



# Connections

*for families touched by special needs*

## What is “Family Centered Care”? Family Voices, Inc. (2008) Guide to Using the Family-Centered Care Self-Assessment Tool *Author: Albuquerque, NM*

Each health care visit is an opportunity for families, youth and health care providers to partner to assure quality health care for the child and to support the family’s needs in raising their child. This enhanced aspect of the family and health care provider relationship is called family-centered care. The foundation of family-centered care is the partnership between families and professionals. Key to this partnership is the following:

- Families and professionals work together in the best interest of the child and the family.
- As the child grows, s/he assumes a partnership role.
- There is mutual respect for the skills and expertise each partner brings to the relationship.
- Trust is fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Within that framework, ten components of family-centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993) Family-centered care accomplishes the following:

1. Acknowledges the family as the constant in a child’s life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

## My Experience with Medical Home *by Suri Linares*

My name is Suri Linares, I am a parent of three children; a 9 year old boy, 3 year old girl, and 21 month old baby boy who was born with Down Syndrome. When we were told that my baby had Down Syndrome it was devastating because we didn’t know what to expect in the future.

My baby had open heart surgery when he was 14 days old and remained hospitalized for 27 more days to recover from surgery. From the first time we visited my baby’s pediatrician we received special treatment. I don’t speak English and our pediatrician always takes the time to explain and clarify our doubts. He makes sure we comprehend what is going on around my baby’s medical needs. He always has a bilingual nurse available during our office visits and whenever he needs to communicate with us.

The support we receive from our pediatrician makes our new responsibility of caring for a child with special needs less frustrating. Good communication and continuous care from our pediatrician, nurses, and office staff permits our son to see his specialists always in a timely manner, and gives my family piece of mind. If you don’t have good communication with your doctors, talk to them to improve communication, but if this is not possible, research for new doctors. Remember this is all about your child’s health!

## ¿Qué es "Cuidado Centrado en la Familia"? *Family Voices, Inc.* (2008) Guía para Utilizar el Instrumento de Autoevaluación de Cuidado Centrado en las Familias.

*Autor: Albuquerque, NM*

Cada visita médica es una oportunidad para familias, adolescentes y proveedores de asistencia médica de asociarse para asegurar asistencia médica de calidad para el niño y para apoyar las necesidades de la familia al educar a su niño. Este aspecto aumentado de la relación entre la familia y el proveedor de asistencia médica es llamado cuidado centrado en la familia. La base del cuidado centrado en la familia es la asociación entre familias y profesionales. La clave de esta unión es la siguiente:

- Las familias y los profesionales trabajan juntos en el mejor interés del niño y de la familia.
- A medida que el niño crece, él/ella asume un papel en la asociación.
- Existe respeto mutuo de las habilidades y experiencia que cada socio aporta a la relación
- La confianza es fundamental.
- El intercambio de comunicación e información es abierto y objetivo.
- Participantes toman las decisiones en conjunto.
- Hay buena voluntad para negociar.

Dentro de ese esquema, se han identificado diez componentes del cuidado centrado en la familia. (El Centro Nacional para el Cuidado Centrado en la Familia (1989); Obispo, Woll y Arango (1993) Cuidado centrado en la familia logra lo siguiente:

1. Reconoce la familia como la constante en la vida de un niño.
2. Aumenta las fortalezas de la familia.
3. Apoya al niño en aprender acerca y participar en su cuidado y toma de decisiones.
4. Respeta la diversidad cultural y tradiciones familiares.
5. Reconoce la importancia de servicios basados en la comunidad
6. Promueve un enfoque individual y de desarrollo
7. Fomenta el apoyo de familia a familia y entre los niños.
8. Apoya a los jóvenes en su transición a la edad adulta.
9. Desarrolla políticas, prácticas y sistemas que son de fácil uso y centrados en las familia en todos los aspectos.
10. Celebra éxitos.

## Mi Experiencia con el Cuidado Médico Centrado en la Familia

*por Suri Linares*

Mi nombre es Suri Linares, soy madre de tres niños; un niño de 9 años, una niña de 3 y un bebé de 21 meses que nació con Síndrome de Down. Al principio cuando me dijeron que mi bebé había nacido con Síndrome de Down fue muy difícil porque no sabía que nos esperaba en el futuro. Mi bebé tubo una cirugía de corazón abierto cuando tenía 14 días de nacido y estuvo 27 días en el hospital para su recuperación.

