home was closing in the private sector due to the home being unsafe and needing numerous repairs. The individuals who had to move and guardians were told DDS was at fault due to not giving funds to the agency. Private providers are cutting their services right now. We are telling families that they will be more efficient but there are already signs that quality is not top priority for some Executive Directors.

From a Case Manager

I am a DDS case manager for a private community facility. This home has had 4 house managers in the last year. The house has constant staff turnover. The 5 fragile residents have had numerous hospitalizations in the last year due to inconsistencies in care. In addition, due to constant staff turnover, Individual Plans are not being carried out. This story is one of many similar stories in other CLAs.

From a Case Manager

I work with resource managers that oversee and manage private provider budgets. A meeting was held two weeks ago to discuss private provider issues which were: the private agencies already in place <u>cannot</u> keep staff and are unable to support residents in the current budget climate.

From a Case Manager

How many individuals who moved into private sector group homes, and then because of their health/behavior, etc., were moved into a nursing home?

From a Guardian

During late September – early October 2016 nine physician-ordered medications were not given. Late September – early October medications given late - - not given within 1-1.5 hour time period physician ordered. Compression stockings not worn during waking hours as ordered by physician. Compression stockings not pulled all the way up leg as ordered by physician. Went to laboratory for same blood draw twice. Given breakfast food house told in writing person does not like - will not eat. Person was not given anything they would eat. Person would have gone to day program without eating if guardian had not been present and took resident out of house and gave them breakfast.

Resident given day old sandwich to have for lunch at day program. Guardian tossed out sandwich and gave resident a fresh sandwich and drink and fruit/cookie for a complete day program lunch.

Guardian supplies resident's home with milk, drinks, breakfast foods – turkey sausage, fruit, muffins, waffles, sugar-free syrup, bacon. Also provides food for lunch at day program. Sugar-free jelly, low-fat peanut butter, tuna fish, juice, drinks, fruit cups, protein bars, etc.

Rap music is played extremely loud in the residence very early a.m. before/while residents are in bed. Rap music played extremely loud during transporting residents to day program.

From a Therapist

Music Therapy Services had been provided to the residents of the Southbury Training School (STS) for decades. Bringing music to the lives of this special population of individuals with intellectual disabilities had been a wonderful and joyous and regular activity. Sadly, in May of 2016, the State of Connecticut gave layoff notice to the two music therapists employed at the Southbury Training School.

An unfortunate additional "victim" of these layoffs has been the Music Therapy Intern program at Southbury Training School. For years, the STS Music Therapy Department has secured volunteer, nom-paid Interns from colleges and universities around the country. These interns were students majoring in music therapy who came to Southbury Training School for a semester or sometimes half a year. For their benefit, they obtained hands-on experience working to provide music therapy to the intellectually disabled population at the Southbury Training School. However, the benefit to the people living at the Southbury Training School by the presence of the music therapy interns was immense. Highly enthusiastic and motivated young adults provided their creative music therapy services free of charge to the STS residents. The quality and enthusiasm of these interns cannot be over-stated. But alas; the elimination of the Music Therapists also eliminated the Music Therapy interns who worked for free.

Another “victim” has been the public at large with the cancellation of the Gatehouse Summer Concert Series. The Music Therapy Department at STS had been working with an endowment to bring concerts to Southbury Training School during June through August - - with a concert every Tuesday from 6:00 to 8:00 p.m. These concerts were open to the public, and well-attended by people from surrounding communities, including group homes for people with disabilities. Another shining jewel, brought to everyone by the STS Music Therapy Department has been lost with the layoff of the STS Music Therapists.

Lastly, in another insult to the residents of the Southbury Training School, stemming from the layoffs of their Music Therapists, they may now pay for music therapy services out of their own personal savings accounts. Music Therapy had been a service provided them as a benefit of living at STS. And not every person living at STS has the finances to pay for things such as this. In fact the majority probably do not have the funds available because Connecticut takes most of their disability benefit check to offset the cost of care. In addition, because of Title 19, the majority of the individuals at STS are not able to really save any substantial sum of money in the bank anyway. So, it is doubly or triply difficult for the STS residents to pay for Music Therapy Services out of their own shallow pockets.

