

Good morning to the esteemed members of the Disability Concerns Subcommittee. My name is Joe Stone. I am a surrogate Family Living Provider in Albuquerque under the State of New Mexico DD Waiver program and a member in good standing of the New Mexico Waiver Providers Association.

It has been my honor and privilege to provide services for a 42 year old individual for nearly 7 of the 32 years I have known this exciting young man.

Approximately six and a half months ago, on March 1st of this year, I received a telephone call from a dear friend of mine advising me that she, also a Family Living Provider, had just been informed of plans by the State's Developmental Disability Supports Division, of coming deep, broad and sweeping changes, to this most necessary of support programs.

Needless to say, this was certainly not the first time I had been apprised of coming changes.

As I listened to her summation of the situation, I was reminded of the changes proposed some two and a half years ago when then, just as now, sweeping change and enacted reform were rolled out beneath our feet without so much as a breath of warning.

The difference between the changes proposed then and the challenges Family Living Providers are facing today, are nothing more than premeditated determination.

In January of 2010, then Director of the DDS; Mikki Rogers, issued a simple one page letter outlining severe cost cutting measures, which would take effect directly and most disproportionately, on the Family Living community in less than a single month.

With the good fortune of cuts being announced then during the 30 day legislative session, many Caregivers were afforded the opportunity to petition their legislators and as can be said, "cooler heads prevailed", resulting in more equitable across-the-board reductions being implemented and at that time with input from the Direct Service Provider community. At that time, Direct Service Providers; such as those in Family Living, were given the opportunity to cite areas in which they felt cuts could be made within their own specific budgets.

Such however, was not the case in the 2012 announced cuts. What's worse, not only did Direct Service Providers not have the luxury of actionable input, Direct Service Caregivers in our association's opinion were seemingly, almost purposely, denied information on the direction and intent of the DDS, except in instances where such information was delivered on a "decisions-made" or an "after-the-fact" basis.

Compounding problems in 2012 was the ironic timing of the announcement of this round of cuts, which again with calculating precision, came almost within the echo of the gavel's drop at the close this year's legislative session. Conveniently, this made it too late for constituents to seek remedy through their State Representative or Senator.

Adding insult to injury the cuts and changes announced in the new DD Waiver, have been played out over a much longer period of time, not that much unlike a recent Hollywood action movie suggesting a runaway train whose locomotive slowly begins to leave the yard, then later pick up speed with neither an engineer aboard, nor brakes.

Lastly, making this an uncomfortably anxious period for the entire DD Waiver “field-contingency”, has been the near constant change, revamping, postponement and uncertainty. This often giving many Provider’s; and the agencies to whom they are contracted, an impression of the cart more often than not, preceding the horse.

In the opinion of the New Mexico Waiver Providers Association, much of the dilemma today can be traced back to a number of public hearings which were held in the latter part of 2010. At that time, Direct Service Providers were introduced to the concept of an assessment test which would provide benchmark planning for individual’s budget.

The basis of this assessment test was twofold. First to establish for the DDS, the costs being incurred and the resultant value thereof in services and therapies and second, to establish a new classification system extending the current three levels of care into anywhere from (at that time) six to sixteen possible classifications. In the end the DOH has settled on eight categories designed to permit the State to more readily identify groups of similarly disabled individuals, permitting the creation or perhaps the illusion, of a more comprehensive service delivery model.

I’ve little doubt the committee has not yet heard of the Supports Intensity Scale Test. The SIS test as it is known and referred to, was created by Washington D.C. based AAIDD. The *American Association on Intellectual and Developmental Disabilities*.

The SIS Test is cold, clinical and calculating. Perhaps that is not how it was designed, but that is certainly how it is being perceived. Introduced at a time when New Mexico was unsure of its commitment to the DD Waiver population and even less sure of the solvency and financial sustainability of its future, the SIS Test was not brought through the front door like a knight in shining armor, but rather in the night, like a thief through the back door.

And like a thief in the night the results of this test are now seeking to rob its victims of the freedom, independence and security they have not only come to expect, but they have certainly come to rely on.

Originally with full support of the Direct Service Provider community the SIS was heralded as a tested and trusted, viable assessment tool. Within a year of its introduction however, many throughout the DD Waiver are finding themselves confused, disillusioned, angry and betrayed. So what could possibly have caused such a change in perception?

Again, I point to the DDS.

