CENTER FOR
DEVELOPMENT
& DISABILITY

# HM 51/ SM 79
# ACTION PLAN TO MEET THE NEEDS OF YOUTH AND ADULTS IN NEW MEXICO WITH AUTISM SPECTRUM DISORDER.

2017 Regular Legislative Session

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# HM 51/ SM 79
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# Summary of HM 51/SM 79 Recommendations

Both policy and funding recommendations have emerged from this task force's work. Below is a summary of both:

## *Policy Recommendations*

- Due to the new 1 in 59 prevalence, the Legislative Finance Committee should consider developing an ASD specific waiver through Medicaid.

- The task force recommends annual reports from the Superintendent of Insurance and HSD/ Medicaid on the use and costs of ABA in NM.

- DDSD should develop regulation that DD Waiver eligibility be based the most current Diagnostic and Statistical Manual of Mental Disorders (DSM 5).

- The task force appreciated the opportunity to study the specific issues brought forth by HM 51/ SM 79. In doing so, the group identified more gaps, issues, and challenges. The work continues to evolve. The group recommends addressing autism issues either through ongoing legislative memorials or through appropriate executive action, creating a NM office on autism spectrum disorder.

- Licensure for behavior analysts in New Mexico.

## *Funding Recommendations*

Restore 3 million dollars of state general fund spending on Autism Spectrum Disorder:

Task 1:
A new Medicaid behavioral health benefit specifically for adults with autism spectrum disorder:
$800,000 to the Department of Health to increase diagnostic capacity to include adults:

(Note: there is $100k in the FY '19 budget for adult ABA, so that is not included in these totals.)

- $500,000 to the Department of Health to contract with the University of New Mexico, Center for Development and Disability to develop and implement diagnostic services for individuals over the age of 21, and to shorten the waiting time of older children and youth seeking an ASD diagnosis

- $300,000 to the Department of Health to contract with New Mexico State University to develop and implement a diagnostic clinic for younger children.

Task 2:

A plan for developing in state resources and procedures for youth with autism spectrum disorder: $1,200,000

☐ Recurring funding of $1 million dollars to the Department of Health to contract with University of New Mexico to develop higher levels of care placement in New Mexico by collaboration with UNM Psychiatry and the Center for Development and Disability to develop and implement a coordinated service system for youth and young adults with ASD and challenging behaviors that include:

- In patient hospitalization with individualized behavioral health treatment that results in a plan to be implemented in lower levels of care.
- Residential treatment for children and youth meeting that level of care, focusing on ABA to extinguish maladaptive behaviors and build appropriate skills and replacement behaviors.
- Specialized group home services for children and youth either stepping down from higher levels of care or requiring group home programming for therapeutic purposes.
- Set up research protocol for treatment, which would look specifically at outcomes and costs.
    - ☐ Two hundred thousand dollars to the Children, Youth, and Families Department to: develop a high fidelity wraparound model specifically for high need individuals with ASD. Consider this model for individuals recommended for residential treatment or currently in residential treatment and are close to discharge.
    - ☐ Note: the legislature funded an Autism Oversight Team in 2014, with the recurring amount $100 thousand dollars to the Behavioral Health Services Division of HSD. The intent of the team was discharge planning for individuals with ASD in residential treatment; because the high fidelity wraparound process could be useful in discharge planning, it is worth considering that those monies be transferred to CYFD for ASD wraparound, increasing the total amount to three hundred thousand dollars annually.

Task 3:

- ☐ Development of expedited Developmental Disabilities Waiver criteria for youth and adults discharging from residential treatment
- ☐ $250,000 to the Department of Health for the transition of 4 youth a year from residential treatment to DD waiver placement.

Task 4:

- ☐ Recurring funding - $750,000 to Department of Health
    - o $100,000 to contract with psychologists with expertise in the diagnosis of autism to provide technical assistance with DD Waiver applications;

  - $250,000 to contract with the University of New Mexico Center for Development and Disability to develop, implement and evaluate programs for youth and adults interested in post-secondary, vocational, or life skills opportunities;
  - $250,000 to contract with New Mexico State University to develop, implement and evaluate programs for youth and adults interested in post-secondary, vocational, or life skills opportunities.
  - $150,000 to contract with UNM CDD or another entity to research the feasibility of an ASD self-reported registry or some other method of integration of data sources such as the Early Childhood Integrated Data System (ECIDS) Some of the tasks necessary to proceed will be to establish governance and oversight of any registry, platform or data base, define the scope and rigor needed, define the data set and outcomes and develop a protocol. This type of data may require approval by an Institutional Review Board as protected health information will be stored or accessed.

Due to the 2018 increased prevalence rates, the HM 51 /SM 79 task force recommends that the legislature allocate an additional two million dollars. One million eight hundred thousand dollars to the Department of Health for ASD diagnosis and service:

- Five hundred thousand dollars to the University of New Mexico Center for Development and Disability for ASD diagnosis;
- Five hundred thousand dollars to New Mexico State University for ASD diagnosis;
- Four hundred thousand dollars to New Mexico State University to develop and implement programs for youth and adults interested in post-secondary, vocational, or life skills opportunities.
- Four hundred thousand dollars to the University of New Mexico Center for Development and Disability to develop and implement programs for youth and adults interested in post-secondary, vocational, or life skills opportunities.

Two hundred thousand dollars to the Children, Youth, and Families Department to maintain autism specific wraparound for children and youth with ASD and challenging behaviors who are either at risk for residential treatment or who are discharging from treatment back to their home and community.

# HM 51, SM 79 Action Plan/Funding Priorities

## Purpose

HM 51 sponsored by Representative Liz Thomson, and SM 79 sponsored by Senator Linda Lopez in the 2017 legislative session requested the Autism Programs at the University of New Mexico Center for Development and Disability to convene a task force to study ways to develop and implement programs for older youth and adults with autism spectrum disorder (ASD). The expected result is an action plan and funding priorities using evidence-based interventions. The task force met three times during the summer of 2017 with other numerous correspondences, meetings and contacts for specific information.

Four specific tasks were set out in the Memorial. These include:

1) Development of a Medicaid benefit specifically for adults
2) Plan for developing in state resources and procedures for youth
3) Development of an expedited DD waiver for those discharged from RTC
4) Development of programs for youth and adults who do not meet criteria for DD waiver

The group discussed the four specific tasks set out in the memorial. The Autism Programs staff and the legislative sponsors requested additional time in order to review literature and data to provide a thorough report to the Legislative Health and Human Services Committee and the Legislative Finance Committee.

## Findings

Autism spectrum disorder (ASD) is a neurodevelopment disorder that can cause significant social, communication and behavioral challenges. About 1 in 59 children have autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. ASD occurs in all racial, ethnic, and socioeconomic groups. ASD is about 4.5 times more common among boys (1 in 42) than among girls (1 in 189). If we apply the CDC prevalence broadly to the population of New Mexico, this would result in 28,900 individuals of all ages with ASD. Currently we do not have firm data in New Mexico to determine the numbers of individuals with ASD nor the breakdown of children, youth and adults who have ASD, however a rough estimate would indicate approximately 8,000 children under the age of 8 have ASD.

The task force initially investigated the "state of the state" in terms of ASD services. Many needs emerged from stakeholders during these meetings and subsequent research of systems for adults with ASD in New Mexico. Some of these needs voiced by stakeholders include:

- Lack of appropriate, individualized transition plans for youth with ASD
- Lack of post-secondary opportunities
- Lack of employment opportunities
- Difficulties with transitioning to an adult medical system
- Difficulties with navigating NM systems (for both parents and self-advocates)
- Lack of provider expertise around needs of adults with ASD

The task force found a lack of specific data around numbers of adults with ASD in our state who were meaningfully employed, were enrolled in post-secondary education, who have appropriate housing, or who have adequate medical insurance.

The task force then looked nationally to determine what data might exist to help us understand the nature of the issues. The lack of this data for youth and adults with ASD appears to be persistent across the nation; however, one report did illuminate many of the needs that we see here in New Mexico. “Young Adults and Transitioning Youth with Autism Spectrum Disorder” prepared by the Department of Health & Human Services in its 2017 report to Congress, echoed almost verbatim what is seen here in New Mexico on a national level. In addition, the report to Congress compared trends of youth and adults with ASD to other individuals with disabilities. According to the “Young Adults and Transitioning Youth with Autism Spectrum Disorder,” the following is noteworthy:
Compared to all students who received special education and related services under IDEA, students with ASD who also received these services are:

- More likely to have a co-occurring chronic health or mental health condition (43% versus 28%)
- Less likely to be able to manage and develop friendships independently:
  - More likely to experience communication challenges (50% vs. 29%)
  - Less likely to manage activities of daily living independently (17% vs 46%)
  - Less likely to report getting together with friends weekly (29% vs. 52%)
- Less likely to prepare for college and employment:
  - Less likely to have input into their IEP and transition planning (41% vs 59%)
  - Less likely to have taken a college entrance or placement test (29% vs 42%)
  - Less likely to have had paid work experiences in the past year (23% to 40%)

Data also indicates that young adults (ages 20-25) with ASD who had been in special education are:

- Less likely to have ever lived independently away from their parents (19%) – compared to more than 66% for those with serious mental illness and 34% with intellectual disabilities
- More likely to receive Supplemental Social Security
- Less likely to have ever worked in their 20s—58% compared to 90% for individuals with emotional disturbance, speech language impairments, and learning disabilities and 74% of those with intellectual disabilities
- Less like to have ever participated in postsecondary education or training of any kind—36% of youth with ASD had participated.

Again, given limited data we can make no conclusion about whether the above statistics hold true for our New Mexico youth and adults with ASD, however as recommendations are made and as new programs are developed, it is important to keep these national findings in our thinking.

Other disturbing facts around health and wellness are beginning to emerge. According to the "Young Adults and Transitioning Youth with ASD," adults with ASD when compared to the general population:

- Die an average of 16 years earlier than people not on the spectrum
- Are 40 times more likely to die prematurely of a neurological condition such as epilepsy
- Are at heightened risk for co-morbid conditions such as depression and anxiety
- Are at a higher risk for diseases such as diabetes and heart disease.

Clearly, the issues of young adults and adults with ASD differ greatly from adults with other disabilities as well as from the general population. The effects of ASD as a whole appear to decrease opportunities for a variety of basic life activities. Given this, there is a need for specific supports and services for these individuals as they move into adulthood.

Another resource used in the development of this report was the National Collaborative on Workforce and Disability, "Guideposts for Success," Second Edition, 2016. Although this publication addresses disabilities in general, it nonetheless is applicable to the ASD population. The article discusses five guideposts for success for individuals with disabilities. These guideposts outline clear predictors of success for students with disabilities as they transition to adulthood; as such, they should be intentionally included in any plan that deals with transition and employment or post-secondary access. These include:

- School based preparatory experiences; students with disabilities should:
  - Use transition plans to drive personal instruction and to continue transition process post-schooling
  - Develop knowledge of reasonable accommodations they can request in educational settings; these in turn will assist students to request these accommodations in other settings
- Career preparation and work-based learning experiences to include:
  - Opportunities to explore a range of work based experiences such as site visits and job shadowing
  - Multiple on the job training experiences (paid and unpaid)
  - Communication of their disability-related work support and accommodation needs
  - Practice in the formal request of appropriate supports and reasonable accommodations in education, training and employment settings.
- Youth development and leadership to include:
  - Peer-to-peer mentoring opportunities
  - Training in skills such as self-advocacy
  - Access to mentors and role models, including persons with and without disabilities
  - An understanding of disability history, culture, and disability public policy issues as well as their rights and responsibilities.
- Connecting activities which may include:
  - Acquisition of appropriate assistive technologies
  - Community orientation and travel training (accessible transportation, bus, housing, etc.)

    - Exposure to independent living centers and other community based support service agencies
    - Personal assistance services such as readers, interpreters, attendants, service animals
    - Benefits-planning counseling in the transition from public assistance to self-sufficiency.
- Family involvement & supports to include:
    - Family understanding of the youth's  disability and its effect on education, employment and future living options
    - Knowledge of rights and responsibilities under various disability related legislations
    - Knowledge of and access to programs, services, supports and accommodations available for youth with disabilities
    - Understanding how individualized, person-centered planning tools may assist youth in achieving transition goals and objectives.

The summary of the "Young Adults and Transitioning Youth with ASD," made specific recommendations for systems for adults with ASD.  The Report acknowledged ASD as a subset of a larger disability community and discussed the need for continued support for the larger disability issues.  These recommendations are applicable to New Mexico and while possibly outside of the scope of this Memorial are worth noting as they provide an over-arching set of recommendations and directions with which we should be thoughtful.  The overall recommendations to policy maker and those involved in system development include the following:

Goal 1:  Design, develop, evaluate and implement cohesive programs that enable delivery of services in a coordinated, comprehensive and individualized manner.
Goal 2:  Conduct research to test the efficacy of new and existing service and support models designed to improve outcomes for youth and young adults with ASD.
Goal 3:  Increase access to and the quality of services and supports
Goal 4:  Assure the health, wellbeing and full integration into community life of youth and young adults with ASD
Goal 5:  Increase provider training and public acceptance of differences and strengths associated with ASD
Goal 6:  Alleviate the growing burden of navigating multiple system for individuals and their families.

