

Learning Disabilities Association of New York State Tiered Services Proposal

STATEMENT OF NEED

The Learning Disabilities Association of New York State (LDA of NYS) is a private not-for-profit organization that advocates for a broad range of community-based supports and services for people of all ages who live with specific learning disabilities and neurological impairments. LDA's mission is to work collaboratively with individuals, families and the community through its network of regional affiliates to empower and enable these children and adults to lead independent, productive and fulfilling lives.

OMRDD has always been and to this day remains, LDA of NYS' primary "home" for services. LDA of NYS' relationship with OMRDD spans several decades and LDA is recognized as one of OMRDD's primary provider associations. Oftentimes, LDA of NYS' regional affiliates have stepped in to serve individuals with complex learning and other neurologically based disabilities when other agencies have said they can't help them due to lack of established OMRDD eligibility. However, LDA of NYS, through its it's network of regional affiliates has encountered increasing difficulty in serving individuals with specific learning disabilities (SLD), high functioning autism spectrum disorders, Asperger's Syndrome, and a number of other complex neurological impairments, because these individuals are increasingly deemed ineligible for state and federally funded services. Specifically, and all too often, these individuals' disabilities are viewed as "not significant enough" to warrant eligibility for funding that is available through state entities like the Office of Mental Retardation and Developmental Disabilities (OMRDD). Unfortunately, these individuals are then left to navigate their lives and the challenges of their disabilities with minimal or no assistance. As a result they often live lives of great difficulty and vulnerability— lives that may include extended periods of incarceration, lifelong dependence on public assistance, substance abuse, and victimization, coupled with a myriad of other negative and undesirable outcomes.

The situation has dramatically worsened over the last 15 years. In 1993 OMRDD, in an effort to provide services to greater number of individuals, introduced the Medicaid Waiver to their delivery system. Through this process OMRDD was able to introduce a number of new funding concepts. Beginning with the Community Service Expansion Plan (CSEP) followed by a multi year effort titled NYS Cares; OMRDD was able to increase the number of people being served and provide a greater level of services being offered. Today, with the exception of family support services, the delivery system is completely immersed into the Medicaid funding stream.

Unfortunately, greater reliance on Medicaid has also meant greater scrutiny on meeting federal eligibility guidelines for not only developmental disabilities but also the federal guidelines for Intermediate Care Facilities (ICF). In the beginning, NYS OMRDD relied on the judgment of the service providers to establish eligibility. This approach was clearly flawed because providers were predominantly utilizing guidelines for

developmental disability and not ICF eligibility. Furthermore, there was virtually no continuity between providers to say nothing about regional disparities.

While NYS OMRDD would have had minimal difficulty meeting the threshold for developmental disability services, the threshold for ICF eligibility was a completely different matter. This second issue required a completely different approach. Progressively, NYS OMRDD increased their involvement in deciding individual eligibility. Most of this involvement occurred at the local level through a greater reliance on regional Developmental Disability Service Offices (DDSO).

However even this approach experienced problems. With only the state definition available, each DDSO was allowed to interpret it on a regional basis, which resulted in numerous problems and regional disparities. There were many cases where someone was found eligible in one region and when they relocated to a different region within NYS, they were denied eligibility by the new DDSO.

As for specific problem areas, the first major area was the actual definition of a developmental disability. For example, in the NYS definition of a developmental disability, dyslexia which is the most common form of a specific learning disability (SLD) is listed as a developmental disability. Yet it is consistently dismissed by most regional DDSO staff as not being a qualifying developmental disability. Furthermore, recent research has clearly established SLD as a neurobiological disorder of the brain and simply not related to how a child performs in school. This further establishes SLD as a qualifying disability under the neurological impairment (NI) classification, which is also listed in both the federal and state definition of a developmental disability. Other examples of this type of problem with the definition include other types of neurological disorders such as Asperger's Syndrome and Fragile X Syndrome. The most common reason given by the various DDSOs is that the IQ is too high which in actuality has no relationship to these types of disorders.

