DDAWNY Family Committee Meeting Minutes/Notes

May 17, 2016

ASPPIRE of WNY

7 Community Drive Cheektowaga, New York

1. General Update:
   1. The Transformation Panel (T.P.) – Meeting in Albany with T.P. provided overview of project management process, tools and methodology that will be used to plan and implement the 61 recommendations.

The DDAWNY Family Committee (F.C.) previously responded with a position paper on the draft recommendation document issued in January which included the following:

* + 1. Concerns:
       1. A sound working plan for the 61 recommendations made to the T.P. Consistent Methodology needed:
          1. Working Plan must include detailed tasks, accountabilities, dependencies, completion dates, regulatory & fiscal concerns, etc.
          2. The needs of individuals and families are complex and great thought to detail is needed.
       2. We NEED to see solid CONTENT/Working Plans that follow the above criteria and more.
  1. Community Champion Process:
     1. The FC is searching for people of influence within society and the community to help address the needs of individuals and families. Anyone with potential candidates to fill the role is requested to see a core team member.
  2. Statewide Group Update:
     1. MAKE LEGISLATIVE MEETINGS a top priority and TAKE YOUR LOVED ONE with you!!!!!
        1. Between this and our next meeting in June make an appointment with your legislator(s).
        2. Kathy met with Senator Robert Ortt (N.Y.S. Chair for Mental Health and Developmental Disabilities.)
     2. The state wide group is also looking for T.P. plan specifics and wants it to be a pro-active process.
     3. Transition failures are a reality and must be addressed.
        1. More than 1,000 people are “Priority 1” in NYS. What is the plan?
        2. There is to be $10 million appropriated across NYS’s DDRO’s
           1. We want WNY to get their fair share.
           2. Who is allocating it?
           3. How will it be allocated?
     4. A key point to remember in advocating for your loved one…Just because they or your family is approved for a service doesn’t mean you will get a service.
        1. Staffing hold-ups?
        2. Financial hold-ups?
        3. Etc…
     5. These are the same issues across the state.
     6. We have heard from a similar group in Connecticut and their issues are the same as NYS’s.
     7. EVERYBODY NEEDS to make legislative appointments and VISITS!!!!!

1. OPWDD Update - Kirk Mauer (DDRO 1 – Director) and Kevin Penberthy (DDRO 1 – Deputy Director) – DDRO is dealing with systemic issues.
   1. In Roads (Example) – Respite supports are very significant resource to families.
      1. Unfortunately there was a rush to a solution that proved to be unsupportive of individuals and families.
      2. Advocacy was critical in getting the Health Department to realize how vital this support is. Therefore the Federal Government has delayed deadlines in order to “get it right”. ADVOCACY from families is what accomplished this result.
   2. Transformation Panel – Have 61 recommendations for across NYS.
      1. OPWDD lives in the “here and now” and the challenge is to address these 61 issues.
         1. The Goal – OPWDD could address all 61 issues simultaneously and do poorly or prioritize them and do well.
         2. The recommendations have been divided up and prioritized in shape and substance.
         3. The next stage is to put together a road map/structure in order to address these in an orderly fashion.
      2. It is understood that there is urgency for individuals and families.
      3. The key is through advocacy to hold their feet to the fire in Albany.
   3. Residential:
      1. NYS CARES List was a mess.
      2. Certified Residential Opportunity (CRO) list/registry – a mechanism used to determine residential need.
         1. Individual with highest need aligned with appropriate levels/environment.
         2. “Priorities” are now “Categories”.
            1. Category One (1) – Most Intensive Need.
            2. Category Two (2) – Second Most Intensive Need.
            3. Category Three (3) – Least Most Intensive Need.
         3. IF you were on the previous NY CARES List, this does NOT put you on the CRO list/registry. You MUST ask your Medicaid Service Coordinator (MSC) and or DDRO to confirm if you are on the list/registry and what category your loved one occupies.
            1. Inform your MSC of your loved one’s possible change of need that has taken place to intensify the need for CRO placement.
         4. Brief Category “Definitions”:
            1. Category 1: Approximately 200 individuals in WNY

Individual is at imminent risk to health and safety.