Interestingly, many of the current task force recommendations align with the above systems recommendations.  It is also not surprising that some of the recommendations of the HM 51 / SM 79 autism task force are the same as made in previous years.  Gaps in the system remain; however, there have been some policy successes.  A table at the back of this report compares the three different sets of findings, recommendations and policy successes.

## Discussion

This is the third time the autism community has come together through legislative request. Senate Bill 197 resulted in a study group that made policy and funding recommendations to the legislative finance committee in 2007. The autism service plan written for Senate Memorial 20 –House Memorial 44 to the interim Health and Human Services committee also made policy and funding recommendations in 2012.

Neither the funding recommendations made in 2007 nor in 2012 became reality. State general funding for ASD has been cut significantly since 2007. At the same time, the prevalence of autism has increased from 1 in 150 in 2007 to 1 in 59 today. (The latest prevalence rate increased in May 2018 according to findings of the Centers for Disease Control). These funding cuts have resulted in the cancellation of popular programs, and the inability for existing programs to deliver services in a timely fashion. The growing numbers of individuals with ASD add to challenges in service delivery. It is expected that each year more and more individuals with ASD will leave secondary schools and enter into adulthood and will require supports and services.

Some critical legislation has resulted in positive impacts for children with ASD and their families. New Mexico passed autism insurance mandates in 2009 and 2012 and added the ABA benefit to Centennial Care in 2015 as an EPSDT benefit. It is estimated that 1,121 Centennial Care members with ASD received services from 22 approved providers in 2017 and spending has increased to $3.8 million by the end of 2017. This represents a significant change for the population of children and youth with ASD and their families who are Medicaid eligible. In addition, CYFD added ABA coverage and funding for their program that serves undocumented children.

### *Discussion Task 1: Development of a Medicaid benefit specifically for adults*

Given the funding through Centennial Care, the numbers of Board Certified Behavior Analysts has steadily risen and the BCBA registry now lists 66 total BCBA eligible to practice in New Mexico. Several on the registry are actually University professors who do not practice or have moved out of state. During task force discussions with representative BCBAs, the consensus was that opening the ABA benefit to adults would require some workforce training given that most BCBAs work with children and youth and that many of the adults who might receive services were those with challenging behaviors.

The task force also discussed the need for licensure for the BCBAs in the state of New Mexico. Although these providers are able to bill Medicaid, they are not able to bill all insurances. Licensure is a national priority for BCBAs.

The self-insured (ERISA) marketplace still does not require autism coverage. A number of NM families have ERISA coverage. These families report out of pocket costs for autism therapies that are prohibitive ($85 - $120 per hour, multiple times weekly).

As the Medicaid benefit through Centennial Care is an EPSDT benefit, individuals over the age of 21 were not receiving ABA services through this benefit. Representative Elizabeth Thomson sponsored HB 403 during the 2017 regular legislative session. HB 403 removed age caps from the state's ABA benefit. The bill passed the House but died in Senate Finance. The Fiscal Impact Report for HB 403 estimated a cost of 90 thousand general fund dollars to implement the program. In the 2018 legislative session, Representative Thomson added one hundred thousand dollars to the state's Medicaid budget to serve individuals with ASD. Her intention for the funding was to implement ABA for adults. The budget language was not as clear as Representative Thomson's intent, so she wrote both the HSD Cabinet secretary, the chair of the legislative finance committee, and appropriate staff. To date, adult coverage for ABA services has not been put into place.

The federal Mental Health Parity and Addiction Equity Act (MHPAEA) requires Medicaid managed care programs to offer the same level of coverage for behavioral health as for physical health. NM now offers Applied Behavior Analysis (ABA) to Medicaid eligible children with ASD, but not to adults. In discussions with state agencies, it is noted that ABA is classified in NM's parity analysis as Medical/Surgical; as such, MHPAEA does not apply. The differing views of where treatments for ASD reside is one that has been discussed for many years within the state. Within the framework of children's Medicaid (EPSDT), NM meets mental health parity. However, ASD is a lifelong disability, and adults with ASD have behavioral health needs. Other services that adults with ASD may need such as psychiatry, speech therapy, and occupational therapy are available now through the NM state Medicaid plan. Expanding the Medicaid coverage of ABA to adults would offer evidence based behavioral health treatment specifically for ASD that is now required through MHPAEA. Currently, BHSD does not believe that NM Medicaid is in MHPAEA non-compliance for not having an adult ABA benefit. Members of our task force have felt some confusion over how age caps could possibly be in compliance with MHPAEA and have felt that denials of ABA for adults is denying the only behavioral intervention that has shown efficacy. The task force does recognize that our state has had positive results of enrolling children and recruiting providers once ABA became a covered benefit. The task force is confident that similar results will follow when an adult ABA benefit is established.

Adding ABA for adults to Medicaid comes with the issue of providing quality ASD diagnosis for adults in New Mexico. Currently, there are no providers in the state with experience or expertise to make adult diagnoses. Not only are there no practitioners with specific ASD expertise, but also wait times for diagnostic evaluations tend be long. For example, the CDD Autism Spectrum Evaluation Clinic (ASEC) and the Early Childhood Evaluation Program (ECEP) reports a total wait list of 452 clients with the following breakdown in terms of age: under 36 months – 149; 3 to 4 – 148; 5 to 11 – 225; 12 to 17 – 69; and 18 to 22 – 10.

Although other providers in the state are beginning to give an initial diagnosis, only about 10-15% of families have wished to be removed from the CDD/ASEC waiting list. The task force recommends expanded services through UNM/CDD for adults and the development of diagnostic services at New Mexico State University.

The National Standards Project, Phase 2, National Autism Center (2015) reviewed existing research findings on the efficacy of a variety of treatments. Through literature review, the project identified established, emerging and unestablished interventions for all ages. Specifically for adults (22+ years), the project states that the only established treatments, those with the highest rigor in terms of efficacy, were behavioral interventions utilizing applied behavior analytic interventions to increase adaptive behaviors and decrease challenging behaviors. Applied behavior analysis is the process of systematically applying interventions based upon the principles of learning. The category of interventions reported as established for 22+ are antecedent interventions and consequent interventions. Examples include prompting, extinction, differential reinforcement of incompatible behavior (DRI), choice and functional communication training. Only one intervention fell into the emerging level of evidence, which was vocational training. The authors warn that before we can be fully confident of this intervention, more high quality studies are needed. Interventions identified as falling into the unestablished level of evidence included: cognitive behavioral intervention, modeling, music therapy and sensory integration. Currently, there is little or no evidence to draw conclusions about their effectiveness with individuals with ASD.

## *Discussion Task 2: Plan for developing in state resources and procedures for youth*

Members of the task force received and read the joint LFC, HSD, CYFD report "Results First," (2017) and agreed with the premise that behavioral health dollars are spent heavily on residential treatment rather than evidence based community programs. This is especially true for children with ASD. The task force was disappointed to learn that neither the diagnosis of ASD nor Intellectual Disability were included in all aspects of that report. The group then asked for data about residential treatment from both the Centennial Care MCO's and the Behavioral Health Services Division. The data provided indicated that there are about 24 children with ASD currently in residential treatment out of state. The MCO's did not share costs with the task force members, but informal calls to some of the residential treatment facilities indicated amounts of around $24,000 per month/$288,000 per year per child. The task force felt that the data was not complete, and looked for additional information.

OptumHealth New Mexico compiled data on costs during their four-year contract as the single entity with the NM Behavioral Health Purchasing Collaborative. They found that nine out of ten of the highest cost individuals were children under the age of 19 with a diagnosis of ASD, at the average cost of $686, 290.00 per person. They estimated spending $54,000,000 dollars on 150 high needs individuals under the age of 19. Some of the Optum recommendations align with those of previous autism memorial reports. Their 2013 findings are still relevant today. (The Optum paper is included in the supporting documents section of this report.)

There are systems within our state to support youth and/or young adults. Many of these systems connect to public school, community programs or behavioral health programs. While there is nothing prohibiting the use of existing systems for individuals with ASD, the evidence demonstrates that outcomes tend to be poorer for individuals with ASD than for others with disabilities. One strategy is to infuse autism specific information, training and expertise into already existing systems.

One example of this could be to provide ASD specific training for transition coordinators hired by the NM Public Education Department. These transition coordinators are statewide and by providing this information about the specific needs of this population more successful transitions for our youth with ASD may occur. Transition coordinators could attend statewide existing training without charge or could view archived webinars located at the UNM CDD. Another example of this could be to provide ASD specific Information into CYFD's high fidelity wraparound service pilot. Wraparound is an ecologically based process building on the collective action of a team to mobilize resources and talents from a variety of sources to support families in their communities. In the wraparound process a team of people are brought together around all the components of a family's life incorporating their history, culture, relationships and other relevant information to address their challenges and formulate possible solutions. Wraparound also includes a series of practice steps bringing a group of people together to craft and match services, supports and interventions to meet unique family needs. Often referred to as a process rather than a service or particular type of intervention, Wraparound integrates and builds on a variety of concepts from a range of sources. This integrative nature makes Wraparound particularly adaptive to the organization, context and people involved in implementation. Wraparound has four main tenants: a) grounded in strengths perspective, b) driven by needs, c) supported by an effective team process, and d) determined by families.

High fidelity wraparound services have evidence to support their use with children and youth who require more costly levels of care in their community. In several states, high fidelity wraparound services have shown positive effects in terms of both client outcomes and decrease in costs. If wraparound could be provided to some of our individuals with ASD and challenging behaviors, it may actually reduce costs and impact the numbers of children who are in out of state residential treatment. Currently, CYFD has provided training for 18 individuals to provide wraparound services for 50 youth from Bernalillo County. These are youth who are in a residential treatment facility or who are likely to be placed in one given their levels of need. This effort is part of grant funding; if it is shown effective, it will likely expand statewide.

Although the data available feels incomplete, it is clear that NM lacks a coordinated system to serve individuals with ASD and challenging behavior.  The MCO's currently contract with residential treatment centers that do not offer evidence based interventions for ASD as part of their therapeutic programs. While they are safe environments, these residential treatment centers often do not meet individual behavioral health needs.  Outcomes are problematic. This is concerning both clinically and fiscally.

Our current approach to levels of care complicates the issue.  Fitting individuals with ASD into health categories and billing mechanisms is a disservice.  For example, task force members talked recently with one of the MCOs about discharging a 19-year-old back to New Mexico from residential treatment in Texas.  He requires more supervision and behavioral health care than is available in his community, but does not yet have DD Waiver funding. Task force members suggested that a DD Waiver supported living agency act as a specialized group home, a step down from a residential treatment center.  The MCO could fund the placement at an enhanced rate through a single case agreement.  The individual could then transition to DD Waiver funding when allocated.  While the group agreed and the proposal has merit, challenges with billing, licensing, and treatment goals may prove insurmountable.  This young man may have to remain in Texas until he receives a DD Waiver allocation.

Task force members also recently met with leadership at another MCO about meaningful planning for this population.  This MCO suggested that all the MCOs pool their resources to tackle these issues.  The collaborative approach by Centennial Care MCOs has not worked historically for this population.  The task force understands the importance and the complexities of this necessary endeavor, and welcomes any new efforts.

Clearly, the state of New Mexico needs to plan for the population of individuals who have challenging behaviors and who are out of state.

The task force recommends charging the University of New Mexico, Department of Psychiatry and the CDD with developing an array of services for this population.  Giving the University of New Mexico the opportunity to serve challenging individuals at different levels of care will benefit individual children and youth with ASD as well as allow the state to develop a coordinated and comprehensive system, fulfilling a long time goal of the NM autism community.  The state can develop professional capacity.  Children can remain close to their families and communities.  An additional factor for this task is the recent CMS Family First Act that will go into effect in 2021.  The rule will limit out of home placement through Medicaid and requires treatment facilities to use evidence -based interventions.  An array of services through the University of New Mexico will comply with these new federal regulations and requirements.

### *Discussion Task 3: Development of an expedited DD waiver for those discharged from RTC*

Some teens and young adults with ASD (like the young man in Texas) remain in residential placement, both in and out of state, because they cannot return home for safety reasons. Since the DD Waiver offers supported living services to individuals who are at least seventeen years old, the task force sent the following proposed expedited criteria to the Developmental Disabilities Services Division (DDSD) of the Department of Health:

"Individuals of at least seventeen years of age who are in residential treatment and require supported living services in order to return safely to the community."

DDSD rejected the proposed criteria. The task force is unable to complete this specific assignment. The group supports the funding recommendation with the idea that the two hundred and fifty thousand dollars to the Department of Health allows DDSD an opportunity to transition four youth a year from residential treatment to DD Waiver placement.

### *Discussion Task 4: Development of programs for youth and adults who do not meet criteria for DD waiver.*

Before addressing the task of programming for individuals with ASD who do not meet DD Waiver criteria, the task force is concerned that many individuals with ASD may meet criteria. DDSD has changed criteria for the waiver over the past dozen years. At one time, when autism was under the umbrella of the pervasive developmental disorders in the DSM IV, the department considered all those diagnoses (autistic disorder, Asperger, pervasive developmental disorder not otherwise specified, Rett Syndrome) to be related conditions that would qualify an individual for the waiver if they had impairments in a number of significant life areas. The department then limited that to a diagnosis of autistic disorder. These diagnoses are subjective in nature, and often vary with provider expertise. The DSM IV pervasive developmental disorders include significant developmental disabilities disregarded in current DD Waiver criteria. Furthermore, DDSD still uses DSM IV criteria; the standard of care since 2013 has been the DSM 5, which updates the diagnosis to autism spectrum disorder.

