

Testimony on DDS 2022-27 Draft Strategic Plan

I am the parent of a 37-year-old daughter with autism and IDD, who receives services from DDS. I offer the following testimony that has been born from both my personal experiences as a mother, but also as a past Abuse Investigator with The Office of Protection and Advocacy.

I deeply appreciate the leadership and commitment I have witnessed from DDS in the last trying years. It has been my overwhelming experiences that the Department has many sincerely devoted individuals, who are committed to providing support to individuals with IDD.

In reviewing the proposed DDS Strategic Plan, I am struck with what I believe to be critical components missing in the proposal. I wholeheartedly endorse all that Win Evarts from the ARC cited as areas that need to be more clearly defined and perhaps more importantly measured. Accountability for ensuring that the Individual's Plan is successfully implemented, progress measured, and corrective actions implemented are the assurance that the money and time spent on our loved ones is qualitatively making a difference in supporting meaningful lives. These quality-of-life indicators and measurements are not currently tied to a scale that specifically measures client/consumer satisfaction. Other than extremely generalized probes that occur at the yearly client review, there is nothing to ensure our loved ones receive supports that improve or even strive to correct identified areas of weakness. For example, if my daughter's IP states that she will use her communication 3 times a day, and this goal is not achieved, who assures that corrective actions are taken? I suggest that the Strategic Plan commit to collaboratively (families and self-advocates with equal representation as stakeholders) creating a Quality of Life Assessment Tool that will directly impact all service providers by funding and defunding incentives. In other words, agencies and service providers become accountable to those they serve. Again, it would be important that there be family representation on all committees to ensure families and their loved ones as equal stakeholders.

Secondly, it saddens me that there is not a clear Bill of Rights for Individuals with Disabilities and their families. Although there is a Programmatic Administrative Review Process for individuals and their families when there is a dispute regarding services by the department, there is no clear pathway when a providers' actions violate the individual's basic rights. I am attaching some of the principles identified in the UN Convention on the Rights of Individuals with Disabilities and rights consistent with the mission of DDS, to provide an overview

of how DDS might create such a Bill of Rights. This should be followed by the establishment of a small complaint panel that would oversee possible complaints and create resolutions. This will serve families and individuals working with the private providers.

The attached document serves to provide an overview of the concepts of a Bill of Rights. I request that DDS include in the proposed Strategic Plan, the establishment of a Client/Family Bill of Rights and establish a panel or program that includes family representation to monitor and resolve complaints.

I am available to discuss these areas. These suggestions were established as priorities in the Family Focus Action Group, which has been meeting over the past three months. I can say from my facilitation of these meetings that there is a uniformly held viewpoint that families want more measurable outcomes, accountability by the agencies and providers and a clear pathway to be included in the development of any future DDS Policies or Programs. The expression, “Nothing about Us, without Us” seems to summarize the sentiments most succinctly I have repeatedly heard expressed.

Thank-you for this opportunity. I look forward to working more closely with DDS, the families and individuals receiving services and supports.

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Bill of Rights

Guiding Principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD)

There are eight guiding principles that underlie the Convention and each one of its specific articles:

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

Non-discrimination

Full and effective participation and inclusion in society

Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

Equality of opportunity

Accessibility

Equality between men and women

Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

CT DDS Mission with Respect to Rights of Individuals

A key component of the DDS mission includes the vision statement that "Individuals know their rights and responsibilities and pursue opportunities to live the life they choose."

People with intellectual and/or developmental disabilities have the same basic legal, civil and human rights as other citizens.

All individuals regardless of ability need the opportunity to effectively advocate for themselves and to exercise their rights.

All citizens should understand their rights and be able to have the same opportunities as everyone else.

Basic rights such as where to live and with whom, having control and responsibility for our finances, the right to work, the right to have relationships of our choice, the right to choose

how and where we spend our time, and the right to be treated equally, with dignity and respect are all basic human rights that all people, regardless of ability should experience.

Individuals with disabilities have the right to make their own choices and to lead self-determined lives where they have choice and control, freedom, authority and support to live as responsible and equal citizens.

However the enjoyment of these rights as described above are not manifested by individuals with disabilities and their families receiving services by providers in our state (Please see attached testimonies).

Purpose

Therefore we propose the establishment of a **Consumer Complaint Process** to fairly resolve disputes brought by clients and families by creating a mechanism for clients and their families to work out **rights violations** by providers contracted by DDS for services. The Consumer Complaint Process is the procedure to use when client and families believe that a provider has violated or improperly withheld a right to which they are entitled under rights given to persons with disabilities by the CT DDS and The United Nations Convention. Under this process, we are asking that the provider, change its procedures for dealing with the complainant and others in the future.

Action

We are requesting this committee to take legislative action to authorize the creation of a Complaint Resolution Process for clients and their families receiving services through the Department of Developmental Services and private providers. We are requesting the DDS to develop and promote policies and procedures guiding the use the Consumer Complaint Process by the parties in response to Legislative authority.