

DDAWNY Written Testimony
Assembly Committee Hearing
October 20, 2015

Assembly member Gunther and Members of the Assembly Mental Hygiene Committee

My Name is John R. Drexelius, Jr. and I am the Government Affairs counsel for the Developmental Disability Alliance of Western New York - DDAWNY.

DDAWNY is a collaborative group of member voluntary agencies that provide services and supports to people with developmental disabilities in the Western and Finger Lakes regions of New York.

Our member agencies, working actively with their consumers, families and self advocates to help shape services to meet their needs, provide a wide range of services in multiple settings, including residential and housing supports, day programming, family support and respite, transportation and vocational & employment services, including career development and assistance in finding competitive work in integrated settings.

DDAWNY has also formed a Family Committee to give voice to the people served in the disability arena, but who are often unheard

DDAWNY is pleased to provide comment to the Assembly Standing Committee on Mental Health and Developmental Disabilities. DDAWNY appreciates the committee seeking to identify barriers to implementing the Transformation Agreement successfully.

OPWDD indicates the goal of transforming our system of support is to improve the lives of the people it serves.

DDAWNY is extremely troubled by the very significant negative impact recently implemented rate restructuring activities related to the transformation are having on providers and the ability of these providers to provide quality supports and services.

New supportive employment and prevocational service funding has dramatically reduced revenue streams necessary to support the same levels of service needs at pre-transformation rate levels. New restrictions on Clinic funding and overnight Respite services will result in the loss of significant services and supports in the community.

Rate restructuring (euphemistically called "rate rationalization" is causing significant fiscal distress, Provider agencies report a 50% reductions in funding for Employment and Pre-Vocational services, significant reductions in funding for residential and day habilitation for a substantial number of providers (generally those dealing with the more complex cases involving complex medical issues

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and/or behavioral/SMI dual populations) potential cuts to respite that may leave many families with much less respite than they currently have -- DOH is working on this (respite) and saying "trust us" -- however recent experience with DOH rate setting suggests they are not to be trusted., completely inadequate rates for self direction, -- which OPWDD can not or will not explain in terms of its methodology and which do not begin to adequately support the housing, day activity and transportation costs necessary to self-direct - especially the cost necessary to manage, hire and retain quality staff to assist, combined with the negative attitude of CMS toward the NYS system, it appears our system is tottering on a cliff. Some are suggesting by the time we get to managed care, there will not be many providers left to provide the services MCOs will need us to provide.

DDAWNY providers are having an extremely difficult time attracting workers to the field. Wages are a significant issue, especially with state policy rewarding those who serve french fries and polish nails but ignore the plight of direct support professionals who on a day to day basis, feed, bathe and toilet individuals with Intellectual Disabilities -- our workers are doing double shifts, working second jobs and living in supportive housing - just to make ends meet. We can't pay more because we are nearly completely dependent on the Medicaid payment rates the state and CMS have imposed on us. As someone recently said "Poor reimbursement rates violate peoples' right to integration."

According to a recent statewide survey, nearly 20% of all direct support workers left their position last year, Nearly 30% left within the first six months of employment. Statewide, providers report that 8% of the available direct support positions available are vacant. As a result, providers are forced to ask existing workers to work overtime. Overtime hours are increasing and staff morale is becoming an increasing issue. Of course, the new Federal overtime rules will have a massive negative impact on many of our agencies.

These new transformation rate restructurings are being implemented without any significant effort by OPWDD to lessen the crushing and unnecessary over regulation of the field. Without real and significant regulatory reform, compliance costs, already significantly in excess of what other human service agencies face in other New York state regulated areas are growing exponentially. As compliance costs increase, and with revenues related to service delivery dramatically reduced, DDAWNY is concerned about both the fiscal viability of many of our provider agencies and also the ability of remaining provider agencies to continue to provide quality supports and services to all who are eligible for these supports and services.

At the recent Transformational Forums parents, advocates and providers made a plea for the State to recognize that a very significant portion of the population it serves are not qualified to work and have significant day habilitation needs which are not being adequately addressed as part of the transformation agenda.

DDAWNY believes OPWDD needs to recognize that a very significant portion of the population it serves are not qualified to work and have significant day habilitation needs which are not being adequately addressed as part of the transformation agenda.

According to recent State Education Department documents only 5% of students with disabilities are leaving high school "college or career ready".

In 2013, 2834 Students with severe cognitive disabilities took the New York State Alternative Assessment. Generally these students are going to leave school with a Skills and Achievement Commencement Credential (SACC).

This credential is not recognized by employers or the United State's Military as a high school diploma and without a diploma, only a very few low paying jobs will be available to this group of students. OPWDD's transformation agenda fails to address the critical day support needs of this population.

The state spends significant sums educating students with disabilities. Having these individuals regress at home, isolated and not engaged with the greater community is unacceptable and resources must be dedicated to allowing additional day activities, beyond the world of work.

We all strongly believe that the needs of individuals with disabilities must be respected and state policy ought to support a wide range of choices for people with disabilities in where they live, work and otherwise participate in the community. Currently there are no choices, just closed doors and overburdened family caregivers offered few options and less resources and supports.

DDAWNY also believes OPWDD has grossly underestimated the cost, complexity and willingness of natural "unpaid" supports to move to a self-directed model of service delivery.

The current PRA amounts are grossly inadequate, fail to appropriately differentiate levels of acuity of service need and fail to address the ability of family and friends of an individual with significant developmental disabilities or the person with developmental disabilities to manage services.

