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FISCAL IMPACT REPORT

ORIGINAL DATE 1/24/2020
 SPONSOR Thomson/Ferrary LAST UPDATED 1/31/2020 HB 55
 SHORT TITLE Autism Disorder Supports and Services SB _____
 ANALYST Chilton

APPROPRIATION (dollars in thousands)

Appropriation		Recurring or Nonrecurring	Fund Affected
FY20	FY21		
	\$2,500.0	Recurring	General Fund

(Parenthesis () Indicate Expenditure Decreases)

ESTIMATED ADDITIONAL OPERATING BUDGET IMPACT (dollars in thousands)

	FY20	FY21	FY22	3 Year Total Cost	Recurring or Nonrecurring	Fund Affected
Total		\$120.0	\$120.0	\$240.0	Recurring	General Fund

(Parenthesis () Indicate Expenditure Decreases)

SOURCES OF INFORMATION

LFC Files

Responses Received From

Department of Health (DOH)

Children Youth and Families Department (CYFD)

University of New Mexico Health Sciences Center (UNM HSC)

New Mexico State University (NMSU)

SUMMARY

Synopsis of Bill

House Bill 55, appropriates \$2.5 million from the general fund to the Departments of Health (DOH) and Children Youth and Families (CYFD) for the purpose of expanding services available in New Mexico for children, adults and families affected by autism spectrum disorders.

The \$2.5 million appropriation would be used to contract with subunits of educational institutions in the northern and southern parts of the state, as follows:

- \$250 thousand to New Mexico state university (NMSU) for establishment and operation of a regional autism office

- \$300 thousand to NMSU for programs for youth and adults with autism spectrum disorder (ASD) not given developmental disabilities Medicaid waiver (DDWP) support
- \$250 thousand to the University of New Mexico’s Center for Development and Disability (UNM CDD) for analysis and alignment of systems of care for individuals with ASD and their families
- \$300 thousand to UNM CDD for youth and adults with autism spectrum disorder (ASD) not given developmental disabilities Medicaid waiver (DDWP) support
- \$450 thousand to UNM CDD for development of services to adults with ASD, and to fund autism evaluations for children
- \$150 thousand the UNM CDD for establishment of an ASD registry and for research into ASD
- \$300 thousand for CYFD to develop wraparound services for children with ASD with “high acuity of need”
- \$500 thousand to UNM CDD for development of model services for individuals with “high acuity of need” ASD requiring inpatient hospitalizations, residential or group home services.

The first six of these specified appropriations are to DOH, totaling \$1.7 million, the last two are to CYFD, totaling \$800 thousand, for a grand total of \$2.5 million.

FISCAL IMPLICATIONS

The appropriation of \$2.5 million contained in this bill is a recurring expense to the general fund. Any unexpended or unencumbered balance remaining at the end of each fiscal year shall revert to the general fund.

Much of the appropriation is to be used to contract with entities in Albuquerque and Las Cruces to provide services and programs in the north and south portions of the state, respectively. However, administrative functions will exact a personnel cost on each agency: DOH did not indicate a need for additional positions to do so, but CYFD indicated the following need: “Proper management of the expanded CYFD workload necessary to ensure complete and appropriate implementation of the program expansion supported by this funding will require a minimum of two (2) additional FTE Wraparound coordinators (\$60,000/year/position).”

SIGNIFICANT ISSUES

There is general agreement that the prevalence of autism is increasing. It was thought to be very rare in 1943 when Johns Hopkins University child psychiatrist described eleven children with what he called autism. A brief history of the diagnosis of autism, from Parents Magazine, is reproduced below:

1943: American child psychiatrist Leo Kanner, M.D., publishes a paper describing 11 children who were highly intelligent but displayed "a powerful desire for aloneness" and "an obsessive insistence on persistent sameness." He later names their condition "early infantile autism."

1944: A German scientist named Hans Asperger describes a "milder" form of autism now known as Asperger's Syndrome. The cases he reported were all boys who were highly intelligent but had trouble with social interactions and specific obsessive interests.

1967: Psychologist Bruno Bettelheim popularizes the theory that "refrigerator mothers," as he termed them, caused autism by not loving their children enough. (Spoiler alert: This is completely false.) "Post-World War II, there was a lot of psychoanalytic work done on autism where researchers looked solely at the impact of life experiences," explains *Parents* advisor Fred Volkmar, M.D., director of the Child Study Center at Yale University School of Medicine and editor-in-chief of the *Journal of Autism & Developmental Disorders*. "They didn't consider the role of biology or genetics, which we now understand to be the main cause." Autism is also classified under schizophrenia in the *International Statistical Classification of Diseases and Related Health Problems*, although scientists now know there is no link between the conditions.

