



GWYᎠ DBF
CHEROKEE NATION[®]
Health Services

Autism Task Force Report

Background

On April 4, 2023, Chief Chuck Hoskin, Jr., and Deputy Chief Bryan Warner announced significant new measures aimed at improving autism diagnosis and treatment within Cherokee Nation. The initiative included the formulation of a dedicated Task Force on the Cherokee Nation Autism Initiative.

Chief Hoskin signed the Executive Order establishing the Task Force on the Cherokee Nation Autism Initiative, which mandates the Task Force to assess the current services and resources available to patients and families within the Cherokee Nation Health Services (CNHS) system.

The Task Force has been charged with providing further recommendations on how to enhance the Tribes autism initiatives. A comprehensive final report is expected to be issued no later than March 1, 2024

Task Force Activity

The Task Force convened monthly meetings to conduct a comprehensive analysis of existing programs designed to support autistic Cherokee citizens and their caregivers. During these sessions, the Task Force identified gaps in support and services and then developed a detailed list of goals along with corresponding operational activities to reach those goals.

Community engagement and information dissemination was a central component of the Task Force analysis. As a part of this, two hybrid (in-person and virtual participation) community gatherings were organized to present the Task Force's activities, purpose, objectives, and to gather critical feedback from Cherokee citizens.

The community town hall meetings, convened in in January and February of 2024, provided an opportunity for open dialogue and feedback from participants. The discussions centered on various key themes, including:

- ❖ Caregiver support
- ❖ Wait times for testing and accessing resources
- ❖ Creating inclusive care environments
- ❖ Enhancing access to behavioral therapy
- ❖ Workforce development for autistic individuals
- ❖ Identifying available resources and suggesting additional ones

These topics are crucial in shaping the ongoing efforts to improve autism diagnosis and treatment within the Cherokee Nation.

Progress to date

The Autism Taskforce identified funding to allow Rehabilitation providers the opportunity to complete additional courses and education on autism evaluation and treatment. The training helped to support the adoption of standard screening protocols across all of Cherokee Nation

Health Services for developmental disabilities, ensuring that all pediatric Cherokee citizens and beneficiaries of the health system have the earliest opportunities at diagnostic referral, intervention, support, and services.

There has been collaboration with Pervasive Parenting for Adolescent Social and Caregiver Support. Monthly groups are open to the public, with a zoom link provided for online attendance. The evolution of this partnership and collaboration maximizes resources and service options.

The Autism Taskforce presented at the Cherokee Nation Children's Cabinet and made a request for other departments to share information for an Intercept Map, identifying the present system state for all departments throughout Cherokee Nation. Receipt of this information allows the Task Force to identify gaps, areas of improvement, short- and long-term goals, and a strategic plan to address needs across the lifespan. All CNHS health centers gave feedback for community resources in their respective areas.

The National Council on Disability's "*Understanding Disabilities in American Indian & Alaska Native Communities Toolkit Guide*" was distributed to all Cherokee Nation Health Services providers. Dissemination of this information promotes working toward improved care coordination for patients by providing education and resources to providers and case managers. (Attachment 1)

Cherokee Nation Health Services integrated behavioral health providers in Primary Care, Pediatrics, Women's Clinic and the Resident Clinic at Cherokee Nation Outpatient Health Center. Expansion is planned to offer these services at additional CNHS health centers in the near future. Integrated behavioral health provides patient-centered care by placing behavioral health providers in the primary care setting. Integrated care creates a team approach to treating patients holistically.

Cherokee Nation Health Services added a "Smart Zone" addition into the Electronic Health Record (EHR) for patients that have sensory deficits. The Smart Zone will alert Cherokee Nation Health Service EHR users of the patients previously identified, specific sensory deficit needs.

Behavioral Health purchased and implemented Modified Checklist for Autism in Toddlers (M-CHAT) testing for Cherokee Nation Health Services pediatric patients up to age 4. Additional screening tools (SCQ- Social Communication Questionnaire and BASC-3 Behavior Assessment System for Children, 3rd Edition) were purchased and implemented to accommodate additional age groups and to allow for administration of the test via telehealth.

