

BEACH CENTER STORIES

Caring Providers and a Loving Family Make a Difference: Harper's Story

For first-time parents who had a normal pregnancy and typical delivery, the news was a shock. About 24 hours after Harper was born, Melissa and Jason first heard about the possibility of their daughter having Down syndrome. This story describes how his parents and their professional partners worked together for enhance Harper's quality of life. Included are resources for more information.

Beach Center on Disability

Making a Sustainable Difference in Quality of Life



Harper's Story

Caring Providers and a Loving Family Make a Difference

For first time parents who had a normal pregnancy and typical delivery, the news was a shock. About 24 hours after Harper was born, Melissa and Jason first heard about the possibility of their daughter having Down syndrome. With no immediate health issues often present with children who have Down syndrome, no one except Jason, who is a pharmacist, questioned the possibility. He looked for some common characteristics of infants with Down syndrome but didn't notice any in his daughter. Early chromosomal testing gave an initial indication of Down syndrome and about two weeks later, Harper was referred to Children's Mercy Hospital where a formal diagnosis was confirmed.

Fortunately, their physician understood that Melissa and Jason would have many questions and asked them to write them down. Two days after Harper was born, their physician sat down with Melissa and Jason and listened to all their concerns. "We were lucky because she was nothing but positive and helpful with getting resources," says Melissa.

A Warm Welcome

When the search for a childcare program began, Melissa and Jason were able to enroll Harper into a program at the University of Kansas. "When I first called the program, I felt like the coordinator there was gushing over the telephone to get my daughter into their program," Melissa said. As the new mother of a daughter with Down syndrome, such a warm welcome was the start of a good relationship.

Melissa learned about her local Infant-Toddler Coordinating Council (ICC), now called TINY-K (check spelling) program through the coordinator in the childcare program. When Melissa first contacted ICC, she was not only impressed by the available services and support but also by the positive attitudes of the staff. Shortly after the initial

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contact, the ICC team visited with the family and discussed their goals, visions, and needs. "From their confidence and positive attitudes, I knew that they are going to do whatever they can do for Harper," said Melissa. From that point on, Harper has received such services as occupational and physical therapy, and speech language therapy.

To serve families best, the ICC staff team held a weekly meeting. In the meeting, the service providers, such as Cassi who is one of the primary providers for Harper, discussed where they were and what they need to focus on. According to Cassi, focusing on what every family needs and providing support based on those needs is the key role of an early interventionist. By incorporating several different models such as the transdisciplinary model, primary provider model, and coaching model, the team was able to pursue the same goal in various ways. For example, when Cassi visited, she not only worked on motor skills but she also tried to embed Harper's speech goals into their time together.

Staying on the Same Page

Melissa and Jason wanted to provide Harper consistent support at home, at her childcare program, and during ICC visits. In response, the team came up with the idea of rotating the location of visits between the home and childcare program. Melissa said, “Harper spends seven hours at the child care program every day. It is important to keep them on same page.”

After every ICC service provider visit, a note was provided containing information on what Harper did, what they had worked on, and what need to be addressed next. Melissa treasured these notes not only because she could learn what had happened during the visits to the childcare program but also because of the way the notes were written. “Every parent loves to see positive comments,” Melissa said.

In addition to ICC and the early childhood program services, Melissa and Jason did their best at home. When the ICC staff visited, Melissa and Jason took turns being at home and meeting the service providers. It allowed both parents to be on the same page regarding Harper and to be able to provide consistent support.

Family Strengths

One of the strengths of the family was the support they received from their extended family. The first grandchild on both sides of the family, Harper basks in the attention and love expressed by the entire family.

Jason also was a source of strength. He knew how to find information and handled it well. He always wanted to be involved in Harper’s education. From the day Harper came home from the hospital, Jason read to Harper everyday. Melissa calls the reading time “their thing.” She strongly believes that Jason being an involved father has contributed positively to their daughter’s development.

