

Task Force to Study the Needs of Adults with Intellectual Disability

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Testimony

submitted by

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vomiting and diarrhea stopped. At our next visit, the Indian doctor recommended that we start Nestle's powdered milk formula called, "Nan" and the baby began drinking out of a bottle. I then named him Amasai (Hebrew for 'Yahweh has borne ' or carried) Eliab (Greek and Aramaic for 'God is Father') Oduor (my Kenyan married name). My Kenyan husband and the biological mom went to court in Mombasa and we formally adopted Amasai..

I figured there might be developmental delays given his severe malnutrition so early in life. As time went on, however, in addition to the fact that Ami could not hold up his head or sit up, I began to notice asymmetry in his body – the left ribcage was protruding higher than the right –his spine wasn't straight, and one buttock seemed under developed. I took him to a Kenyan pediatrician who nonchalantly said, "this child's skull bones are fusing already and his head is small, he is micro-cephalic and perhaps has CP; continue what you are doing and bring him back in one month's time." We left the exam room and in the waiting area, I thought; "I'd better find his mother" and then ashamed of myself for thinking such a thing, fell to my knees and looked into what was becoming an extraordinarily beautiful face and said, "I am your mother, it's you and me from here on out."

For some of you this may seem to be a bit NUTS but I had experienced failed marriages and seven miscarriages. For me, this micro-cephalic child with no head control was a gift from God; the only being that was acquainted with the depth of the sorrow of my motherless and now post-hysterectomy heart.

My son, Amasai or Ami (as he is fondly referred to) will be 27-years-of-age in March of this year. He has Cerebral Palsy, Spina Bifida (Occulta) is quadriplegic, has Gastro Esophageal Reflux Disease, Dysphasia, is non-verbal, eats via G-tube, must be urinary catheterized every 4 hours, has a Cecsotomy tube to irrigate his colon daily to facilitate bowel movements due to a neurogenic bladder and bowel. He also has a host of other medical conditions.

However, he is AWAKE (a neurological term used to describe the alertness of a person with ID), happy, kind, discerning, handsome, and the very best human being that I know. He has been raised at home in a subsidized apartment; just the two of us - with in-home support staff. He completed High School in 2014 at age 21 and got a diploma and a compensatory year of education due to the LEAs failure to provide education in 2011 when a group home's failures caused hydro-nephrosis of his kidneys . Ami co-teaches with me at the Yale School of Nursing through Operation House Call. OHC is an initiative started by the ARC of Massachusetts to familiarize Advance Practice Registered Nursing students at Yale with the intellectually disabled and medically complex. As you may know APRNs are being strategically utilized throughout the healthcare system many times as an alternative to more costly physicians. These practitioners need to feel comfortable and knowledgeable when working with our population and their families and OHC has wisely stepped up to integrate IDD into the Yale APRN curriculum.

I would like to take a moment to reflect on what Lois Nitche, the mom who presented to us on December 4th said in her testimony. Her statement was as profound as it is true. She said, "There is no US verses THEM," referring to parents/guardians and the DDS.

What is DDS? DDS is a state agency **dedicated to serving** the needs of the intellectually and developmentally disabled by providing services that meet their individual needs, mitigate barriers to independence, and foster sound social integration into community.

How is this achieved? Through the effort, generosity, talent and skill of individuals with intellectual and developmental disabilities, their families and guardians, DDS employees CT taxpayers, and CT Legislators. This task requires the best each of us. If the any of us fail, we all fail but we all know it is possible to succeed, at the very least in our commitment to provide quality, compassionate care.

While it is easy to agree on goals, it is important to realistically identify areas of potential conflict that potentially sabotage our ability to realize those goals. As you know, bureaucracies are systems characterized by processes and practices designed to meet goals. Both processes and practices, however, must be continually monitored to ensure that:

- **Clients are respected and treated as individuals not objects with highly individualized medical and social needs.** This means at a minimum that clients are addressed by their name and told what is about to happen. In addition, client equipment and supplies cannot be "borrowed" for other clients. Finally, it means that each new client presents a learning curve. New practices, medical as well as social, must be learned by caretakers.
- **Parents/Guardians who have been working with Doctors and Nurses for years to provide in home care are viewed as valuable resources.** Parents/guardians that have been involved with their child's spiritual, scholastic, medical, psychological and therapeutic development for years have worked with numerous professionals of all types and caliber. These parents have developed instincts, and relationships that bridge disciplines. At the same time the support needs of parents/guardians providing in-home care need to be studied. Young parents/guardians may have many children, other families are characterized by aging parent(s), many, many are isolated and lack financial security because of their child's care needs. Efforts to bring parents/guardians together show great promise in overcoming isolation and also enabling parents/guardians to become a resource to each other.
- **Local medical and psychiatric communities are "mined" for best practice, as well as opportunities for on-going staff development, and evaluation of services.**

Budgetary constraints are always with us. However, creative ways of reorganizing staff along with the hiring of more experts can efficiently build the Department into something that the State can be proud of, that

employees are proud to work for, that families trust and revere, and private providers can seek to emulate. For example:

- Hiring 1 or 2 persons to head each therapeutic discipline (i.e. PT, OT, SLP),
- Hiring a Medical and Psychiatric APRN to work under Dr. Bagby-Young to facilitate the training necessary throughout the respective nursing departments.
- Assign RNs as group home managers so that they can supervise and train Direct Care workers on cross-contamination, hygiene, etc.
- Assign RNs to oversee teams of LPNs who circulate throughout day programs. My son could not attend a day program because there were no nurses in day programs (which in and of itself is a risk to the well-being of this “protected class”).
- Collect and publish data on the characteristics of the client population, their families/guardians, the services most in demand, etc.

I've said a lot in this testimony but the bottom line is that Adults with Intellectual and Developmental Disabilities need an agency that competently addresses their needs in a respectful and caring way.

The population includes a wide variety of Intellectual, physical, psychiatric, and social diagnoses. Families are as varied as the individuals served and both the individual and their family or guardians need to actively participate in the developmental evolution of their child's life and the renovation of OUR DDS. I understand that there are Regional Advisory Councils (RACs) and the DDS Council all of which include families and guardians. DDS has done a commendable job of reaching out to individuals and their families and guardians to ask for our input. It has often been met by complaints; fact is,

We All Need to do Better.

To families....it is extremely difficult raising a child with special needs. Whether it is Intellectual Disability, Autism, or any medical or psychiatric disorder; even typical child rearing is challenging. Personally, I raised my son alone without support from family or even my church family. I learned to depend on my Creator and leaned and relied on my spiritual life...which has graciously brought me through thus far and even now He's holding my right hand.

Parents are more powerful than they realize, but they will become ineffective if they remain uninvolved in parent and other support/advisory efforts. Community is vitally important on this journey and face-to-face encounters provide comfort and confidence as we learn from one another and see that we are not alone but among a group of folks that understand what it's like. You can find humor and laugh about it. We are all on this journey and we have to learn to TRUST one another.

Most importantly, we must commit to becoming **TRUSTWORTHY**.

And understand that.....

Trustworthiness is borne of character, not titles and definitely not of egos.

Thank you, for your attention!