PARTNERING TO MAKE SERVICES EASIER TO USE FOR LATINO FAMILIES WITH CYSHCN: EXAMPLES FROM UTAH

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Presenters: Chuck Norlin, MD
    Vanessa Berrio, RN
    Lourdes Avila
    Julie Moreno

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## Today’s Discussion/Agenda

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Webinar Learning Objectives

- Increase awareness and knowledge of the ease of use of services for Latino families with CYSHCN (in particular, Utah)
- Explore how the presenting organizations can serve as a model for other states/organizations
- Examine specific examples of partnerships, activities, and lessons learned to make services easier to use for Latino CYSHCN in Utah
Latino Families with CYSHCN in Utah

- **2010 Census**
  - 13% of the Utah population is Hispanic/Latino
  - 10% of Latino population is of Mexican descent

- **National Survey for Children with Special Health Care Needs 2009-10 (Indicator 5-Ease of Use of Community-Based Services)**
  - 50% of Latinos indicated that services were not easy to use
  - 70% of respondents that spoke language other than English did not find services easy to use
Family Partners in Practice

Key partners in improving the quality of service and care in practice.

Chuck Norlin, MD
Director, Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ)
Medical Director and Principal Investigator, Children’s Healthcare Improvement Collaboration (CHIC)
Professor, Department of Pediatrics, University of Utah School of Medicine
Family Partners in Practice

Family Partners are parents of patients in the practice who are recruited and agree to serve in one or more of the following roles:

- Advisor to the practice from the family/patient/consumer perspective
- Advisor on issues related to specific chronic conditions in children
- Help in identifying and connecting families with local services and resources
Family Partners in Practice

Family Partner roles (cont.):

- Provide support for other families
  - A willing ear/perspective/sounding board
  - Identifying resources and services in the community
  - Navigating the health care system
  - Addressing family issues (extended family, siblings)
  - Advocating for their child and family
Family Partners in Practice

Find and collaborate with your local:

- Family Voices organization  [www.familyvoices.org](http://www.familyvoices.org)
- Family to Family Health Information Center  [www.familyvoices.org/f2f-grantees](http://www.familyvoices.org/f2f-grantees)
Family Partners in Practice

Recruit Family Partners based on:

- Enthusiasm
- Experience
- Passion
- Relationship with clinicians and/or practice
- Involvement in support group or community events
Family Partners in Practice

Provide a job description and written agreement

- Sample job description available at www.communitybasedservices.org/webinars

- If the role is primarily advisory, expectations should be limited

- If they also help families coordinate resources and provide emotional support, a formal job description and adequate reimbursement should be offered
Compensation is the right thing to do, but…

- Make sure it doesn’t jeopardize benefits (too much income to qualify for Medicaid or other specific services)
- Could aim to just cover costs related to their advisory roles (mileage, child care, etc.) — not over $600/year
- If paying for time, consider employing them
Family Partners in Practice

Make the agreement time-limited, usually a year

- Makes it easier for either party to end the relationship
- But allow for renewal upon both parties’ agreement, and provide for renegotiation at each renewal
Family Partners in Practice

Identify and leverage each Family Partner’s strengths and passions, particularly related to a clinical area (e.g., mental health, disabilities, etc.)
Family Partners in Practice

Two or more Family Partners will bring the benefits of different strengths, knowledge bases, and passions.

- Cultural brokers – e.g., Promotoras who have children with special needs can address language and cultural needs
- Family Advisory Committee could provide broad representation
Assign to a practice team member the responsibility for ensuring Family Partner(s) are engaged with the practice (aware of meetings, asked for feedback, supported, etc.)

- Protect the relationship between the family and the clinician!
- Offer timelines to support transitioning new families in and allow senior family leaders to pursue new areas of advocacy
Family Partners in Practice

Discuss the need to set boundaries and support them in communicating and enforcing the boundaries

- Expectations will differ for “employed” and “volunteer” Family Partners regarding who they represent
Family Partners in Practice

Develop, disseminate, and periodically reinvigorate processes for referring patients and families to the Family Partner(s)

☐ Most reliable to ask parent if it’s OK to give their information to the Partner, provide a written explanation of the Partner’s role, and have the Partner initiate the call

☐ Document appropriately in patient records
Family Partners in Practice

Provide training on HIPAA and understand how it impacts their role

Sample training slides available at www.communitybasedservices.org/webinars (be sure to adapt to your setting and check with any relevant authorities)
Family Partners in Practice

