



AGRABILITY CHIT CHAT

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BACK TO SCHOOL – KIDS WITH DISABILITIES

As summer comes to an end, kids are getting ready to head back to school. This month, as part of an honors project to complete her business degree at Iowa State University, student Nancy Qvale writes about her granddaughter, Kya, who will be starting kindergarten this August. Nancy's project was focused on working with the school to ensure that Kya has a positive experience. This newsletter also includes resources for parents of children with disabilities. (EH)

KYA'S STORY

By Nancy Qvale

October 1, 1998. A miracle occurs in Ames, Iowa. A child is born. A girl, Kya Evangeline. Unlike the hundreds of other, similar miracles that occurred across the nation that day, Kya was special. She was born with an upper extremity limb deficiency. She has a small stump on her left shoulder. Her short right arm ends with two fingers that can flex and extend at the wrist.

For a variety of reasons, Kya has been staying with us, her maternal grandparents, on and off her entire life. She has been living with us steadily for the last 2 1/2 years, after we got her enrolled in a full-time daycare.

Kya knows she is different from her friends, but her positive attitude and inventiveness

have kept her, for the most part, at the same limits as her peers. She is an otherwise normal, happy, intelligent, charming, outgoing five-year-old, who is excited about attending dance class and starting school in the fall. Her personality overshadows her disability to the point that people often don't even notice her lack of arms.

The reality of life and her limitations have been addressed by many helpful ideas, people and devices with only one or two major hold backs, such as going to the bathroom by herself. Kya's strong intelligence and creativity have given her the edge to overcome her physical limitations, leaving only small minded people and childish remarks hardest to deal with.

Play

When Kya asked for a bicycle so she could ride around with her friends, we turned to the Iowa State University Mechanical Engineering Department. There, freshman students, as a class project, modified a green machine so Kya could steer it with her shoulders and upper arms.

On the playground, one of Kya's favorite things to do is swing. We look for playgrounds that have swings with a plastic coating on the chains so Kya can wrap her upper arms around them without hurting her

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skin. We also look for playgrounds where the slides have steps, rather than ladders. We enrolled Kya in dance class to improve her balance, since many dance steps require balance and flexibility. The lessons are helping in these areas and provide good exercise for her heart, muscle tone, and spirit. The positive feedback she receives from her instructor helps her maintain a positive self image and sense of self worth. Watching her during the lessons has helped to lessen our fear of her running and falling.

Kya also loves to play with her video games and her remote controlled truck. She places the controllers on the floor and runs them with her feet, showing great dexterity.

Learning and School

Kya receives medical treatment for her limb deficiency at the Shriner's Hospital in St. Paul, Minnesota. The Shriners have custom fitted two different prosthetic arms for Kya, which she no longer uses, as they are heavy and cumbersome. However, the Shriners have provided three adaptive devices that Kya does use and will help her in school.

The first item is a pair of scissors. The scissors have been secured into a piece of wood. The exposed handle has a flat surface. Kya uses one foot to guide paper into the scissors and the other foot to press down on the handle and cut where she wants.

Second, the Shriners provided a table top easel equipped with a clamp at the top. Paper or a book can be secured under the clamp and Kya can then draw or color without her long hair getting in her way.

The third item is a wrist band. The band is made of wide elastic. There is another piece of elastic that has been attached, forming a pocket. The pocket can be used to hold items such as a color, a pen, or silverware.

One item available commercially from stores such as Wal-Mart and Target is the Fisher-Price Touch Pad. This educational toy has a good selection of books available, and because it recognizes a touch, Kya can use her feet to play with it.

Personal Care

Kya uses an electric toothbrush to brush her teeth. She can hold it and move it around with her right arm. We have installed hand held shower units in both the shower and the bathtub. We have also installed body jets in the shower. This helps Kya to wash and rinse herself in all the areas that she can reach. We have purchased a device to allow Kya to wipe herself after using the toilet.