1977: Research on twins finds that autism is largely caused by genetics and biological differences in brain development.

1980: "Infantile autism" is listed in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) for the first time; the condition is also officially separated from childhood schizophrenia.

1987: The DSM replaces "infantile autism" with a more expansive definition of "autism disorder," and includes a checklist of diagnostic criteria. UCLA psychologist Ivar Lovaas, Ph.D., publishes the first study showing how intensive behavior therapy can help children with autism--thus giving new hope to parents.

1988: The movie *Rain Man* is released. It stars Dustin Hoffman as an autistic savant who has a photographic memory and can calculate huge numbers in his head. "This was important for raising public awareness of the disorder," Dr. Volkmar notes, although not every kid on the autism spectrum has these kinds of skills.

1991: The federal government makes autism a special education category. Public schools begin identifying children on the spectrum and offering them special services.

1994: Asperger's Syndrome is added to the DSM, expanding the autism spectrum to include milder cases in which individuals tend to be more highly functioning.

1998: A study published in *The Lancet* suggests that the measles-mumps-rubella (MMR) vaccine causes autism. This finding was quickly debunked.

2000: Vaccine manufacturers remove thimerosal (a mercury-based preservative) from all routinely given childhood vaccines due to public fears about its role in autism--even though, again, the vaccine-autism link has been debunked.

2009: The U.S. Centers for Disease Control and Prevention (CDC) estimates that 1 in 110 children have autism spectrum disorders, up from 1 in 150 in 2007, though the CDC notes that the increase stems at least in part from improved screening and diagnostic techniques.

2013: The DSM-5 folds all subcategories of the condition into one umbrella diagnosis of autism spectrum disorder (ASD). Asperger's Syndrome is no longer considered a separate condition. ASD is defined by two categories: 1) Impaired social communication and/or interaction. 2) Restricted and/or repetitive behaviors.

The prevalence of autism spectrum disorder was estimated by the Centers for Disease Control (CDC) in 2014 to be approximately one in every 59 children at age eight years, with males affected about four times more frequently than females. Translated to an annual New Mexico birth cohort of approximately 24,000, this would indicate more than 400 children born each year who would eventually be diagnosed as having an autism spectrum disorder. UNM HSC notes that “funding cuts [to UNM’s Center for Development and Disability (CDD) for ASD services] have occurred at the same time that numbers of individuals with ASD have significantly increased.”

While the severity of autism varies greatly from one patient to another, the majority require special services from an early age; only some are able to appear to compensate entirely for their disabilities. It is clear that early diagnosis and treatment has a major positive effect on outcome.

Pediatricians and others providing medical care for children are urged by their professional organizations to screen all of their patients for signs and symptoms of ASD. Anecdotal evidence would suggest that it is sometimes difficult to access specialized services for children with suspected ASD once the suspicion is raised.

New Mexico Autism Society executive director Christina Angel estimates that the average family needing confirmation or denial of a diagnosis of autism faces a nine to 24 month waiting list for services, with the wait being longer for those living farther from Albuquerque, where virtually all services are currently located. These waiting times, for CDD are corroborated by UNM HSC. Ms. Angel stated that many families living in southern New Mexico, in particular, find it more expedient to be seen by providers in Texas. UNM HSC comments that “The establishment of a southern hub will insure that children will receive timely diagnostic evaluations closer to their home.”

ASD exacts a high price on families of children with those disorders as well. Delay in diagnosis thus affects not only the child but also the family. Family support is delayed, and autism-specific therapy is usually not begun until after diagnosis. Much evidence exists that early therapy, especially applied behavioral analysis (ABA) results in an improved outcome.

DOH comments on these issues:

According to the Centers for Disease Control (CDC) Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. People with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called Autism Spectrum Disorder <https://www.cdc.gov/ncbddd/autism/data.html>. ASD is reported to occur in all racial, ethnic, and socioeconomic groups. ASD is about 4 times more common among boys than among girls. There is no published data on the prevalence of autism in adults.

This legislation would support efforts underway at New Mexico State University and the University of New Mexico. New Mexico State University is opening a new autism diagnostic center in Las Cruces to improve access for families in the southern region of the State. There is also graduate certificate training for students interested in ASD and the provision of supports and services. The UNM Center for Development and Disability Autism Programs are a collection of programs that are centered on autism spectrum disorders including clinical and diagnostic services, training and technical assistance as well as family services and supports. The programs are staffed by individuals with specific expertise in ASD. The services serve people statewide but are provided mostly in Albuquerque...