Don’t be afraid to ask them to do stuff; they can always say no (be sure to respond appropriately when they do)

- Have regular meeting times and consistent communications
- Families are valuable resources with critical expertise; they’re not just consumers
Family Partners in Practice

- Ask them for honest feedback on clinic processes, forms, physical plant, etc. (and respond when they do).
- They also are a voice of the customer and are a tremendous source of ideas for improvement.
Family Partners in Practice

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Many thanks to

- Gina Pola-Money, Director, Utah Family Voices and long-time partner in improving Medical Homes
- Kristi Colleran, Senior Program Manager, CHIC and UPIQ
Introduction to the Utah Parent Center
Introducing….

The Utah Parent Center
Phone: 801.272.1051
Email: info@utahparentcenter.org
Website: www.utahparentcenter.org
We are parents helping parents.

The Utah Parent Center (UPC or Center) is a statewide private, nonprofit organization founded in 1984. Staff at the Center are primarily parents of children and young adults with disabilities and special needs. Our mission is to help their children with disabilities to live included, productive lives as members of the community.
If Your Child Has Special Needs, So Do You!

What We Do:
We provide FREE training, information and assistance to parents of children and youth with ALL disabilities: physical, mental, learning and emotional – and to the professionals who work with them.

Special Projects include:
- Utah Family Voices Family to Family Health Information Center
- Family to Family Network

Individual Assistance
Information & Referral
Workshops
A CHILD WITH SPECIAL NEEDS IN YOUR FAMILY

Presented by the Utah Parent Center
AUTISM

What is Autism and is there help or hope?
Is Your Child a Target of Bullying?

Intervention Strategies for Parents of Children with Disabilities
Let's Talk!

TOOLS FOR CONSTRUCTIVE COMMUNICATION

Use them...they work!!!
Transition from Early Intervention to Preschool: What You Need to Know Before Your Child’s Third Birthday
FROM ‘NO’ WHERE…

…TO ‘KNOW’ WHERE
GETTING AND KEEPING THE FIRST JOB

A curriculum created by the National Family Advocacy Support and Training (FAST) Project, a project of PACER Center: fastfamilysupport.org
PARENTS AS PARTNERS IN THE IEP PROCESS WORKSHOP
Positive Behavior Supports and Interventions

Home and School
STRATEGIES THAT PROMOTE PARENT-PROFESSIONAL PARTNERSHIPS
STRESS AND WHAT TO DO ABOUT IT!
HOW TO SUCCESSFULLY NAVIGATE, ADVOCATE, AND NEGOTIATE WITHIN PUBLIC SERVICE SYSTEMS

Interest Based Negotiation and Advocacy Skills Training
Utah Parent Center
Volunteer Program

Community Resource Volunteers
IEP Coach Volunteers

By parents...For parents...
Family Links is a collaboration of a variety of disability organizations in the community who work together to bring educational speakers and conference to parents and family members of individuals with disabilities.

Visit www.utahfamilylinks.org for more information.
Contact the Utah Parent Center to obtain resource and referral information on school services, specific disabilities and community resources...

Let us help you!

801.272.1051 or 1.800.468.1160
Thank you for coming!
If you would like more information or are in need of individual assistance, please contact the Utah Parent Center.

OUR MAIN OFFICE HAS MOVED!
Utah Parent Center
801-272-1051 or 800-468-1160
www.utahparentcenter.org
230 West 200 South, Suite 1101, Salt Lake City, Utah, 84101
THE SOUTH MAIN CLINIC
A MODEL FOR COMMUNITY COLLABORATION

Vanessa Berrio, RN
Pediatric Nurse
University of Utah
South Main Clinic

- Established in 1995
- Collaboration with
  - University of Utah
  - Department of Pediatrics
  - Department of Obstetrics and Gynecology
- Salt Lake Valley Health Department
  - Family Health Services Division
Goals of the South Main Clinic

To provide:

- High quality, comprehensive, and cost-effective prenatal and pediatric care to underserved women and children in our community
- Care to specialized populations that lack access to appropriate services while sharing community resources
- Training for medical students, residents, nurse practitioners, and physician assistants to encourage lifelong enthusiasm to care for the underserved
- A resource for scholarly activity regarding the care of these populations
South Main Clinic
A team of The University of Utah and Salt Lake Valley Health Department

- **Children’s Health**
  - Checkups
  - Sick visits
  - Comprehensive medical care
  - Special health care needs
  - Full time Spanish interpretation
  - Phone interpretation

