

AUTISM+ PROGRAMS / CDD Lyn Wilson, Lynette Torivio, Felicia Nevarez



#### Indigenous Peoples' Land and Territory Acknowledgement

Founded in 1889, the University of New Mexico sits on the traditional homelands of the Pueblo of Sandia. The original peoples of New Mexico – Pueblo, Navajo, and Apache – since time immemorial, have deep connections to the land and have made significant contributions to the broader community statewide. We honor the land itself and those who remain stewards of this land throughout the generations and also acknowledge our committed relationship to Indigenous peoples. We gratefully recognize our history.



# Telling our Stories: Family and Provider Perspectives in Autism

Autism Imagine Conference



## Objectives

•Understand the perspectives of 3 Native families journey with autism

- •Learn how one family has navigated their way through an autism diagnosis into adulthood, the challenges they faced and how they addressed them.
- •Participants will learn about the basics principles of Applied Behavior Analysis and hear the perspective of a providers experience when supporting native families.



### Storytelling

- In this project we worked with Native families to help them share their stories and create a space for community education and awareness.
- Storytelling is an inherent part of Native culture and is how we share information, history, lessons and hand down traditions.
- Natural way of sharing information





## Autism in Indigenous communities

 Indigenous views on autism often differ from western views which often see autism as a disorder or disability. Indigenous social constructs and wellness philosophies may not view autism in this way, but as a difference or uniqueness of an individual.





#### The stories

- We hope that this project can give strength to families on their own journey with autism and spread awareness in our communities.
- We are sharing 3 families journeys with autism and their strengths as well as challenges along the way





### YONA

- Navajo teenager from traditional Navajo family
- Mother felt that something was different when he was a baby
- Slow hitting milestones
- Biggest challenge is that mom had to advocate for a diagnosis and services, still constantly advocating
- Researched autism as a family and had to educate themselves on it in order to better support him
- Yona is doing well now and has a great team supporting him toward independence

"We found our harmony and balance through our culture and ceremonies"





#### Yona's family would like other families to know...

"Early intervention and finding a way to work with your child is best. You have to work together with the programs and laws to make things happen. You have to advocate. Also allow your child to practice independence and don't be afraid to reach out. "



### NOAH

- Kewa/Cochiti teenager
- Loves gaming and Pokeman and Spiderman
- Mother felt something was different almost immediately.
- Was shy and attached to mom and had a lot of meltdowns but stayed under the radar until he needed more support in grades 7 and 8 when he was diagnosed.
- Main challenge was getting a diagnosis, an earlier diagnosis would have been helpful.
- Also knew he needed support but didn't know what he needed, kept asking and wasn't heard.
- Asked 'what did I do? Did I make him this way?"

"What really matters though, is that the people around him know and accept him the way he is. They don't say that he is different."





#### Noah's family would like other families to know...

"The tribe doesn't really have autism resources at this point. Programs should educate and be out in the community more. Teachers should be more educated to be able to spot the signs. We need more autism awareness and information especially in Native communities."



#### CK

- Menominee/Navajo first grader
- Loves dinosaurs and huge interest in learning. Although he has autism, he is very social and empathetic
- Home schooled where he is getting more services and time
- Biggest challenge was being isolated. Also stigma around autism and adjusting to his needs.
- "ABA doesn't align with our traditional values, our traditional ways of parenting are what we need regardless of whether our children have autism."
- "I wish I could say you are not alone, but a lot of times you are"

"Traditionally, we revolve around our kids, we put their comfort before ours. We adjust to him and not make him adjust to our needs. Our children are precious beings. It's not about him being autistic. It's about me bringing him into this world."





#### CK's family would like other families to know...

"In the future I hope there are more therapies across the board for our kids other than ABA. Remember, the ability to say "no" is an option. It has made me slow down and take in the moments."



#### Strengths

- Traditional values provide support
- Families have become strong advocates
- Community and family support







## Challenges

- Isolation
- Self-blame
- Stigma
- Hard to get a diagnosis
- Not knowing what was needed to support child
- Have to advocate for everything
- Accommodations not sufficient, having to make major life changes to support needs
- Not enough community education about autism
- No tribal resources
- ABA not aligning with traditional values





#### Lessons Learned

- Cultural resiliency plays a huge part in the success of the child
- Community and family ties are also extremely important
- More community education is needed
- More tribal supports are needed



# **Provider Perspectives**



# What is Applied Behavior Analysis ABA?

• <u>A science in which strategies derived from the</u> principles of behavior are applied to increase socially significant behavior and research is used to identify what causes and maintains the behaviors within a given environment.





#### Antecedent, Behavior, Consequence

<u>Antecedent</u> (what happens right before the behavior of concern) Behavior (the behavior of concern)

<u>Consequence</u>

(what happens right after the behavior of concern)



#### Communication









## **My Experience**

#### (Community/Schools/Families)

- Ask clarifying questions with your contact for the tribal community.
- Introduce myself to everyone:
  - You are new to the community, the community will want to know who you are and what you are doing there.
- **Provide a simple explanation of why you are visiting their community** 
  - At times it can be conveyed that service providers are there to "fix" their children.
    Explain how your services can help support the child, parents or community gain a better understanding of how their child learns.



#### My Experience (Community/Schools/Families)

- Ask what school/family what their goals are for this child
  - What is socially significant to you might not be socially significant to the family.
- <u>Welcome any and all that want to observe your work with the</u> <u>school/community/child.</u>
  - Take time to answer any and all the questions about your approach or what you are doing with the child.
  - Do not be surprised if a family member steps into "help" during your session.
  - Explain why the child might be responding they way they are
- Explain what progress can look like.



# CDD Autism Portal: Family Training

#### https://cdd.health.unm.edu/autismportal/online-

#### For Parents

This series is designed in collaboration with the New Mexico Public Education Department to help parents and caregivers learn to support positive behavior and teach functional skills within the home and to bridge these lessons between the home and school environments.

11 Considerations for Students with Autism Spectrum Disorder	+
Building Motivation & Cooperation	+
Changing Behavior	+
Functional Communication Training	+
Functional Life Skills	+
Functions of Behavior	+
IEP Best Practices	+
IFSP vs. IEP	+



#### **ABA Visualized**



https://abavisualized.com/



#### **Skill Videos**



#### Video Model of Evidence Based Strategies for Individuals with Autism





# **Support in School Setting**

There is a team at the CDD that can help provide further training and support to educators with supporting students with Autism.

- Provide classroom resources
- Direct training and support
- Professional Development Opportunities

#### **Request Services**

To learn more or to request our services for your educational team, contact Patrick Blevins MA, BCBA by email at prblevins@unmmg.org or by calling 505-272-2611 or 505-238-9762.

https://unmhealth.org/services/development-disabilities/programs/autism-programs/autismschool-services.html



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#### **Contact Information:**



Felicia Nevarez, M.Ed

**Educational Consultant** 

Fnevarez@salud.unm.edu

Patrick Blevins, MA BCBA Manager of BCBA Services prblevins@unmmg.org