According to DDSD, the current DD definition has been in place since the CMS waiver renewal in 2011. Due to multiple DDW systems changes during the 2016 renewal period, the division decided not to make significant changes to the waiver. The definition is under review by DOH and HSD. To begin the process, DDSD convened a work-group comprised of professionals from UNM, private citizens, DDSD and HSD staff. The workgroup reviewed reports on eligibility and journal articles outlining national trends and best practices. The work-group also reviewed federal and NM DD definitions as evidence to inform their work."

The task force recommends that DDSD continue to seek technical assistance in updating their criteria with CMS and reviewing applications of individuals with DSM IV diagnoses of any of the pervasive developmental disorders and DSM 5 diagnoses of autism spectrum disorder.

It is important to note that in the most recent students of ASD prevalence (May 2018), 31% of the children exhibited an intellectual disability. As more of these children enter adulthood, the vast majority of them will likely have cognitive skills similar to their non-ASD peers. Many will not quality for the DD waiver but given outcome information, will still require supports for independent living, post-secondary education, vocational training and employment.

The task force examined a number of promising programs for youth and adults with ASD who need help with post–secondary, education, vocational programming, or life skills training. Many of the programs researched include a peer support model. Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. Peer support is widely used in behavioral health systems and could be useful as we look at this group of individuals with ASD who will likely not qualify for the DD waiver.

The group recommends that New Mexico State University and the University of New Mexico collaborate on the development and implementation of programs that would assist transition age individuals in acquiring skills necessary to enhance their opportunities, for college, employment, and quality of life. It is strongly recommended that peer support be included in new programs that will be developed. It is also strongly recommended that NMSU and UNM include elements of the "Guideposts for Success", which include school based preparation experiences, career preparation, and work based experiences, youth development and leadership, connecting activities, and family involvement and supports in any model developed. Charging NMSU and UNM to develop, implement, and evaluate these programs will insure that the programs' reach will be statewide and that similar programs will be developed at each University. It is also expected that after these programs are implemented and evaluated that appropriate community members and agencies will be trained to replicate these on their own.

## Action Plan and Funding Priorities:

The action plan/funding priorities below reflects the complexities of the tasks assigned by the Memorial and the need for continuing planning. The task force structured funding recommendations to align with the restoration of the original three million dollars of legislative funding for autism services in New Mexico. As already mentioned, the work has been ongoing. Task force members have been willing to explore new ideas to fulfill need.
Recommendation: Restore three million dollars in autism funding

Specific funding recommendations below reflect and are equal to these dollars restoration.

*Task 1:*

- A new Medicaid behavioral health benefit specifically for adults with autism spectrum disorder
    - Recurring funds to Department of Health necessary to implement - $800,00
        - $100,000 to implement Applied Behavior Analysis for adults (already allocated, not included in totals) ,
        - $800,000 to increase diagnostic capacity to include adults
            - $500,000 to University of New Mexico, Center for Development and Disability to develop and implement diagnostic services for individuals over the age of 21, and to shorten the waiting time of older children and youth seeking an ASD diagnosis
            - $300,000 to contract with New Mexico State University to develop and implement a diagnostic clinic for younger children

*Task 2:*

- A plan for developing in state resources and procedures for youth with autism spectrum disorder
    - Recurring funds necessary to implement – $1,200,000

Recommendation 1: Task 2

- Recurring funding of $1 million dollars to the Department of Health to contract with University of New Mexico to
    - Develop higher levels of care placement in New Mexico
    - Collaborate with UNM Psychiatry Department/Health Sciences Center and the Center for Development and Disability to develop and implement a coordinated service system for youth and young adults with ASD and challenging behaviors that include:
        4. In patient hospitalization with individualized behavioral health treatment that results in a plan that can be implemented in lower levels of care.
        5. Residential treatment for children and youth meeting that level of care, focusing on ABA to extinguish maladaptive behaviors and build appropriate skills and replacement behaviors.
        6. Specialized group home services for children and youth either stepping down from higher levels of care or requiring group home programming for therapeutic purposes.
- Set up research protocol for treatment, which would look specifically at outcomes and costs.

Recommendation 2: Task 2

- Recurring funding of two hundred thousand dollars to the Children, Youth, and Families Department to:

    - Develop a high fidelity wraparound model specifically for high need individuals with ASD. Consider this model for individuals recommended for residential treatment or currently in residential treatment and are close to discharge.

Recommendation 3: Task 2

- While insurance issues are not a task force charge, the group realized the systems gap. Gaining more information from both the NM Superintendent of Insurance and HSD/Medicaid about the use and cost of ABA is critical to meeting individual need and future planning. The task force recommends that the NM Superintendent of Insurance and HSD/ Medicaid compile annual reports on ABA. The Missouri Department of Insurance has issued such reports for the past seven years. Their work could be an important model for New Mexico.

Recommendation 4: Task 2

- Recommendation to the NM PED that transition coordinators receive ASD specific training to insure that the individualized needs of these individuals is taken into account.

## *Task 3:*

- Development of expedited Developmental Disabilities Waiver criteria for youth and adults discharging from residential treatment
    - DDSD to develop regulation that Waiver eligibility be based the most current diagnostic manual (DSM 5)
    - Recurring funds necessary to implement - $250,000 to the Department of Health for the transition of 4 youth a year from residential treat to DD waiver placement.

## *Task 4:*

- Development of programs for youth and adults who do not meet the criteria for the Developmental Disabilities Waiver
    - Recurring funds necessary to implement- $750,000 to Department of Health
        - $100,000 to contract with psychologists with expertise in the diagnosis of autism to provide technical assistance with DD Waiver applications; DDSD to develop regulation that Waiver eligibility be based the most current diagnostic manual (DSM 5)
        - $250,000 to contract with the University of New Mexico Center for Development and Disability to develop, implement and evaluate programs for youth and adults interested in post-secondary, vocational, or life skills opportunities;
        - $250,000 to contract with New Mexico State University to develop, implement and evaluate programs for youth and adults interested in post-secondary, vocational, or life skills opportunities.
        - $150,000 to contract with UNM CDD or another entity to research the feasibility of an ASD self-reported registry or some other method of integration of data sources such as the Early Childhood Integrated Data System (ECIDS). Some of the tasks necessary to proceed will be to establish governance and oversight of any registry, platform or data base, define the scope and rigor needed, define the data set and

outcomes and develop a protocol. This type of data will require approval by an Institutional Review Board as protected health information will be stored or accessed.

The HM 51/ SM 79 work group believes that the above $3,000,000 in funding recommendations are necessary to fulfill the four important tasks brought forth by the legislature. Each of the four specific tasks complement each other and are the foundation for an appropriate service delivery system for youth and adults with ASD in New Mexico. The group hopes that as the state develops professional capacity in ASD that the legislature will continue to work with the community to fund new programs as well as shift existing funding when appropriate to meet new need.

## Future Directions

The new 1 in 59 prevalence numbers announced by the Centers for Disease Control and Prevention in May 2018 are alarming. The task force finds that while the three million dollars in our initial recommendations are necessary, more funding will be required to meet growing need. The HM 51/SM 79 task force recommends that the legislature allocate an additional two million dollars. One million eight hundred thousand dollars to the Department of Health for ASD diagnosis and services:

- Five hundred thousand dollars to the University of New Mexico Center for Development and Disability for ASD diagnosis;
- Five hundred thousand dollars to New Mexico State University for ASD diagnosis;
- Four hundred thousand dollars to New Mexico State University to develop and implement programs for youth and adults interested in post-secondary, vocational, or life skills opportunities.
- Four hundred thousand dollars to the University of New Mexico Center for Development and Disability to develop and implement programs for youth and adults interested in post-secondary, vocational, or life skills opportunities.

Two hundred thousand dollars to the Children, Youth, and Families Department to maintain autism specific wraparound for children and youth with ASD and challenging behaviors who are either at risk for residential treatment or who are discharging from treatment back to their home and community.

## Concluding thoughts

The task force recommends the restoration of the $3,000,000 in state general funds to support ongoing needs. It further recommends that given the ever-increasing prevalence, two million in recurring funding be appropriated to adequately address the growing needs of individuals with ASD and their families. Due to the 1 in 59 prevalence, the Legislative Finance Committee should consider developing an ASD specific waiver through Medicaid.

The task force appreciated the opportunity to study the specific issues brought forth by HM 51/ SM 79. In doing so, the group identified more gaps, issues, and challenges. The work continues to evolve. The group recommends that autism issues be addressed through either ongoing legislative memorials or appropriate executive action, creating a NM office on autism spectrum disorder.

## References:

*National Standards Project: Addressing the Need for Evidence-Based Practice Guidelines for Autism Spectrum Disorder,* Phase 2, National Autism Center, 2015.
http://www.autismdiagnostics.com/assets/Resources/NSP2.pdf
*Guideposts for Success,* National Collaborative on Workforce and Disability, Second Edition, 2016. http://www.ncwd-youth.info/wp-content/uploads/2018/03/Guideposts-for-Success-English-Print-Quality-1.pdf
*Missouri Department of Insurance Autism Report*:
https://insurance.mo.gov/consumers/autismFAQ/documents/2017AutismReportFinal02012018.pdf
*Young Adults and Transitioning Youth with Autism Spectrum Disorder,* 2017 Report to Congress. Department of Health and Human Services, 2017.
https://www.hhs.gov/sites/default/files/2017AutismReport.pdf

## Supporting Documents:

Finding of Legislative Efforts
White Paper Optum
FIRN
ABA Analysis
M. Needs
Adult ABA
PT

| SB 197 Study Group Findings, 2007 | SM 20 – HM 44 Stakeholder Findings, 2012 | HM 51 – SM 79 Task Force Findings, 2018 |
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| The Centers for Disease Control (CDC) has placed the prevalence of ASD at 1 in 150 children from birth to 21 years of age. Based on the CDC guide, approximately 3,000 New Mexico children have some level of ASD diagnosis | The Centers for Disease Control (CDC) has placed the prevalence of ASD at 1 in 88 children from birth to 8 years of age. Based on the CDC guide, approximately 5,000 New Mexico children have some level of ASD diagnosis | The Centers for Disease Control (CDC) has placed the prevalence of ASD as 1 in 59 children from birth to 8 years of age. Based on the CDC guide, approximately 8,000 New Mexico children have some level of ASD diagnosis. |
| State and independent agencies do not have surveillance and registry programs in place to accurately identify and track individuals with an ASD diagnosis. Therefore, it is currently impossible to provide legislators or health care and service professionals with a complete picture of ASD needs in the state | Same finding | Same finding |
| The state does not have an evidence-based, intensive behavioral intervention (IBI) service definition. Applied behavioral analysis (ABA) is a nationally recognized early intervention service that is highly effective at addressing the core deficits of ASD, improve adaptive skills, and improve the individual and family's quality of life. New Mexicans with ASD need access to IBI services. | The state developed a general funds Adaptive Skill Building program through DOH that serves 65 children ages 5 -18.. Medicaid has provided billing instructions for Behavior Management Services to provide Adaptive Skill Building Services to Medicaid eligible children, ages 0-5. About 30 children receive this service.<br>(An estimated 5,000 children with ASD in NM most likely need some form of autism treatment.) | The state added Applied Behavior Analysis (ABA) as an EPSDT benefit in 2015. In 2017, CYFD added ABA to their program that serves undocumented children. |

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| The state does not have specialized ASD practitioners to deliver ABA designed services to individuals with ASD. Currently, there is only one (1) board-certified ABA provider in the state | There are currently 15 board certified behavior analysts (BCBA) in the state. The majority of them are working either at the university of New Mexico or for a school system.<br>BCBAs operate with a certificate rather than a license, causing challenges to billing for ABA services through insurance or Medicaid, as well as issues around professional expertise in ASD | There are currently 66 board certified behavior analysts (BCBA) in NM. Not all of them provide direct services to children with autism.<br>BCBAs continue to operate with a certificate rather than a license, causing challenges to billing for ABA services through insurance as well as issues around professional expertise in ASD. |
| Individuals with ASD requiring services affect virtually every state agency; however, each department views ASD differently ,such as a behavioral health disorder or physical health disorder or developmental disability, and each has different points of entry for obtaining services. | Autism Spectrum Disorder is often called “the orphan disability.” State agencies struggle with coordinating and collaborating in the creation of an integrated system of care for children with ASD. In New Mexico, the Medical Assistance Division funds ASD specific services through behavioral health and Through EPSDT for physical health needs. Until recently, the Public Education Department has not participated with meaningful input in the design of a system of care for children with ASD. Mandated, consistent and fully engaged participation by each state agency that provides services to children with ASD would facilitate movements towards a fully integrated ASD system of care. | Same findings. |

