

Hello  
March



# Medically Fragile Newsletter



CENTER FOR  
DEVELOPMENT  
& DISABILITY

March 2023 | Medically Fragile Case Management Program |

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HAPPY  
*St. Patrick's Day*

## Family Advisory Board Update

THE MFCMP FAMILY ADVISORY BOARD (FAB) IS IN A REGROUPING AND RECRUITING PHASE AND IS IN NEED OF NEW MEMBERS.

THE MISSION OF THE FAB IS TO IMPROVE THE QUALITY OF LIFE FOR INDIVIDUALS WHO ARE MEDICALLY FRAGILE AND THEIR FAMILIES.

THE FAB HISTORICALLY HAS HELPED BY ADVISING ON THE DEVELOPMENT OF POLICY, FACILITATING ACCESS TO SUPPORTS, AND HELPING IMPROVE DELIVERY OF SERVICES.

FAB MEETINGS ARE CURRENTLY ON HOLD WITH MORE INFORMATION TO COME.

IF YOU ARE INTERESTED IN JOINING THE FAB, PLEASE CONTACT VAIL WOODARD AT [VWOODARD@SALUD.UNM.EDU](mailto:VWOODARD@SALUD.UNM.EDU).

## Introduction of new Director

My name is Ann Marie Parmenter and I am the new Director of the Medically Fragile Case Management Program.

I have had the honor of being a Nurse Case Manager with the program for the last 5 years. I have been dedicated to pediatric nursing for more than 20 years.

Although our long-time director, Christy Barden, leaves very large shoes to fill, I am excited to lead the Medically Fragile Program.

Christy worked very hard with Vail Woodard and myself the past few years to ensure whoever took this position as Director would have a smooth transition.

I feel confident the program will remain successful and continue to provide the excellent service it has provided over the last 35 years.

I am grateful to have this opportunity.

Please do not hesitate to reach out to share your feedback. I'd love to hear any kudos or areas where we may be able to improve.

*I can be reached at 505-362-6932 or by email [amparmenter@salud.unm.edu](mailto:amparmenter@salud.unm.edu).*

**Just a gentle reminder....please, please stay in touch.**

A month can be a long time.

Please let your nurse case manager know if anything comes up between your monthly visits.

We **especially** need to know right away of the following:

- Hospitalization
- ER visits
- Changes in address and/or telephone number

In the event of hospitalization and ER visits, we want to be there to support you.

Please share with your hospital staff that your loved one is on the Medically Fragile Program.

Please share your loved one's nurse case manager's name and number.

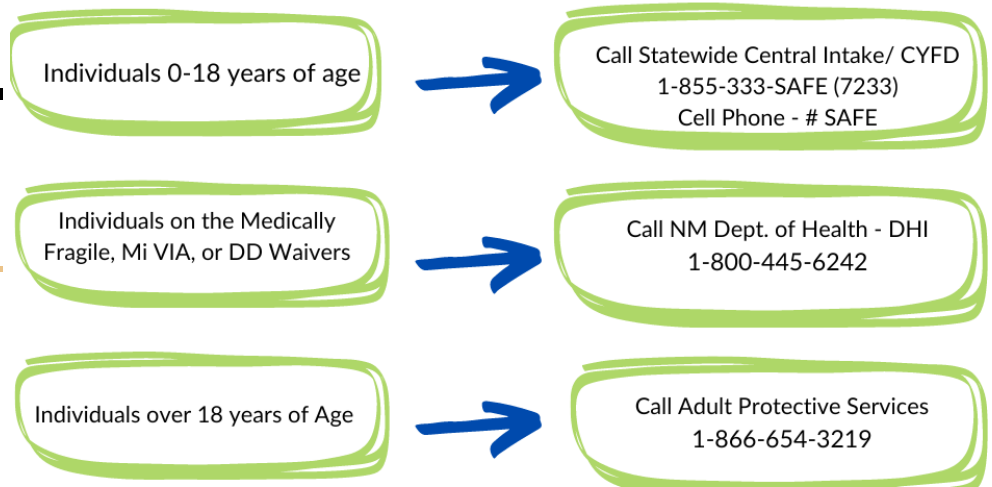
We want to help make sure you have everything you need at discharge, so it is a safe, smooth transition home.