Harper’s Gifts

Melissa and Jason believe that Harper has brought many wonderful things to their lives, not the least of which was getting to know people such as Cassi. Melissa and Jason believe the services they received gave them an enormous amount of support.

Currently, Jason and Melissa are actively involved in organizations such as the Down Syndrome Guild and TINY-K. The Down Syndrome Guild provides educational tools for parents, educators, and healthcare providers and sponsors social activities for parents and children. Jason and Melissa each have served on the board and assist with fundraising.

Melissa’s advice to other parents? “Don’t be afraid to ask questions.” She feels strongly that parents should have high expectations for their child, this is reflected in the expectations of service providers.

Following Harper’s third birthday, Melissa and Jason attended their first IEP (Individualized Educational Program) meeting. It was very different from what they were used to, but Cassi and another staff member were there to advocate for the family. Although Cassi is no longer the primary service provider for Harper, Melissa knows that Cassi will be there for Harper anytime. Cassi agrees. “They have my phone number on speed dial. They can call me anytime. They are my family.”

Resources Recommended by Melissa, Jason, and others

Local Resources in Kansas

Douglas County Infant-Toddler Coordinating Council (Tiny 'K'):

<http://www.dcicc.org/>

The Douglas County Infant-Toddler Coordinating Council provides a comprehensive delivery and support system for all children and families in the Douglas County Area, with special emphasis on young children, birth to three years of age, who have special needs.

Douglas County ICC
2619 W 6th Street, Suite B
Lawrence, KS 66046
Phone: (785) 843-3059; Fax: (785) 843-3562
E-mail: tinykdena@sunflower.com

Down Syndrome Guild of Greater Kansas City

<http://www.kcdsg.org/>

The Down Syndrome Guild is a non-profit volunteer organization whose mission is to provide support and resources for individuals with Down syndrome and their families. The Guild provides new parents a 'New Beginnings Magazine' and a complimentary copy of the book *Babies with Down Syndrome: A New parents' Guide*.

Down Syndrome Guild of Greater Kansas City
10200 W. 75th Street, Suite 281
Shawnee Mission, KS 66204
Phone: 913-384-4848; Fax: 913-384-4949
913-384-9898 (24-hour Phone Information Line)
Email: kcdsg@sbcglobal.net

First Downs for Down Syndrome (FDFDS)

<http://www.kcbuddywalk.org/index.php>

First Downs for Down Syndrome is an organization that teams with the Kansas City Chiefs Offensive Line to raise money for Down syndrome organizations locally and nationally, to increase awareness of Down syndrome, and to create positive images of those with Down syndrome.

First Downs for Down Syndrome

10000 W 75th St., Suite 220

Shawnee Mission, KS 66204

Phone: 913.722.2499; Fax: 913.722.2466

Down Syndrome Clinic – The Children’s Mercy Hospital

<http://www.childrens-mercy.org/mso/dept/docu/other/view.asp?dept=19&docu=20>

The Down Syndrome Clinic serves as a consultative service and screening mechanism for children with Down syndrome from birth through adolescence. A team of professionals works together to problem solve and to improve the quality of life for both the child and the family.

Down Syndrome Clinic
The Children's Mercy Hospital
2401 Gillham Road
Kansas City, MO 64108
(816) 234-3290

Internet

The National Fathers Network

<http://www.fathersnetwork.org/>

The Fathers Network focuses on supporting fathers and families of children with special health care needs and developmental disabilities. All information is in both English and Spanish. The network offers resources, events calendar, and family stories and photos.

Down Syndrome:

Below is a list of various informational resources on Down syndrome.

Down Syndrome: Health issues

<http://www.ds-health.com/>

This site provides articles related to health issues of people with Down syndrome.

Down Syndrome: For new parents

<http://www.downsyn.com/>

The website was opened by a parent of child with Down syndrome. It provides general information on Down syndrome as well as recommendations for relatives and recommended books and DVDs.

