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October 16, 2013

The Arc of Virginia's Comments on Medicaid Reform

Thank you for the opportunity to provide comment on the implementation strategies outlined in the Medicaid Reform budget language. As a statewide organization of and for people with intellectual and developmental disabilities (I/DD) and their families, The Arc of Virginia has a deep and vested interest in the pending Medicaid Reform issues affecting people with I/DD. Established in 1955, our mission is to promote and protect the human rights of people with I/DD and actively support their full inclusion and participation in the community throughout their lifetimes. We are a state chapter of The Arc of the United States, the nation's oldest and largest organization for people with I/DD, and are comprised of 25 local chapters from across the Commonwealth.

The Arc of Virginia's comments will focus on the "Phase 3" reforms that related to long-term services and supports for individuals with intellectual and developmental disabilities. The budget describes these reforms as: "The Department of Medical Assistance Services shall seek reforms to include all remaining Medicaid populations and services including long-term care and home-and community-based waiver services into cost-effective, managed and coordinated delivery systems. The department shall begin designing the process and obtaining federal authority to transition all remaining Medicaid beneficiaries into a coordinated delivery system. A report shall be provided to the 2014 General Assembly regarding the progress of design and implementing such reforms."

Current Reforms of the I/DD System:

The Arc of Virginia supports reforms of the I/DD service system that are consistent with the U.S. v Virginia settlement agreement and with the Commonwealth's stated policy priority of improving access to quality, community-based care for Virginians with I/DD. These Medicaid reforms include:

- **Transitioning Virginia's service system for people with I/DD from one that is reliant on large, segregated, state institutions to one that is focused on integrated community-based services;**
- **Preventing costly and unnecessary institutionalization by providing help to families on the ID/DD Waiver waiting lists;**
- **Redesigning the ID/DD Waiver program so that it better serves people with intellectual and developmental disabilities, including those with complex needs, in the most integrated settings;**

Virginia's use of large state institutions to serve people with intellectual and developmental disabilities is an outmoded and costly model of care. It costs \$225,000 per person, per year in Medicaid dollars to keep an individual with ID/DD in a state operated facility. It is much less expensive to serve someone with equivalent needs in an integrated community-based setting. Community settings are not only more cost effective; they also provide a higher quality of care and are more individualized. Moving to a community-based system of care will help the Commonwealth more effectively manage resources and improve the system of service delivery.

This is important because there are currently more than 7,600 Virginians with intellectual and developmental disabilities who are on waiting lists for community-based care. More than half of these individuals are in urgent need due to crisis situations such as living with an aging or ill caregiver, aging out of foster care, risk of abuse or neglect or are homeless. Thousands of these Virginians and their families have been waiting several years for needed supports. Providing help to these individuals is a cost-effective strategy that prevents unnecessary institutionalization. It will also help state comply with the Americans with Disabilities Act as interpreted by the *Olmsted* decision.

In order to implement these important reforms, expand access to services and facilitate safe and successful transitions to community based services, Virginia must take steps to reform its ID/DD Waiver program. This reform is occurring through DBHDS' ID/DD Waiver redesign initiative. *(Please Note: The Arc of Virginia will be providing the Medicaid Innovation and Reform Commission with separate comments related to this specific reform effort when they are submitted to DBHDS.)* Since Waiver Reform will not be complete until FY2016, it is essential that the Commonwealth provide "bridge funds" to develop quality, community-based services to facilitate safe and successful transitions, particularly for the Northern Virginia region. Doing so will help the Commonwealth achieve these long overdue reforms safely and responsibly, keeping people safe and truly improving access to quality care.

Proposal to Transition I/DD Services to Capitated Managed Care:

The Arc urges caution when contemplating the use of managed care for long-term services and supports for people with ID/DD, especially when based on use of private, for-profit insurance agencies who lack experience and expertise in the area of I/DD services and supports. Transitioning from a fee-for-service to a capitated managed care system is a complex undertaking which, if carried out in a haphazard, hasty manner, will place the health and well-being of Medicaid beneficiaries with severe disabilities at risk

For beneficiaries with I/DD, any shift to a system of managed long-term services and supports (MLTSS) needs to be synchronized with efforts to fulfill the Commonwealth's obligations under the terms of the I/DD settlement agreement with the U.S. Department of Justice (USDOJ), including planned reductions in the training center population, extension of supports to persons on service waiting lists, and fundamental reforms in the delivery of community-based services. DBHDS must also be allowed to complete its historic reform of the ID and DD Waiver programs, which is currently underway, before any transition to managed care. **The Arc of Virginia cannot support a shift to a Medicaid managed care system that would undermine achievement of the goals of the settlement agreement and Waiver Reform, therefore, recommends that the enrollment of persons with I/DD in managed care be postponed until progress on achieving the system reform goals outlined in the settlement agreement is well advanced and the Waiver Reform process is complete.**