Initially, “normed” on a test population of 500 DD Waiver recipients statewide, little if any information was disseminated to those involved prior to the testing process.

As many may know, each DD Waiver recipient carries with them a “team”. The team is comprised of a cadre of support people from a Case Manager and Service Coordinator, down to the Provider, Therapists, parents and of course, the individual themselves.

In many instances, I as well as other members of the Waiver Providers Association have heard on numerous occasions and continue to hear with ongoing regularity, that little preparation or informative dialogue, instruction or education; is being presented to anyone in advance of the SIS Test. The lack of this education, compounded by a general misunderstanding of the potential ramifications of the deficit-based examination, has resulted in a significant number of resultant scores being deemed by team members, as being in error, if not simply unquestionably, wrong.

As if the lack of an understanding in what to expect in the SIS Test isn’t bad enough, comes word in an April 30, 2012 email, that individuals who score at the higher end of the SIS Test will no longer qualify for residential care services, such as Family Living, even though a pre-requisite of induction to the DD Waiver has always been the qualification for residency in a Medicaid recognized Intermediate Care Facility for the Intellectually or Developmentally Disabled.

The higher functioning classifications of the SIS Test identified categorically as “A” and “B”, cite competence and performance capabilities of the developmentally disabled individual in line with a person who can live independently with minimal team support.

While the assumption can be made that a high-functioning individual will score well on the SIS Test the results of the test which is designed to measure disability, is in fact, being used to assess capability. In other words, while the SIS Test nationally is designed to measure what supports a person needs in order to perform successfully in society, the SIS Test in New Mexico targets a determination of how much support the individual should do without.

Frustratingly, our Provider Association is aware of at least one case where an individual deemed by the medical profession as; “legally blind”, was scored an “A”. Another DD Waiver recipient, a known fire-starter, scored as a “B”. Another case in which a female 56 years in age, who functions mentally as a three year old, scored a “B” in her SIS test and while developmental disability advocates are quick to point out that individuals with Down’s Syndrome run a wide gamut, there seems to be an almost uncanny preponderance of these individuals routinely scoring A’s and B’s. The list of anomalies, if that’s what indeed can be construed here, goes on and on.

In championing the DDSD’s contention that individuals receiving high scores such as an “A” or “B” on the SIS test can justifiably lose residential care, comes the assertion that these individuals will be just as well, if not even best served by the introduction of natural supports. Natural Supports in “Waiver talk” are unpaid

people...persons who assist the special needs individual with everyday tasks without compensation.

On the surface the proposal sounds quite promising; after all, there is a discernible group, who on occasion, questions the philosophy of paying parents or other family members to care for loved ones. While we could argue the ideologies of these people, I much prefer to counter their claims with several genuine, unadulterated, facts.

Shortly after moving to New Mexico in 1980, I met and befriended the fellow I provide services for, as well as his parents. The young man was all of ten years old and as working families of the day and age go, this autistic, ambulatory, mentally handicapped, minimally verbal boy, was the unwitting participant in the modern two-working parent American family dream. In the end though, it wasn't a dream, it became a nightmare.

In order to make ends meet, this young man's parents, often either working similar shifts or one working while the other slept, began to engage inanimate natural supports, the first and most popular being television. In time however, it was observed by this individual's parents that the young man overwhelmingly preferred to sit at home sucking his thumb in front of the TV over any attempt to integrate socially either with peers and playmates or in family planned outings.

In attempts to offset the possible long term effects this type of isolation could foster under the guise of autistic behavior, the child's parents next reached out to friends, neighbors, and fellow church members...anyone who could take the boy a few hours at a time. At one point, even I accepted turns caring for a youngster whose only concern was that the electric box of images in the corner; entertained him.

And then came the call. It wasn't right away, as I remember, it took nearly two years. I was at work one afternoon when the boy's mother called me, sobbing uncontrollably. Once I was able to calm her, she related to me that she had only minutes before received a call from the mother of three other boys. The other mother had called to inquire as to whether the parents of this boy were aware that a mutual friend of both families was possibly sexually abusing my friend's son during these "natural support" facilitations. In the ensuing investigation, word came back from my friend's son, yes he had.

The parents, now plunged into complete and total devastation, worked to pick up the pieces.

As time went on the culprit was convicted, served his time and was released. The family learned to trust fewer people and the television became a focal point in the young man's life. To this day, when this fellow walks into a room with a group of people and a television, the machine, not the people get this young man's full attention.