Behavioral Health Problems

DDS had in the past provided safe and effective treatment for individuals who have the combination of ID and psychiatric disabilities. Those are individuals who have the most risk to themselves and others and who private providers are reluctant to support. One of my clients suffered deterioration in a private provider and had much involvement by police for assault, running away . . . finding days. He had multiple emergency room visits and brief psychotic stays. Eventually the provider said they could no longer put their staff at risk. In Meriden DDS had a secure treatment facility called the Transition Unit. It provides effective and safe place and programming which gradually reintegrated individuals into the community. After a long psychotic stay he was offered this placement. But the offer was withdrawn as the neighboring DDS homes had closed and there is no longer a large enough pool of staffing to adequately and safely treat at the unit. He returned to minimal treatment with a private provider and is at risk for both further psychotic admissions and incarceration.

Behavioral Health, Saving Money by Medicating the Client

I’ve seen over the 30 years being a state employee, that hurt me and torment me is how I’ve worked so hard to get our residents off these medications. Using behavior methods and now that our residents are going to the private providers they are put back on the medication. It diminishes their quality of life and causes regression. Our residents see us, they cry out for help.

Staffing in the Private Program and Quality of Life

Private day program agencies have lost several staff (quit, fried, etc.) and have not been able to maintain group employment contracts, job developers, etc. As a result clients are having # of work days reduced, jobs lost, and they are often warehoused at the private agency site during the day watching videos or looking thru books on "job skills." It has reduced their self-esteem, pride, motivation while increasing behaviors.

A Difficult Challenge for a Guardian

My example highlights systematic problems in caring for individuals who are potentially dangerous related to irreversible brain damage.

Said simply, not all intellectually disabled adults can be served by privatization. For example, my son is a DDS client who has been failed by the private sector repeatedly . . . He is highly susceptible to victimization due to his cognitive limitations. Impaired judgment and brain dysregulation cause him to be highly impulsive and potentially dangerous when [he] feels misunderstood, which is often. His individualized service plan stipulates 24/7 care and a 2:1 staff to client ratio. He is a highly impaired adult and would be best cared for in a regional campus congregate care setting.

But the State's anti-congregate care position leaves young adults like my son continuously at risk to adverse outcomes. Our family has been through the Request for Proposal (RFP) process three (3) times for a private group home placement since his 18th birthday; each time lasting weeks to months. Twice the providers pulled out at the last minute, and once the plug was pulled by my son's DDS case manager. She recognized the placement parameters simply could not ensure her client's safety or the safety of his staff and the community at large. Each of these events brought anticipation and anxiety to my son followed by utter heartbreak.

After the State expanded its group-home search to Massachusetts's agencies, a placement was made. My son, our family and the State were sold a bill of goods and promised the moon – all in a location too far from home to truly monitor. The two years that ensued were horrible. It was a tiny, overcrowded house with insufficient, under skilled staffing. Abuse and neglect was eventually substantiated, and my son return to Connecticut in an emergency respite status, battered and defeated by the utter lack of compassionate care. He was hospitalized a dozen times during those two years, and it took 6 months in a DDS respite center to stabilize him so he was no longer an eminent threat to self and others. Since his stabilization and the subsequent 3 yrs. that have followed him receiving DDS-residential services, he has not required a hospitalization - not even once!

Acute psychiatric crisis or destructive behaviors seen in some DDS clients is often a sign of internal or external stresses, and this is particularly true in my son's case. When he engaged in property damage in his private sector group home, the agency's response was to seek sedation through hospitalization; a pattern that was repeated over and over again.

