

CenterLines

Center for Disabilities and Development *Useful News for Families*

A Special Treat for Taylor

By Mary Hubbard, MLS, and Katie Laubscher, PT DPT, PCS

Taylor Phillips is perched on her chair in the speech therapy suite of the Center for Disabilities and Development at University of Iowa Children's Hospital. Laura Bohnenkamp, a speech language pathologist, is leading Taylor through a raucous reading of the children's book *Mostly Monsterly* by Tami Sauer. The two of them bob and growl in turn, mimicking the heroine of the book, Bernadette, in her highest form of mayhem. Taylor relates well to Bernadette because she herself is going to be a monster for Halloween – a very colorful rainbow monster. The feisty 4-year-old from rural Jefferson County has the perfect personality to pull it off, laughs Taylor's mother, Lisa Phillips.



conference guests of the American Physical Therapy Association Section on Pediatrics (SoPAC). Entered in the "Send a Family to SoPAC" contest by her physical therapist, Katie Laubscher, Taylor was chosen for the prize.

The family has their choice of sightseeing venues and can attend whatever conference sessions and events they choose. Many conference sessions are focused on up-to-date research about therapy interventions, adaptive mobility, and adapted recreation activities for children who, like Taylor, have cerebral palsy or other developmental disabilities. There are

fun activities as well, such as an adapted tai chi fitness class to which the family has been invited. Best of all, the AMBUCS Organization will be presenting Taylor with an adaptive tricycle at their Amtryke Rodeo on

Before the Halloween festivities, however, Taylor and her family have a pleasant mission to fulfill. She, her brothers, Brody (age 6) and Blake (3 mos.), and her parents, Josh and Lisa, will take a trip in October to St. Louis as



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Saturday, Oct. 24. The family was able to assist in selection of the tricycle this summer, so Taylor will have time to enjoy her favorite outdoor activity well before the snow falls.

Taylor has spastic quadriplegia with hypertonia, meaning her limbs are stiff. She had surgery earlier this year to relieve some of the tautness in her ankles and hamstring muscle and is beginning to work on sitting skills. In addition to speech and physical therapies, Taylor spends time each week working on

dressings skills in occupational therapy with Jan Jasper and Deanna Daugherty. Three hours of back-to-back therapy sessions per week tire Taylor, but she never gives up. A hard worker, Taylor is imbued with amazing resilience and quick intelligence. "Her mind is a million miles ahead of her body," says Lisa.

The Phillipses, a family of recreational enthusiasts, include Taylor in all of their activities. She loves riding tandem bike with her father and hanging out on their acreage with her brother,

Brody. The family fishing spot is an adapted fishing pier at Lake Sugema near Keosauqua. This summer, Taylor caught her first fish—a small bluegill—with her pink Barbie® fishing rod. No doubt Taylor looks forward to the day when she can help her baby brother, Blake, reel in his first catch. "We don't treat Taylor any differently," says Lisa. "Cerebral palsy doesn't define her. She's our 'little monster' and she will refuse to let it define her."



App Spotlight:

by Laura Bohnenkamp, MA, CCC, SLP

Endless Numbers is a highly engaging educational app featuring numbers 1-100. For each number, the app provides interactive puzzles and animations to reinforce number recognition, counting, sequence, quantity and early addition. The animated characters are amusing and appealing for all learners. Download the free version from the Apple App Store.



A New School Year and a Jumble of Letters

by Anne Tabor, MPH, RD/LD

The new school year has begun. Parents are back in their school routines – setting the alarm, getting their children up and dressed for school. The school building looks the same to most parents and children. There may be a new teacher or classroom. However, for many schools what is happening inside the classroom is very different.

Sometimes people who work in school seem to speak a different language. They use many acronyms, a jumble of letters: IEP, IFSP, AEA, RtI, PBIS, SI and now TLC and MTSS. What do they all mean? It can be confusing.

For the second year in a row, Iowa schools will be highlighting programs that help students reach performance goals in school. These goals are set by the state. They are called the Iowa Core. The Core is everything a child needs to know to get through school.