Dressing

Kya can, for the most part, undress herself. She has no trouble taking off a dress or shirt, but still needs some assistance removing pants, shorts, and underwear. There are reach devices available to help with this task, but we have not tried them yet. We purchase sleeveless tops and dresses, and cut off the sleeves on clothing when needed. We look for shoes that Kya can slip on and off herself, or shoes that are fastened with Velcro. Kya needs cooler clothing than other children, because she does not dissipate heat as quickly as someone with full arms.

The adaptations we have made for Kya in our home and in our lifestyle have been reasonably inexpensive and easy to accomplish. Kya requires patience from us. It takes her more time to eat, dress, bathe, and maneuver stairs. All of the extra time and effort on our part is richly rewarded every time Kya smiles and says "I love you, Grandma."

If you would like to contact me, I can be reached via email at nqvale@iastate.edu or

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seqvale@mchsi.com. Or you may call me at 515-232-1800 (home) or 515-294-1676 (work). I would be delighted to talk to you about Kya or someone special in your life.

RESOURCES

The **Parent Advocacy Coalition for Educational Rights** (PACER Center) is an organization whose goal is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. The PACER Center can answer questions and offer one-on-one help. They also publish a newsletter and offer many free publications related to special education and disabilities. For more information, visit their website at www.pacer.org or call 1-888-248-0822.

“Possibilities: A Financial Resource Book for Parents of Children with Disabilities” is a straightforward guide to money management and financial resources targeted to parents of a child, under the age of 8, who has a disability. To order a copy, contact the PACER Center at 1-888-248-0822.

The **Child Health Specialty Clinics** (CHSC) is a public Health Program of the University of Iowa that offers services to children and young adults up to 22 years of age who have or are at risk for chronic illness, disability, or health-related educational or behavioral problem. CHSC has 14 regional centers throughout Iowa, each offering a combination of clinic services, care coordination services, and family support services. Call 1-319-356-1118 or go to www.medicine.uiowa.edu/chsc for information on the center nearest you.

The **National Dissemination Center for Children with Disabilities**, formerly the National Information Center for Children

and Youth with Disabilities (NICHCY) is a national information and referral center that provides information on disabilities and disability related issues for families, educators, and other professionals. Visit their website at www.nichcy.org or call 1-800-695-0285.

For an overview of the different waivers available to Iowans (including the **Ill and Handicaped Waiver**), visit the website of the **Iowa Respite and Crisis Care Coalition** at www.irccc.com/fundingoptions.htm

The **National Family Caregivers Association** (NFCA) have valuable tips for family caregivers as well as news and information on caregiving. Visit www.nfcares.org or call 1-800-896-3650.

Healthy and Well Kids in Iowa (HAWK-I) is a program that provides free or low cost health insurance for Iowa children in families with limited incomes. Find out more by calling 1-800-257-8563 or by visiting their website at www.hawk-i.org.

The **Shiners Hospitals for Children** is a network of hospitals that provide expert, no-cost orthopedic and burn care to children under 18. There are 22 hospitals throughout the United States, including one in Minnesota. For more information, contact the Shriners at 1-800-237-5055 or see their webpage at www.shrinershq.org/

Iowa COMPASS is a free statewide information and referral service for people with disabilities, their families, their service providers and other members of the community. They maintain information on over 6000 local, state, and national agencies and programs and have information specialists available to help you. Call 1-800-779-2001 or see their website at www.medicine.uiowa.edu/iowacompass/

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UPCOMING EVENTS

Freewheeler Picnic

Saturday, August 7th at 1:00pm

New Hampton Library

Everyone shares expenses

IOWA AGRABILITY - A joint effort of ISU Extension and the Rural Solutions Program of Easter Seals Iowa. The program can help farm family members with a disability stay in farming.

This newsletter from the Iowa AgrAbility Project will be sent monthly to AgrAbility families and other interested individuals. Please send comments and suggestions to:

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