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**Health Care Reform: Ensuring Comprehensive Needs of Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illness are Addressed
NADD US Public Policy Statement - One Year Later Update and Next Steps**

In October 2014, NADD sponsored a national policy forum for key stakeholders in North Bethesda, MD. Representatives included families, federal agencies, managed care organizations, disability associations, providers and advocates. The focus was on NADD's US Public Policy Committee's position statement, *Including Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illness: Challenges that Must Be Addressed in Health Care Reform* (<http://thenadd.org/wp-content/uploads/2013/10/NADD-Position-Statement-on-letterhead1.pdf>). Participants responded to the policy statement and initiated a strategic planning process to ensure that needs of individuals with co-occurring IDD and mental illness are addressed in our changing health care environment. The strategic plan focuses on four areas each addressed through a subcommittee.

The first priority - Cost/Cost Savings chaired by Christina Carter, Smoky Mountain MCO CEO, collected and analyzed available data from Smoky Mountain to support initial prevalence information on costs and cost savings to spur governmental attention to enhanced community services and adoption of best practices. The sample came from persons being served within the North Carolina (NC) Innovations is the Home and Community Based Waiver. Of the 1570 people who were participating in the Waiver, a sample of 211 participants was randomly selected. 52% were confirmed to have a co-occurring mental health diagnosis. From the sample of 211 people, 20 people were randomly selected who are diagnosed with IDD and a co-occurring mental health disorder; 20 additional people selected who are diagnosed with an IDD or related condition; and the total sample size of 40 people. The cost data was pulled from paid Medicaid paid claims between 1/1/14 and 1/1/15. Data did not control for age, gender, race, physical health status, or residential setting. Resulting findings identified that:

- IDD only group ranged in age from 11-73
- Co-occurring group ranged in age from 16-61
- Co-occurring group included (but was not limited to) the following MH diagnoses of

OCD, Schizoaffective Disorder, GAD, MDD, Disruptive Behavior Disorder, Anxiety and NOS, PTSD, ADHD, Bipolar, Depression Conclusions from the data review:

- « It generally costs more to support individuals with co-occurring conditions
- There are opportunities to utilize best practices to address co-occurring needs from prevention level to acute level
- Integrated care and inter-disciplinary collaboration are critical
- Training is required to grow expertise on evidence-based treatment of individuals with co-occurring IDD/MH in the provider community

The second priority - Federal Agency Coordination chaired by Vicki Gottlich, Department of Health and Human Services, Administration for Community Living Director, Center for Policy and Evaluation, identified how federal are each currently enhancing services and policies for individuals with IDD and MI disorders. The resulting report will be available by

early 2016. The intended next step will be to review and collaborate on a research agenda including attention by at least ASPE, NIDILRR, and NIH to:

- Establish baseline of who we are talking about
- Be more inclusive in research practices
- Support research for establishing evidence based practices
- Adapt evidence based practices to this population
- Environmental scan of what states are doing

The third priority - State Inter System Collaboration chaired by David Miller, NASMHPD Project Director (and next steps to be co-chaired with NASDDS). The revised process and outcome, supported with NASMHPD funding, is a written report based that NASMHPD collaborated on with Georgetown University Center for Child and Human Development, National TA Center for Children's Mental Health. The learning community resulting report was with 3 states regarding their modeling approaches and lessons learned to addressing children and youth with IDD and co-occurring mental illness. The following identifies how these states addressed the target population:

- **State A:**
 - o No System of Care (SOC) infrastructure for any population
 - o Poised to roll out a state-wide initiative
- **State B:**
 - o SOC infrastructure at both local and state levels but target population not included
 - o Limited connection between the two levels
- **State C:**
 - o Had a fully implemented SOC infrastructure for children, which included the target population

Field Implications:

- * There is a huge need to support the target population
- * It isn't necessarily about finding new money but about collaborating to serve this population through policy, infrastructure and service/support changes
- * Cross-agency data collection is important to making decisions
- * Collaborative work focused on this population would reduce states' vulnerability to legal action
- » Having an independent facilitator, not associated with state government, to assist with strategic planning is extremely important Next steps include using the paper as a springboard for continued planning by this Subcommittee; support of a NASMHPD and Georgetown call with state mental health children's coordinators; and a NASMHPD sponsored webinar with state mental health commissioners.

The fourth priority - State MCO Contract Specifications chaired by Jeff Keilson, Senior Vice President, Advocates is addressing MCOs' lessons learned from effective programs and development of state-MCO/ACO contract specifications, mandated outcomes or other requirements as well as contract specifications/requirements between MCOs/ACOs and service providers. This subcommittee consists of all stakeholders including MCO representatives. Its report will include provider and MCO recommendations regarding:

- Diversion from emergency departments

- Reductions of hospitalizations and re-hospitalizations, both medical and psychiatric
- Reduction of length of hospital stay
- Effective care coordination provided by people/agencies who know the needs of people with I/DD
- Investment in long term services and supports that impact physical health and behavioral health expenditures
- Integration of physical health, behavioral health and long term services and supports
- Pilot or local initiatives that work Next steps are to:
 - Expand involvement of interested people/organizations across the country, including Medicaid
 - Complete gathering information through survey and other methods
 - Finalize recommendations for states and MCOs/ACOs
 - Distribute to key stakeholders

In summary, the combination of subcommittee product reports will identify next steps in ensuring that the October 2014 Policy Statement Meeting's strategic plan results in actions to address the Statement's identified issues and challenges in addressing health reform across the nation.