

Comments  
from the  
New York State Rehabilitation Association's  
Policy Committee  
on  
Draft Recommendations of the Transformation Panel  
convened by  
NYS Office for People With Developmental Disabilities

Moving beyond a system organized to care for people by type and group, to supporting an individual in full pursuit of citizenship is nothing less than transformational. Implementing a change of this nature requires radical shifts in thinking, behaving and individual/provider relationship. With all the success the developmental disability systems have had in evolving away from institutions to community services, the move towards citizenship remains stuck for many individuals. Working towards this purpose is less an exercise in designing a total solution for all, and more a matter of navigating uncharted social fields. True transformation of our current services to individualized supports requires a regulatory context that encourages - rather than inhibits - creativity. In an over-prescribed world, the innovative thinking and action that is necessary to birth the next generation of supports is dampened. Our interest in truly transforming the life experience for a person with a developmental disability requires an act of social innovation and the nurturing space and resources to make it happen.

Our comments are directed towards this notion that transformational change requires experimentation and testing of new support approaches to complex problems that are immune to current technologies. Specifically, we need to give oxygen to innovators in self-direction, employment, managing care and housing. The assumption is that we don't have the answers, but we are seeking solutions. We believe in the process of learning and innovating, better solutions will emerge. From this point a transformational shift will occur.

That said, the draft Transformation Panel recommendations are, frankly, underwhelming - offering high level concepts that are largely difficult to argue against. Few tangible approaches and details make them uninformative. Where details are offered, they read almost as a "to do" list. This blueprint appears to lack the specificity necessary to result in any change that could be perceived as "transformational."

As a diverse cross-section of providers of services to individuals with intellectual and developmental disabilities, we stand ready to help shape the system of the future – one that is sustainable, will provide access to people unsupported or under-supported, and address those instances where individuals and families hold onto resources they don't necessarily need out of fear they will lose access to those resources should the need arise in the future. Government, and providers acting on behalf of government, are responsible for being good stewards of the public's resources. That responsibility is best accomplished when policies and operational structures are focused on the best individual outcomes. And, as has remained true since the first days of community-based supports, the best individual outcomes are achieved in an environment that encourages innovation and creativity, rather than one that enforces compliance, only allows prescribed methods, and penalizes supports that do not conform with strict conventions. We stand, eager to take on the challenges of a transformation, if OPWDD can create an environment in which that is possible. Please consider our comments with this spirit in mind.

## WORKFORCE

The current difficulties to recruit and retain quality candidates for direct support roles have reached crisis levels. The recent NYS initiative to increase the minimum wage for fast food workers has exacerbated the staffing problem significantly. Now, the proposed 2016/17 Executive Budget contains a \$15 statewide minimum wage, but includes only a \$.03 per hour increase to move DSP salaries to the newly mandated pay levels. What has been an everyday challenge to recruit direct support professionals (DSPs) now presents the greatest threat to the continued delivery of supports to individuals with developmental disabilities in NYS.

The lack of emphasis in the Transformational Plan recommendations on workforce investment is disconcerting, given that DSPs are the core of service delivery. The Panel's recommendations in this area must include increased funding for competitive wages and related development initiatives (e.g., credentialing, career advancements). The ability to continue delivering supports depends entirely on an experienced, professional workforce that can make a reasonable living doing this work. The consequences of failing to fund developmental disability services agencies this year, who will have to comply with an increased minimum wage and compete for qualified employees with other sectors that have higher mandated compensation rates, cannot be understated: systemic failure will begin.

## FLEXIBLE SUPPORTS

The call to support each person's life trajectory disrupts our current menu of program offerings and moves us into individual supports design. Supporting people with developmental disabilities as citizens, as opposed to clients of a system, necessitates a shift from uniform and predictable services to emergent and flexible supports. The recommendations of the Transformational Panel identify the importance of flexibility in the sections related to residential and employment/life.

Understanding how critical it is that government acknowledges their role in creating a regulatory context for innovations in supports design is a great step towards aligning our services with our goals

for transformation. Now we must take additional steps towards clarifying what is meant by flexibility. Will current services be blended to allow for fluid movement between employment, community membership and volunteer experiences and home life? Will highly prescriptive regulations, onerous paperwork and cumbersome approval processes be suspended in favor of organic and ongoing support arrangements? Will supports be easily adjusted to address intensity of individual needs as they arise?

Truly, the move from stable and bureaucratic programs to flexible supports is transformational. Should the challenging questions articulated above remain unanswered – we will remain stuck in the current service environment.

## SELF-DETERMINATION

Moving individuals into the driver seat of their own lives is imperative when considering the transition from client to citizen. While important as an overall guiding principle for a population of individuals with developmental disabilities, on the personal day-to-day level, unique individual solutions are difficult to envision and enact in today's service system. How to translate our current program-based system into an individually responsive arrangement is largely unexplored territory.

Again, the devil is in the details. Current self-directed arrangements are tied to waiver service categories and their requisite paperwork requirements. Perhaps it is fair to say that what is required is more flexibility of funding, not less, as is the case with the present arrangement. Applying concepts of self-direction to current traditional waiver programs is even more confounding.

While the Transformation Panel recommendations clearly embrace the intention to infuse self-direction into our service environment, they give us no additional clarity about how to do this other than offering a high concept. With additional clarity we hope to empower individuals with disabilities in the decision making process by allowing them to create market competition among various options for getting supports – essentially allowing individuals to shop for the “best deal” or the supports that best fit their needs.