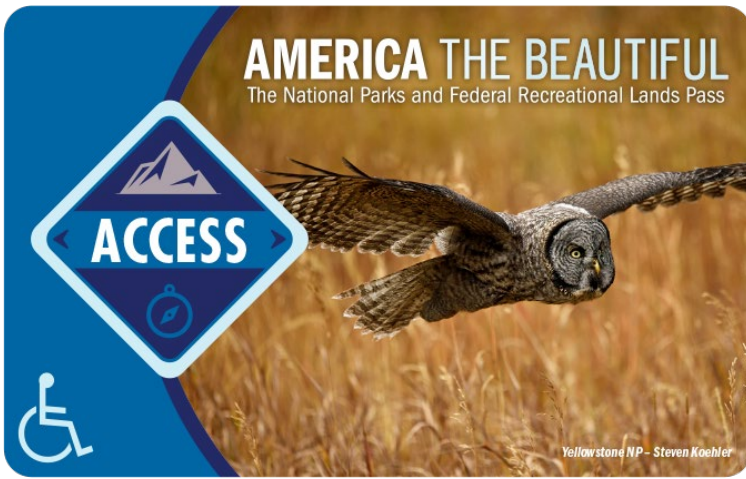
## ABUSE NEGLECT EXPLOTATION REPORT IT!

In case of an Emergency call 911

*Remember to report any  
suspected abuse, neglect, or  
exploitation!*



Lines are open 24/7. When you call the numbers above, you can remain anonymous and all the information is kept confidential.



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## America the Beautiful-The National Parks and Federal Recreational Lands Access Pass

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### What is the America the Beautiful- The National Parks and Federal Recreational Lands Access Pass?

The Interagency Access Pass is part of the America the Beautiful – The National Parks and Federal Recreational Lands Pass series and is available free for US citizens or permanent residents with permanent disabilities.

### Who is eligible to get an Interagency Access Pass?

The Interagency Access Pass may be issued to US citizens or permanent residents of any age that have been medically determined to have a permanent disability (does not have to be a 100% disability) that severely limits one or more major life activities.

For more information visit:

<https://www.nps.gov/subjects/accessibility/interagency-access-pass.htm>



*UNLEASH THE POSSIBILITIES*  
Carrie Tingley Hospital Foundation

**It's never too early to think about Summer Camp!**

### CAMP ADVENTURE (SUMMER CAMP)

Camp Adventure is a summer adaptive camp for children 6 to 19-years-old living with permanent disabilities. Camp Adventure allows children and teens the opportunity to unleash their possibilities!

During camp, campers enjoy sports, art, music, and games. Most importantly, they have fun and create lasting friendships and memories. Camp is staffed by qualified instructors and volunteers who provide instruction, encouragement, and support.

### Camp Adventure 2023

- Albuquerque - June 19-23
- Las Cruces - June 27-30
- Farmington - July 11-14
- Gallup - July 18-21

[Click Here for More Information](#)



## Free Explora Membership!

Hello families,

I have been in contact with *Explora!* And they have agreed to give each family in our program a **free year membership!**

This will be One Membership per Household. This will be a family membership which includes: up to 6 people within a family; at least one member must be 18+.

If you would like to receive a free year membership I will need to add your information to Explora. This information will include: Primary Adult First and Last Name, your address, city, state, zip code, email, phone number, and let me know if you need the instructions sent in Spanish.

Please respond to me ([nrajala@salud.unm.edu](mailto:nrajala@salud.unm.edu)) with the following information if you would like to receive this membership!

Hola familias,

¡He estado en contacto con Explora! ¡Y han accedido a dar a cada familia en nuestro programa una membresía gratis por un año!

Esta será una membresía por hogar. Esta será una membresía familiar que incluye: hasta 6 personas dentro de una familia; al menos un miembro debe ser mayor de 18 años.

Si desea recibir una membresía de un año gratis, tendré que agregar su información a Explora. Esta información incluirá: nombre y apellido del adulto principal, su dirección, ciudad, estado, código postal, correo electrónico, número de teléfono y, si necesita que le enviemos las instrucciones en español, hágamelos saber.

¡Por favor, respóndame con la siguiente información si desea recibir esta membresía! ([nrajala@salud.unm.edu](mailto:nrajala@salud.unm.edu))





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*MARCH 21<sup>ST</sup>*

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**March 21<sup>st</sup> is World Down Syndrome Day!**

#LotsOfSocks

Put some colour on your feet!

Get noticed and start a conversation about #WorldDownSyndromeDay.

You can get involved or buy your socks at our #LotsOfSocks website.