These new programs in schools help both kids and teachers. Iowa has joined other states and now calls for a different kind of teaching. It is called a Multi-Tiered System of Support, or MTSS. This system has been shown to help students learn more. It is a system that looks at individual teaching methods

for students that need help. This system really is a new name for what is now occurring in Iowa schools under a program called Response to Intervention (RtI).

MTSS has three tiers, or levels, of support for kids in school:

Tier I or Universal Support:

This level of teaching is what each student gets.

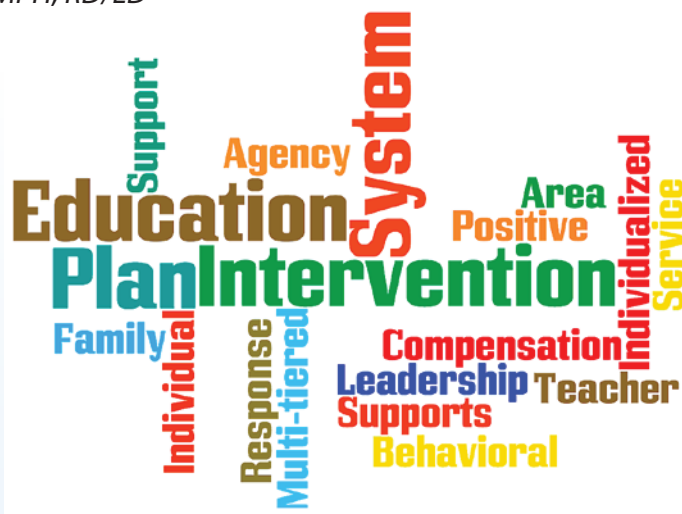
Tier II or Targeted Support:

This can be a little extra support for students that are having trouble with learning. Students that already know what is being taught can get new, exciting lessons.

Tier III or Intensive Support:

This level of support is for students who are considerably behind other kids in their class.

With MTSS, tests are given to all children in a school. The results for each child are compared to the Iowa Core. If a child falls below the Core level of knowledge, a new teaching goal is set for them. A special type of lesson is given to that student. This is over and above what is given to all kids. This is called



supplemental instruction. This student would be getting Tier II support.

Types of supplemental instruction are decided by schools and teachers. For example, students who are having more trouble reading may meet in a small group where the teacher talks about vocabulary words from a story and they then read the story aloud.

A child's progress is watched more closely when they are getting supplemental instruction. If the student is not making progress, other teaching methods are tried. Each time the teacher tries a new lesson, they record how it worked. Keeping data like this helps match teaching styles to a child's

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learning style. This adds to the possibility that the child will have success in school. There is no set amount of time that supplemental instruction has to be given. When the student reaches their goal they are back on Tier I level of support.

MTSS has been shown to speed up learning for all children, including children in special education. General education and special education teachers work together to teach special education students. Students in special education are also given tests to see how they best learn. Then the teachers form a team to decide what each child needs to learn whether they are on an Individualized Education Plan (IEP) or not.

Across the country people compare 4th grade children on IEPs and those who do not have an IEP. Iowa ranked at the bottom of all states when it came to the “achievement gap” between these children. There was a 59% difference in skills levels. The Iowa Department of Education is working to close this gap and give better education to children on IEPs. One way is to find schools where the gap is smaller and learn what they are doing.

Here are some of the common things these schools do:

- Strong pledge from school and district leaders

- Routine testing for all students and then targeted value instruction
- General and special education staff sharing responsibility for students
- High expectations for students on IEPs
- Understanding that a disability does not define expectations for a child
- Strong staff bonds with students
- Students on IEPs get Core instruction and more
- Use of teaching plans that have been proven to work
- Teachers feel empowered

“While it’s essential to be part of the broader education reform, we know that is not sufficient for students with IEPs,” Ms. Barbara Guy, Iowa’s Director of Special Education, is quoted saying. “We cannot expect our teachers to refocus classroom instruction and methods overnight without the proper tools. So in addition to our partnerships in implementing the Iowa Core and MTSS, we will continue to identify instructional strategies and other supports that are specific to students on IEPs.”

Teachers are getting extra support also. The Iowa legislature passed a funding bill to help. It is called the Teacher Leadership and Compensation System, TLC. This system rewards the best teachers. It encourages teachers to share what teaching methods work best.