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| Fragmentation in systems of care leaves individuals with ASD unable to construct appropriate and sustainable service plans. In most situations, families and adult consumers need to purchase out-of-pocket services or do without where service gaps exist between agencies or in private funding sources. | The autism private insurance mandate of 2009 has been helpful to families with that sort of coverage. The Adaptive Skill Building Programs through general fund dollars and Medicaid have been helpful to families.<br>The challenges remain that families with public insurance cannot get autism treatment, and the Adaptive Skill Building Programs through DOH and Medicaid serve only a small number of eligible participants. | Autism insurance for public employees began in 2015. Private insurance coverage for autism became available in 2009. The state added ABA as an EPSDT benefit in 2015. ABA is available on the NM Exchange. Only ERISA plans are not required to offer autism coverage. |
| New Mexico children with ASD that need out-of-home residential care are currently being placed in out-of-state facilities. New Mexico providers have not developed this service. Cost reimbursement is significantly different as out-of-state providers receive between $500-800 per day compared to an in-state rate of $350 per day. | The Autism Oversight team was formed in 2010 by Linda Roebuck-Homer, director of the Behavioral Health Purchasing Collaborative and Secretary of Health, Alfredo Vigil. The purpose of the team is to identify gaps in services, and attempt to establish wraparound services for five children in residential treatment, and then make recommendations to build capacity in New Mexico to serve children with autism and aggressive and self-injurious behavior. The team made its first recommendations in the fall of 2011. There has been no response from the Collaborative.<br>There are currently 27 children with ASD in | Although it was funded by the legislature in 2014, BHSD disbanded the Autism Oversight Team citing health privacy and proprietary issues. They have instead focused efforts on the implementation of the ABA benefit through Medicaid. There are at least 30 children with ASD in residential treatment centers, both in and out of state. Medicaid continues to fund residential treatment for individuals with ASD. The task force believes that more money is spent annually on 30 children with ASD in residential treatment than has been allocated for autism programs in NM. |

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|  | residential treatment centers. 19 are placed within NM, and 8 are placed out of state, all of whom are funded 100% through Medicaid. There is now an in state residential treatment center. The facility charges the same rate as the out of state providers. (The amount is considered proprietary information by Optum, but is substantially higher than the published Medicaid rate.) Although it is not necessarily a cost savings to have children placed in state, it is better for them to be closer to home. |  |
| Adults with ASD that are able and willing to work lack the support and service systems to gain and maintain employment. These "maintenance" services are currently unavailable for most adults with ASD | The Developmental Disabilities Planning Council issued a report in 2010 on Adults with Autism. The report emphasized the lack of employment opportunities for adults with autism who are not on the Developmental Disabilities Waiver. | Same findings as in 2007 and 2012 .The task force developed a number of recommendations for adults with ASD who do not meet criteria for the DD Waiver. These recommendations cannot be implemented without a significant increase in funding. |
| As ASD youths mature, the state does not have appropriate housing to accommodate their needs. Housing arrangements must address specific aspects of the disorders, such as delayed or inappropriate social skills, communication abilities, and inflexibility in changes in daily living. | The Adults with Autism report by the DDPC recommended that an array of housing options to meet the needs of both lower and higher functioning adults with autism. The report recommendations have not been addressed by either the administration or the legislature. | Although housing options for adults with ASD are scarce, the task force was not charged with addressing housing issues. |

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## *Behavioral Health High Utilizers/High Cost during OptumHealth NM Tenure*

### OVEVIEW:

On July 1, 2009 OptumHealth NM began managing NM's Behavioral Health Medicaid, State and other Federal dollars for consumers in need of Mental Health or Substance Abuse services as part of a 4 year contract with the Behavioral Health Purchasing Collaborative. A data pull of the top 150 highest cost consumers was done from the go live date of July 1, 2009 to December 22, 2012. We wanted to identify, through data, current patterns and trends of the current highest cost consumers in order to ascertain who the highest need consumers are and what inefficiencies there may be through service gaps in NM. Our premise is also based on out of home care as the highest cost and that consumers who showed up on this list would be in out of home care for a long, if not indefinite, period of time. Our belief is consumers should receive the "right care at the right time at the right place" and so the question will also be if the consumers on this top utilizer list are in, in fact, receiving the right care at the right facility or place.

In this analysis we will look at five components:

- Initial assumptions
- Data Findings – Top 50 consumer list and top 150 consumer list.
- Current internal OptumHealth initiatives and ongoing work on this High Utilizer/High Cost group
- Top diagnoses in high utilizer/high cost group care: barriers to treatment, current system work in process, and recommendations by diagnosis
- Overall recommendations into Centennial Care.

### INITIAL ASSUMPTIONS:

Based on our individual and collective experience in managing care and coordination of care, both at OptumHealth and in prior State and provider job experiences, the assumption of the highest utilizer/highest cost consumers were as follows:

1) Consumers with Autism Spectrum Disorder (ASD): Autism or Pervasive Developmental Disorder (PDD);
2) Consumers with both Mental Illness and Developmental Disabilities such as Mental retardation (MI/DD);
3) Consumers with Traumatic Brain Injuries (TBI); and
4) Consumers having both a cognitive disorder (i.e. Borderline Intellectual Functioning) and an aggressive disorders (i.e. Intermittent Explosive Disorder).

These assumptions made were due a variety of different observations. One was the ongoing round-the-clock high needs that consumers in these four categories may require. Also, due to the lack of specialty providers in NM able to treat some of these identified diagnoses such as Autism in community settings, children with a diagnosis of ADD or MR may end up in higher levels of care.

There is a lack of providers in NM working with child or adult consumers who need 24 hour oversight or care treating people with MR or TBIs or borderline cognitive disorders compounded with aggressive behaviors. Even if there were providers able offering this type of care for NM, the question of benefit coverage and how it would funded – Medical, Behavioral or Developmental Disability - is still not clear for many of these consumers.

In the cases of TBI with the current carve out model in NM, the medical MCO may deem that the aggressive symptoms that come from the TBI are behavioral and therefore treatment coverage should be accessed through behavioral health benefit. Conversely, the Behavioral Health MCO may conclude that since the TBI is a medical diagnosis and the behaviors are a result of the TBI, that the treatment should be accessed through the medical side. Ultimately however, it is the behavioral health providers that have more experience in working with aggressive behaviors and by virtue of desperation to find a provider that will be able to both care for these individuals and work with the aggressive behaviors these consumers are more likely to be receiving services through behavioral health providers.

Overall, our experience, and now assumption, is that many consumers who do qualify for DD (Developmental Disability) waiver services currently fall to Behavioral Health providers because of the approximate 10 year wait list to get on the DD waiver. There is also not a benefit for residential services for anyone under the age of 18 (with rare exceptions being made by the DDSD Dir. for person over 17 years old).

The probability of cost is also higher if these consumers with developmental delays who are under 18 years of age are in Child Youth Family Department (CYFD) custody, or in a guardian's custody but that guardian is unable to care for the consumer due to being elderly (such as a grandparent) or not being able to provide a stable environment due to poverty and/or the guardian having his or her own physical or behavioral health issues.

**FINDINGS**:

Of the four assumption categories, only two are valid:

1) Consumers with Autism Spectrum Disorder (ASD); and
2) Consumers with both Mental Illness and Developmental Disabilities such as Mental retardation (MI/DD).

We did not find a large pattern of consumers with TBI or cognitive borderline functioning with aggressive disorders in the top 150 High Utilizers/High Cost. However, of the two assumptions that are valid, the percentage rate of consumers with ASD and/or Mental Retardation is much higher than initially thought. We have broken this data down into two lists, the top 50 and the top 150.

**50 consumers: Cost is $25,165,371.20 for period of July 1, 2009 through December 22, 2012.**

*Consumers with ASD/PDD or DD (Mental Retardation):*

- 45 people have a diagnosis that includes ASD/PDD, MR or both, or 90% of the top 50.
- Of the 45 people above, 31 consumers have MR, and out of those consumers 19 are also diagnosed with ASD/PDD.
- 29 consumers have ASD or PDD with MR or another diagnosis.
- 82% of people with MR are diagnosed as mild MR with additional diagnoses, only 18 % have severe or moderate MR.
- 90% of the top 10 high utilizers have ASD or PDD/NOS for an average cost of $686,289.00 per person.
- Of the 31 consumers with an MR diagnosis: 6 in CYFD custody, 3 Title IV adopt, 3 have had JJS involvement.

*Other statistics:*

- Average per person cost of $503,267.00.
- NOS diagnoses billed = $15,064,413.19.
- 98% of the High Utilizers are currently children/youth under the age of 19, One consumer is 22 years old.
- 1 consumer has a TBI.
- 1 consumer is Navajo.

**150 consumers: $54,861,758.72 for period of July 1, 2009 through December 22, 2012.**

*Consumers with ASD or MR:*

- 97 of 150 consumers have ASD/PDD, MR or a combination of the two diagnoses.
    - 68 with MR
    - 28 have ASD/ PDD
    - 17 ASD, with 5 also MR
    - 40 have PDD, with 23 also MR
- 68 have MR, 30 of those involved in CYFD, JJS, or Tribal custody.

*Other Statistics:*

- Average per person cost of $365,745.05.
- 55 of the 150 of the consumers are CYFD, CYFD involved or Title IV adopt.
- 131 consumers are approximately 18 years or younger (born in 1994 or later).
- 2 have Tribal custody/involvement.
- 18 consumers involved with Juvenile Justice Services (JJS).
- 46 consumers have an ADHD diagnosis, 29 of these consumers also have ASD/PDD or MR

- 18 consumers have a diagnosis of Oppositional Defiant Disorder (ODD), 12 of the consumers with this diagnosis also have an MR or an ASD/PDD diagnosis.
- 44 have a PTSD diagnosis.
- 22 consumers have a Reactive Attachment Disorder (RAD) diagnosis.
- 20 have a Bipolar diagnosis.
- 102 have some type of NOS (Not Otherwise Specified) diagnosis.
- 4 have Fetal Alcohol Syndrome diagnosis (FAS).
- 6 consumers note seizures.
- 5 consumers have a TBI.
- 4 consumers are deaf.

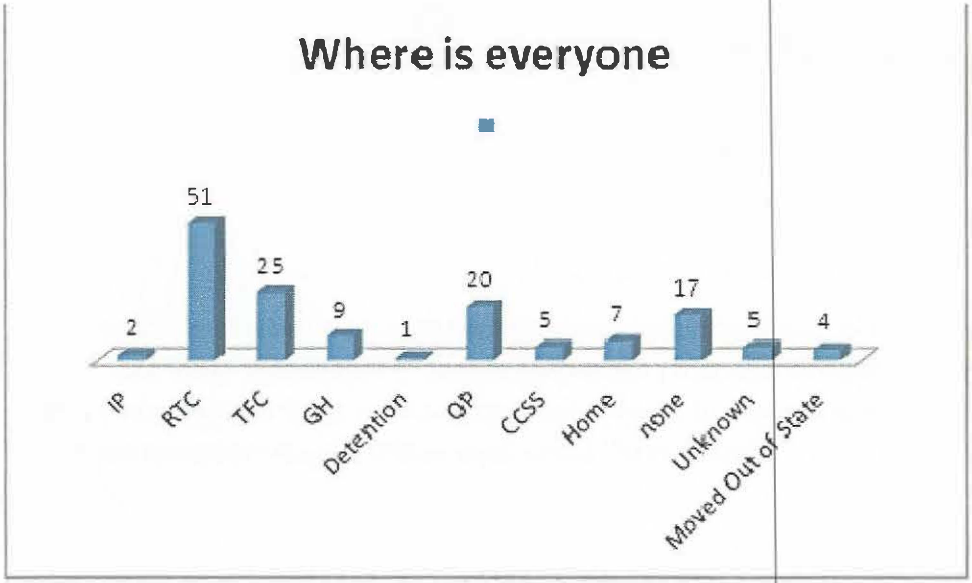
This data shows the unprecedented reliance on the New Mexico Behavioral Health system for children who require services for developmental delays, specifically ASD and MR. With 97 out of 150 consumers having one or both of these diagnoses, that is almost exactly 2/3rds of the top utilizer list. The consumers that have a TBI or are low functioning and aggressive may be an issue in access to care in NM but the data does not support an overall trend of this specific population being one of the highest cost utilizers.

Additionally the amount of NOS diagnosis is a trend that was surprisingly high and may be contributed to a variety of factors. Overall, these children have complicated and high needs, especially if there is a developmental delay and additionally there has been some abuse or trauma in that child's life. A child with ASD or MR will process and express oneself in ways that are different and at times may appear more impulsive or disruptive to an assessor who does not have specific training in ASD or MR. Another possibility for this trend is that children with developmental delays may not have been diagnosed correctly at one time or another and have received BH diagnoses that continue to stay with the consumer. Or the provider is still unclear if the behavioral symptom stems from a developmental or behavioral health disorder. Also, in order to receive BH services a consumer must have a BH diagnosis, and so some children that have a primary diagnosis of MR or Autism may also be assessed by BH providers for any BH diagnoses as well to ensure services. If the child was in the DD system there may or may not have been an additional BH diagnosis attached to that child. Currently, $15,064,413.19 has been paid for NOS diagnoses for the top 50 high utilizers after years of institutional and out of home care. People in institutional care for so long should be getting the right care, which happens more accurately with the right diagnoses.