## MANAGED CARE

The field of developmental disabilities largely understands that managed care for the population of individuals with developmental disabilities will eventually come. We also understand that managed care is the State's method of shifting risk to the field. Our concern is that it be done the right way and by those that understand the needs and valued outcomes necessary for people with IDD.

However, given the lack of experience in successfully implementing a managed care model for services and supports to individuals with developmental disabilities anywhere in the United States, this area is an excellent example of where planful and careful experimentation is the wisest approach. Case in point is the IDD FIDA, which seeks to demonstrate effective care coordination and appropriate levels of risk for individuals with developmental disabilities receiving Medicaid and Medicare funded supports. Unfortunately, the principles embodied in the IDD FIDA appear largely

ignored. Instead, a mostly typical managed care medical/insurance approach is being pursued, wherein the State would rely upon a health insurance model that has, frankly, failed miserably when it comes to habilitative and long-term supports.

The model being discussed publicly would capitate payments to existing health insurance MCOs and have them coordinate health care while contracting with an IDD conglomerate to coordinate habilitative and long term supports. Finally, all residential habilitation in certified housing would remain on a fee for service basis. This approach is misguided in a number of ways:

1. Instead of proposing a system that is designed to manage all of a person's needs, this approach splits the person into three parts; health/medical, non-residential habilitation and residential supports. Instead of the care coordination that could be achieved by managed care this design focuses on (and, likely guarantees) uncoordinated care. In addition, the approach of leaving existing residential supports as fee for service guarantees a more difficult process for any MCO trying to coordinate that part of a person's life.
2. This approach puts Health Insurance MCOs in charge of all the funds, even though medical is only 14% of the total supports and habilitation is much more significant to the life supports that people with IDD rely upon. It also initiates the resource decision with entities that are risked-based and do much to avoid people with pre-existing conditions and are constantly "creaming" in order to generate their 12% (6% overhead; 6% profit). It also put the funding in the hands of corporations that make care decisions based upon business statistics (such as dropping independent practitioners from their provider base) versus knowledge and consumer need.
3. Instead of streamlining overhead, this approach triples the number of entities requiring administrative and overhead funding without considering if any value is added.

The draft recommendations suggest that managed care and value based payments are the answers to parents' fears about the future for their loved ones. In fact, when the questions being asked by parents relate to addressing the needs of their loved ones, and listening to their concerns about the needs and responding to them, existing MCOs and their practices are far from the answer that gives them comfort. Nonetheless, we believe that many of the fears of families regarding managed care can be addressed with good options demonstrated in the spirit of innovation and the process of learning from trying new things articulated earlier. The IDD FIDA is one such example - if it proves effective, we should seek to expand and replicate that model; if it proves ineffective or produces unforeseen consequences that are no better than the current system, we should try other, new approaches.

## VALUE-BASED PAYMENTS

Value-Based Payments are thought to have utility in rewarding the elimination of unnecessary health care and achieving good health outcomes. Their relevancy and fit with supporting individuals with developmental disabilities achieve real life outcomes in the community remains untried, therefore untested. We consider the application of value-based payments to services for the developmentally disabled both exciting and daunting.

It is exciting because of the opportunity to disrupt ways of providing services by incentivizing new support forms in the area of individualizing supports. This new concept can not only create the flexibility necessary to innovatively and holistically meet individual needs, but make self-determined individual outcomes the paramount concern of providers.

It is daunting because personal life outcomes are difficult to measure and locate a payment friendly outcome. Additionally, this field has only just begun a very long journey to identify outcomes and ways to measure them. This may take decades, in part due to the complexities related to living a life as a person with a developmental disability in today's world. That said, we recognize that the social determinants of health are now better understood, which correlate well with the needs of the IDD population in day-to-day, habilitative supports. Providers are in a unique position and can lend greatly to the effort to define how life roles are factors in shaping health and wellness for the people we support and are a critical component of the delivery system that will be most effective. We are most eager for the conversation about Value-Based Payments for the IDD population to begin in earnest and stand prepared to contribute what we can.

Lastly, due to a history of exclusion, people with developmental disabilities require life experiences and the learning that comes from trials of success and failure before finding an outcome that fits. We must be cautious not to establish one-dimensional incentive systems that penalize providers as they support an individual through the natural ups and downs of life (e.g., getting fired from a job that wasn't a "good fit").

## REGULATORY FRAMEWORK

Under the heading of "Flexibility and Responsiveness" the draft recommendations call for streamlining regulations. The irony of this statement, in light of the onslaught of regulations, policy directives and administrative directive memoranda (ADMs) that are constantly being developed by the State, is remarkable. Just to name a few, consider the Justice Center and the processes it requires, the Article 16 clinics with the Certificates of Need, and the latest Medicaid transporter enrollment requirements. In fact, during the past year there have been at least 20 more of these directives. Each one requires the establishment of new policies and procedures that must be developed, communicated and involve training of all staff. Hardly the environment that promotes innovation and creativity, we discussed earlier.

True transformation would focus upon looking at the current regulatory framework and determining the value added by the mountains of requirements and paperwork. In addition, these unfunded mandates should also be looked at in light of the impact they have on staff's ability to provide direct support to the people they support.

## CONCLUSION

In closing, we consider these draft recommendations incomplete. While many of the concepts have merit, collectively, they fall short of a transformational guidebook, as billed. Instead, alterations and additional detail are needed before these recommendations can be considered as "transformational."

Thank you for the opportunity to comment.

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