



# Champions for Inclusive Communities Star Community

## Utah County, UT

Utah County is located in the heart of the state of Utah, approximately 45 miles south of Salt Lake City. As of 2008, the population of the area was estimated to be over 500,000. The cities of Orem and Provo combined make up the county's metropolitan area. The county is part of a growing community that has a long history of working together to support children and families.

This collaboration is supported by the leadership and vision of a family-initiated program called "Kids on the Move," which is an early intervention (EI) program that meets the needs of children from the time they're born until they are three years old. This is the story of how Kids on the Move, together with other key community partners, is ensuring children with special health care needs are fully involved in their community.

### Families: The Driving Force

As early as the 1980s, families have been the driving force in developing needed services in the Utah County community. Kids on the Move (KOTM) was started by two mothers of children with Down Syndrome as a volunteer program to provide developmentally appropriate, family-centered early intervention services. From the beginning, these early family leaders spread a philosophy among the community that was inclusive of all children and supportive of families. When the State of Utah requested proposals from interested parties to provide the formal EI services under a state contract, Kids On the Move applied for and won the contract. Although this brought organizational changes, the family focus has been maintained over the years as the number of children enrolled grew to its current level of over 500 per month. Since these early beginnings, KOTM has also become the Early Head Start provider for Utah County. Families continue to be strong voices in the community today.

Family leadership has been sustained at multiple levels. Within KOTM, three "graduate parents"—parents whose children were in KOTM but have moved on to the school system—are part of the governing board of directors of the organization, which also includes parents of minority cultures.

Additionally, family input regarding the program is gathered on a monthly basis via a telephone survey. Families are asked about their satisfaction with the program and the staff, as well as about any unmet needs for their child and family. This information is a driving force when it comes to the quality of services at KOTM.

To connect parents throughout the community, the five-year old Utah County Special Needs Conference, which is now funded and supported by multiple community partners, is spearheaded by parent leaders. Maria Whitcomb, a medical home family leader, was a driving force in establishing the conference and has mentored Jodi Hansen to serve as co-chair. The conference committee also includes a Latino family leader. Local school district advocacy groups, state agencies, early intervention providers, and community mental health partners sponsor the conference, providing staff time, money, printing, and publicity. Kids on the Move continues to serve as a co-sponsor, which provides much-needed sustainability.

According to Jodi, there are other "doors" that families in Utah County may enter to network with other families and find support. The Family-to-Family network has a strong presence in Utah County, providing families with training as well as a way to network informally and provide support for one another.

### Working Towards a Medical Home

Kids on the Move is supportive of medical homes. They work closely within Part C Early Intervention regulations to promote the role of the medical home by not supplanting the existing family-medical home relationships. Almost all families consent for information sharing with the medical home; the EI nurse reviews all

medical information from both the doctor and family, and follows up with both parties as needed. With the family's permission, the child's doctor receives information every 6 months about the services the family receives and the child's developmental status. This has turned out to be an excellent opportunity to raise Doctor awareness of EI services and to strengthen the parent-medical home relationship.

That's not all Kids on the Move is doing. After every Individualized Family Service Plan (IFSP) meeting, an EI provider alerts the child's physician to the fact that the child is receiving EI services. They also include information about the services they're receiving and main developmental concerns. Physicians receive these assessment reports every 6 months. This strategy was developed after asking the physicians what information was most important that they know. Because of these reports, physicians in the community feel connected with the EI program and are calling EI more often about referrals and concerns.

### Early Head Start: A Key Partner

The Early Head Start (EHS) program has also been a key partner in promoting medical homes. For example, an EHS oral health grant brought local pediatricians together to receive training from pediatric dentists on how to incorporate oral health screening into the well child checkup. The grant also made it possible to offer free tooth sealants for all kids, not just those in Early Head Start.

### Screening in the Community

In addition to encouraging early and continuous screening via the child's medical home, Utah County has numerous examples of community collaboration to ensure early and continuous screening.

### What makes a Star Community?

ChampionsInC has created the Star Communities program to recognize exceptional communities.

Star Communities will show excellence in 6 Performance Measures:

- Families are partners
- A "Medical Home" provides coordinated care
- Children receive early and continuous screening
- Families have adequate funding/insurance to pay for services
- Services are organized so families can use them easily and are satisfied
- Youth receive necessary services to make the transition to adult life

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The county has a pediatric ophthalmologist who met with Kids on the Move and offered to do free vision screening, funded by the local Lions club. KOTM themselves does annual otoacoustic emission (OAE) screening for the kids they see. And nurses from the health department even conduct home visits and refer children who have raised a red flag to early intervention.