**Current internal OptumHealth initiatives and ongoing work on this High Utilizer/High Cost group:**

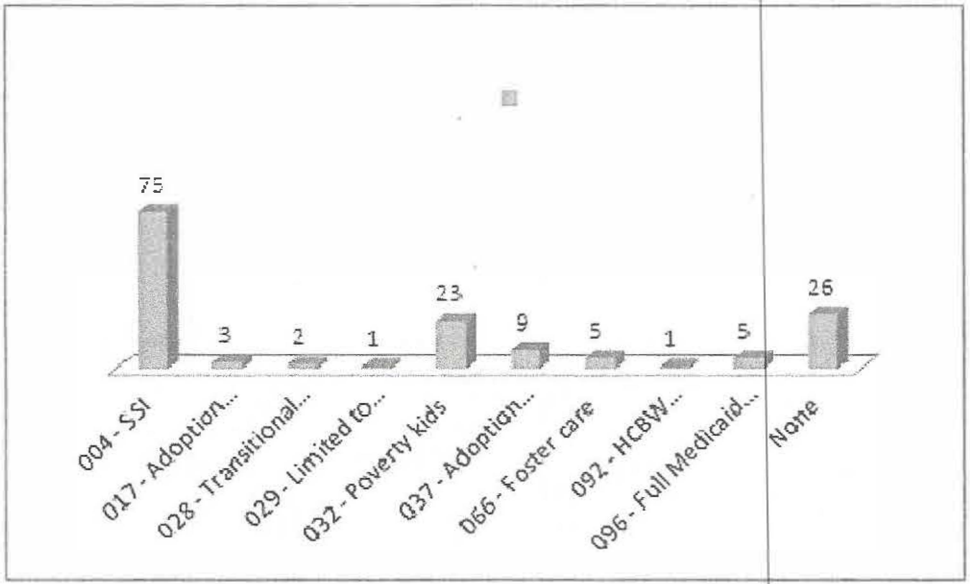
The OptumHealth NM Clinical Department has a team of Care Coordinators and Care Advocates that specifically began focusing on this target population in February of 2013 and have target goals they will be measured by the end of 2013. The overarching goal of this group is: ***Implement interventions both on a systems level and on an individual consumer level to decrease ongoing high utilization of Behavioral Heath out-of-home services when consumers would be better served by quality, community based services or would be more appropriately served by other service systems outside of Behavioral Health.***

Continued analysis of this data is being done by this group. Of the data analysis done to date in March of 2013, this team has looked at where these consumers currently reside – RTC, community, TFC, group home - and also if the consumers are currently receiving SSI or any other subsidy in conjunction with receiving treatment in Medicaid funded out-of-home services. Below is an initial breakdown of where the consumers are currently being treated and how many consumers are receiving subsides.



There are 88 consumers who are currently in out of home level of care, and 51 of those are in RTC. This number tells us that close to half of the high utilizers are *currently in the community*, although they had to have received a higher level of care at one time in order to be on the high utilizer/high cost list. This is hopeful number in that consumers have discharged to community-based services and are not in an institution or out of the community.

The next graph, below, is a list by type of SSI or subsidies currently being received.



Current discussion in the group has begun to focus on ways to determine if SSI and adoption subsidies funds are being used appropriately and effectively while these consumers are out of home, and alternative recommendations on what types of specific therapeutic services could be additionally paid for through these funds if a child is in a "bundled rate" service such as RTC using BH Medicaid dollars.

**Top diagnoses in high utilizer/high cost group care: Autism Spectrum Disorder (ASD) barriers to treatment, current system work in progress, and recommendations by diagnosis.**

Clearly ASD is one diagnosis that the BH system is spending an inordinate amount of dollars on and this would be due in large part to treating the consumer in institutional settings. There is much research and belief that treatment for ASD should not be done in an institutional setting or that an institutional setting may not be required if a child is diagnosed with Autism early in childhood and receives early intensive intervention in the home. Early intervention (before age 5) has the best prognosis.

Of the top 150 high utilizers/high cost consumers, consumers with diagnosis of ASD account for $7,502,332 spent in the last 3.5 years and consumers with diagnosis of PDD account for $16,590,353 spent in the last 3.5 years. The consumers with these diagnoses also may have MR and/or other BH diagnoses that require treatment in intensive settings. However, even if we take a portion of the $23,000,000 that was spent in the last 3.5 years on less than 150 consumers and could divert it to specialty programs that focus on early assessment and a continuum of community based treatment, we may see better individual outcomes overall and would be able serve many more more children and families.

Below is a summary of**identified barriers** for treatment of ASD in NM:

- Lack of specialty providers for both assessment and treatment.
- Early assessment and treatment equals better outcomes, but an assessment at UNM CDD which is the primary specialty provider in the state of NM can be a 6 month wait and then there is a lack of community/ outpatient providers once the assessment completed.
- ASD is not "owned" by any state agency in NM, no funds appropriated to manage services or oversight of policies for ASD. People with ASD *may* be treated using BH funds or DD funds but there is not clear direction or ownership in the DD or BH systems of care.
- Lack of effective RTCs in NM with a specialty of treating ASD and as a result, many of these children are currently receiving services out of state.
- Lack of continuum of services starting with parent/family education and no easy access for a parent, guardian or provider who needs to find treatment for a child with ASD.
- Lack of DD waiver services due to 10 year waiting list and services are not targeted for children even if a child was on the DD waiver.
- Children in CYFD custody are much more difficult to place with a foster family who wouldn't have specific training on working with a special needs child so would need a specialized foster care or treatment foster care but currently there is no specialized TFC for ASD.
- Schools do not maintain accountability for student.

**NM system work completed and ongoing:**

- Autism Oversight Team: participants comprised of HSD/MAD, DOH/DDSD, CYFD, OHNM, PED, UNM CDC. Beginning 2010 the AOT assessed NM service system and barriers by working on individual cases to bring up to 5 consumers with Autism back into NM and augmenting wraparound services for the consumer. Senate Memorial 20 requesting that the State develop a service plan for ASD through an Autism Memorial Task force and that the service plan include both the proposed policy development and the funding necessary to begin implementation (attachment 3).
- Memo from NM PED on partnering with RTCs and BH sent July 19, 2012 (attachment 4).
- OHNM partnering with DDSD much more closely through some special projects than previously.
- Collaborated with DDPC and ASD experts to develop the "DDPC Adult Autism Plan" (attachment 5).

**Recommendations on ASD:**

1. Implement the 2012 Autism Memorial Taskforce recommendations (attachment 5).

2. Research and implement a NM version of the Fraser Center model (attachment 7).
3. Develop an MOU with DOH/DDSD that states the MCO/Medicaid is responsible for treatment prior to age 18, at age 18 consumers on the DD waiver waiting list will automatically receive an expedited DD waiver.
4. MOU with PED or individual school districts that the school will pay the educational component if a child is in RTC.
5. Inter-departmental staffing for all high utilizer youth to include the MCO, DOH/DDSD, the school, CSA if eligible, consumer and family/guardian, and CYFD and the UNM Autism project if involved.
6. Increased partnering with DDSD before age 18 to supplement services through State General Funds (respite, Behavior Support Consulting...)
7. Coordinate with the DDSD FIT (Family Infant Toddler) program for community based early childhood services.
8. Develop an ASD specific Non Accredited RTC in NM.
9. Create an Office of Autism to coordinate ASD services across agency/funding lines.
10. Integrate treatment- SLP, OT, PT.
11. Parent/family training opportunites.
12. Partner with RTCs, schools, CSAs, families to improve discharge planning process using the templates and process developed by the Autism Oversight Team (attachment 8 and 9).
13. Adaptive Skill Building (ASB)- increase access to these Medicaid services past children under the age of 5 (ABA $11.25 per 15 min x 20 hours a week= $900 a week, $3,600 a month or $43,200 a year).
14. Continue actions created to bring kids home from OOS RTCs (attachment 10).
15. Have an Autism Summit to include self-advocates, families, guardians, MCOs, DOH, UNM/CDD, Schools, providers, NM Autism Society (NM AS), Medicaid, advocates, to bring the community together to begin fully working together.
16. Expand provider services using ASD expertise: Example: Michael Langford, previous Exec. Dir. of TX Hill who has specifically trained staff wanting to move to Albuquerque. Here is an opportunity to support an expert provider who NM has been sending kids to for years for the treatment of Autism, to begin working in NM. However, in our opinion the State needs to own this expansion and bringing this expertise in state and provide the ongoing and continuous support and full collaboration of state stakeholders. Additionally these specialty providers may

need specialty rates that may need to be blended with Medicaid, CYFD and DOH in partnership with the LCA (Licensing Authority).

17. Ensure consistency in policies throughout departments. This is where the Office of Autism could come in if there were one. For example, The Medicaid ASB guidelines are more comprehensive than the DOH/DDSD guidelines for ASB.
18. Review and implement recommendations from the "DDPC Adult Autism Plan".
19. Increase utilization of ICF/MRs.
20. Establish ASD support groups/training for families, both biological families, foster care and TFC families.

**Top diagnoses in high utilizer/high cost group care: Mental Retardation (MR) / Developmental Disabilities (DD) barriers to treatment, current system work in progress, and recommendations by diagnosis.**

68 out of the top 150 high utilizers/high cost consumers had a diagnosis of Mental Retardation and 58 of the 150 consumers have involvement with CYFD or tribal custody. Many of these high cost consumers with MR are in State custody. Many of these consumers with MR are in institutional settings. Mental Retardation is an Axis II diagnosis and in and of itself is not covered under BH benefits. The health benefits for a MR diagnosis that a consumer may receive is through the DD waiver. However, as we have pointed out before, it is 10+ years on a waiting list before a consumer may be able to access services through the DD waiver. For a DD consumer that does get on the DD waiver but is under 18 and does not have a family home, or needs constant care in a supervised setting, or requires a RTC/institutional level of care, there is no service through the DD waiver. Therefore, many times these consumers become involved in the BH system of care that does have residential treatment as indicated in this data.

**Summary of Barriers:**

- Lack of specialty providers, especially DD and medical providers.
- Lack of community and outpatient providers.
- Lack of accessible DD waiver services.
- DOH does not have any ongoing residential waiver services to offer until age18, including out of home care.
- 10+ year waiting list for DD waiver.
- School IEPs offer varying degrees of assistance, but are not coordinated with current BH treatment.

- Children in CYFD don't have parents to receive training so need to go into specialized TFC or foster care but there is no specialized TFC. Or the child is not in CYFD custody but the guardian unable to care for child as elderly (such as a grandparent) or have multiple kids in the house.

**Current system work done or in progress:**

- Monthly trainings for 18 months were sponsored by Optum and DDSD for BH and DD providers.
- Recruited experienced DD waiver therapists to become Optum network providers.
- Partnering with stakeholders including DDSD, DDPC, Center for Self-Advocacy, the Governor's Commission on Disabilities, DRNM, CYFD, Medicaid, ALTSD, Brain Injury Assoc.
- Sponsor the SW Conference on Disabilities.
- See attachment 11 for more complete details.

**Recommendations by Diagnosis:**

1. Develop an MOU with DOH/DDSD that states the MCO/Medicaid is responsible for treatment prior to age 18, at age 18 consumers on the DD waiver waiting list will automatically receive an expedited DD waiver.
2. MOU with PED or individual school districts that the school will pay the educational component if a child is in RTC.
3. Expedited DD waiver for consumers in TLS who are on the DD waiver waiting list.
4. Inter-departmental staffings for all high utilizer youth to include the MCO, DOH/DDSD, the school, CSA if eligible, consumer and family/guardian, and CYFD if involved.
5. Ensure every youth with an MR diagnosis or suspected disability applies for the DD waiver.
6. Integrated treatment- SLP OT PT.
7. Training for providers, families, guardians, self-advocates.
8. Develop a DD specific Group Home and experienced TFC agency.
9. Increase rates and revise regulations for DD specialized Group Home and DD specialized TFC.
10. Increase MI/DD expertise of community based services so youth can remain at home.
11. Increased partnering with DDSD before age 18 to supplement services through State General Funds (respite, Behavior Support Consulting...)
12. Coordinate with the DDSD FIT (Family Infant Toddler) program for community based early childhood services

13. Increase utilization of ICF/MRs if consumer is appropriate for this level of care.
14. Establish support groups/training for families, both biological families, foster care and TFC families.

**OVERALL recommendations/suggestions**

A fraction of the dollars spent on 150 individuals over 3.5 years could instead assist in building a continuum of services for thousands of New Mexicans who are under 21, diagnosed with ASD and/or MR, and in need of ongoing specialized services. We have many institutionalized children and youth in NM due to a lack of community and early childhood services, and these youth are waiting now for a DD waiver allocation that may or may not come up at 18. There will be many more years in institutions for some of these individuals at this high cost, and there is an alarming gap in services at 21, when these individuals will no longer qualify for RTC benefit under Medicaid. There are limited ICF/MRs that do not generally take consumers with complex DDMI behaviors. These individuals, as they age out, may be homeless and may end up in inpatient, jail, or dead. 25 DDMI individuals are currently being "held harmless" in Transitional Living Service (TLS) although they will not transition to independent care. Their future is uncertain with Centennial Care, as TLS is not a core Medicaid benefit but paid through under a different discretionary bucket.