To once again add insult to injury, the embarrassment of the ordeal has left this young man scarred for life. He exhibits a debilitating degree of social skills, no interest in developing relationships; he is self-conscious in topics of any discussion sexual in nature. He is uncomfortable disrobing and although repeatedly received medals for swimming in

Special Olympics prior to the horrible, unspeakable acts performed upon him, he to this day will not return to a pool for fear of children in his proximity.

In his own words, “he doesn’t want to think that what happened to him; could ever happen by someone else, to them.”

Because the experience left this young man with a diagnosis of Post-traumatic Stress Disorder, he will be subject to behavior consultation for the remainder of his life. Behavior consultation I might further point out, that comes now under fire by the DDS, through those same resultant higher level scores from the now infamous “SIS Test.”

While we can do little for what did happen to this fine young man, we certainly owe it to each and every other person in another’s care the guarantee of safety, the promise of protection and the commitment of respect every person, special needs or not, deserves.

But how can we do that? If you think about it, the answer is not that difficult and for the money, isn’t that expensive either.

The one thing every DD Waiver Direct Service Family Living Provider has over every unpaid natural support and the one thing the DDS seems reticent to embrace, is training.

Family Living Providers are trained and tested annually in life saving, as well as life safety responsibilities. As a result, the cost of a trained Family Living Provider working their 24/7/365 commitment, literally becomes, a very inexpensive insurance policy.

It is doubtful in my estimation that families will be able to find unpaid natural supports to provide any reasonable degree of consistent care. Compound this with the many special needs of the disability population; needs which often can include specialized transportation, one-on-one supervision, individualized training in behavioral issues; again which can often include restraint, logic and on-your-toes problem solving.

Curiously, while the DDS adamantly imposes an annual recertification for Direct Service Providers in assisting individuals with medication delivery, the same division expresses confidences unseen and unfounded in either the reality or practicality, that unpaid natural supports...and likely unpaid natural supports with little or no medical background or understanding, will successfully assist individuals with special needs, correctly, safely and repeatedly.

Often medications can be time sensitive. Administration prior to or significantly after a directed time, can exacerbate an illness or condition dramatically...and all this as the State Board of Pharmacy continues to report New Mexico leads the nation in prescription drug overdose deaths.

Today, every successful DD Waiver recipient in Family Living can cite the Family Living Provider for their marked degree of success. And yes, every unsuccessful Family Living client can be said to have been failed by their Provider.

Unlike natural supports, Family Living Providers understand that the most successful individuals draw from the most successful of situations. It is becoming a consensus of our Providers Association however, that individuals scoring higher grades on their SIS Tests aren't being rewarded for overcoming obstacles, but rather they are being penalized for their success.

Removing residential services from higher scoring SIS Test examinees virtually sets these special needs members at the edge of their nest and with a resulting boot over the side, the benediction of, "hope you can fly," is uttered.

From the public hearings in 2010 through the months of February and March, 2012, when a number of public hearings were held statewide to take input from stakeholders and waiver recipients alike, I can attest, even affirm on a Bible, I never once heard anything about the loss or termination of residential Direct Service Family Living Provider services to anyone, regardless of their placement on any assessment.

This lack in the forthcoming of information from the upper echelon of DDSD, continues to foster an atmosphere in which each time there is any word from "on high", Providers accept it now with an unprecedented degree of trepidation.

In closing, I would be remiss if I did not take a moment and address the burgeoning, "Waiting List". This list now spans many years and upwards of 6,000 developmentally and intellectually disabled individuals. While the New Mexico Waiver Providers Association encourages the State to remediate this growing number of eligible inductees, we cannot, in good faith or conscience, abdicate the genuinely important and truly necessary contributions that Family Living and Family Living Providers bring to the DD Waiver.

Simply put, we truly hope for the day every DD Waiver candidate can be a DD Waiver participant. New clients cannot, however, come onto the waiver at the expense of current Provider's being pushed off. Doing so constructively changes nothing and continues to leave a population of the disabled community at risk, un-served and un-protected. Left to their own devices, in an atmosphere begging an opportunity of endangerment, it logically would be only a matter of time before malfeasance would intervene, leaving another family devastated, an individual a victim and likely, the State of New Mexico in a posture of defensive litigation.

I very sincerely thank you for your time.

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(For the New Mexico Waiver Providers Association)