

ALANA'S STORY - - A PLEA TO CONCERNED DDS LEADERSHIP

FROM MICHAEL AND MARIA MCNULTY, STAMFORD, CT

“One size fits all” innumerable telemarketers and store owners

“This one is just right” Goldilocks

We want DDS to know the details of Alana's situation. We also want DDS to understand the numerous reasons why the SAIL Program at Chapel Haven is “just right” for her.

Alana is affected by a low IQ, ADHD, and other neurological deficits. She has made progress in many important areas of life, but also still has severe problems in other important areas of life.

On the positive side, Alana has made great strides since her arrival at Chapel Haven in 2007. She graduated from the Residence Program in 2009. She is currently in the SAIL program. She is employed at three different paying part time jobs. She uses local buses to go to malls, movies, and other events in New Haven without assistance. She rides Metro North to get back to Stamford unescorted. She walks unassisted within the local community to stores, the laundromat, restaurants, and other cultural and economic attractions in the Westville/New Haven area. She participates in Special Olympics, and in Chapel Haven's recreation and classes.

All of these capabilities have been cultivated and nurtured by Chapel Haven staff. Alana continues to grow and develop new skills through their efforts. At the same time, Alana's progress and continued participation in each of these important areas of life requires continued support and oversight. For an excellent and straightforward example, her main job doing maintenance work at Groton Sub Base would not be possible without the support of transportation and job coaching services.

A more subtle example of this requirement for support and oversight makes it possible for her to successfully exist in and to participate meaningfully in the community at large. In a broad and obvious sense, Alana independently participates in the economic, social and cultural life of the Westville and Greater New Haven area. In this broad and obvious sense, she is able to take a bus, get to a mall or downtown cultural event without staff being physically present. The subtlety of Alana's abilities in these areas lies in her unique combination of capabilities and deficits. In her case, the knowledge that a staff person is at her residence and constantly concerned for her safety and knowledgeable of her whereabouts even though not physically with her, is an unseen but important enabling support. Without this support, Alana would not be able to move about freely in the community as she now does. This is because Alana's most severe

deficit is in the area of her personal security, particularly the risks of sexual predation and inappropriate relationships.

Over the years, Alana has been victimized in these areas more than once. The issue is complex. While Alana shows significant and improved capabilities in some areas, her ability to perceive danger or threats to her personal security is virtually non-existent. The very people-pleasing and co-operative attitude that makes her so successful on many fronts also leaves her open to being taken advantage of by peers and community members who are seeking inappropriate or opportunistic sexual gratification.

In spite of the use of numerous strategies and excellent efforts by Chapel Haven staff, Alana has made little improvement in this area. In untutored medical imagery, it is as if the part of Alana's brain that would give her the ability to discern the danger in a particular social situation or to understand the nuances and signals inherent in interactions between men and women never developed or was permanently removed or deactivated.

While it is unnecessary to go into the details of each of these incidents, one occurrence in particular is excruciatingly relevant to DDS's attempts to curtail funding for the tuition required for Alana to be in the SAIL program.

In 2009, Alana graduated from Chapel Haven's Residence Program. (The most restrictive program of Chapel Haven's programs from which all participants are expected to graduate in two years.) At that time, all concerned, including Maria and I as Alana's parents, Chapel Haven staff, her then therapist and DDS felt that Alana could be successful in an independent apartment setting. She was paired with a roommate who was slightly older. The thought was that the slightly older lady might be a good example or even possibly a mentor for Alana.

Unfortunately, the roommate had her own friends and her own ideas of how the apartment should be run. Alana was physically restricted to certain areas of the apartment by the roommate. The roommate also completely excluded Alana from the apartment when "her own friends" came over. She was embarrassed by certain aspects of Alana's behaviors.

Alana did not tell anybody, including her assigned staff support person about these occurrences. She did not want to create a problem, and she was trying to get the roommate to like her. The physical exclusion from the apartment left Alana alone on the dark streets. It eventually led to Alana spending the night sleeping with an independent living male community member with whom she had no prior or ongoing relationship.

Eventually, Alana informed us of what had happened. The incident revealed the shortcomings of an independent apartment setting for Alana. Her reluctance to cause problems for others, especially those who she is trying to befriend led to a lack of self advocacy. At the same time, the assigned staff person was not in a position to figure out what was going on because she was

not constantly present on the premises nor was she expected to continuously “keep tabs” on Alana.

The SAIL format permits Alana to be in the least restrictive setting permitted by her abilities. It also addresses her particular vulnerability in a way that is effective without being unnecessarily intrusive on her freedom. The SAIL format facilitates her ability to partake of the life of the community at large with a substantial degree of freedom of choice. Alana has the ability to go to a store, go to a movie, go to a restaurant or other establishment without physical accompaniment.

In addition to affording Alana these choices for inclusion in the community at large, the SAIL format also affords Alana another important option that she can take advantage of at her own choosing. It gives her the ability to associate with and form helpful and enjoyable relationships with her peers who have special needs. While the goal and aspiration of community inclusion is important, the positive value of close peer to peer relationships **must not be undervalued!** Our own observations unquestionably reveal that on a day to day basis Alana is in her happiest state when she is involved with her peers. Her negative behaviors (ticking, hyperverbosity, and general nervousness) decline substantially or even disappear at these times. SAIL thus offers her the **best of both worlds** AND SAIL offers her the **CHOICE of both of these bests** at her discretion.

The SAIL format imposes responsibility as well as freedom. Alana is expected to abide by the rules of SAIL - particularly to inform staff of her whereabouts, and unless involved in some planned activity, to be back in her apartment at night at a pre-set reasonable hour. More importantly, Alana knows there is a point person and other staff members who are continuously “keeping tabs” on her activities. Perhaps **most importantly**, the SAIL format provides a constant person back at Alana’s home who is truly familiar on a **real time basis** with Alana’s specific needs and concerns **independently of Alana’s ability to report problems.**

There is no “one size fits all” solution to any special needs person’s situation. Trying to impose one by simply refusing to fund a type of program on a generalized or “blanket” basis is illogical and counterproductive.

In Alana’s case, SAIL’s mixture of freedom and responsibility is “just right”. It is a correct balance of freedom and non intrusive oversight that could only exist in the unique physical setup of SAIL. She is truly located within the community at large, but given an appropriate **and effective** level of supervision.

Alana is currently living up to the maximum potential afforded by her strong points, while receiving optimal protection from the risk posed by her weak points. Any other effective protection from these risks would require a more restrictive placement.

It goes without saying that to remove Alana from the only home she has known for the past eight years would set her back on so many levels. As it is, although we are tremendously grateful for

the help we do receive from DDS, the cuts to residential funding have been a great financial strain for us, and the worries about Alana's future have increased exponentially.

No child or adult with disabilities should be forgotten, left adrift without the necessary care and services they must have to survive, when parents and loved ones can no longer serve as caregivers. We implore DDS and the legislature of the State of Connecticut, to find solutions that will benefit all those with disabilities today and in the future.

We thank you for listening.