According to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, a guide created by the American Psychiatric Association used to diagnose mental disorders, people with ASD have:

- Difficulty with communication and interaction with other people
- Restricted interests and repetitive behaviors
- Symptoms that hurt the person's ability to function properly in school, work, and other areas of life

Autism is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience. ASD occurs in all ethnic, racial, and economic groups. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and ability to function. The American Academy of Pediatrics recommends that all children be screened for autism. All caregivers should talk to their doctor about ASD screening or evaluation.

Treatment for ASD should begin as soon as possible after diagnosis. Early treatment for ASD is important as proper care can reduce individuals' difficulties while helping them learn new skills and make the most of their strengths. The wide range of issues facing people with ASD means that there is no single best treatment for ASD. Working closely with a doctor or health care professional is an important part of finding the right

treatment program. <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>.

UNM HSC mentions poor outcomes for patients with ASD:

In researching outcomes for the ASD population, it is significant to note that this population has poorer outcomes in the areas of health, employment, post-secondary education, and other indicators.

Outcomes are worse when compared to individuals with either an intellectual disability or serious mental illness (Young Adults & Transitioning Youth with ASD, 2017 report to Congress) Young adults with ASD are:

- More likely to have chronic health or mental health conditions
- Less likely to be able to manage and develop friendships
- Less likely to prepare for college and employment
- Less likely to live independently away from parents
- More likely to receive SSI
- Less likely to have ever worked in their twenties
- Less likely to have ever participated in postsecondary education or training of any kind.

UNM HSC also notes that “Increased diagnostic capacity is critical... Funding is necessary to support increased capacity; this will reduce wait time for families. Another critical need is for the development of diagnostic services for adults with suspected ASD. Adults are often misdiagnosed and there is a need to develop capacity in our state for this age group. Not only are additional evaluation slots for evaluation critical, capacity building for community providers who can make diagnoses is also essential. Currently, the CDD has 3 open faculty psychology positions to recruit nationally for individuals with specific autism spectrum diagnostic experience.”

NMSU comments as follows:

The impact of this disorder on individuals, their families and on the community cannot be adequately expressed in words. The result ASD impacts two crucial individual attributes that allow one to carry out the most basic functions in our society, interpersonal interaction and communication. Without these basic functions, individuals cannot enjoy the most fundamental of quality of life experiences and their dependence on society increases while their ability to function independently decreases.

Support is crucial for families who, on the average, must set aside an estimated \$60,000 per year for specialized treatment and this cost is meager in relation to the cost associated with lost wages related to increased demands on one or both parents. Costs increase with the severity of ASD in addition to those costs due to co-occurrence of other disabilities.

Early diagnosis and intervention is the most cost efficient approach given that this is a lifelong condition.

NMSU is developing an Autism Diagnostic Center to help fill the great need for a diagnostic center in southern New Mexico. Currently there is a two-year wait time for initial diagnosis, which must be attained to receive services.

CYFD comments on the importance of “wraparound services,” to be funded through CYFD using funds provided in HB55. Wraparound services are defined elsewhere as “Services used to help children with autism spectrum disorder work towards independence. They provide families with the resources, techniques and interventions necessary to help children reach desired independence goals.” CYFD’s comments follow:

One of CYFD/BHS’s strategic planks is that “Multi-system involved children and youth with complex behavioral health and substance use disorders will be served in their communities, have less system involvement, and more social supports.” A primary initiative under this plank is the implementation of high fidelity wraparound statewide.

This bill expands support services for children, youth, and adults with ASD by increasing services and supports for this population. CYFD Behavioral Health Services (BHS) Wraparound Unit will work to expand Wraparound service provision and provide the training, coaching and technical assistance for Wraparound Facilitators and Coaches. The funding will help CYFD provide Wraparound to individuals with ASD prior to needing a higher acuity placement. CYFD BHS will also work with the identified Managed Care Organizations to identify and support the use of high fidelity wraparound as additional support for individuals with ASD with high acuity needs. Efforts will need to be aligned with existing Applied Behavioral Analysis (ABA) services provided to children and youth experiencing ASD.

Extensive compendia of resources on autism are available through the CDC, at <https://www.cdc.gov/ncbddd/autism/index.html>, and from the American Academy of Pediatrics, at <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Pages/autism-initiatives.aspx>.

ADMINISTRATIVE IMPLICATIONS

DOH and CYFD are required to disburse the funds provided in HB55; there is no allowance in the appropriation for personnel costs of these functions.

WHAT WILL BE THE CONSEQUENCES OF NOT ENACTING THIS BILL

Families and children facing a possible diagnosis of ASD will continue to wait nine to 24 months for confirmation of the diagnosis and for appropriate services to be offered, and certain therapies and services that would be funded through the bill’s appropriations would not be made available.

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