As the State transitions to Centennial Care, OptumHealth NM recommends that the State considers:

- Starting an Office of Autism.
- Developing an MOU with DOH/DDSD that states the MCO/Medicaid is responsible for treatment prior to age 18, at age 18 consumers on the DD waiver waiting list will automatically receive an expedited DD waiver.
- Developing an MOU with PED or individual school districts that the school will pay the educational component if a child is in RTC.
- Expediting a DD waiver for the hold harmless consumers in TLS who are on the DD waiver waiting list.
- Consider that certain high utilizer populations becomes FFS not MCO.
- Consider pricing of contracts to include expectation that many of these high utilizer individuals will need long term institutional settings if MCOs continue overall responsibility through BH providers of the under 21 population.
- The State, not the MCOS, own and direct the build out of the service system for these individuals.
- Is BH the right system to serve ASD and DDMI children and youth? If so, thoughtfully expand the BH system and educate.

# FISCAL IMPACT REPORT

| | | | | | |
|---|---|---|---|---|---|
| | | **ORIGINAL DATE** | 2/23/17 | | |
| **SPONSOR** | Thomson | **LAST UPDATED** | 3/03/17 | **HB** | 403/aHHHC |
| **SHORT TITLE** | Autism Spectrum Coverage Regardless of Age | | | **SB** | |
| | | | | **ANALYST** | Chilton |

## ESTIMATED ADDITIONAL OPERATING BUDGET IMPACT (dollars in thousands)

| | FY18 | FY19 | FY20 | 3 Year Total Cost | Recurring or Nonrecurring | Fund Affected |
|---|---|---|---|---|---|---|
| **State share*** | $83.85 | $89.55 | $98.10 | $271.50 | Recurring | General Fund |
| **Federal share*** | $642.2 | $636.5 | $627.9 | $1,906.5 | Recurring | Federal Matching funds |

(Parenthesis ( ) Indicate Expenditure Decreases) * State and federal shares of the cost are figured using the current declining federal share of the cost of providing Medicaid coverage to the Medicaid expansion population (94% for **calendar** 2018, 93% for calendar 2019, and 92% for calendar 2020.

Relates to House Bills 283 and 367, House Memorial 51, Senate Joint Memorial 2, and Senate Memorial 79.

## SOURCES OF INFORMATION

LFC Files

Responses Received From
Department of Health (DOH)
Human Services Department (HSD)

## SUMMARY

### Synopsis of Amendment

The amendment makes two unrelated changes:

1) It removes the exclusion for coverage of services provided for children with autism through the federal Individuals with Disabilities Education Act, and
2) Removes the statement that "autism spectrum disorder" can be defined by any edition of the American Psychiatric Association's Diagnostic and Statistical Manual. It would be assumed (although not stated in the amended bill) that the current edition would be used.

### Synopsis of Original Bill

House Bill 403 refers to children and adults covered by Medicaid. Regarding those with a condition meeting the criteria for autism spectrum disorder contained in the Diagnostic and Statistical Manual of Mental Disorders, Medicaid would be required to pay for services not subject to age restrictions, cost-sharing, or dollar limits. The services to be included, upon being prescribed by a treating physician according to a treatment plan:

- Screening for autism spectrum disorder (ASD)
- Speech therapy
- Occupational therapy
- Physical therapy
- Applied behavior analysis

Services could not be denied on the basis that they are habilitative or rehabilitative, but could be subject to some restrictions according to review of medical necessity and other general exclusions.

The treatment plan specified must include diagnosis, treatment types with duration and frequency, anticipated goals of treatment, frequency with which the plan would be updated, and be signed by the physician.

## FISCAL IMPLICATIONS

HSD provides extensive analysis of the costs to provide expanded services through Medicaid to New Mexicans with autism spectrum disorders, which are summarized in the table above. Their longer analysis is included as the attachment. HSD's analysis takes into account the differing federal matches available for traditional Medicaid and for the Medicaid expansion population and the declining federal match for the latter (and thus increasing state cost for the Medicaid expansion group). No analysis can take into account possible changes to the Affordable Care Act and to the Medicaid program.

## SIGNIFICANT ISSUES

The bill specifies "treating physician;" whereas some children and adults with ASD may be cared for by nurse practitioners or physician assistants.

Autism spectrum disorder, not defined in this bill, has been diagnosed with greater and greater frequency in recent years. In fact, the definition has changed as well, with at least part of the observed increase in diagnosis due to the changes in definition. The cause of most cases of ASD is not known. In 2013, the American Psychiatric Association consolidated under the umbrella term the previously used terms Asperger syndrome, pervasive developmental disorder – not otherwise specified, autistic disorder, and childhood disintegrative disorder. Children with the relatively rare Rett Syndrome usually fall within this spectrum. All in all, the prevalence of autism has increased over the past 50 years from one in one thousand to CDC's most recent estimate of one in 68.

DOH notes that Medicaid already pays for Applied Behavioral Analysis (ABA) for children with a diagnosis of an autism spectrum disorder through age 21, but that the bill would allow payment for ABA at any age.

DOH also notes that its "Developmental Disabilities Supports Division (DDSD) provides a variety of other autism services to both children and adults with ASD who are not Medicaid eligible. These include: recreational respite; diagnostic evaluations; training on evidence based practices; technical assistance to agencies and teams; family support; a summer camp; and autism flexible services." DOH calls attention to the importance of University of New Mexico autism programs in building capacity for services such as would be provided under House Bill 403.

The Merriam Webster medical dictionary defines applied behavior analysis as "psychological therapy that uses techniques (such as operant conditioning) developed from the objective analysis of observable behavior to make changes to socially significant behaviors that are abnormal or harmful." A Los Angeles Times article in 2001 stated that "it uses rewards—goldfish crackers, playing with toys, praise—to teach children all kinds of behaviors, lessons and life skills, step by tiny step, in intensive, one-on-one drills." Applied behavior analysis has been best studied among children. With regard to just one symptom of ASD, aggression, a recent review article concluded "The bulk of the treatment dollars are flowing to programs for small children. This approach has become the norm. These kids need and deserve the best possible services the professional community can provide. However, the bulk of the population of persons with ASD is not small children; these older individuals are not cured, and many of them evince aggression. More research in the older adult population is warranted." (Mattson JL, Jang J. Treating aggression in persons with autism spectrum disorder. Research in Developmental Disabilities, 2014.)

**RELATIONSHIP** with House Memorial 51 and Senate Memorial 79, identical memorials to study the needs of children and adults on the autism spectrum.

**RELATIONSHIP** with House Bill 367, which would require health insurance companies to cover services for individuals with autism spectrum disorders regardless of age and without a cap on services (per year or per lifetime) different from annual and lifetime caps for other disorders. HB367 applies to other forms of insurance similar requirements to those envisioned under this bill for Medicaid.

**RELATIONSHIP** with Senate Joint Memorial 2, which would add Rett Syndrome to the list of conditions qualifying a person for the DD Waiver (virtually all patients with the genetic Rett Syndrome have an autism spectrum disorder, but only a small proportion of patients with autism spectrum disorders have Rett Syndrome).

**RELATIONSHIP** with House Bill 283, which would provide persons diagnosed with a communication disorder (many patients with autism spectrum disorder have communication disorders) with identification that would allow law enforcement officers to know that alternate methods of communication with drivers with those disorders were needed.

## WHAT WILL BE THE CONSEQUENCES OF NOT ENACTING THIS BILL

Coverage for services for children with an autism spectrum disorder and Medicaid would remain generally inclusive of all recommended therapies, but coverage for Medicaid-covered adults with autism spectrum disorders would be spotty, as at present.

LAC/al/jle

## HUMAN SERVICES DEPARTMENT CALCULATION OF FISCAL IMPLICATIONS OF HB 370.

The fiscal impact of this bill would be to extend ASD services to all full-benefit Medicaid recipients aged 21 and above.

The current expenditure for ASD services for children is approximately $2.1 million per year.

However, there are specific issues that need to be considered when estimating the financial impact of treating adults.

- The intensity of services to children are greater than would be expected for adults because the goals for the adult would be more related to the function and regulation of the adult, as opposed to intensity of services to a child to significantly change the future functioning of the child.

- Not all services that are known to be effective for children through evidence based studies are shown to be effective for adults. Under federal rules, therapies directed toward the adult population would have to be known to have a positive effect over time before such therapies can be included in an individualized adult treatment plan. The treatment plan for an adult may be less robust than for a child because the treatment goals for the adult would be different.

The bill would extend ASD services to two different groups of adults, each with a separate financial impact.

1. The "other adult group"

   Estimated Utilization of ASD Services:
   In order to provide an approximate number of individuals currently enrolled in the other adult group population which may require ASD treatment, the following was considered:

   a. The size of the population of children to that of the other adult group;

   b. The percent of children in the Medical Assistance program receiving ASD services in 2016.

   Based on these populations, HSD estimates the total number of adults enrolled in the Medicaid Expansion category who may require ASD treatment to be 95 recipients.

   Estimated financial impact:
   While the average cost per child ASD recipient is $15,000, it is not anticipated that the cost of treating an adult would be that high. The adult may be more stabilized and the services rendered to an adult are typically less intensive than those services rendered to a child, so the estimated cost of treating an adult would be approximately $6,000 per year per recipient. The additional expenditure would be up to $570,000 annually. The

Federal matching rate for the “other adult group” is 95% for 2017; 94% for 2018; and 93% for 2019. The estimated general fund cost for FY 2018 is $37,050.

2. Remaining Medicaid adults in full benefit categories of Medicaid

   Estimated Utilization of ASD Services:
   Using the same method as for “the other adult group”, HSD estimates the total number of remaining Medicaid adults who may require ASD treatment at 26 recipients.

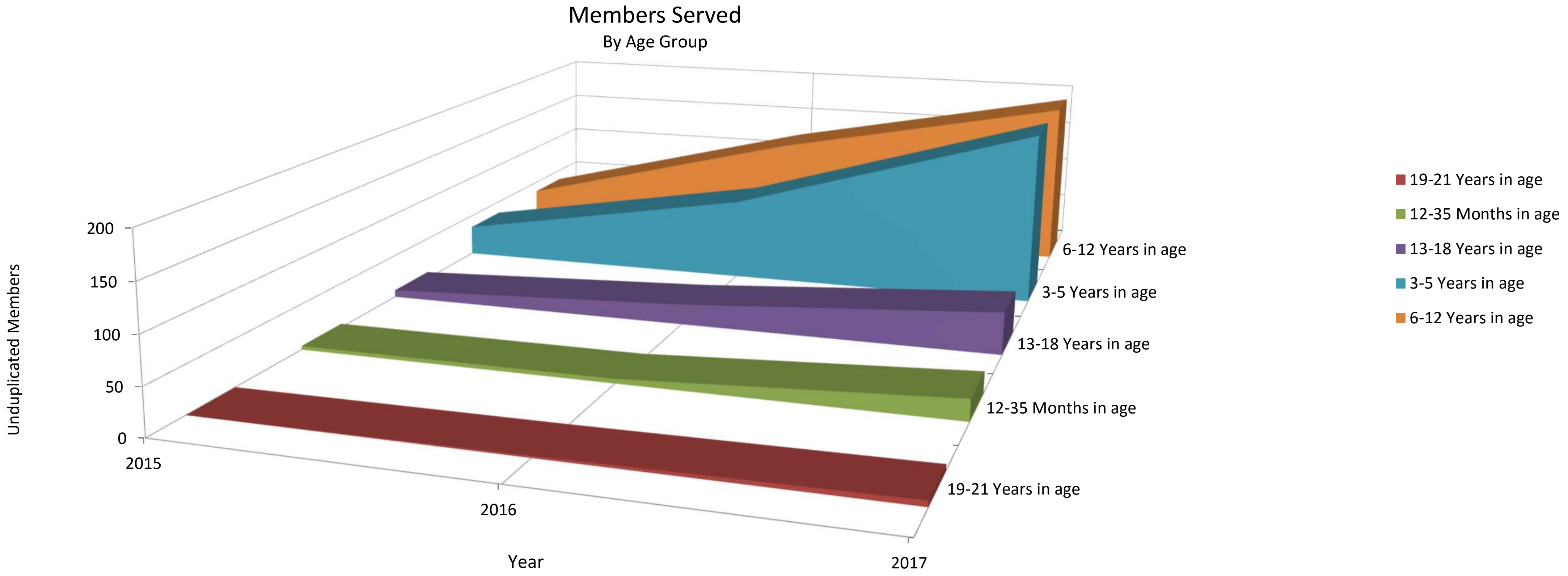
   Estimated financial impact:
   Using the same method as stated under “the other adult group” calculation, it is estimated there were would be a cost of $6,000 annually for these additional recipients, the estimated additional expenditure would be up to $156,000 annually. For these adults that are not in the Medicaid Expansion group, the federal match rate is approximately 70% of expenditures. The estimated general fund cost for FY 2018 is $46,800.

Adding the estimated financial impact of the Medicaid Expansion adult group and the remaining adults in Medicaid that could potentially use ASD services, the total estimated financial impact is $726,000 annually. The estimated total general fund cost for FY 2018 is $83,850.

