

**Testimony of  
Quality Trust for Individuals with Disabilities**

**Performance Oversight Hearing:  
The  
Department on Disability Services  
Fiscal Year 2016**

**Councilmember Brianne K. Nadeau  
Committee on Human Services**

**February 15, 2017**

Good morning, my name is Jimi Lethbridge. I am the Deputy Director of Programs for Quality Trust for Individuals with Disabilities (QT). QT is an independent nonprofit advocacy organization founded as part of a 2001 Settlement Agreement in the *Evans* class action lawsuit, which closed Forest Haven, the District's institution for children and adults with intellectual and other developmental disabilities. Our mission is to help people with developmental disabilities in the District of Columbia solve problems, achieve personal goals and meaningfully contribute within their community. We do this through our role as an independent monitor and advocate safeguarding people who may seek or are receiving services and supports through the Department of Disability Services.

Any discussion of the performance of DDS in Fiscal Year 2016 must necessarily begin with the fact that on January 10, 2017, the *Evans* parties agreed to vacate all outstanding orders, ending the case after nearly 41 years. This is an important development for the District as well as people with disabilities and their supporters. It took the sustained effort of a great many people over several years to create the structures and systems necessary to demonstrate compliance with court orders. Now that the euphoria of that day has passed, it is time for the Department on Disability Services to go beyond compliance to the work required to fulfill its mission to "provide innovative high quality services that enable people with disabilities to lead meaningful and productive lives as vital members of their families, schools, workplaces and communities in every neighborhood in the District of Columbia."

As time is brief, I will do my best to quickly summarize the four points contained in my written testimony.

- Use of the Home and Community Based Medicaid waiver (HCBS),
- Completion of timely Individualized Service Plans (ISP's) and;
- Completion of timely and thorough investigations of Serious Reportable Incidents (SRI's)
- Revisions to and current status of DDS' intake Policy & Procedure

**1. Use of the HCBS Waiver**

The HCBS waiver is a funding stream within Medicaid that allows states to provide services in community based, rather than institutional, settings. Since 2008, the District has secured hundreds of millions of dollars of Medicaid funding to provide lesser restrictive residential and

day program options for people receiving services and supports. States submit renewals for their waivers every five years, and 2017 is a renewal year for the District.

During the past year, we participated in an advisory group that reviewed and made recommendations to DDS on current and future service definitions, provider qualifications, and rates of provider reimbursement for the waiver renewal. Based on that experience, we note that DDS is making progress in ensuring its HCBS waiver evolves over time to address the needs of District residents with intellectual disabilities to be able to work and live in more integrated settings. Like most states the District has relied on a model of large segregated day programs. To address concerns about the need to provide day and vocational services in the least restrictive setting, DDS devised a plan it asserts will achieve better employment and community integration outcomes for people. It will be important that options which meet the needs of both people with complex medical issues, as well as those without who have true interest in involvement in their community are developed. We hope the DDS Director Andrew Reese, with his background at the Rehabilitation Services Administration (RSA), will bring new models that expand opportunities for people to shed large segregated day programs in favor of more opportunities for real work at a decent wage. For those people preferring an alternative to work, it is essential that they be given opportunities to engage in social and recreational activities, which provide them with new experiences and choices that may expand their preferences over time.

## **2. Timely Individual Service Plans**

The ISP is the foundational document on which all of the person's preferences and needs are noted, team members are assigned responsibility to provide for those needs, and timelines for completion are agreed upon. It is important that the ISP be completed in a timely manner, but it is essential that the ISP lay out clear expectations, and that those expectations are actually accomplished. It is the DDS Service Coordinator that is responsible for ensuring the ISP is "person centered" and that goals and outcomes are completed successfully. People who have complex medical and behavioral needs and equally complex familial and social lives require advocacy that knows when to intervene and when to allow a person to exercise autonomy and independence. On the whole, the DDS Service Coordinators are accomplishing this mandate, but we do find instances where they do not. One area where we see a need for greater consistency amongst Service Coordinators is completion of monitoring tools. The purpose of these tools is to identify and intervene when a service or support has not been provided, or is not timely. When Service Coordinators fail to provide that oversight role effectively we work with senior leadership at the Developmental Disabilities Administration (DDA) to ensure identified issues are quickly resolved.