Desde el principio yo recibí una atención especial del pediatra de mi niño. Yo no hablo inglés y el pediatra toma el tiempo para explicarnos, aclarar todas nuestras dudas y se asegurarse que comprendemos lo que estaba sucediendo con respecto al cuidado médico de mi bebé. Durante cada visita a su oficina y cuando es necesario comunicarse con nosotros siempre tiene una persona bilingüe disponible.

Este apoyo que hemos recibido del pediatra en la nueva y difícil responsabilidad de tener un niño con necesidades especiales nos ha hecho estas experiencias menos frustrantes. La buena comunicación y el constante seguimiento del personal de la oficina del pediatra ha permitido que mi bebé vea a sus especialistas siempre a tiempo y eso nos da mucha tranquilidad. Yo recomiendo que si usted no tiene una buena comunicación con su doctor hable con él para que esto mejore y si no es posible cambie de doctor. Recuerde que está en juego la salud de sus hijos.

## Ways to Connect

### Northern Nevada Region

**Down Syndrome Network of Northern Nevada** - Speech and Language Workshops and Resource & Information Expo

Saturday, **May 1st** • 2PM - 5PM

This FREE event will feature a variety of organizations and agencies that provide services and assistance to those with Down syndrome. We will have workshops presented by speech therapy specialists from the Reno/Sparks area • **Location:** South Valleys Library, 15650A Wedge Parkway, Reno  
**Website:** [www.DSNNN.org](http://www.DSNNN.org)

**Sun Valley Health & Safety Fair**

Saturday, **May 1st** • 10AM - 1PM

**Location:** Sun Valley Neighborhood Center, 115 W. 6th Avenue  
**Contact:** (775) 674-8555

**Adaptive Whitewater Clinic River Festival**

Saturday, **May 1st** • 11:00AM

Participants will be introduced to basic adaptive whitewater concepts and equipment with an opportunity to float the Truckee River during the Festival. Space is limited - First come, first served!

**Location:** Barbara Bennett Park, downtown Reno

**Contact:** April (775) 333-7765

**Macy's Community Shopping Day** -

Support The Note-Ables

Saturday, May 15th • 12PM - 1PM

Tickets are \$10, 100% of which goes directly to The Note-Ables. Your ticket entitles you to 10-20% off almost everything and a \$10 off coupon with the purchase of \$25 or more! You will also be eligible to enter a drawing for a \$500 shopping spree. Tickets go on sale April 1, 2010.

**Location:** Macy's Reno (Meadowood Mall and Home Store)

**Website:** [www.noteables.org](http://www.noteables.org)

**Bowling for children 14 and up every Wednesday** • May 5, 12, 19 & 26  
3:30PM-5PM • \$3.00 weekly

**Location:** Grand Sierra Bowling Alley

**Contact:** Shauna Nelson (775) 353-7815

**Email:** [shneson@cityofsparks.us](mailto:shneson@cityofsparks.us)

**Website:** [www.sparksrec.com](http://www.sparksrec.com)

**Wheelchair Tennis**

Saturdays, May 8 - June 19

(No class May 29) • 9:30AM - 11AM

Are you interested in the extreme challenge of tennis? It's fun....it's fast! Tennis is a sport for everyone - people who use wheelchairs for mobility and people who don't. Skill development and fun is emphasized. For players of all ages. **Fee:** \$36

**Location:** Whitaker Park Tennis Courts, 550 University Terrace, Reno

**Contact:** (775) 333-7765

**Registration:** (775) 334-2262

**Website:** [www.reno.gov](http://www.reno.gov)

**Disabled Sports Adaptive Golf Instruction** • **Session 2:** Saturdays,

July 10 - August, 14 1PM - 2:30PM

**Session 3:** Thursdays, September 16 - October 21, 11AM - 12:30PM

Adaptive Golf instruction is for beginners or seasoned veterans.

Six week sessions are open to anyone with disabilities. Fees for each 6-week session: \$75 Disabled Sports Members • \$180 Non-members \$30 Annual membership fee ensures eligibility for member rates. Scholarships available if qualified.