## Members Served by Age Group

Source Information: AdHoc ABA Reports:
CY2015, CY2016, Q4 2017 (All MCOs).

| Age | 2015 | | | | | 2016 | | | | | | 2017 | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | UHC | Molina | BCBS | Pres | All MCO Total | UHC | Molina | BCBS | Pres | All MCO Total | Chng Prcnt 2016 \| 2015 | UHC | Molina | BCBS | Pres | All MCO Total | Chng Prcnt 2017\|2016 |
| **Unduplicated total count of members accessing ABA services** | **0** | **26** | **16** | **42** | **84** | **4** | **90** | **50** | **104** | **248** | **195%** ▲ | **18** | **164** | **123** | **161** | **466** | **88%** ▲ |
| Unduplicated total count of members age 12 months through 35 months accessing ABA services | 0 | 2 | 1 | 1 | **4** | 0 | 2 | 1 | 2 | **5** | **25%** ▲ | 1 | 2 | 0 | 20 | **23** | **360%** ▲ |
| Unduplicated total count of members age 3 through 5 accessing ABA services | 0 | 9 | 13 | 13 | **35** | 1 | 40 | 23 | 30 | **94** | **169%** ▲ | 10 | 80 | 56 | 52 | **198** | **111%** ▲ |
| Unduplicated total count of members age 6 through 12 accessing ABA services | 0 | 11 | 2 | 24 | **37** | 3 | 42 | 26 | 53 | **124** | **235%** ▲ | 6 | 65 | 56 | 65 | **192** | **55%** ▲ |
| Unduplicated total count of members age 13 through 18 accessing ABA services | 0 | 4 | 0 | 4 | **8** | 0 | 6 | 0 | 17 | **23** | **188%** ▲ | 1 | 15 | 11 | 20 | **47** | **104%** ▲ |
| Unduplicated total count of members age 19 up to 21 accessing ABA services | 0 | 0 | 0 | 0 | **0** | 0 | 0 | 0 | 2 | **2** | ***Y2015=0** ▲ | 0 | 2 | 0 | 4 | **6** | **200%** ▲ |
| **Total** | | | | | **168** | | | | | **496** | | | | | | **932** | |

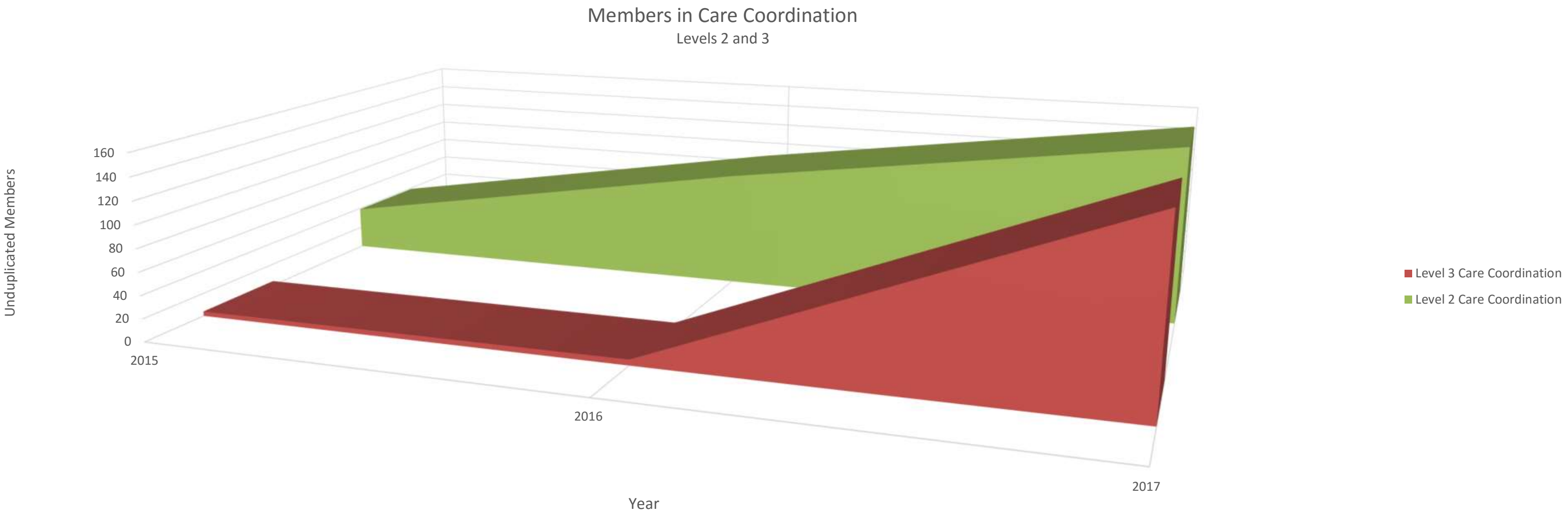


## Members in Care Coordination

Levels 2 & 3

Source Information: AdHoc ABA Reports:
CY2015, CY2016, Q4 2017 (All MCOs).

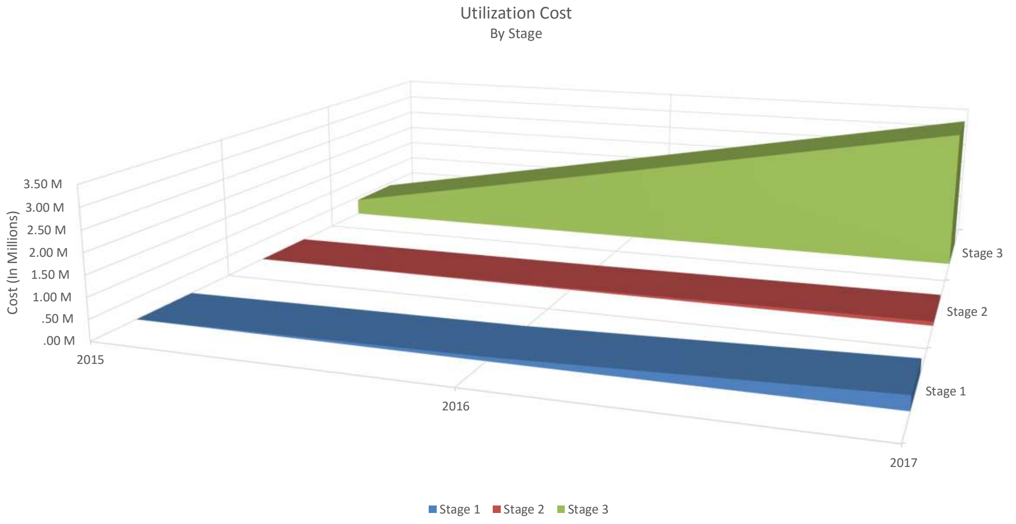
| Age | 2015 | | | | | 2016 | | | | | | 2017 | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | UHC | Molina | BCBS | Pres | All MCO Total | UHC | Molina | BCBS | Pres | All MCO Total | Chng Prcnt 2016 \| 2015 | UHC | Molina | BCBS | Pres | All MCO Total | Chng Prcnt 2016 \| 2015 |
| Unduplicated total count of members in level 2 for care coordination who are receiving ABA | 0 | 18 | 6 | 15 | **39** | 3 | 36 | 19 | 44 | **102** | 162% ▲ | 6 | 47 | 44 | 58 | **155** | 52% ▲ |
| Unduplicated total count of members in level 3 for care coordination who are receiving ABA | 0 | 0 | 2 | 2 | **4** | 0 | 0 | 1 | 4 | **5** | 25% ▲ | 0 | 117 | 11 | 32 | **160** | 3100% ▲ |
| **Total** | | | | | **43** | | | | | **107** | | | | | | **315** | |



## Member Utilization
### Costs by Stage of Services

Source Information: AdHoc ABA Reports:
CY2015, CY2016, Q4 2017 (All MCOs).

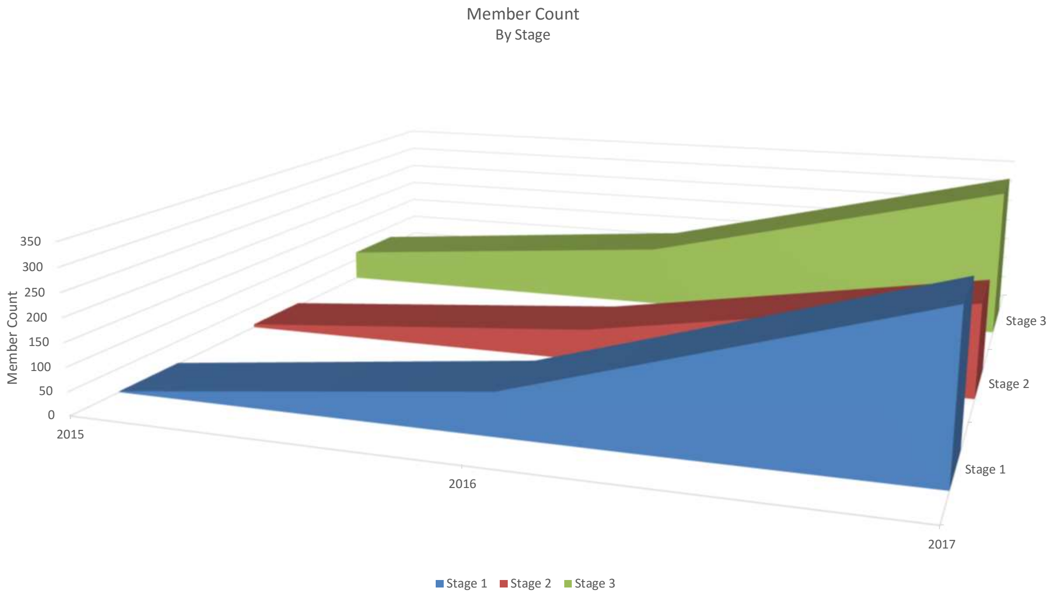
| | 2015 | | | | | 2016 | | | | | | | 2017 | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | Change 2016 \| 2015 | | | | | | | Change 2017 \| 2016 | |
| **Member Utilization** | **UHC** | **Molina** | **BCBS** | **Pres** | **All MCO Total** | **UHC** | **Molina** | **BCBS** | **Pres** | **All MCO Total** | **Chng Dollar** | **Chng Prcnt** | **UHC** | **Molina** | **BCBS** | **Pres** | **All MCO Total** | **Chng Dollar** | **Chng Prcnt** |
| Stage 1 services during reporting time period. | $ - | $ - | $ - | $ 2,600.00 | $ 2,600.00 | $ 861.00 | $ 13,000.00 | $ 23,123.60 | $ 57,811.82 | $ 94,796.42 | $ 92,196.42 | 3546% ▲ | $ 49,438.20 | $ 62,650.00 | $ 58,187.50 | $ 161,610.00 | $ 331,885.70 | $ 237,089.28 | 250% ▲ |
| Stage 2 services during reporting time period. | $ - | $ 2,370.61 | $ 1,448.00 | $ 1,080.50 | $ 4,899.11 | $ - | $ 10,151.00 | $ 17,024.25 | $ 9,690.40 | $ 36,865.65 | $ 31,966.54 | 652% ▲ | $ 4,772.64 | $ 13,283.50 | $ 27,598.45 | $ 54,794.10 | $ 100,448.69 | 63583.04 | 172% ▲ |
| Stage 3 services during reporting time period. | $ - | $ 89,046.00 | $ 102,318.00 | $ 228,429.80 | $ 419,793.80 | $ 196.00 | $ 601,660.00 | $ 526,951.82 | $ 785,888.43 | $ 1,914,696.25 | $ 1,494,902.45 | 356% ▲ | $ 105,645.00 | $ 1,800,162.03 | $ 1,227,804.92 | $ 298,555.59 | $ 3,432,167.54 | $ 1,517,471.29 | 79% ▲ |
| **Total** | | | | | **$ 427,292.91** | | | | | **$ 2,046,358.32** | | | | | | | **$ 3,864,501.93** | | |


Utilization Cost
By Stage

## Member Utilization
### Member Count by Stage of Service

Source Information: AdHoc ABA Reports:
CY2015, CY2016, Q4 2017 (All MCOs).

| | 2015 | | | | | 2016 | | | | | | 2017 | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Stage Level | UHC | Molina | BCBS | Pres | All MCO Total | UHC | Molina | BCBS | Pres | All MCO Total | Change 2016 \| 2015 | UHC | Molina | BCBS | Pres | All MCO Total | Change 2017 \| 2016 |
| Stage 1 services during reporting time period. | 0 | 0 | 0 | 2 | 2 | 3 | 37 | 18 | 32 | 90 | 4400% ▲ | 24 | 60 | 65 | 182 | 331 | 268% ▲ |
| Stage 2 services during reporting time period. | 0 | 3 | 2 | 2 | 7 | 0 | 30 | 21 | 19 | 70 | 900% ▲ | 6 | 42 | 50 | 103 | 201 | 187% ▲ |
| Stage 3 services during reporting time period. | 0 | 23 | 15 | 32 | 70 | 2 | 55 | 33 | 49 | 139 | 99% ▲ | 23 | 115 | 76 | 118 | 332 | 139% ▲ |
| **Total** | | | | | **79** | | | | | **299** | | | | | | **864** | |