I can attest from these most personal experiences that DDS staff are far better prepared to care for our most fragile citizens and highly volatile individuals. When my son engaged in property destruction at the DDS respite center, the direct care staff, with the support of a nurse and clinician, worked to identify the antecedent that caused his the adverse behavioral response, and they were able to assist my son to adapt to the stress.

My son's prognosis remains poor to date – but the pattern of the overuse of potent and potentially dangerous medications has ceased since the placement in a public funded group home began, and his risk for harming self and others has also been greatly reduced.

Experience in the Public Sector

I have seen private sector providers unwilling to accept participants with severe behavior issues. They will accept less challenging behaviors and lower their level of supervision in order to take more participants with less staff.

Private providers are not mandated to maintain the same levels of supervision that public providers are mandated to do. Hence making more unknown injuries.

The average age of private provider staff is 18 - 24. The average age of public provider staff is 30 – 65 years old, [bringing] a higher level of experience, knowledge and ultimately a better work ethic.

A Guardian's Perspective on Progress

I'm a guardian to a 53 year old man who has been in the State system since he was 12 years old. The road to his present state of being is a long process that began when son was denied an education past 12 years of age because he had autism. It took many years of working with other parents to make sure that the law be changed in CT to include all handicapped children the right to education till they were 21 years of age.

I started the League for Autistic Children, Inc. in 1969. Our group worked hard to get legislation to understand how important education was to getting autistic children to reach their potential. The League also found that we needed school programs to make sure that these goals could be met. We managed to get CREC to create a school called DTS on Steele Road, West Hartford, to start a new concept called Behavior Modification. It worked. Parents were also trained in this new concept.

As the years passed, my son was living at home and so he had so many issues I couldn't help him with, such as good judgment, being able to relate to family issues. Bedtime. Keeping his brother who shared a room with him up all night. The list was getting longer & longer and I had to finally give up my son to the State with me as his Guardian.

I have always been involved in Mark's life. Every week-end Mark had the luxury of coming home and Saturday has always been his. To this day this tradition still stands. In 1990 a group home at 395 Church Street was approved for Mark to be a part of a 6 man home. His own bedroom, a loving staff of State workers who bonded with him. He had a job which he still holds at CFW. His life is wonderful and it reflects in his everyday life, going to work every day, helping with chores in this Group Home, going shopping for food, helping to make dinners, set tables, clean up after himself and in general care. Mark checks the daily log each day to see what staff is on and if someone is out sick he is asking to call them and see how they are.

I could go on and on how comfortable Mark is in his Group Home, his second family of loving caregivers that understand him and make him secure when he isn't well or if he needs reassurance that something has changed and he may talk to the staff about it, and they understand. There has not been a day that I do not thank God for the way my son has been treated or schooled, or just the quality of life he has now.

Work Settings . . .

An individual I was the CM for had worked at a job for many years that she enjoyed. It was a joint effort, [a] restaurant cooperatively run by DDS and Green Chimneys, a private agency. Several years ago, DDS pulled out of the restaurant, leaving it to be run completely by the private agency. Very soon this individual no longer had a job. Green Chimneys let her go, in favor of people who needed less support to get the job done.

Transfers With Tragic Outcomes

Resident from STS transferred to group home in Middletown, CT (4/2016). Contact and communication was discouraged—we went to visit him last evening and weren't allowed to step in to the house past the doorway (7:00 p.m.). They walked the resident out to the bus instead of allowing us in.

Transferred resident from S.T.S. to private group home (Sarah Tunxis agency) in Madison, CT (10/12/16). We visited her on 10/27/16—she looked depressed and thin (gaunt). She passed away the next day. We questioned the house she was in, the staff that she had and the policies they were employing. They all seemed woefully inadequate.

Transferred a female resident from S.T.S. to private group home in West Haven, CT. Staff there almost immediately threw away her favorite dolls. She developed maladaptive behaviors—inc. not eating. She became very difficult to handle and had to receive 1:1 staffing coverage—something she never needed at S.T.S.