<https://lotsofsocks.worlddownsyndromeday.org/en-us>

<https://www.worlddownsyndromeday.org/> <https://www.globaldownsyndrome.org/about-down-syndrome/resources/national-down-syndrome-organizations-2/>



**Cerebral Palsy**  
Awareness Month  
MARCH

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March 25<sup>th</sup>

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March is National Cerebral Palsy Awareness Month, and Cerebral Palsy Awareness Day is Friday, March 25th. This initiative was started by a cerebral palsy advocacy group in 2006. Supporters, activists, and advocates celebrate by wearing the color green, using the #GoGreen4CP hashtag, and donating to organizations such as the Cerebral Palsy Foundation.

<https://www.cerebralpalsyguide.com/blog/>.

<https://www.yourcpf.org/advocacy-awareness/>

Please RSVP  
by March 8th  
2023

# Let's paint!



**Painting class with Gilly**  
**Friday, March 10th 2023**



**06:00 pm**

**Pizza Nine**

Price: TBA

Free for anyone  
with an IDD diagnosis

**Gilly USA**  
3199 White Sands Blvd.  
Alamogordo, NM 88310  
(575) 323-4974

For more information  
and to RSVP please  
contact  
Christina @ 575 921 2193

Children's Painting Classes	Adult Painting Classes
1 Class - \$10 Each \$1000 Class Package \$1000	1 Class - \$10 Each Adult Class Package \$1000
10, \$1000 per Pkg \$1000-2000	10, \$1000 per Pkg \$1000-2100
20, \$2000 per Pkg \$2000-4000	20, \$2000 per Pkg \$2000-4200
30, \$3000 per Pkg \$3000-6000	30, \$3000 per Pkg \$3000-6300
40, \$4000 per Pkg \$4000-8000	40, \$4000 per Pkg \$4000-8400
50, \$5000 per Pkg \$5000-10000	50, \$5000 per Pkg \$5000-10500

All Package deals are valid for 12 months.  
Note: Your classes may be used 1 at a time or shared with a group.  
Thank You!  
Gilly USA, Enterprise  
Alamogordo, NM

Let's paint with Gilly

Friday, March 10th 2023

6:00pm

Pizza Nine

Free for anyone with an IDD diagnosis.

Price for everyone else will be tba.

Space is limited.

RSVP by March 8th 2023.

For more information and to RSVP please contact  
Christina @ 575 921 2193

## Want to meet up?

I would love to put together a in person and zoom meets for our families.

I would like this to be a chance to connect with other families in our program and be a safe space to talk, vent, make new friends and talk about subjects that matter to you.

A subject I would like to bring us together about is Homeschooling. If you are a veteran homeschooler, new to homeschool or are interested in homeschool, lets get together and talk!

Please email me ([nrajala@salud.unm.edu](mailto:nrajala@salud.unm.edu)) with 2 day's and times of the day that work best for you, and if you'd like to join in person or via zoom!



### Training Program

*for clinicians, graduate students, self-advocates, educators,  
family members, other professionals, and community leaders*

#### Learn more about:

- Neurodevelopmental disabilities with a focus on autism spectrum disorder
- Leadership
- Person- and family-centered care
- Research and evidence-based practice
- Public policy and legislative advocacy
- Cultural and linguistic responsiveness
- Interdisciplinary practice
- Disability resources in NM

## Now accepting applications!

Apply February 1—May 31, 2023 at

<https://hsc.unm.edu/cdd/training-programs/nmlend/apply.html>

**FOR MORE INFORMATION: Email [HSC-NM-LEND@salud.unm.edu](mailto:HSC-NM-LEND@salud.unm.edu)  
or go to <https://hsc.unm.edu/cdd/training-programs/nmlend/>**

NM LEND is a two-semester, certificate program. It provides graduate-level, interdisciplinary training through Friday seminars and additional activities. There is no cost to participate. Most seminars and activities are via Zoom.

### The NM Leadership Education in Neurodevelopmental & Related Disabilities (NM LEND) Training Program is now accepting applications.

The program is for clinicians, graduate students, self-advocates, educators, family members of persons with disabilities, professionals who work with persons with disabilities, and community leaders. Participants learn more about neurodevelopmental disabilities with a focus on autism spectrum disorder, leadership, person- and family-centered care, research and evidence-based practice, public policy and legislative advocacy, cultural and linguistic responsiveness, interdisciplinary practice and disability resources in NM.

Apply at <https://hsc.unm.edu/cdd/training-programs/nmlend/apply.html> through May. NM LEND is a two-semester, certificate program. It provides graduate-level, interdisciplinary training through Friday seminars and additional activities. Most seminars and activities are via Zoom, but a few activities may require travel to Albuquerque or Santa Fe.