Furthermore, any decision to move Waivers to managed care must reflect the input of individuals with I/DD and their families. People with I/DD cannot provide meaningful feedback until there is an understanding about this significant change in policy would impact access to services and supports. There are many questions that remain unanswered. What are the policy goals driving the initiative? What would the new system of care look like and how would it work differently? Who will decide eligibility and allocation of resources? How will the Commonwealth prevent backsliding into a medical model? How will existing Waiver dollars be protected if the Commonwealth moves to a risk-based model with for-profit providers? How will

the Commonwealth ensure safety and quality if MCOs have no experience in the area managing/providing services for people with I/DD?

Essential Elements to Address in a CMS Concept Paper:

If the Commonwealth decides to pursue capitated managed care for people with I/DD, it appears that DMAS intends to initiate the change process by developing and sharing with CMS a concept paper spelling out the steps the Commonwealth plans to take to transition persons in need of long-term supports to managed care programs over the next few years. It is imperative that DMAS address in its forthcoming concept paper the essential elements of an effective long-term services and supports program as spelled out in guidelines recently issued by CMS.¹ As part of the “thoughtful, deliberative planning process” recommended by CMS, DMAS should include in its forthcoming concept paper:

- A clearly articulated vision of the program’s aims. Long-term supports for individuals with I/DD should: (a) allow such individuals to live full, healthy, participatory lives in communities of their choice; (b) be person-centered, consumer and family driven, and offer a full array of opportunities for self-direction; and (c) afford working age adults with I/DD opportunities to secure and retain competitive employment. This vision is fully consistent with the terms of the settlement agreement with USDOJ.
- Solicit and consider input from disability stakeholders, including individuals with intellectual and developmental disabilities as well as their family members and providers. In keeping with CMS guidance, DMAS should appoint a MLTSS stakeholder advisory group that includes a cross-section of beneficiaries with disabilities, providers of disability services and supports and family members. There should also be an I/DD specific subgroup that is empowered to address issues specific to the I/DD population. The department’s stakeholder engagement strategy should also specify the methods to be employed in involving stakeholders in the MLTSS planning and implementation process. In particular, the engagement strategy should specify the methods the Commonwealth will use to give stakeholders meaningful roles in quality management and oversight, such as designing program evaluations and monitoring performances against the state’s LTSS reform goals.
- Transparency and Provide Continuous Opportunities for Public Comment: Consistent with CMS guidance, DMAS also should outline how it will provide broad opportunities for public input during the development and implementation of the state’s MLTSS plan by: (a) scheduling periodic listening sessions in geographic locations throughout the Commonwealth; and (b) establishing a dedicated website where relevant documents are posted and comments solicited. All people with I/DD and families receiving long-term care services, as well as individuals and families waiting for services, should receive communication about proposed program decisions and have opportunities for public comment.

¹ Centers for Medicaid and CHIP Services, “Guidance to States Using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs,” May 20, 2013

- Analyze existing arrangements for delivering publicly-funded long-term services and supports. With respect to the I/DD population, this analysis should be carried out in collaboration with the Virginia Department of Behavioral Health and Developmental Services (DBHDS), which is the lead program agency for people with I/DD. The aim of the analysis should be to develop a unified approach to administering LTSS at the state, regional and MCO level. Among the critical issues that will need to be resolved is the role of existing case management in overseeing the delivery of I/DD long-term supports as part of a managed care plan. Will the case managers' existing roles in service planning, coordination, service development and oversight be retained or superseded by the integrated care coordination function of the MCOs? And, if the latter approach is adopted, what steps will be taken to ensure continuity of service relationships for individuals with I/DD as they are enrolled in managed care plans? What would be the future role of the CSBs? How would people with I/DD who are not receiving Waiver services be affected by proposed changes?
- Assess the readiness of state government, the MCOs and existing I/DD providers and support systems to effectively implement a MLTSS program, including the provision of education and training for the staff of MCOs, providers, individuals with disabilities and their family members in the key operational components of the system. The MLTSS program should not be initiated until state government, MCOs and disability provider agencies have demonstrated their respective capabilities to effectively administer the program.
- Enhance the provision of home and community-based services (HCBS). Consistent with the state's obligations under the Americans with Disabilities Act as interpreted by the U.S. Supreme Court in *Olmstead v. L.C.* and the I/DD settlement agreement with USDOJ, the goals of the MLTSS program should be compatible with the requirements outlined in CMS regulations and policies governing HCBS. In particular, the concept paper should outline the steps that will be taken to ensure that persons with I/DD gain access to integrated day services and residential supports that promote participation in mainstream community activities.
- Align payment systems with LTSS goals. The concept paper must outline the steps state officials will take to ensure that payment structures are properly aligned with the goals of the MLTSS program. Performance-based incentives and penalties should be built into the payment system to ensure that MCOs and providers are rewarded (or penalized) for successfully (or unsuccessfully) pursuing system-wide reform objectives. In addition, DMAS should review and evaluate payment structures on a regular basis to ensure that rates remain current and are contributing the achievement of the Commonwealth system reform goals.
- Support beneficiaries. Participants in the Commonwealth's MLTSS program should have access to accessible, conflict-free enrollment/disenrollment assistance, support coordination and advocacy