Current rates simply do not support robust and healthy life styles and fail to realistically address transportation costs, wage rates necessary to attract quality staff, staff absenteeism and the complex regulatory environment of this state, including workers compensation and labor law compliance.

Self-direction is akin to running a small business and most individuals eligible for OPWDD services and their circles of support are ill equipped to successfully manage this type of small business.

The Transformation Agenda's overreliance on self-direction as the appropriate model for a significant portion of the population it serves is unrealistic and counter productive.

DDAWNY has significant concerns as to how individuals can find and keep jobs when transportation from and to these jobs is either unavailable or unaffordable.

DDAWNY believe OPWDD needs to maintain and continually update the Residential registry and use web-based portals to permit families to update information.

DDAWNY strongly believes that the needs of individuals with disabilities must be respected and state policy ought to support a wide range of choices for people with disabilities in where they live, work and otherwise participate in the community.

DDAWNY is supportive of OPWDD's vision of a continuum of housing opportunities to ensure that there is a range of residential options available based upon individual needs and abilities.

In particular, DDAWNY believes all people need a choice in where to live. Quality, affordable, accessible housing with the services and supports necessary to permit individuals with disabilities to interact with the community at large is essential.

At the current time there is a critical need for additional supportive housing opportunities for persons with disabilities, particularly for individuals with Intellectual Disabilities or related Developmental Disabilities (ID/DD).

The Transformation Agenda fails to acknowledge the very real need for additional residential development, particularly for those who are medically frail and behaviorally challenged and those who are on waiting lists for residential services.

In addition to affordable and accessible housing individuals with developmental disabilities need accessible and affordable transportation options in order to permit these individuals to pursue employment opportunities, enhance personal independence and productivity, participate more fully in an interdependent society, more fully integrated in the community and enjoy an improved quality of life.

Unlike other managed care populations, most individuals with developmental disabilities will never be able to obtain a drivers license or own a car. In many parts of Region One, particularly in the rural and outer ring suburbs, mass transportation is simply not available.

DDAWNY continues to be troubled by the idea of "assessed need" driving the OPWDD transformation agenda. DDAWNY believes the assessment tools OPWDD is currently using and the scoring levels produced are flawed and do not correlate with the actual staffing needs of individuals being served; as a result OPWDD is badly underestimating current need for services, especially more intensive service needs; the new tool being piloted is badly delayed and we are not at all comfortable believing the scores the new tool produces will correlate with a high degree of confidence to the staffing support needs of individuals who require services

At the present time, OPWDD is using the DDP-2 to develop scores permitting OPWDD to group individuals according to their individual services planning model (ISPM) groupings. Large numbers of Individuals with ISPM scores of "1", representing "low needs", reside in certified settings, attend day habilitation or are living at home with aging caregivers. OPWDD has indicated that the new Front Door process will not allow those with an ISPM score of "1" into a day habilitation program in "99% of cases". The same thinking apparently applies to additional certified housing development. OPWDD is now requiring MSCs to provide substantial additional "justification" to place those with ISPM score of "1" in a certified setting. OPWDD has not issued any guidance or administrative memorandum on what this justification is to contain.

DDAWNY believes the DDP-2 is a flawed instrument. The DDP-2 was never designed to allocate resources. The scores generated in answer to the DDP-2 questions have little if any correlation to the worker staff needs of those being scored. Yet OPWDD and apparently DOB view these numbers as gospel. Of course we only need 474 new certified beds in FY16 if many of those currently in IRA's have scores of "1" and most of those at home or exiting school have scores of "1".

DDAWNY believes this policy assumption is simply wrong.

The DDP-2 scores are seriously flawed and the use of these scores by state and federal policy makers cripples the system redesign by seriously underestimating the actual level of acuity for much of the population we serve and significantly underestimates the staff needed to serve this population and the costs associated with supporting this population.

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DDAWNY rejects the validity of these scores and believes a realistic view of need based upon the person centered planning model given lip service by OPWDD and CMS, driven by a well thought out and data driven plan to address the goals, aspirations and needs of individuals with developmental disabilities ought to be the basis for budget decision making, not inaccurate invalid ISPM groupings based upon scores generated by a flawed assessment tool.

Each year thousands of individuals graduate from special education programming into OPWDD care. DDAWNY fully supports the State's initiatives aimed at increasing the employment opportunities for individuals with developmental disabilities. We applaud the focus on youth graduating from high school and the system changes that are needed to make employment the first and best option.

DDAWNY believes, beginning at age 14, there is a critical need to link a person's individual education plan to the person-centered planning process to achieve greater independence and connection to community-based services and supports. Unfortunately many individuals with developmental disabilities lose their naturally occurring social networks following their transition from the educational system into the adult services system. The OPWDD "Front Door" fails to address the development of the supports necessary to allow these individuals to develop relationships and participate in communities.

Moreover the Front Door fails to appropriately utilize and give appropriate weight to the many SED assessments and tools, including the SED exit documents which have been developed by the education system and which should be used by OPWDD in developing a transition to adult activities.

DDAWNY would urge the Assembly to continue to monitor the Transformation Agenda and address the concerns DDAWNY and others have raised regarding financing, wages, the need for additional day activities, the need for additional housing opportunities, the need for a valid assessment tool, more collaboration between school-based and adult programming in the transition to adult services and the critical role transportation plays in the ability of individuals with developmental disabilities to live a more integrated life.

Respectfully submitted

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