**Location:** Rosewood Lakes Golf Course, 6800 Pembroke Dr., Reno

**Contact:** (530) 581-4161

**Website:** [reservations@disabledsports.net](mailto:reservations@disabledsports.net)

### Southern Nevada Region

**Nevada Infant Immunization and Cover the Uninsured**

Saturday, **May 1st** • 9AM - 1PM

Free immunization for all infants including those that are uninsured.

**Location:** Southwest Medical Associates, 650 N. Nellis (Between Nellis and E. Bonanza) LV

**Contact:** Nevada 211

**Nevada Childhood Cancer Foundation -6<sup>th</sup> Annual "Over head" Trivia Challenge**

Saturday, **May 1st** @ 6PM

Nevada Childhood Cancer Foundation invites you to compete with friends and family for the title of "Most Valuable Brain" Proceeds will benefit Nevada Childhood Cancer Foundation.

**Location:** Sam's Town Hotel, 5111 Boulder Highway, LV

**Contact:** (702) 735-8434

**Juvenile Diabetes Research Foundation 2010 Hope Gala**

Friday, May 7th @ 6PM

Hope Gala in support of Juvenile Diabetes Research Foundation

**Location:** Mandalay Bay Resort and Casino, 3925 Giles Street, LV

**Contact:** (702) 732-4795

**Tutor Training**

Saturday, May 29th

Training parents to instruct children with Autism • **Location:** East Las Vegas Community Center, 250 N. Eastern Avenue, LV

To RSVP **Contact:** The Lovaas Center (702) 877-2520

**2<sup>nd</sup> Annual Golf Tournament in Memory of Margeritte Ann Stewart - Children's Heart Foundation**

Sunday, May 30th @ 6PM

In addition to golf, there will be children's activities, a banquet, a silent auction and raffle! Banquet at 4PM; children's activities at 2PM.

**Location:** Country Club, 500 Greenway Road, Henderson

**Contact:** (702) 967-3522

**Email:** [info@chfn.org](mailto:info@chfn.org)

For more Ways To Connect go to  
[www.familiesnv.org/calendar](http://www.familiesnv.org/calendar)



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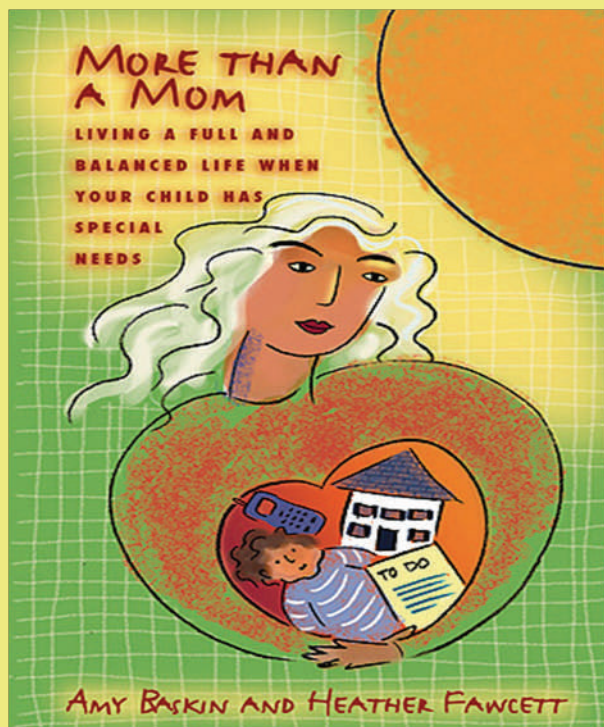
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**More Than a Mom** explores how women can lead rich, fulfilling personal lives while parenting a child with special needs. The authors' skillful blend of research, personal experiences, and feedback from over 500 mothers across North America results in a book that is jam-packed with practical strategies, advice, and reassurance for mothers trying to create more manageable and fulfilling lives.



**More Than a Mom** addresses the universal concerns and questions of all mothers, coupled with the added intensity of raising children with disabilities. This how-to guide looks at the challenges mothers face at home, at work, and within themselves, with special attention paid to:

- Staying healthy both physically and emotionally
- Keeping friendships
- Parenting your other children
- Staying organized
- Maintaining your marriage
- Nurturing interests and goals
- Seeking flexible work options
- Changing careers or starting a business
- Rejoining the workforce
- Finding specialized childcare
- Advocating for your child

Learn more about the book and authors: [www.morethanamom.net](http://www.morethanamom.net)