## A Source of Pride: PICC

Utah County citizens pride themselves on having a wide variety of community-based services available. One of their sources of satisfaction is having the longest-running, most sustainable interagency council in the state. The Partners for Infants and Children Community Council (PICC), which was founded about 13 years ago by Kids on the Move, seeks to build collaborative networks among partners in order to empower parents. PICC focuses on two areas: a) improving parents' access to quality early childhood services and b) giving parents greater information in addressing the social and emotional development in infants and children.

According to Jodie Hansen, a family leader who sits on the council, "PICC has done an amazing job in collaborating with people. Utah County is ahead of the game thanks to PICC." Jodie credits the accomplishments to everyone's willingness to work toward these common goals and leave territorial attitudes behind.

PICC has grown substantially and has received several grants such as a family service grant from the Department of Human Services. The purpose this grant is to "fill in the gaps" to pay for services otherwise not covered for families. Respite care and the medical home were identified as the key priorities of the family service grant. PICC has made strides toward their goal of respite care by funding a respite program called Friday's Kids, which provides care via highly qualified nurses and volunteers. This program has increased respite care services for 50% more families.

PICC has taken the lead in disseminating resource information to agencies such as local pediatrician offices. With support from the United Way resource and referral network and a variety of agencies who serve young children, this resource information is now being put online for broader dissemination.

PICC fosters communication with state policy makers by communicating regularly with the state legislature during their annual sessions. PICC ensures the legislature is educated about early childhood and the importance of the state's Early Childhood Initiative.

## One-Stop Application System

Utah County tries to utilize every method possible to connect families with services. One helpful resource they use is a website called Utah Clicks. Utah Clicks is an online screening and application service that allows users to apply for a variety of state programs such as Medicaid and Head Start all at once. The best part of the website is that it doesn't ask users repetitive, duplicate questions. This makes the application process faster and easier for families. Utah Clicks has received glowing reviews from families and agencies alike.

## KOTM: The "Go-To" Organization

Despite all of these commendable efforts by agencies such as PICC, Kids on the Move is still the community's hub for coordination of early childhood services, with numerous community partners working together to meet the needs of young children. These community partners include agencies that deal with special education as well as primary health care, including collaborative efforts with mental health services.

KOTM also helps link families to dental care, insurance coverage, social services, therapies, and education. They work with organizations such as NAMI, Brigham Young University Department of Psychology, local school districts, the Utah County Council for Partners for Infants and Children, and the Department of Health to provide comprehensive services.

One of the most successful endeavors Kids on the Move has participated in is the "Sib Shop," led by a collaboration between the Brigham Young University psychology department, the local school district, UAMI, and KOTM. Sib Shops are monthly meetings for siblings (7 to 17 years old) of children with disabilities. The group meets every Saturday for three hours to participate in fun, age-appropriate activities. They also offer support sessions that deal with having a sibling with special needs.

## Cultural Competence

Utah County has a significant Spanish-speaking population, and the community is striving to ensure outreach and services are accessible to them. Kids on the Move provides Spanish-speaking advocates for families, KOTM materials have been created in Spanish, and an on-site library with Spanish materials provides useful materials to families.

Other language expertise is accessible through community resources such as the Church of Jesus Christ of Latter Day Saints' Missionary Training Center. This center is based in Utah County and provides language training for international missions. Individuals from the training center who are fluent in a variety of languages are often called upon to translate for a small fee or even for free.

A group called Centro Hispano is also working on making medical care available to the Utah Spanish-speaking community, providing free clinics in the community.

## Transition

One of the leaders in providing transition services to Utah County is the Central Utah Center for Independent Living (CUCIL), located in Provo, Utah. This organization empowers people with disabilities to reach their full potential in community settings through peer support, advocacy, and education. CUCIL provides education, training, and resources in English as well as Spanish. They also offer a Special Needs Registry, which allows residents with special needs an opportunity to provide information to emergency response agencies so those agencies can better plan to serve them in an emergency.

In addition, Utah County has received a grant entitled Utah Transformation for Children and Adolescents (PDF), with the goal of improving the transition process for adolescents with mental health needs. One initial activity from this funding is the creation of a family record system to help families begin to understand the information they'd need over time to help their child qualify for adult services, such as SSI. This tool has the potential to be applicable to all youth with special needs and their families.

## Utah County: Working Together for Families

Utah County, UT epitomizes how a large community can work together to meet the needs of all its children and families, especially those children with special needs. Utah County is an inspiring example of what a strong history of family leadership and sustained collaborative relationships can do to further the work of coordinating care for families of children and youth with special health care needs.

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