Cherokee Nation Grants Management Department has been alerted to monitor for and to notify the Task Force of any upcoming grant opportunities that would benefit patients with autism spectrum disorders and/or communication issues.

Recommendations

1. **Continuous Improvement of Identification and Diagnosis of Autism for Cherokee Citizens-** Continuous improvement efforts should be included in all systems throughout

the Cherokee Nation, including early screening and diagnostic efforts in addition to diagnostic efforts throughout the lifespan. Ongoing waitlists for diagnostic providers are widespread and delays in obtaining a medical diagnosis results in delayed interventions and support, often leading to significant patient and caregiver distress. Considerations for continuous improvement include:

- a. Recruitment and/or contracting to expand the number of diagnostic providers available to Cherokee citizens; including Neuropsychologists, Developmental Pediatricians, Clinical Psychologists, Neurologists, and Pediatric Psychiatrists. Efforts should include reduction of barriers to evaluation in both time and travel.
 - b. Ensuring universal screening for autism and other developmental delays occurs per standards and guidelines throughout the entire Cherokee Nation health and educational systems with a sense of standardization.
 - c. Development of career paths for medical and provider staff through tribal schools, residencies, fellowships, programs, and scholarship support to develop a workforce for clinicians specialized in autism spectrum disorder.
2. **Data Tracking-** Accurate data related to autism rates in Indian Country is largely unknown as nearly all autism research is done in non-native communities. It is critical to start amassing data sets to identify ongoing gaps and needs, as well as federal funding opportunities to support this research in native communities. Data gathering could be accomplished via partnerships with health systems, justice systems, educational systems, Task Force activities, and working collaboratively with federal efforts.
 3. **Housing-** Research suggests that a disproportionate number of autistic individuals experience homelessness and housing insecurity. Recently our Chief and Deputy Chief visited A New Leaf in Owasso and observed a unique housing and support program for those with intellectual and developmental disabilities. Future Cherokee Nation collaborations should evaluate our internal housing options and identify gaps for those with independence challenges and housing insecurity due to disability. Family housing for those with unique needs should also be a consideration, as in some instances accommodation is needed for elopement risks (proximity to bodies of water and high traffic roads).
 4. **Ceremony Accommodations-** Cherokee Nation should review policies, offerings, and accommodation options for all Cherokee Nation gatherings and community events. Accommodation should include sensory rooms/spaces, sign language interpreters, sensory headphones and glasses, and inclusion of special needs groups (drumming, dance, etc.). Culture connection allows individuals to feel anchored and enhance their protective factors.
 5. **Online and Internet Safety-** Due to a heightened risk of victimization and vulnerability for autistic Natives, Cherokee Nation should partner with the National Center for Missing and Exploited Children (NCMEC) (or similar reliable and trusted national organization) on this resource for our community, and support dissemination of information for the community to utilize. Resources should cover vulnerability, grooming, luring, victimization, and safeguarding for self and caretakers.
 6. **Safety-** Some autistic individuals struggle to ensure personal safety, specifically related to elopement and wandering. Specialized alert systems and training are recommended (on a voluntary basis by guardian) for those citizens with such vulnerabilities.

