

CENTER FOR DISABILITIES AND DEVELOPMENT

CenterLines

FRONT AND CENTER WITH USEFUL NEWS FOR FAMILIES!

Parents, did you know...?

There are resources out there in our state to answer your questions!

By Kelly Von Lehmden, Patient/Family Representative, Center for Disabilities and Development

From a parent's perspective here are a few resources I want you to know about:

Iowa COMPASS – Disability Information and Referral –Connecting People to Programs. They offer:

- Phone support and web-based search options to provide information about and referrals to disability related programs and services.
- Product Searches -find devices to help individuals become more independent.
- Funding Searches-identify potential funding sources for your need.
- Used equipment referral service (match buyers and sellers).

Toll free number: 1-800-779-2001

Web site: www.iowacompass.org or

Email: iowa-compass@uiowa.edu

ASK Family Resource Center has a program called the *Parent Training and Information Center of Iowa* (PTI) that focuses on the educational needs of children with disabilities in Iowa. They can assist with:

- Information and training on NCLB/IDEA.
- Skills to effectively participate in the IEP/IFSP process.

- Communication strategies to help improve family and school relationships.
- Information on family support.
- Information about their child's disability.
- Information on disability rights.

Phone: 515-243-1713

Toll free number: 1-800-450-8667

Email: info@askresource.org

Web site: <http://www.askresource.org>

Disability Resource Library (DRL) at the Center for Disabilities and Development. The DRL Librarian has a wealth of knowledge for families. She has expertise in the field of disabilities and can recommend books, videos, or assistive technology to meet your needs.

- Books, software, DVDs, and assistive technology are available for check out.
- Family members can take equipment out on loan to see if the device works for the person with a disability.
- Books can be mailed directly to your home.

Toll-free number: 1-800-272-7713

Local number: 319-356-1345

Email: disability-library@uiowa.edu

Web site: <http://www.healthcare.uiowa.edu/cdd>

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University of Iowa Health Care

Parents, did you know . . . ?
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Parent Educator Connection
(PEC or PEP in your area) A statewide network of parents located in the Area Education Agencies (AEA) across the state.

- Professionals who are parents of children with disabilities are available to assist you.
- IEP/IFSP preparation including strategies to facilitate effective communication with the IEP team is available.
- PEC members can connect you with resources in the school and community.

To contact your local parent representative please call your local AEA or refer to their web site.

COMING SOON!

Annual PEC Conference

If you have children with disabilities in your life, ages birth through 11, this conference is for you!

**From Here to There:
The Path We Share**
Parent & Educator Connection
and Early Childhood Conference

November 8-10, 2009

Iowa State Center

Scheman Building, Ames, IA

Registration: \$35.00

For more information, call 515-281-7143
or email beth.buehler@iowa.gov

KEYNOTERS:

Sunday Evening **The Green Family
Ability Awareness**

Monday Morning **Dan Habib
Including Samuel**

Tuesday Noon **Paula Kluth
Inclusive Classrooms
and Communities**

Simulations help future physicians grow more comfortable communicating with patients with disabilities

by Christopher Clair

Reprinted from FYI (University of Iowa Faculty & Staff News, Oct 12, 2009)

On a September afternoon, Mike Blaser arrived early for an appointment in the University of Iowa Medical Education and Research Facility. He killed time by engaging in typical waiting-room banter for this time of year: football talk.

He discussed the Iowa Hawkeyes' chance for success in 2009 before touching on the rival team from Ames, his admiration for Iowa's coaches over the years, and the numerous times he's enjoyed a game in historic Kinnick Stadium.

Soon enough, it was time for Blaser to enter an exam room. It wasn't long before Dorlyne Henry, a third-year medical student in the UI Carver College of Medicine, joined him. Henry ran through a basic exam with Blaser, peppering her conversation with a mix of health history inquiries and "get to know you" questions.

Once the exam was over, Henry thanked Blaser for his time and asked, "Do you have any suggestions for me?"

"You did what I wanted to see: you were calm, you kept your composure," Blaser replied. "Some people don't keep it together."

Blaser, who has cerebral palsy, was playing the role of patient as part of a series of simulated clinical exams, an experiential training program



Medical student Sarah Fineberg visits with Lucas Lacina during a recent clinical simulation session.

Photo by Tom Jorgensen.

funded by the Iowa Department of Public Health and facilitated by the Carver College of Medicine and the UI Center for Disabilities and Development.

The thrust of these simulations is to give medical students greater confidence when communicating with patients with disabilities or their family members.

"About one in five people in the United States has a significant disability—something that affects mobility, daily activities, cognitive ability, memory function, or emotions," says Scott Lindgren, professor of pediatrics in the Carver College of Medicine who oversees the simulation project. "If you live long enough, you'll have one or several of these disabilities."