The second problem area concerns a candidate's adaptive behavior skill level. The vast majority of DDSO employees who are involved in eligibility decisions have spent the majority of their careers working in the developmental centers (DC). The typical clients found in a DC are usually individuals with severe mental retardation who exhibit the most severe behaviors and usually represent individuals with the greatest needs. Using this as a frame of reference, it is understandable that most DDSO employees would have problems understanding the difficulties faced by individuals with various other forms of a DD who can eek out a barely acceptable existence living in the community.

Based on this type of situation, NYS OMRDD central office undertook an effort to refine eligibility criteria in an effort to make it more uniform. This was done through two field advisory memos that not only named acceptable assessment tools but also defined a clear eligibility process with definitive time lines. For the first time, there was a belief that continuity across the state could be achieved.

Unfortunately, this has not been the case. Several problems continue to plague the system. These are:

- A general lack of current research based knowledge concerning various neurological impairments;
- Attempts to link adaptive behavior levels to IQ scores;
- Continued inconsistency between different regions of the state regarding the definition of a qualifying disability. For example, Asperger's Syndrome is recognized in the western parts of the state but is consistently denied eligibility in the central region.
- Efforts by OMRDD central office to re-norm various assessment tools, without valid research, in an effort to restrict access to the delivery system.

The current situation has been further exacerbated throughout the state by the lack of psychologists who accept Medicaid. Often times, the only available option for individuals on fixed income is to be assessed through an Article 16 or 28 Clinic. Unfortunately, the quality of the assessments available through the clinics is often lacking. For example, in a case from WNY, a young man was assessed at an Article 16 Clinic for eligibility purposes. The individual was diagnosed with a SLD, dyslexia. The psychologist in his written report dismissed a learning disability as a qualifying disability but agreed that he had significant adaptive deficits. In place of OMRDD funded services the psychologist recommended that the young man should go out and find himself a wife who could provide him with natural support that he needs.

LDA-NYS CASE REVIEW STUDY

With this as a backdrop, LDA of NYS NY undertook a case file review of 32 individuals with clearly diagnosed DD, based on the latest research, from two different regions of the state. The individuals selected for review fell into four broad areas based on their adaptive behavior levels. These levels were classified as mild, moderate, severe and profound as assessed by the Adaptive Behavior Assessment System (ABAS). The groups were further separated based on eligibility acceptance by the local DDSO. Fifty percent of the overall group would have been approved for eligibility.

Entering into this, there was an expectation by the review team that the mild and moderate groups would be denied services while the severe and profound groups would have been approved. There was also an expectation that there would be some questionable decisions between the moderate and severe classifications. However, based strictly on the ABAS score, a fairly clear delineation between the approved and unapproved groups should be apparent.

Instead, what was discovered was just the opposite. There were individuals in all four levels of adaptive functioning that were approved for eligibility. There was also one individual in the profound level that was denied eligibility. These erratic decisions were found in both DDSOs and were largely based on the lack of a qualifying disability even though up to date research clearly establishes the developmental aspect of all disabilities

included in the case file review. The bottom line was that you could achieve similar results by simply flipping a coin.

These results contradict recent pronouncements by both NYS OMRDD and the Governor's Office in response to efforts by the NYS Legislative Branch to clarify NYS OMRDD eligibility criteria. These pronouncements have been centered on the fact that NYS OMRDD has achieved consistency throughout the state in implementing current eligibility guidelines and that everyone with a severe handicapping condition, as assessed by a validated adaptive behavior tool, is receiving support and services.

PROPOSED RESPONSE

In order to address these problems, LDA of NYS is proposing the development and implementation of a comprehensive plan that would address all of the critical problems associated with the current system. In order to be successful the plan must be able to do the following:

- First and foremost, the plan must be able to immediately respond to a crisis; Waiting for eligibility approval to occur will only complicate the problem, making extraction all the more difficult. Early intervention services must be available.
- Individuals with cognitive problems are notorious for their inability to honestly self-report difficulties they are experiencing. This often results in adaptive behaviors scores that are significantly higher than reality, which routinely results in eligibility being denied. This phenomenon occurs in not only individuals with neurological impairments and specific learning disabilities but also individuals with other types of developmental disabilities. Therefore the plan must be able to provide in depth information on an individual's adaptive behavior skill level;
- The last major obstacle to overcome is the need for a comprehensive cognitive evaluation that is not based solely on IQ; the comprehensive cognitive evaluation must be done by an experienced clinical or neuro-psychologist who has considerable experience in diagnosing neurological impairments including SLD. Under currently available funding streams, such as Medicaid, this is almost impossible to arrange.
- Finally, the plan, utilizing state funded services must not be a duplication of current Medicaid funded services.