FOR MORE INFORMATION: Email [HSC-NM-LEND@salud.unm.edu](mailto:HSC-NM-LEND@salud.unm.edu) or go to <https://hsc.unm.edu/cdd/training-programs/nmlend/>.





## AYSO VIP Program is now AYSO EPIC

The mission of the AYSO EPIC Program is to provide athletes with disabilities the additional support they need to fully participate in a quality soccer experience. Volunteer buddies help our athletes not only participate but excel in this wonderful program.

We recognize that all individuals need to feel a sense of belonging and acceptance. The VIP program offers that acceptance and carries our philosophy of Everyone Plays to new heights - giving everyone a chance to play.

For more information visit:

<https://ayso.bluesombrero.com/Default.aspx?tabid=862052>



## Adaptive Sports Program New Mexico

**Enhancing the lives of children and adults with disabilities through recreation**

Since 1985, the Adaptive Sports Program New Mexico has offered therapeutic recreational activities to children and adults with disabilities. Today, ASPNM proudly offers a wide variety of adaptive sports year-round, including skiing, snowboarding, watersports, river rafting, yoga, rock climbing and more.

Visit here for more information: <https://www.adaptivesportsprogram.org/>

IF YOU HAVE ANY OTHER SPORT OR ACTIVITIES TO SHARE,  
PLEASE EMAIL NICHOLE AT [NRAJALA@SALUD.UNM.EDU](mailto:NRAJALA@SALUD.UNM.EDU)

**FOR IMMEDIATE RELEASE**

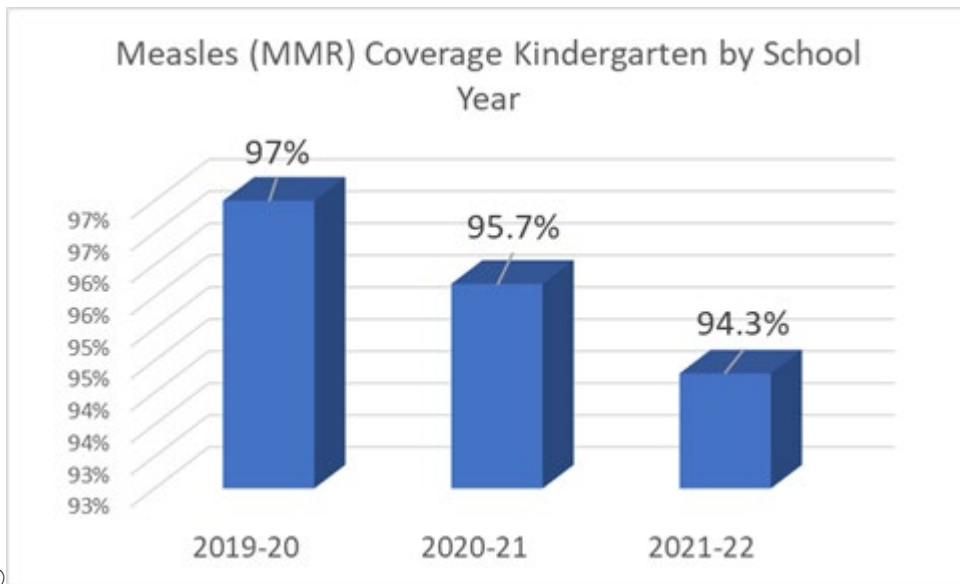
February 17, 2023

**Department of Health recommends parents and guardians check that their children’s immunizations are up to date**

SANTA FE — The New Mexico Department of Health encourages parents and guardians to speak with healthcare providers about childhood and adolescent immunizations, so children can catch up if they have fallen behind schedule.

“There is no better time to schedule a well-child visit to keep your child up to date on their immunizations than right now,” said **DOH Deputy Secretary Dr. Laura Parajon**. “All vaccines are tested to make sure they are safe and effective. Immunization can save your child’s life from life-threatening illnesses like polio and measles.”

Immunization rates for school aged children have declined since 2020 both nationally and in New Mexico. According to the CDC [childhood immunization rates dropped to 94%](#) in the U.S. during 2020-2021. Below is a graph showing vaccination rates for MMR (Measles, Mumps and Rubella) in New Mexico for the last three years - measles is so contagious that coverage should be 95% or higher.



Immunization builds up defenses against chicken pox, hepatitis, whooping cough and more. Parents and guardians are urged to schedule their well-child visits as soon as possible to make sure their kids are healthy and are meeting immunization and developmental milestones.