"Patients with disabilities are not just a small fraction of the population," he continues. "We want our medical

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Simulations help med students grow more comfortable communicating with patients with disabilities
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students to be comfortable communicating in all situations—patients with disabilities comprise one very important group.”

These clinical simulations began for third-year med students in the spring of 2007, and recently have become part of the physician assistant and nurse practitioner training as well. Lindgren coordinates a panel discussion and demonstration on communicating with people with disabilities for first-year students, and he thought that smaller, more hands-on experiences would also benefit medical students.

A small grant from the College of Medicine Educational Development Fund provided the program’s startup money. Once the program was established, funding was obtained from a grant from the Centers for Disease Control and Prevention to the Office of Disability and Health at the Iowa Department of Public Health.

The simulation sessions, which are offered 16 times per year for medical students, are part of the pediatric clerkship, a six-week rotation that all students attend. Both adults and children with physical and/or neurodevelopmental disabilities serve as patients for the simulated exams.

Patients voiced the need for improved communication from their medical providers. “This program was inspired by concerns from people with disabilities—they were not always having great experiences when getting medical care,” Lindgren says. “They wanted this to be better addressed in the early part of medical training.”

Finding people with disabilities to play the role of the patient has not been difficult—typical schedule conflicts such as work or school activities are much bigger hurdles than reticence on the patient’s part.

“Our volunteers have been wonderful,” Lindgren says. “They are not just simulated patients; they also take on the role of teacher, as they are teaching our med students how to interact.”

Some volunteers say the simulations improve their attitudes toward receiving medical care.

“Sometimes it can be a challenge to share information,” Blaser says. “If the physician is comfortable with the patient, the patient will be comfortable as well. That makes me more willing to be someone’s patient.”

Finding a comfort level with the patient—and in the case of young patients, their parents—can lead to more efficient care, Lindgren says. “Parents often are the experts on their own children’s health.”

Jeffrey Cagley, a student who recently participated in the simulation, echoes Lindgren’s sentiment. “Sometimes the parent is the sole means of communication between a child with disabilities and the world at large,” he says. “The parent knows things, sees things that we might not recognize. Bottom line: trust them.”

Lindgren says he feared that students might not find learning to communicate with patients with disabilities as exciting as the biological side of med school, but the simulations have brought out the students’ enthusiasm.

“This simulation is but one brief period, about an hour and a half of a student’s life, but it’s one of those things that a student can build on,” Lindgren adds. “It gives them the

tools to master a variety of challenging clinical experiences.”

Student feedback following the simulations is clear: the students are gaining confidence.

“The student’s worry heading into these situations is that communication with the patient will be difficult or unusual—that’s one of the things we’re working to eliminate,” Lindgren says. “Following the sessions, the students say they are more confident and have a better idea of how to make patients feel comfortable.

“The best thing we hear when we talk with our students is that this experience isn’t a problem—it’s like dealing with any other patient. That’s what we want them to realize.”

Fragile X Clinic

The University of Iowa Children’s Hospital Fragile X Clinic at the Center for Disabilities and Development provides evaluation, treatment and support for individuals with Fragile X syndrome and their families. By providing an interdisciplinary team approach to care, we work with families to improve functional outcomes and quality of life. Medical services include medication evaluation, consultation, and anticipatory health guidance under the direction of a neurodevelopmental pediatrician. Other services available include occupational therapy, speech and language therapy, audiology, nutrition support, social work, and behavioral treatment. Referrals to other important services, such as genetic counseling, can be made as needed.

CDD contact info:
877-686-0031 (toll-free)
319-353-6900 (local)
<http://www.uihealthcare.com/cdd>

CenterLines

Center for Disabilities and Development
University of Iowa Children's Hospital
100 Hawkins Drive
Iowa City IA 52242-1011

Subscription is FREE!

A subscription to **CenterLines for Families** is free. If you would like to subscribe, please send your name and address to:

CenterLines@uiowa.edu

or by regular mail:

Barb Thomas
Center for Disabilities
and Development
University of Iowa
Children's Hospital
100 Hawkins Drive
Iowa City, IA 52242-1011



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The role of the information in this newsletter is not to provide diagnosis or treatment of any illness or condition. We strongly encourage you to discuss the information you find here with your health care and other service providers.

CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uihealthcare.com/cdd. Click on Centerlines for Families.

Newsletter staff

Editors
Amy Mikelson
Elayne Sexsmith
Graphics editor
Lori Popp
Editorial board
Joni Bosch
Barb Thomas
Kelly Von Lehmden

For correspondence relating to the newsletter, or to request permission to reproduce information from it, please contact:

Barb Thomas
Center for Disabilities and Development
University of Iowa Children's Hospital
100 Hawkins Drive
Iowa City, IA 52242-1011
CenterLines@uiowa.edu

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