The approach chosen by LDA is modeled on a methodology currently utilized in the education field for the placement of children into special education services. The methodology, known as Response to Intervention or RTI, is a multi-tiered approach with increasing levels of intervention at the various tiers. If the child continues to have problems by the end of the final tier, the individual is referred to special education.

LDA's proposed system would be similar but scaled back. In the proposed approach, there would be only two tiers, compared to the three tiers common in the education field,

with each tier having an additional service or support being added. If, at the end of the second or final tier, the individual is continuing to have problems in their daily life, the individual would be presented to OMRDD for eligibility determination. However, unlike the current situation, the presentation to OMRDD would include accurate, thorough and professionally evaluated information, which would allow OMRDD to make an accurate evaluation of the individual.

Tier 1 – The key element to tier one is the provision of intensive service navigation, which is similar to service coordination but is time limited and more oriented to crisis intervention. This approach is almost the perfect match to what is being encountered, on a daily basis, by the local affiliates of LDA of NY. It is a very safe assumption that all individuals who seek assistance from a local LDA have some form of a neurological impairment and have recently experienced some type of life changing event that has resulted in some form of a crisis.

Service Navigators primary function is to triage these types of situations by connecting these individuals to appropriate services and supports. In some cases, the connection may be with a generic provider while other times it may require services and supports of a specific agency like OMH, OASIS and/or OMRDD.

This tier could range from 3 to 6 months in duration. If the situation stabilizes, LDA's involvement would end at that point. However, if the need persists and more direct intervention is required, individuals would move into Tier 2.

Tier 2 – The goal of tier two would be focused on two different issues. The first issue to be addressed is the continuation of the Service Navigator's efforts to stabilize the immediate crisis. The health and safety of the consumer must be paramount. As result in tier two, the involvement of the service navigator would intensify. This tier would range for an additional 3 to 6 month period.

The second issue would be to begin a process potentially leading to OMRDD eligibility. This would require the Service Navigator to assess the individual's adaptive behavior levels. It would also include an assessment of an individual's ability to effectively learn and put into practice new adaptive skills. If the individual can readily learn new skills, and the crisis begins to subside, it is conceivable that services would be terminated prior to the conclusion of this tier.

However, if it becomes apparent that the individual is continuing to have major limitations in being able to adapt to life's challenges, the SN would be able to assess their ability from a first person point of view. Through this process, OMRDD would have accurate information available on how substantial the person's handicapping condition truly is and what impact it's having on an individual's daily life.

An optional part of this tier would be the completion of an updated psychological evaluation. As stated earlier, individuals seeking help often lack a comprehensive evaluation with a clear diagnosis. Available Medicaid providers are limited, and their

reports often lack the information that is needed by OMRDD to make definitive answer on eligibility. As a result, this tier would include funds to retain the services of a local licensed clinical or neuro-psychologist, who specializes in the diagnosis of neurological impairments.

This tiered service-delivery model would allow services to be targeted and based on an individual's specific needs, which for some may be more intensive and for others relatively minimal. Only providing services that are truly needed would be more cost effective and a more sensible option than the current "all or nothing" approach that has resulted from the Medicaid Waiver.

REPLICATION

Over the last several years, more and more disability specific groups have reached out to the legislature for special consideration. This consideration has taken many forms from funding requests to the addition of a new category of a developmental disability. Sometimes it is very public such as the recent effort to set aside funds in the current OMRDD allocation specifically for autism or very quiet such as the approval of several member items in the current budget for a variety of epilepsy programs. Supported by this type of success, every indication is that this trend will continue and in all probability grow in size.

By utilizing this type of model, a combination of intake, assessment and crisis intervention, OMRDD will be in position that would, at a minimum, allow it to have a universal theme governing special funding requests that is consistent with its mission of serving individuals with DD.