## **3. Timely & Thorough Investigations of Serious Reportable Incidents**

Amongst the many important roles played by DDS, none is more critical than the timely and thorough investigation of all serious incidents which might bring potential harm; including theft of personal possessions. As recently as 2010, DDS was struggling to complete these reports in a timely and thorough manner. However, since then, we have seen substantial improvements in the DDS Incident Management and Enforcement Unit (IMEU), which continued FY 2016. Their investigatory work now can be relied upon for its timeliness and accuracy. For example, we are seeing IMEU investigations which uncover additional underlying incidents previously uncovered. Those possible incidents are then investigated. In this way, the investigation process, like the role of Service Coordinators is crucial to ensuring that people are protected from harm, and that possible systemic issues are identified and addressed as part of DDS's overall quality

management strategy. That quality management component is a defining aspect of the District's HCBS waiver renewal, and its importance cannot be overstated.

#### 4. DDA Intake Policy and Procedure

Last year, we shared our concern that the DDS Developmental Disabilities Administration (DDA) Intake & Eligibility Unit (I&EDU) was interpreting the eligibility criteria for DDA services in an overly restrictive way. We had seen the I&EDU treat a Full Scale Intelligence Quotient (FSIQ) score of 69 as a "bright line rule," denying applicants with diagnosed intellectual disabilities whose FSIQ happen to fall only a couple points above 69, either before or after they turn 18 years old. As we noted, doing so runs contrary to the practical reality that there is an inherent standard error of measurement (SEM) associated with Full Scale IQs that was expressly recognized by the U.S. Supreme Court in 2014.<sup>1</sup> We called for DDS to revise its I&EDU Procedure.

Over the last year, DDA issued its revised Policy Procedure, which went into effect in October 2016. We understand that DDS is in the process of revising its Procedure to address concerns we raised about its treatment of pre-18 head injuries that may result in intellectual disabilities, which we appreciate. We also are pleased to see that the Procedure now expressly recognizes that the determination of intellectual functioning includes consideration of the SEM associated with the particular IQ test. That is generally consistent with the revisions to the General Provisions of the DDA HCBS Waiver regulations.

However, more needs to be done by DDS to implement this change on the practical level. For example, the DDS DDA website continues to describe eligibility requirements, in that it highlights a 69 or below IQ requirement, without any language caveating it (see <https://dds.dc.gov/node/711822>). Because the website continues to make IQ sound like a bright line rule, people with intellectual disabilities may be being screened or self-screened out during the pre-application phase, when they and their families are considering or exploring their options before formally applying.

In conclusion our monitoring and advocacy activities indicate that, during Fiscal Year 2016, compliance with the court orders in the *Evans* case have been broadly maintained. At the same time, we routinely encounter instances where the system breaks down and does not work as designed or planned. This is not surprising in a system comprised of hundreds of providers employing thousands of people, which interacts with hospitals, private practice doctors and dentists, as well as the community at large. However, it is also something about which we must remain vigilant. Consistent with current expectations for quality systems, DDS/DDA must seek to continually strengthen its ability to identify and remedy individual systems failures before they have significant impacts on people.

The intellectual disabilities service system in the District of Columbia is relatively small, but is also complex. The Department of Disability Services and providers must be ready to adapt to an ever changing world. A generation of people who have moved through the school system since the Individuals with Disabilities in Education Act (IDEA) bring with them different expectations of what it means to receive services and supports. At the same time, services and systems to address the unique characteristics of the remaining approximately 490 people who

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lived at Forest Haven must be maintained in order to ensure their health, welfare and opportunity to enjoy true community integration as they face their later years. The leadership team at DDS has indicated an awareness of and willingness to embrace the transitional nature of the current environment. We look forward to what we hope is a time of dynamic change and enhancement in the coming year.

Thank you and I would be glad to answer any questions