Transferred a female resident from STS to private group home in Oxford, CT. Two weeks later she had a food aspiration and was in the ICU at Griffin Hospital for over a week. She became a DNR/DNI. She has recovered but remains a DNR/DNI and was very close to death.

. . . more tragedy . . .

My favorite client had a tube in his head that might clog and 911 would need to be called. His initial ARC staff knew this but just a year and a half later his staff had turned over so much they'd lost this knowledge and he died. They thought he was "taking a nap."

Nursing Care

A complex medically involved young woman was moved to a private CLA and within 2 weeks she was hospitalized after a choking/aspiration episode. She was witnessed by guardian/mom being fed incorrectly. The young woman ended up with a G-tube and was discharged from the hospital back to a public CLA because her mother was vocal and refused to allow her daughter to return to private.
The State provides a summer camp experience for young children and young adults for 6 weeks every summer in Killingly. It is a happy, happy place that these children would never be able to have if Camp Quinebaug was not given public positions every summer. Check out the Facebook page called Friends of Camp Q.

Having sat in on Mortality Review Committee I have seen how the services in nursing are different. The private nurses have little or no experience with DD and the training for private nurses is non-existent and there are many stories from Mortality Review that have poor outcomes.

The Importance of Training

As a case manager I've had to help/train house managers from private agencies on writing IPs, teaching strategies, etc., because with private agency high turnover they are not able to provide training to these managers.

. . . more on training . . .

State run group homes that have been converted or closed redistribute staff to group homes that have essential/site specific skills such as PT/OT/medical that need to be retrained to continue care for individuals. This theme will continue in private sector but wouldn't have qualified staff to train staff.

. . . and more on training, from a private case management supervisor . . .

I work as a private case mgr. (oversee private agencies). One of the biggest concerns with the private agencies is the constant turnover of staff and house managers. I spend too much time training house managers to ensure waiver services remain in place. The constant change allows zero growth for our clients, only periods of adjustment to new staff. Information gets lost on how to best care for our individuals.

Staffing in Private Agencies

I witness[ed] the inconsistency in staff working for this private agency. The agency was constantly hiring new staff. In my three and half years, I was the only staff left since day one.

I witness how the agency reduced the number of staff. On third shift, instead of having two awake staff on duty, they had one staff awake and one staff sleeping. After six months the agency decided there was no need for two staff on third shift. At that time I did not know how unsafe this was. This group home had only three residents, but one of them was violent and was restraint approved. A minimum of two staff is needed to perform a restraint.

Privatizing and Care

I used to work in a group home for 3 years (Hinkley St.) which the State closed and sold to private provider. I was very close with the clients (3) that lived there and was concerned about them. I started working 3rd shift weekends for the private provider on top of my 1st shift state work. The training I took was about 2 hours long, not as informative or extensive as DDS. I was med certified and none of the staff for them were. I was asked to pass meds for my clients as well as another home they took over, before I went to my 1st shift job. I was also paid to come and pass meds to the house's clients while off duty. These clients would not have gotten their meds or not on time if I was not available – the care for my former clients went downhill. I ended up leaving the private provider due to the load being too much. After I left a client died due to staff bringing her to their house and avoiding her breathing problems by not bringing her nebulizer. Also the turnaround of staff was high due to the pay compared to work required.

Privatizing and the Aging Client

My client, B, was in his 70s and was utilizing a private agency for many years until the private agency began to change staff that B had grown attached to. When B questioned why his staff member was being changed and why he was being sent new staff he did not know, he was told by the managers of the private agency "change is good." B was extremely upset - what the private agency did not realize was that, to an individual with disabilities in their late 70s, change is <u>NOT</u> good. This case manager donated her personal time to assist B to exercise portability of his funding by having him tell her in his own words why he wants to fire the agency. This case manager wrote his exact words down and then spelled the entire document to him so that he could write what he said and feel that he did it himself. We mailed the portability/termination letter to the private agency and this case manager assisted B to hire his longtime home health aide and two of his former private agency staff as self-hires so that he was able to choose who worked with him with no "surprise" staff he didn't know or trust.

