



As North Carolina embarks on its continued transformation of the Medicaid system, The Autism Society of North Carolina renews its commitment to statements made in 2010-2016 regarding the needs of individuals on the autism spectrum. In those statements we have made it clear that individuals with IDD, including autism, have unique needs for ongoing supports that may change, but do not diminish over time. We thank the Department for the opportunity to provide feedback and hope we continue to be a respected and engaged party throughout system transformation.

"Individuals with intellectual and/or developmental disabilities (I/DD), including autism spectrum disorder, have life-long conditions which need quality habilitative services and skilled supports that build and maintain skills needed for maximum independence. This is different from persons with mental illness and addiction in a "recovery model" focused on prevention and intervention to promote recovery. People with autism and I/DD do not recover; they gain and maintain skills through habilitative supports. Managed care waivers, as currently designed, offer few advantages for individuals with I/DD and others who need long term services. Much of the "savings" in managed care is found in prevention and keeping individuals "well" to avoid costs in the future, freeing up funds to be used to provide service to others in need. Since people with autism and I/DD need habilitation and a level of supports for life, the way to find "savings" in I/DD managed care is often by reducing services and supports. "

As North Carolina embarks on its continued transformation of the Medicaid system, ASNC stands by the statement made in past years that while we recognize the advantages to the state of North Carolina in using a per member per month payment arrangement in a managed care model to manage the cost of health care that in order for individual with autism to live integrated into their communities, The Autism Society of North Carolina advocates for a developmental disability system that provides a continuum of quality supports and services based on individual needs, which may not be best managed using such a model. A true continuum of care would include including the following:

The system should be based on appropriate outcomes for individuals with long term needs. One that expects habilitative, residential or personal care services to taper off, expects a measured reduction in care over time, or expects recovery, is not addressing the lifetime needs of people with IDD. Services may change, they may address new goals or needs, but they should be appropriate to the long term needs of the individual. One caveat to consider particular for autism is the use of treatment services as well, where there tapering off as outcomes are met (for example ABA). Services should be accessible based on need, diagnosis, etc. Right service – right time.

System management must recognize the need for specialty services focused on community integration that go beyond traditional health care. An appropriate system manager/management system would be able to effectively understand the relationship between health, employment, stable long term housing, meaningful days, and quality of life and direct a benefit package that includes all these things.

Choice should not be optional. Individuals with IDD and their families must have a choice of benefit packages and/or system managers and not be consigned to a single choice based on their place of residence in North Carolina or their "Medicaid county of origin." If the system intends to use managed care principles for IDD habilitative services, than a choice of managed care providers for the individual served and competition amongst at least two managed care organizations is important to assure effective service delivery.

Individuals can access a basic benefit package across system managers. While choice and competition are important, a *basic* IDD benefit package should be set across the system so that an individual's basic set of needs for daily living, community integration, services, treatment and skilled supports are met regardless.

Streamline the process of accessing services, finding a provider, managing care, appealing grievances and other system bureaucracy for individuals and families using the Medicaid IDD system, as well as for providers. System managers should be able to provide a menu of benefits, a reasonable connection to providers who are trained and able to work with the individual, and an easy way to address grievances or appeal changes. Providers should be able to easily understand the process for paneling/network entry, credentialing, utilization management, medical necessity clinical guidelines, documentation management, billing, etc. These items should not be in conflict between provider, state or system manager level IT systems. Standardization and ample published expectations are crucial administratively. Services really should be less siloed not only by funders, but by age, location and type. There should be seamless integration between services offered for those 0-3, 3-adults, vocational services, etc. These services should be offered consistently no matter where a person lives. Support an all-payer and provider database that can be accessed in real time. Align payment reform and incentives with valued outcomes, quality improvement, and education. Expand use of technology in primary and specialty care and in-home supports and support parity reimbursement.

Independent third party case management based on best practice for individuals with autism and other I/DD remains. The current system includes no case management to assist individuals and families in navigating a complex system. Even with a more streamlined system, many services and resources will remain outside Medicaid and require support to access. In our current managed care model, the Local Management Entity determines available providers, funding and eligibility for services. There should be a level of independence between determining an individual's needs and appropriate funding. This is a critical firewall in any system that serves vulnerable populations. Case Management needs to be available to link individuals and their families through the complex and siloed systems in our state.

Developmental disability funds must remain in the system that serves people with I/DD. Too many people with autism spectrum disorder and I/DD are on waiting lists for services. While people with autism and I/DD need life-long supports, we miss many opportunities to reduce the severity of their disabilities by not providing services when they are critically needed. The current system allows for excess funds to be retained for purposes other than expansion of services, incentivizes reductions in service array and individual budgets, and has no provisions for the statewide management of "savings" to be utilized to address critical needs.

(i) options or supports waivers for those waiting for full waiver slots should be considered. Those with IDD waiting for Innovations waivers or other IDD services do not have any entitlement to services. Currently there are services in the 1915(b)(c) waiver that are an entitlement for people with mental illness and addiction; no such entitlement exists to services for people with I/DD. Integration of care will NOT address the complete lack of IDD services for those on waitlists. They may already be able to access physical health care, medication or other "traditional" Medicaid benefits but none of those things will address their need for developmentally specific interventions, treatment options, help with activities of daily living, and behavioral interventions. Waiver options such as (i) services options or supports waivers could prevent crisis and ensure that people remain in their communities and out of crisis.

Protections for people with autism and I/DD must remain in place. Currently people living in ICF-MR's have the right to due process should they be moved; they need to retain the same rights to service and supports if they leave an ICF-MR. Protect individuals currently receiving services through IPRS and Innovations from significant service reductions by maintaining levels of service needed per individual.

Use an evidence based method of resource allocation for people with I/DD and provide transparency in utilization management. The Supports Intensity Scale was not designed to be used as a resource allocation tool and the Supports Needs Matrix does not take into account the area the person lives, the availability or lack thereof of family or community support, and many other individual factors. The tool has not been validated for use with children. The tool does not count areas of socialization and communication measures which completely overlooks the core deficits of autism. These may eventually prove to be a useful tools for assessing need and assigning a basic budget framework, but should not be used in isolation from a person centered process of determining a person's needs for services. Everyone has unique needs outside of a score on a test.

Set objective benchmarks for the quality of services and supports. In a managed care system that limits choice of providers there is an even greater need to assure that objective standards be set for the quality of service providers. Incentives and value should be rewarded for providers. Those specialty providers who are able to deliver on unique outcomes in a far more effective way than others should have a mechanism for value based pricing.

Bring together stakeholders, including families and advocates in a meaningful process to develop plans and review the implementation of any changes to the system. A meaningful process is more than providing an open forum for feedback. Focus groups, one on one information gathering, case studies, intentional use of local and state CFACs and other groups is imperative that consumers have voice. All might be useful in gathering information about what is working, what is not and what is needed. Most families and individuals operate in isolation, especially those waiting for services. They have limited opportunity to travel, access transportation, including finding appropriate care for loved ones. Making changes this significant without listening to stakeholders has previously lead to failures.