- **Teen Health**
  - Checkups, medical care, sick visits
  - Birth control
  - Screenings and treatments for sexually transmitted diseases
  - Sports physicals

- **Teen Mom**
  - Prenatal Care with Nurse Midwives
  - Strong support system with other teens
  - Psychological, financial, substance abuse, and educational support

- **Foster Clinic**
  - Serves children and teens at:
    - South Main Clinic
    - Christmas Box House
    - Youth Detention Center

- **WIC**
  - Services for women and their children
    - 0-5 years old:
      - Breastfeeding support
      - Nutrition education
      - Food support

- **Immunizations**
  - Immunizations for all ages
  - Walk-ins welcome

- **Women’s Services**
  - OB care for women of all ages
  - Family Planning

- **Women’s Cancer Screening**
  - Breast and cervical cancer screening for women 40-64 years
  - BeWise program for ages 50-64 (cholesterol, blood pressure, glucose testing, lifestyle counseling)
SOUTH MAIN CLINIC

**SERVICES AND SUPPORTIVE RESOURCES**

- Interpreters for diverse populations
- Financial assistance
  - Medicaid office in clinic
  - Sliding Scale
  - Financial counseling
- Substance abuse counseling
- Mental Health Resources (therapy, referrals, psych med management)
- Free Legal clinic monthly
- Public Giving Library
- Public Health Nurses
- Lactation Support
- Holy Cross Ministries Promotoras (family partners):
  - CSHCN support groups – Niños Especiales/ Familias Fuertes
  - Medical Home Parent Partner
  - Parenting Classes
  - Car-seat classes and installation
SPECIFIC SERVICES FOR CYSHCN AND EXPANDING PARTNERSHIPS

Wendy Hobson-Rohrer, MD, MSPH, FAAP
Pediatric Medical Director, South Main Clinic
Director, Niños Especiales/Familias Fuertes
Understanding Needs of CYSHCN

- Qualitative research using focus groups
  - Questions designed to identify themes
    - Family support needs
    - How families receive support
    - How families would prefer to receive support
  - Led by trained independent facilitators
  - Content simultaneously transcribed and taped
Healthy Tomorrows Grant

- Maternal Child Health Bureau
- American Academy of Pediatrics

- To stimulate innovative community based programs that employ prevention strategies to promote access to health care for children and their families nationwide.
EL PROGRAMA DE LAS PROMOTORAS AND NIÑOS ESPECIALES / FAMILIAS FUERTES SPECIAL CHILDREN / STRONG FAMILIES

Lourdes Avila
Promotora and Family Partner
Holy Cross Ministries
Niños Especiales Familias Fuertes

- Support group developed by HCM promotoras
Contact and support from Utah State University and students of URLEND (Utah Regional Leadership Education in Neurodevelopmental Disabilities)

- These presentations are very helpful because they give parents vital information about health topics such as autism, occupational therapy, transition support, school services, guardianship, speech therapy, down syndrome, early intervention, self-esteem, cerebral palsy, epilepsy and convulsions, parent psychological support and so on.

- Parents can also get more information about specific medical conditions pertaining to their own children.

- Spanish speaking interpreter helps!
• 3 sessions a month
• 2 in the afternoon
• 1 evening session
Growing up
Summer Fun!
Christmas Party
Medical Home Project

- Shared goal of the medical home team is to provide the best healthcare, coordination of services, resources, and referrals to promote the maximum potential of a child with special healthcare needs.
Medical Home Project

- **Family Partners**
  - Provide information and support to the medical home and the families of the children with special health care needs
  - Establish and maintain lines of communication between families and the medical home team
  - Provide families with information, parent to parent support
  - Connect parents with community services, organizations, and agencies
  - Emotional support ➔ Sometimes just listening is what parents need!
Lessons Learned

- Families can serve as advisors to other families and are important liaisons to providers
- Teach families how to navigate, advocate, and negotiate within public service systems
- Have staff that is bilingual and knowledgeable about the community and available resources
- House many services in the same physical location
- Partnering is important (URLEND pulls resources from 5 states)
- Medical home is important for all CSHCN
  - Provide support for its implementation with attention to linguistic and cultural factors
Acknowledgements

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Questions/Comments
Thank you for participating in this webinar! Your feedback is very valuable. Please take a moment to complete this brief [survey](#)!
For an archived recording of this webinar and other resources, please visit www.communitybasedservices.org