7. **Guardianships**- Some autistic individuals do not possess the ability to provide for their own care and safety throughout adulthood; therefore, guardianships are sometimes appropriate.
 - a. Cherokee Nation should make available guardianship educational/informational sessions twice annually (hybrid- in-person and virtual participation) and disseminate guardianship community resources.
 - b. Cherokee Nation should conduct a review of relevant tribal codes/statutes or consider the creation of a code/statute that covers this need.
8. **Abuse and Neglect**- Autistic individuals are disproportionately represented in the survivors of neglect and abuse research. Cherokee Nation citizens would greatly benefit from inter-departmental Cherokee Nation partnerships with cross-collaboration and training on neglect, abuse, interventions and recovery after victimization, and handling of caseloads for those with autism.
 - a. Efforts should include forensic interviewing and use of advocates through the course of investigations and potential court proceedings.
9. **Crisis Stabilization & Mental Health Treatment**- Research indicates a 78% co-occurring rate between autism and serious mental illness. Autistic individuals have a significantly increased risk of suicide (ideation, attempts, and death) compared to non-autistic individuals, and an elevated rate of de-stabilization.
 - a. Suicide Prevention: Zero Suicide and other suicide prevention efforts must include autistic citizens. Suicide prevention efforts should include marketing, community engagement, inclusive materials, and specialized training for staff.
 - b. Crisis Stabilization: Work to develop a Cherokee Nation crisis response system for mental health, partnering with local Urgent Recovery Crisis (URCs) centers, inpatient civil psychiatric hospitals, and mobile crisis response. More specifically, a crisis response that addresses and allows for dual-diagnosed (autism and mental illness) individuals to receive adequate and high-quality services in a timely manner is needed.
 - c. Address service gaps for crisis response including geographical challenges, pay source and coverage, provider specialization, and delays.
 - d. Train Cherokee Nation mental health providers on autism, including camouflaging, risks of deregulation and self-harm, verbal skill loss, diagnostic overshadowing, and appropriate caretaker engagement.
 - e. Create mental health screening for caretakers and appropriate support and services for this population. Caretakers on average neglect personal preventative care, experience negative mental health struggle, and die prematurely. Systems of service and support are critical to the health and wellbeing of the caregiver.
10. **Workforce Development**- Purpose and inclusion are critical for autistic individuals, as many possess the ability to contribute to the workforce. Cherokee Nation should consider the below:
 - a. Creation of a workforce development initiative to allow for training in skill areas that are attainable for this population.
 - b. Implementation of accommodation policies for those with neurodiversity when possible, including caretaker accommodations.

- c. Facilitation of low barrier/public serving employment opportunities for those needing accommodations. Model this after proven agencies, such as Not Your Average Joe (coffee shop) or A New Leaf (gardening and garden store/events).
11. **College/Vocational Scholarships**- It is recommended that Cherokee Nation review current scholarship programming to ensure inclusion for diverse populations, specifically related to non-traditional vocational training programs and high support college costs associated with special needs.
 - a. Examples: NSU RiverHawks Scholar Program, OU SPARK 360, OU Sooner Works
 12. **Lifespan**- Autistic youth age into adulthood and old age, therefore, it is essential to involve initiatives and departments that address adult and elder services. Specific considerations include:
 - a. Autism training, support services, socialization activities, and other needed essential services.
 - b. Housing specific options.
 13. **Social Support Groups**- Social support and opportunities for autistic citizens to develop friendships, purpose, and a sense of community are extremely important to overall wellbeing.
 - a. Cherokee Nation should consider working to develop opportunities for autistic citizens to engage in the development of social support groups and activities throughout the Nation.
 - b. There are currently several private non-profits working on this very issue, and partnerships with them would be helpful for our citizens.
 14. **Law Enforcement & Justice System**- Research overwhelmingly demonstrates that autistic individuals are more likely to have justice system and law enforcement contact; therefore, it is essential to train and provide tools to both systems that specifically prepare them to minimize negative experiences and outcomes for autistic citizens and their families.
 - a. Law enforcement officers should participate in annual autism training, focused on use of sensory kits, communication aides, handling of sensory aversive individuals, and options for diversion into care when appropriate. Sensory kits should be purchased for law enforcement vehicles and other first responders.
 - b. Justice system settings should have ongoing training on accommodations necessary for autistic individuals, inclusive of sensory needs, communication and comprehension barriers, environment and process visual aids and reminders, etc.
 15. **Health System**- Autistic individuals experience an elevated rate of physical conditions and syndromes. CNHS should consider making available sensory soothing kits in health settings, in addition to ongoing training for staff. Training elements should include methods of handling and interacting with autistic individuals, specifically those with sensory aversion, communication and comprehension difficulties, and co-occurring conditions.
 16. **Community Communication**- Visibility matters, and it is important to distribute consistent and ongoing resources for communities, highlighting the various services and efforts for our autistic citizens and their families. Beneficial communication can occur in the form of postings on social media, employment e-mail blasts, and features in the Cherokee Phoenix. It is recommended that the Task Force continues activities and

considers holding additional community engagement meetings at locations across the Cherokee Nation reservation.