Unsafe Situations – Homelessness, abuse/neglect, hospitalized, cannot return to previous living situation.

Need home “yesterday”.

* + - * 1. Category 2: 179 individuals in WNY

Individual has imminent risk of becoming Category One.

There is increased risk to their health and safety, or they are a risk to themselves and others.

* + - * 1. Category 3: Approximately 200 individuals in WNY

Placement is needed.

Caregivers are aging.

Health situations of caregivers are changing.

Natural or Paired Supports cannot be done or are non-existent.

They do not want to go into CRISIS!

* + 1. Residential Request List (RRL)
       1. Agency Residential Vacancy
          1. Agency contacts DDRO – “What does vacancy look like?”
          2. The agency is provided with 1 or 2 individuals who are Category 1 and work their way through Category 2’s and Category 3’s
          3. Individual and Family’s Level of Urgency may determine residential placement location:

7 Counties in WNY?

17 Counties of Region One (1)?

Somewhere throughout NYS?

* + - 1. How may openings occur?
         1. Movement
         2. Resident’s Demise
         3. OPWDD estimates 10-15% in Certified Homes could reside in Uncertified Residential options.

In the event of this type of movement there needs to be a “Safety Net” in place for those who may be unsuccessful.

Service providers have grouped together for a “pilot program” to provide “safety nets”.

* 1. ’16-’17 NYS Budget – The Budget is now 1.5 months old/in effect.
     1. OPWDD budget is 4.5% greater than last year’s budget.
     2. There is $120 Million for new development of ALL types. For people coming into the system and those in the system already.
        1. ½ ($60 Million) must be expended on those individuals living at home with aging caregivers and those individuals graduating/transitioning from school.
           1. $10 Million of this $60 Million will be divided up between the 5 Regions of NYS.
           2. + or - $2 Million per Region.
           3. Looking to meet the Category 2 & 3 Individuals.
           4. Local Task Force Team is being formed to determine how to divide the money.
           5. Advise how to bets use resources.
           6. Accept any idea as to how best use money.
           7. Rules not composed as of yet for the Task Force – Look for 30 – 60 days down the road.
        2. $15 Million is earmarked for Affordable Integrated Housing Opportunities across the State.
  2. Direct Service Providers (DSP’s) Wages
     1. More people need care than are available to provide care.
     2. Many caregivers are exhibiting a need for caregivers themselves.
  3. Comprehensive Assessment System (CAS) – OPWDD’s & NYS’s better methodology to assess needs of individuals.
     1. DDP 2 was 1970’s Technology.???
     2. CAS brings valid assessment tool to Managed Care.
     3. CAS is in Development and Validation stage.
     4. It has been used and validated in small groups.
     5. CAS has yet to be used broadly.
     6. It is not “perfect” but significantly better than DDP 2
     7. Feds say, “If you want funding, use it!”
  4. Workshops
     1. Every Workshop is developing a Transformation Plan.
     2. Every Workshop is Transforming.
     3. Criteria is being developed for Transformation.
     4. There are two (2) options provided to agencies:
        1. Option 1 - Agency can continue if 40% of workshop workforce are non-disabled (60% have a developmental disability) and other work is taken into facility.
        2. Option 2 – Agency can continue with 75% of workforce having a developmental disability (25% non-disabled workforce) but have an extra burden of proof of integrated opportunities is needed.
        3. Until option work settings have achieved option 1 or 2, new applicants will not be considered.
     5. Goal – Businesses to “look” closer to everyday lives.
        1. Diversified population(s).
        2. Interfacing with the community.

NEXT DDAWNY Family Committee Meeting – June 21, 2016 – Plan on Attending!!!!!