Parents are the most important person for their child’s learning. As routines are put in place at home, here are a few steps for parents:

- Make reading an everyday habit at home.
- Keep track of and help with homework.
- Ask teachers how your child is doing.
- Learn more about the curricula and how the teachers are teaching.
- Go to parent/teacher and other school meetings.

Education assessment and consultations are available at the Center for Disabilities and Development (CDD) when there are concerns about a child’s progress in school. These assessments can include a complete look at what is happening in school. CDD staff can have direct contact with school teachers and/or AEA staff. They can give a child a standard academic test to see the child’s grade level and how they learn best. The CDD Education Consultants can discuss ways parents can help their child in school.

Appointments for an education consultation can be made by calling the CDD Scheduling Center, (319) 353-6900 or (877) 686-0031 (toll-free).



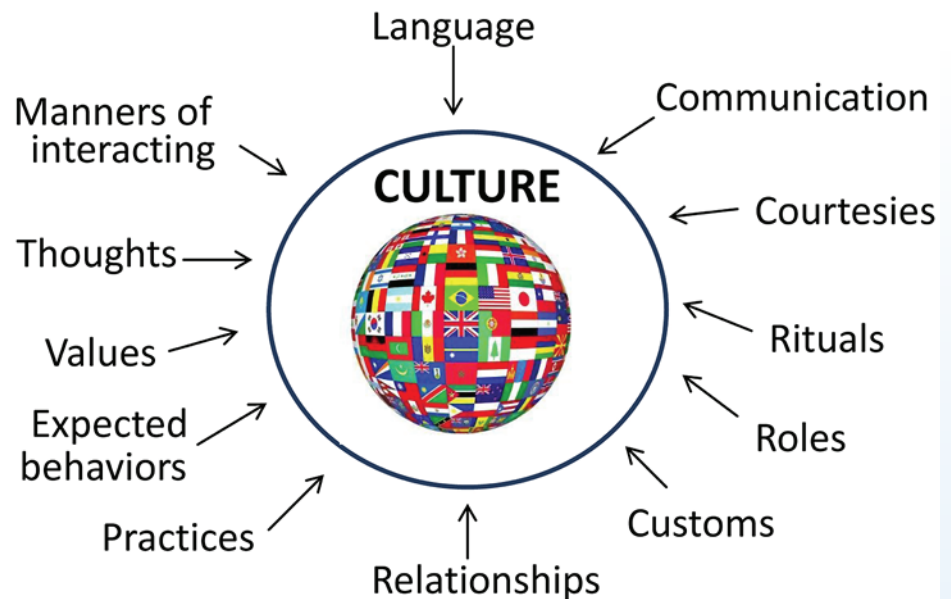
Culturally Responsive Health Care

By Anne Tabor, MPH, RD/LD

It is important to understand people from different cultures. When people have different ideas about how to live, it is called diversity. Culture is a pattern of ideas, customs and behaviors shared by a certain group of people. A person's culture can affect how they think about health, disease and illness and the best way to treat illness. Culture is always changing. Our beliefs are often passed to our children.

Language, religion, race, sex, socio-economic class, and age are some of the things that make up culture. It is important to remember not all people with the same background have the same beliefs. It is helpful to share what you believe about medicine or therapy with your health care worker. This will help them know what will work best for you and your child.

In Iowa there are now many people with different backgrounds. The largest, non-white group is Hispanic followed by African Americans. There are many smaller groups of people with different backgrounds in Iowa. One way to track the number of these groups is to look at schools. The number of



languages spoken in a school gives a sense of how many different groups are living in one area.

In Marshalltown there are 32 languages spoken. There are over 100 languages spoken in the Des Moines school district. Native Americans living in Sioux City come from 29 tribes. Sudanese living around Storm Lake speak nine different languages.

Health care workers give better care to patients when they know about their way of life. People listen better when the doctor or staff knows more about them. In health care this is called being cultural competent or having cultural humility.

Health care workers should take these steps to become culturally competent:

- Be aware of their own values and beliefs and how they relate with their patients.
- Learn facts about health beliefs and habits of different people.
- Respect differences in all people.