services. DMAS' concept paper should spell out the steps that will be taken to ensure that MLTSS program enrollees (and potential enrollees) gain access to such support. The paper also should explain how existing enrollment, support coordination and advocacy functions available to Medicaid beneficiaries with I/DD will be integrated into the planned MLTSS program.

- Person-centered services and supports. DMAS' concept paper should outline the steps that will be taken to ensure that standardized needs assessment and person-centered planning processes are used by MCOs and providers of direct services and supports. In addition, the paper should describe how standardized assessment instruments and service planning processes will be adapted to the particular needs of persons with I/DD as well as other sub-populations of MLTSS recipients. The resulting service plan must reflect the participant's and, where applicable, the caregiver's needs and preferences and show how those needs will be met through a combination of covered services plus community supports otherwise available
- Comprehensive, integrated services. The concept paper should describe the actions to be taken to ensure that Medallion II enrollees receive an integrated array of physical and behavioral health services as well as long-term services and supports. In particular, the paper should describe: (a) how acute medical and behavioral supports will be coordinated with the delivery of long-term services and supports without subordinating efforts to integrate such individuals into the mainstream life of the community; and (b) the assistance that will be available to help enrollees with disabilities and their family members to access the full range of needed care and supports from multiple providers in a coordinated manner.
- Recruiting and maintaining a network of qualified providers. DMAS' concept paper should spell out the steps that will be taken to encourage providers of long-term services and supports to enroll in MCO provider networks, thus: (a) improving the odds that enrollees will gain access to the services and supports they need; and (b) minimizing the disruptions in participant-provider relations inherent in transitioning to a managed care system.
- Robust participant protections. The concept paper should specify the safeguards that will be in place to identify, report and investigate critical incidents that occur within the MLTSS system and ensure that prompt corrective actions are taken. Among the principal components of such safeguards are a clear statement of participant rights and responsibilities, a critical incident management system with provisions for preventing abuse, neglect and exploitation, plus a grievance and appeals and a fair hearing process.
- A comprehensive quality management and improvement system. DMAS' concept paper should sketch out the principal components of a comprehensive quality management plan that encompasses preventive and acute health care and behavioral health services as well as long-term services and

supports. The long-term services and supports components of the quality management system for person with I/DD should build upon the system currently in place for ID and DD waiver services and include outcome measures approach to the need of applicable sub-populations receiving LTSS. Representatives from these sub-populations should be involved in the process of establishing and validating MLTSS quality measures. Possible improvements in the systems should be weighed, but the existing I/DD quality management system is compatible with existing CMS guidelines as contained in the technical guide to organizing and delivering home and community-based waiver services.²

- A system-wide approach to improving services. The first step in Medicaid Reform is committing to a truly community-based system of support. If I/DD Waiver services are placed into a managed care model, it is absolutely essential that all other parts of the system (Training Centers, private ICFs, nursing homes) be included as well. Cost savings achieved through managed care must be reinvested into expanding access to community-based services for people who do not currently have Waiver services. This system wide approach would allow the state to effectively use its resources to serve as many people as possible, promote integration and ensure compliance with ADA and Olmstead.

Again, in keeping with CMS guidance, DMAS should post a copy of its MLTSS concept paper on its website and solicit public comments. Following the closure of the public comment period, the department should issue a summary of the comments received as well as the changes made in response to such comments.

In closing, we wish to reiterate our concern that there has been very little discussion about the sweeping changes proposed and how they will affect people with I/DD and their families. More than 9,000 Virginians with intellectual and developmental disabilities are currently receiving community-based services in order to avoid unnecessary institutionalization. An additional 7,800 individuals with I/DD are waiting for services. Changes to the I/DD service system affect the lives of these individuals, such as where (and how) they live, work and recreate. Despite the very personal nature of the policy discussion, people with I/DD and their families have not been consulted.

Again, we appreciate the opportunity to provide comment on the Medicaid Reform initiative and we look forward to continued dialogue. Please let us know if further explanation is needed to clarify any of the points we have raised in these comments [REDACTED] Thank you.

² Application for a Sec. 1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria, Version 3.5, 2007
[REDACTED]