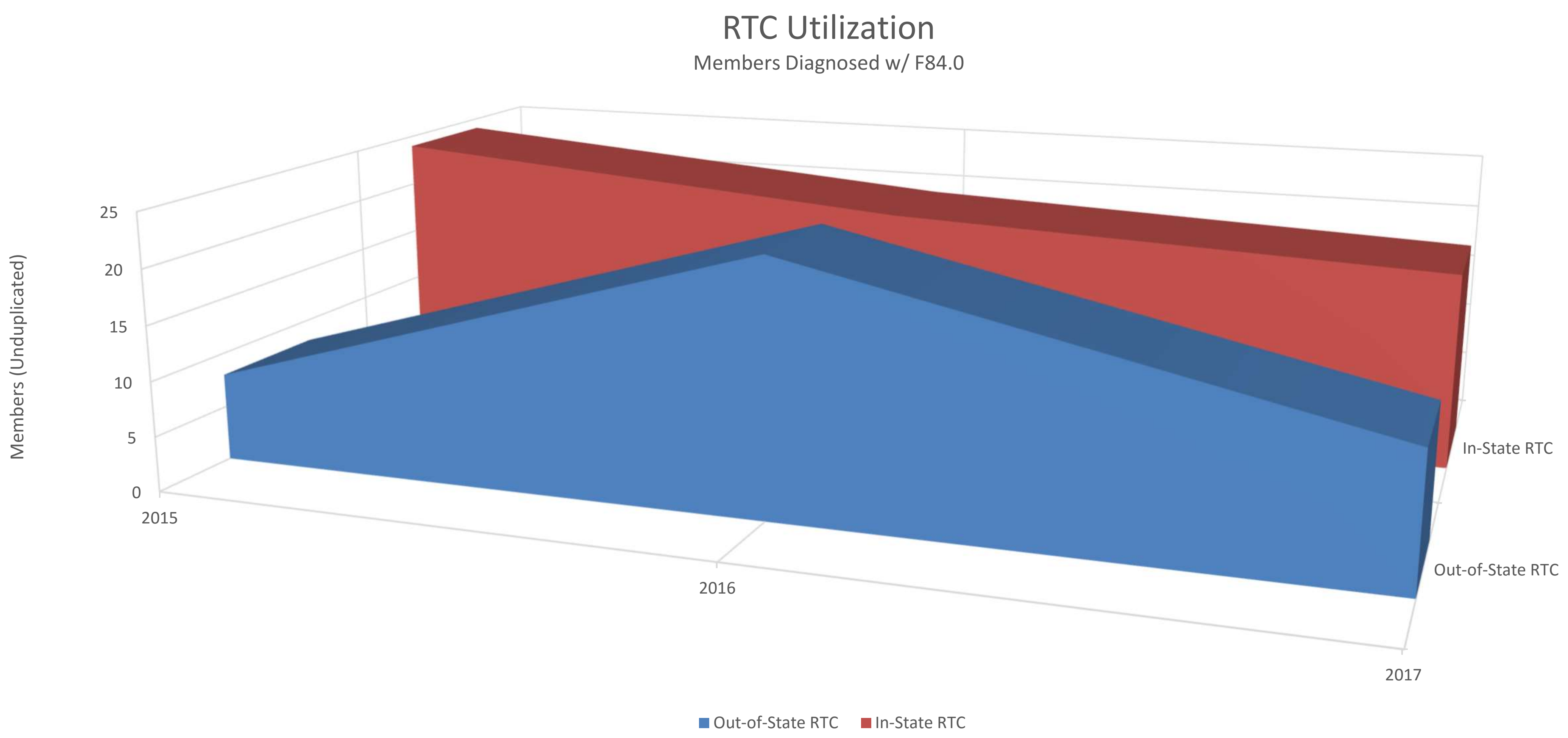

Member Count
By Stage

# RTC Utilization

In-State and Out-of-State RTCs

Source Information: AdHoc ABA Reports:
CY2015, CY2016, Q4 2017 (All MCOs).

| | 2015 | | | | | 2016 | | | | | | 2017 | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | UHC | Molina | BCBS | Pres | All MCO Total | UHC | Molina | BCBS | Pres | All MCO Total | Chng % | UHC | Molina | BCBS | Pres | All MCO Total | Chng % |
| Unduplicated total count of members with F84.0 diagnosis in in-state RTC | 1 | 12 | 3 | 8 | 24 | 0 | 1 | 7 | 12 | 20 | -17% ▼ | 0 | 3 | 4 | 11 | 18 | -10% ▼ |
| Unduplicated total count of members with F84.0 diagnosis in out-of-state RTC | 0 | 0 | 0 | 8 | 8 | 0 | 7 | 1 | 15 | 23 | 188% ▲ | 0 | 6 | 0 | 6 | 12 | -48% ▼ |
| **Total** | | | | | **32** | | | | | **43** | | | | | | **30** | |



# A Parent's Perspective

My son graduated high school in 2015. He attends UNM, drives and volunteers at a non-profit. He is extremely intelligent, kind, funny, loves to play guitar and has two cats. My son also has autism.

When he was four years old, we applied for the DD Waiver and waited eagerly on a waiting list for eight long years. I can still recall the day he was denied those services. Let me tell you about his journey as an adult.

Immediately upon graduation from high school, my son lost his small, structured community that supported him. He no longer had an IEP, daily contact with friends, and a familiar schedule. Routines changed, friends moved away, and university classes contained three hundred students. This happens to everyone, yet this caused my son to lose previously acquired skills.

The first new challenge was waking in the morning for a new school schedule. My son sleeps with sound eliminating headphones, heavy blankets, and an eye mask. This is part of his autism. He has to deprive himself of all sensory stimulation in order to sleep, yet there is no guarantee he will stay asleep all night. Exhaustion combined with sensory strategies create a challenging environment for waking.

My son also struggles with driving. He is an excellent driver, however he has an inability to focus on directions when he is giving so much attention to proper driving skills. He comfortably drives five places.

School at UNM has been an ongoing challenge as well. Teachers have asked him why he is weird, picking up on his flat affect and unusual "accent". They have asked him to keep his body still, not knowing that to stay focused he has to sway and pace. Professors do not use visual supports that help him understand content, and a full course load for him is no more than nine credit hours. Stress associated with college has caused new self-injurious behaviors. All of which culminated in a semester off college.

Social engagement continues to remain a great challenge. Initiating social contact is painful for my son. This includes texting, phone calls, email, and social media. Even if he attends a social gathering with friends, he voluntarily returns home at bedtime as to not impede his sleep routine. Not to mention the social challenges created by a limited diet of twelve foods. A struggle he has worked on for years.

My son did have a job for three years. He was hired as a food preparer, yet his job remained dining room cleaner the entire time. He has been looking for a new job for the past year. He has submitted handfuls of applications, attended three interviews, received several rejection letters, and is still without work.

These are just a few of the adult challenges my son faces. He has many gifts as well, and the world is missing out on knowing the incredible human I call my son.

## A Parent's Perspective

There's a learner on the outskirts of the Gila National Forest who turns 21 years old early in 2018. He is a good-looking young man with a ready smile who loves to walk, travel and explore. If he's out walking with a small group, you'll likely find him in the front of the pack, leading the way. He grew up in New Mexico's special education program at the neighborhood public school, is a whiz at puzzles, laughs a lot and is a big fan of the local fast food joints.

For most young people in America, turning 21 marks the official launch into adulthood. It's the birthday our society has deemed the milestone that places a person's options and opportunities directly into their hands to make as much as possible out of their future. But this young man's story will take a dark turn on his birthday purely because he happens to be on the autism spectrum and live in New Mexico. Instead of helping him gain more autonomy, the state's policy to age out critical applied behavioral health support at the age of 21 will halt the growth he has gained in recent months.

Despite years of effort by his parents, this young man didn't start receiving much-needed applied behavioral therapy – a highly customized 1:1 treatment at an intense weekly dosage typically focused on reducing problem behaviors while building up skills critical to independent living - until the beginning of the summer of 2017.

Even though he is non-vocal, since beginning this therapy, his parents discovered he has the ability to independently make his desires and needs known via a speech generation device. He had access to the device for several years, but it had been no more useful to him than a doormat. But this summer, without anyone else touching or prompting him, he daily communicates where he wants to go, when he wants to go and what he wants once he gets there. He doesn't yet choose to use this skill all of the time, but the frequency is significantly increasing. In addition, he's tolerating activities and experiences that had always seemed too much for him. He has a long history of hitting and aggressively pulling on people's fingers to demonstrate he was getting upset, but week by week, "talking" is replacing those problem behaviors. Now, he's actively making choices about how he spends his days, when just a few months ago it seemed that was beyond his interest or ability. As their summer of surprises gives way to Fall, his parents suddenly find themselves in conversations about the possibility of him eventually going to work or volunteering somewhere and becoming a productive citizen; something they hadn’t even whispered for years.

The fact they can dare to relight the once-extinguished dream of daily productivity for their son just months before his 21st birthday is cruelly ironic. While his neurotypical peers celebrate the opening of doors into independent adulthood, turning 21 marks the day that his options and opportunities shrink down into a tiny pinpoint of light that emit from the singular hope that the net his parents carefully stitched together each day of his childhood holds long enough for New Mexico to realize that adolescents with autism become adults with autism overnight.

All of his life, his parents fought and fought for the therapy needed to help him learn skills that didn’t develop naturally, hoping to slow the ever-increasing gap between him and his peers. They realized that his lack of effective communication was a severe and growing barrier and they asked numerous times for speech language pathologists to work with their son, but they repeatedly were told that known were available who were comfortable working with him because of problem behaviors. In response, they pushed for behavioral support to address the problem behaviors that were a barrier to his treatment. Finally, after years of frustration and effort, after years of denials and watching their son slip further and further behind others in his age group, he was approved to receive behavioral therapy, just months before he ages out. In just a few short months, they’ve watched him make progress in areas they know could eventually reduce the amount of support and financial aid he’ll need from society by virtue of gaining the skills to contribute. This had not been an option for him before this summer.

If he had a diagnosis such as cancer, New Mexico would continue services because the system recognizes that a person with such an issue the day before his 21st birthday wakes up still needing support the day he turns 21 and so the treatment options continue. But because this young man has autism, that’s not what will happen despite the fact that behavioral therapy is considered a medical necessity for him.

Instead, he will go to sleep having been able to receive critical behavioral therapy that in just a few short months has opened his communication pathways and is breaking down social barriers that have slowed down his progress his entire life. He’s finally learning to tolerate not getting what he prefers all of the time without getting upset, which is a critical skill when we fast forward to the phase of his life when his parents no longer are available to stretch tight the net that has kept him safe and his daily routine comfortable throughout his childhood. He is developing a level of autonomy that assures he can make his needs and desires known at a level he’s never had before. And most importantly, he’s learning to independently communicate with people who don’t know the meaning of his every look and movement. When his parents no longer are available to him, that skill will dramatically reduce his risk of harm.

While he’s responded very well this summer, he still has to make up for nearly a lifetime without adequate training. Unfortunately, the State of New Mexico will not provide parity for him or any other adult with autism.

This summer, while watching their son’s growth in just a few months of applied behavior analysis, his parents discovered that being “disabled” is not defined by a doctor’s diagnosis, but by whether or not a person receives and responds to training needed to develop the skills required to live as an independent adult.

In this case, this young man has proven he can acquire important new skills, but in February, he’ll again suffer from the same disadvantage he’s experienced since childhood – he is an individual with autism who lives in New Mexico.

THCS

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www.texashillcountryschool.com

To whom it may concern,

P. has been with us at the Texas Hill Country School since 10/28/2011. He is Autistic and very limited verbally. When he arrived here, he was extremely noncompliant to all programmatic and academic activity, and it was very difficult to take him out in the community (he would become aggressive in vehicles, or try to run away). He was also very physically aggressive (head-butting, hitting) towards staff members and peers. He struggled with being socially/sexually appropriate as well – He'd almost constantly have his hands down his pants, or attempt to touch his genitals to staff or students through his clothing. Over the years, P. has made amazing progress, but his disability is lifelong. His physical aggression is much lower, and he participates in programmatic activities, academic lessons, and community social reintegration activities (swimming, park, movies, etc.) much more appropriately with maximum staff support. If a step down program in New Mexico was available, he would be a perfect candidate. If returned home without appropriate supports, he would regress tremendously.

P. is now 18 – almost 19 years old. He is "next in line" for the DD waiver allocation, but we are currently still waiting. During this time, he has been dropped from his Medicaid plan is currently not funded (although we were assured we'd be reimbursed) while the issue is being resolved. This is a huge, unnecessary struggle for P., and other NM residents being served out of state that have similar issues when they turn 18. We currently serve 4 other students from NM with Autism who are 18 or nearing their 18th birthday, and are finding themselves in the same dilemma of not being ready to go home, but needing a lateral transition to a facility in NM similar to ours, or a step down to an appropriate group home setting and the resources or funding just aren't available.

At the Texas Hill Country School, we love working with these clients and seeing the tremendous improvements, but their disabilities will not just "go away" as they reach adulthood. There needs to either be a better plan for continued funding through adulthood at THCS (and our affiliates that serve adults through the continuum of care) or the resources to transition to an appropriate permanent home in NM.

Sincerely,

Michelle Stires

Program Director, LCCA

Texas Hill Country School