All common vaccines are available at [your local public health office](#) or by speaking with the medical provider of your choice. You can find a complete list of immunizations available [here](#).

# ***Weaving Colors:***

## **AUTISM & THE NATIVE COMMUNITY**

A presentation series for families dedicated to discussing important topics on autism and how they are viewed and addressed in the native culture.

**Join us Wed. March 15th 2023**

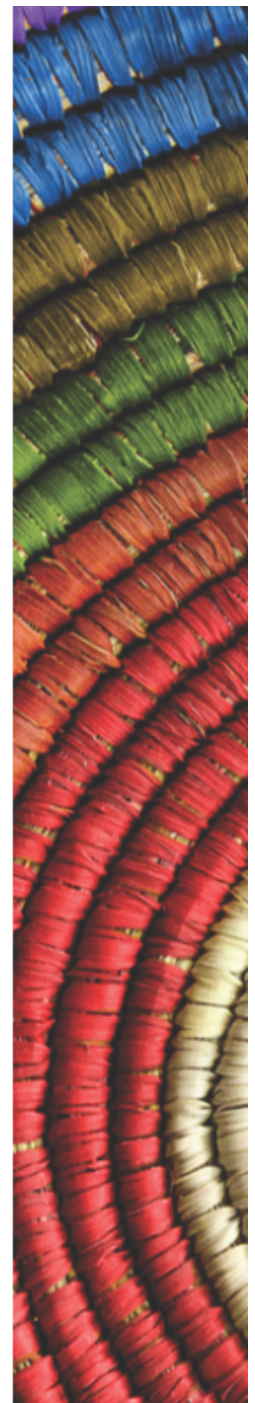
**1 - 2:30pm MST**

**Autism and Lessons of Female Rain: A Diné mother's perspective of disability and advocacy for culturally-sustaining practices of care.**

**Presenter: Sandra Yellowhorse-Kapeli**



Mother, scholar, teacher, advocate, community member and international PhD Candidate at Te Puna Wananga, School of Maori and Indigenous Education at the University of Auckland in New Zealand. My research focuses on Diné perspectives of disability.



**To register, please scan the QR code or Click HERE**



***HSC-AutismPrograms@salud.unm.edu***







**Record Keeping**  
**Tuesday, March 14th**  
**10:00am-11:00am**

Learn about record-keeping for your child's healthcare and education information. Learn how to organize and utilize these documents in advocating for your child.

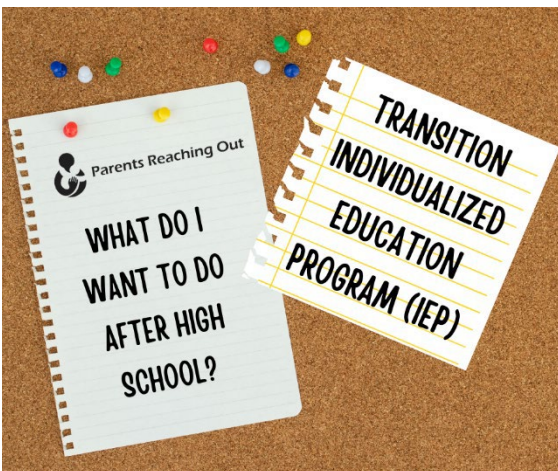
[Register Here](#)



**Forward@14**  
**Saturday, March 4th**  
**10:00am-12:00pm**

Forward@14 is a series of workshops designed for youth to gain more knowledge and understanding about important transitions they will experience.

[Register Here](#)



**Transition Individualized Education Program (IEP)**  
**Thursday, March 9th**  
**4:30pm-5:30pm**

You will learn how to best assist your student with an IEP in the transition process and help them plan their next steps after high school.

[Register Here](#)





**Student-Led Individualized Education Program (IEP) Meeting**  
**Thursday, March 16th**  
**4:30pm-5:30pm**

Learn how to lead your own IEP meeting and have a significant role in the special education planning process