The University of Iowa (UI) encourages students and staff to respect differences between people. The Office of Equal Opportunity and Diversity has pulled together a lot of facts on their web page. University

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staff can take tests to see how culturally sensitive they are. Cultural sensitivity is to know that differences exist between people and to value those beliefs. That means one thought is not better or worse; it is not right or wrong. You can see this web page at <http://www.uiowa.edu/~eodccdiv/index.shtml>.

The University is giving staff chances to learn about diversity. In June, the University of Iowa Hospitals and Clinics hosted a workshop called "Culturally Responsive in Health Care." The University of Iowa has increased their pledge to be sensitive to people of all backgrounds. They have purchased an internet service called CultureVision™. This web based tool is easy to use and has tips for different cultural groups. CultureVision™ has information about:

- Concepts of health
- Beliefs, religion, and spirituality
- Language and communication
- Family customs
- Food and eating habits
- Health promotion and disease prevention
- Sickness-related issues
- Mental health issues
- Treatment issues
- Labor, birth, and after care
- Death and dying
- Terminology
- Etiquette

University of Iowa Hospitals and Clinics will be training CultureVision™ Ambassadors this fall. The "Ambassadors" will be ready to help other staff feel comfortable using the CultureVision™ data base.

Doctors and health care staff want to be your partner for decisions about health care or treatment. They want families to ask questions and share their thoughts. "Ask Me Three" is a program that encourages patients to ask questions like these at their visit:

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?

Doctors and staff at the Center for Disabilities and Development are happy to answer all questions families have when coming to clinic. We encourage families to share what is important to them and what they think when recommendations for medication or treatment are given.



CultureVision™

On-the-spot access to culturally competent patient care

ImPACT Your Child's Life

by Kelly Pelzel, PhD

What is It? ImPACT is for young children with autism. ImPACT stands for "Improving Parents as Communication Teachers." It was developed by Brooke Ingersoll and Anna Dvortcsak. ImPACT is offered at the Center for Disabilities and Development/ University of Iowa Children's Hospital Autism Center. The Autism Center has four ImPACT therapists. The Autism Center offers ImPACT in the fall and spring. Caregivers are taught how to help develop their child's social and communication skills.

Caregivers are coached on following the child's lead in play as well as prompting the child for a response and then rewarding that response. Caregivers also learn how to up the number of times their child engages with them. Studies show these strategies work!

How Can I Learn ImPACT? If you want to learn more about ImPACT at the University of Iowa Children's Hospital (UICH), please contact this author at kelly-pelzel@uiowa.edu. If you want to learn ImPACT techniques (but cannot participate in the UICH program), consider reading the 2010 ImPACT parent manual. It is called "Teaching Social

Communication to Children with Autism." It can be checked out from CDD's Disability Resource Library. The manual describes the ImPACT strategies and how to use them at home. Also, the Michigan State University is currently researching an online version of the ImPACT materials. If you are interested in participating in their research, please see their ImPACT Online website: <https://psychology.msu.edu/autismlab/impactonline/>.



FREE: Wandering Safety Toolkit!

by Kelly Pelzel, PhD

In 2012 the National Autism Association released the **Big Red Safety Toolkit**, which is available for free download at: <http://awaare.org/>. It is for caregivers of people with autism spectrum disorder (ASD). There is also a version for first responders. Some people with ASD are prone to wandering, eloping, running, and bolting from safe areas. The caregiver toolkit provides some ideas and even some templates and forms to help caregivers keep loved ones safe. Some of the ideas in this toolkit may also be appropriate for people without ASD who are prone to wandering. The toolkit includes the following:

- ☐ Caregiver Checklist
- ☐ Family Wandering Emergency Plan
- ☐ First-responder Profile Form
- ☐ Swimming Lessons Tool
- ☐ Root-cause Scenario & Strategies Tool
- ☐ Stop Sign Prompts
- ☐ Social Stories
- ☐ Caregiver Log
- ☐ Sample IEP Letter
- ☐ How To Get Tracking Technology In Your Town
- ☐ General Awareness Letter
- ☐ Five Affordable Safety Tools
- ☐ Caregiver Resources



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lies 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.uichildrens.org/cdd**. Click on Centerlines for Families.

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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.