My client, K, was scheduled to move from one apartment to another in a different town. His brother had moved his larger items into the new apartment and when he asked his private agency staff to help him

move the remainder of his belongings he was told they would not help him as the town to which he was moving was "one town outside the area we support." Panicked and anxious, K called case manager who drove over ½ hour to meet him and help pack him in her own car. She transported him to the new apartment, helped him unpack and clean, and since he lacked items he needed immediately such as smoke detectors, carbon monoxide detector, shower curtain and staple foods, case manager took him shopping and paid for these items herself, as he had little money. We returned to K's apartment and set up, installed and put away what we bought. The agency sent new staff K had never met shortly before CM left at 8:00 p.m. (workday was over at 3) and since K was anxious about staying with someone he'd never met before CM remained to break the ice between K and the brand new and inexperienced agency staff. K was so upset by this experience and others like it at the hands of an agency who appeared to have little regard for his feelings as compared to a case manager with who he was familiar and gladly gave her personal time and money.

From a Guardian

[Name omitted] has Down's Syndrome and was able to enjoy an independent lifestyle living in his own apartment with assistance from State of Connecticut staff. As he grew older it became apparent that he needed more care. He moved into Pomfret Street. He settled in becoming comfortable in his new home. Change in his life is difficult for him at this stage of his life. When he and the others were relocated to Liberty Highway the transition went well because the staff went with them so there was still the familiarity of the staff.

He is content at his home now and I am very concerned that a severe life change such as is being proposed will severely impact his quality of life. I am hoping that the decision to privatize and eliminate the only home he has known for many years is stopped so he can live out the remainder of his life contented and comfortable.

. . . and another Guardian . . .

D. has been at Liberty Highway for 10 plus years and has had his health go down a bit; the staff at this house knows him and what to do if he should have an issue. He is part blind and has dementia and needs to be watched 24-7 along with eating habits. I do not think putting private staff is going to be a well thought out plan for this house. Their people have come to trust and respect this staff and removing them will have a lasting effect on them.

Staff Stress in Private Companies

Generally the staff are over stressed in private companies. They have such large staff turnover the managers are doing direct care. They don't have time to do IPs or take care of waiver services. They have many mistakes and the agency will have fines. Six medically involved individuals stuck in snow

storm for four days without any offer of assistance by private provider. Maintenance man never came to help.

A Professional on Changes

I have worked in this field for 33 years, in just two homes, one that was closed and re-opened as the Storrs Respite Center . . . We have four men aged 48 to 60 who are high functioning but diagnosed with various disorders in the Explosive Anger area. One of our gentleman is a sex offender who once served time in jail for that behavior (ages ago, now, but it remains part of who he is.)

I have seen and certainly heard of the things that can happen in privatization. The main thing happening right now is the lack of DDS oversight in homes that have been converted. From non-med-certified staff in homes where there are several controlled drugs in use, not no accountability or locked meds, to insufficient or non-existent training in lifting, transfers, dysphagia (a VERY serious issue with many, many residents, including our four) and lack of PMT (physical Management Training putting residents and staff alike in danger.

Of course the wages in the private sector lead to very high turnover of staff. Inconsistencies are very difficult for this population---lack of trust and lack of consistent programs is detrimental. Over the years, consistent staff fosters care, and support that people depend on. It helps them thrive. Staff become like family.

That has certainly been my experience as a caregiver. More than just a "state employee." I care deeply about and for the people I am charged with serving. I have worked with amazing co-workers in the past as well as now. I have never heard of anyone in the private sector experiencing this.

Facilities Questions

Many of my private providers (even b/f this push to privatize) have been unable to staff basic shifts with consistent staff. They have been using temp. agencies. This has caused stress to many individuals + has caused behavioral outbursts, missed doctors' appt., inadequate services.
(I) did quality reviews in May 2016 + found several safety concerns in priv. provider houses (holes in ceiling-bathrooms needing desperate [repair].