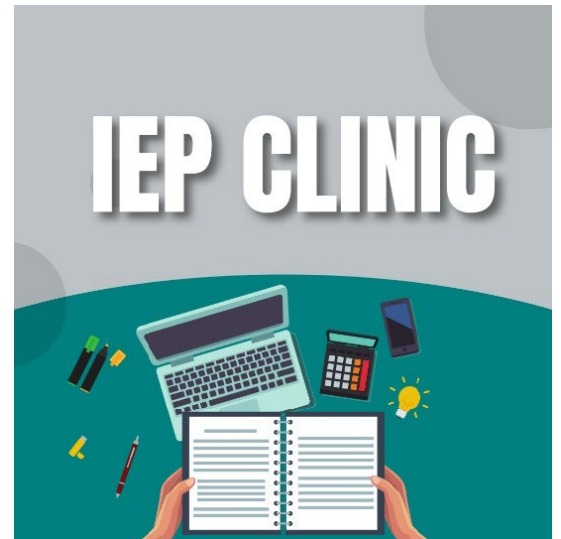
[Register Here](#)



**Disability Awareness**  
**Thursday, March 23rd**  
**4:30pm-5:30pm**

You will learn about the importance of disability awareness in your life.

[Register Here](#)



**Individualized Education Program (IEP) Clinic**  
**Tuesday, March 28th**  
**5:30pm-6:30pm**

This month's focus will be on the IEP Team. You will understand the roles and responsibilities of each IEP team member and why they are so important in your student's IEP.

[Register Here](#)

# Do you want to change special education policy?

## Join us to...

- Enhance your knowledge of the Individuals with Disabilities Education Act (IDEA)
- Develop your advocacy skills with legislators
- Influence change in the next IDEA reauthorization

## Who can participate?

Parents or caregivers of children with individualized education programs (IEPs) **and** students (aged 14-26) with IEPs

## What will I do?

- Attend a **free** 6-hour training focused on IDEA and legislative advocacy
- Participate in a focus group about advocacy in special education
- Complete surveys to document the effectiveness of the training
- Be videotaped (for less than three minutes) sharing your concerns about IDEA

## When and Where?

- April 29, 2023  
(Saturday; from 10am-4 pm)
- The Arc of New Mexico  
(5130 Masthead St NE, Albuquerque, NM 87109)



## All participants will receive:

- Two \$25 gift cards (\$50 altogether)
- Your edited videotaped testimonial with your legislators' contact information so you can forward your concerns to your legislators.

If you are interested in participating, please complete the online registration and pre-survey here:

Parents and caregivers:  
[https://redcap.link/Spring2023\\_nonran](https://redcap.link/Spring2023_nonran)

Youth:  
[https://redcap.link/youth\\_pre-survey](https://redcap.link/youth_pre-survey)

This study is funded by the Spencer Foundation.  
The study is in collaboration with **Parents Reaching Out**.

If you have questions, contact:  
Zach Rossetti - [zsr@bu.edu](mailto:zsr@bu.edu), 617-353-6419, or  
Meghan Burke - [meghanbm@illinois.edu](mailto:meghanbm@illinois.edu), 217-300-1226



## Autism Family & Provider Resource Team

A two-way collaboration between your family and our team can yield the best results for your loved one.

We are a state-wide team of resource specialist able to assist individuals on the autism spectrum, families, and providers in locating autism specific resources as well as guidance in navigating the various systems associated with autism.



Please Contact Us At:

(505) 272-1852

Toll-Free 1-800-270-1861

[HSC-AutismPrograms@salud.unm.edu](mailto:HSC-AutismPrograms@salud.unm.edu)

The CDD's Autism Family and Provider Resource Team is here to assist individuals on the autism spectrum, families and providers in locating autism specific resources as well as guidance in navigating the various systems associated with autism. They team is also available for behavioral health needs unrelated to autism as well!

Please reach out to them with any questions or for more information!



## Equipo de Recursos de Autismo Para Familias y Proveedores.

La colaboración entre su familia y nuestro equipo puede producir los mejores resultados para su ser querido.

Somos un equipo de especialistas en recursos de autismo y ayudamos a las personas en el espectro autista, a sus familias y a los proveedores a localizar recursos específicos, así como orientación para navegar por los diversos sistemas asociados con el autismo y abarcamos todo el estado de Nuevo México.

El Equipo de recursos para proveedores y familias de autismo de CDD está aquí para ayudar a las personas en el espectro del autismo, las familias y los proveedores a localizar recursos específicos para el autismo, así como orientación para navegar los sistemas asociados con el autismo. ¡El equipo también está disponible para necesidades de salud conductual no relacionadas con el autismo!

¡Comuníquese con ellos con cualquier pregunta o para obtener más información!



Por favor contáctenos al:

505-272-1852

Llame gratis al 1-800-270-1861

Correo electrónico

[HSC-AutismPrograms@salud.unm.edu](mailto:HSC-AutismPrograms@salud.unm.edu)