17. **Respite-** Cherokee Nation should work with local non-profits and programs within our system to support respite opportunities for caretakers, focused on assisting with burnout and overall caretaker wellness.
18. **Case Manager-** All Cherokee Nation nurse case managers will be educated on inclusive care and knowledge of appropriate resources available. Patient Experience contact information will be shared so that self-advocates and caregivers can be linked to appropriate services. Family Care Managers will be trained in autism support resources and ready to help and assist individuals and families with autism resources available within CNHS as well as other community supports.
19. **Augmentative and Alternative Communication Devices (AAC device)-** Non-verbal individuals with autism need an AAC device so they can functionally express their wants/needs to family, peers, and medical providers. It is recommended that Cherokee Nation Health Services identify internal or external resources for these needs. Options could include the ability for CNHS Speech Therapy providers to perform and complete full communication assessments and recommend devices, and/or the initiation of contracts with therapy clinics that provide this service.
20. **Applied Behavior Analysis (ABA) Therapy-** ABA is considered an evidence-based best practice treatment by the US Surgeon General and by the American Psychological Association. ABA has passed scientific tests of its usefulness, quality, and effectiveness. ABA is a therapy based on the science of learning and behavior for children with autism. ABA therapy includes many different techniques, with a focus on positive reinforcement. All of these techniques focus on antecedents (what happens before a behavior occurs), behavior (what they did), and consequences (what happens after the behavior).
 - a. Cherokee Nation should consider employing a Board Certified Behavior Analyst (BCBA) and Registered Behavior Technicians (RBTs) for patients with autism to receive this treatment if warranted. Alternatively, Cherokee Nation may consider the development of a contract with ABA therapy sites to allow Cherokee citizens to receive care at no/low cost out of pocket.
 - b. ABA contracts and/or services should be available both in clinic settings and in home settings.
 - c. ABA contracts and/or services should be available for a variety of age ranges, not just ages 8 and under.
21. **Educational Systems and Supports-** Autistic youth often need various levels of support and services throughout their youth to ensure that their educational experience is rewarding and beneficial. It is recommended that all Cherokee Nation educational systems ensure training on governing laws for special needs students and their caretakers. Caretaker support for Individualized Education Plan (IEP) meetings is essential to maximize the intended benefits of IEPs and ensure a thorough understanding of rights and protections.
22. **License Plates-** As both a safety precaution for autistic drivers and caretakers with an autistic citizen in the vehicle, many states have authorized optional autism specific plates on vehicles. In addition to safety, these license plates serve as a community stigma

reduction tool and sales portions can be used to support autism efforts within the Cherokee Nation identified in this report.

a. Example:



The members of this Task Force appreciate the opportunity to explore the current services and resources available to those affected by autism. The Task Force feels confident that the recommendations contained herein will not only improve services to the citizens of the Cherokee Nation and to the patients of Cherokee Nation Health Services but will enhance and enrich their lives.

Respectfully,

DocuSigned by:

Rebecca Shepherd

F03B942058814DE

Rebecca Shepherd, DNP, RN (Chairperson)

DocuSigned by:

Leah Baxter

F34BE9C989D647B...

Leah Baxter, DO FAAP

DocuSigned by:

Amber Tiehen, PT, DPT

5501F99298D4248...

Amber Tiehen, PT, DPT, OCS, CSRS

DocuSigned by:

Juli Skinner

8720664C734F429...

Juli Skinner, MSW, LMSW

DocuSigned by:

Crystal Hernandez

6DF48E67880E489...

Crystal Hernandez, Psy.D., MBA