Down Syndrome Quarterly

<http://www.denison.edu/collaborations/dsq/>

Down Syndrome Quarterly is an interdisciplinary journal devoted to advancing the state of knowledge on Down syndrome.

National Down Syndrome Society

<http://www.ndss.org/>

This website is an information source on Down syndrome. It provides recent research, health information, educational information for people with Down syndrome and their families

National Association for Down Syndrome

<http://www.nads.org/>

This website primary serves people in the Chicago area, but it provides resource lists and fact sheets. Discussion board is available as well.

National Down Syndrome Congress

<http://www.ndscenter.org/>

The purpose of the NDSC is to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information dissemination on all aspects of Down syndrome. It provides resources for families and newsletters.

Books

Stray-Gundersen, K. (Eds.). (1995). *Babies with Down syndrome: A new parent's guide (2nd ed.)*. Bethesda: Woodbine House.

Stallings, G., & Cook, S. (1997). *Another season: A coach's story of raising an exceptional son*. New York: Little, Brown and Company.

Melissa, Jason, and Harper: Support Matrix and Tips

Family Quality of Life Domains	For Parents	For Service Providers
Family Interaction	<ul style="list-style-type: none"> • <i>Accept support from extended family members</i> – Extended family members can be an immense source of emotional support in a number of ways. 	<ul style="list-style-type: none"> • <i>First impression is important!</i> –The first impression is critical in building a relationship. During the initial contact or initial home visit, let the family feel that they are welcomed to programs. Moreover, showing parents that
Parenting	<ul style="list-style-type: none"> • <i>Involve fathers</i> - Often many fathers do not have enough chances to be involved in their child's education. Recognize that many fathers want to be involved. Let the child 	
Emotional Well-Being	<ul style="list-style-type: none"> • <i>Celebrate and share good news with each other</i> - share yours and your child's accomplishments and successes with family, friends, and providers. • <i>Get involved</i> – Seek out support groups, locally and online, that address your concerns and interests. 	<ul style="list-style-type: none"> • <i>Be accessible</i> - Whether by cell phone or by email, make it easy and comfortable for the family to reach you • <i>Be a friend – not just the expert</i> - Establish a relationship built on trust and mutual respect. Truly listen to the family and identify what is important to them. Share problem solving and decision-making.
Physical/Material Well-Being		
Disability-Related Support	<ul style="list-style-type: none"> • <i>Keep asking questions</i> - There are no ridiculous questions. It is okay to admit you don't know everything. Whenever you have questions, don't be afraid of asking. Remember what you're doing is for your child. • <i>Have high expectations for providers</i> - Providers can support you in various ways. When you clearly tell your expectations, providers will try to find ways to meet your expectation. Don't underestimate them! 	<ul style="list-style-type: none"> • <i>Be flexible</i> - Some parents might want providers to visit both homes and schools so that everyone can be on the same page. In some cases, fathers or other family members want to be involved in their child's education. Recognize the family's preferences and needs and be flexible. • <i>Provide smooth transitions out of services</i> - When transitioning out of a set of services, ask the needs of the family and continue periodic follow-up visits to ensure their needs are still being met. If the family wants, attend IEP meetings and visit schools for the family.

This story does not constitute medical, legal or any other type of professional advice. The Beach Center on Disability website and its stories are provided as a public service. Although the staff at the Beach Center works hard to provide quality information and content on the website, the Beach Center cannot guarantee the accuracy, completeness, timeliness, or suitability of the information in any particular document, on any particular web page, or for any particular purpose. If you believe any information provided in this story is unclear or inaccurate, please inform us by sending comments to Hbeachcenter@ku.edu. In no event shall the Beach Center be liable for any special, indirect, or consequential damages resulting from the use of information provided in this story.

Beach Center on Disability

The University of Kansas

1200 Sunnyside Avenue, 3136 Haworth Hall • Lawrence, Kansas 66045

Telephone: 785.864.7600 • TTY: 785.864.3434

www.beachcenter.org

