

CenterLines

Center for Disabilities and Development *Useful News for Families*

Breaking the News: Disability and the Family

Mary Hubbard, Librarian, CDD Disability Resource Library

Learning that your child has a disability is never easy. Parents struggle to understand. Many grieve. Others are in denial. Sometimes grieving and denial occur in the same household. When the primary caregivers are at odds, family stress is elevated. Add to this drama the extended family. There are relatives to inform. What will you say? How will they handle the news?

First and foremost, be attentive to your immediate family. Your child with a disability hasn't changed, but you have. Share a private talk with each sibling. Explain the diagnosis as simply as possible. Be honest about how the family routine will change. Answer their questions; books from the local library directed to specific age ranges are always helpful. Make sure that each child knows that she or he is a cherished individual.



When you are ready to embrace a larger role, begin by educating yourself about the diagnosis. Your knowledge will give you confidence to discuss the status of your child with others. Begin by reading information in small doses from reliable websites: MedlinePlus, and the National Center for Learning Disabilities (NCLD.org) have health and family resources in English and in Spanish. DVDs are often helpful for busy families who are not readers. Educational films can be useful tools to shape ideas for families.

There is no way that you can predict how people will react to news of a disability. Those closest to you may surprise you with a wary look or a hurtful comment.

Books are helpful in this regard. Author Alyson Beytien has an excellent chapter on extended family opportunities in her book, *Autism Every Day*. Judy Winter, author of *Breakthrough Parenting for Children with Special Needs*, contends that "extended family" now means allies, friends, and support networks. This

will probably be your first test of advocacy for your child. To understand what is at stake, read *Disability is Natural: Revolutionary Common Sense about People with Disabilities*, by Kathie Snow.

As you venture into the community with your child, attempt to find commonality with those around you. Set your own example of pride in your child. The resources that follow may help you on your journey. All items can be found at the Disability Resource Library, Center for Disabilities and Development, Iowa City.

Films

Knestrict, T., Gardner, J. & Dorrell, K. (2010). *Welcome to Holland*. Chicago, IL: Learning Seed Co.

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University of Iowa Health Care

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Resiliency in families raising children with special needs.

Mayo, A. F. (2007). *Just like anyone: 5 stories from the Ann Sullivan Center of Peru*. [Lima, Perú]: [Ann Sullivan Center of Peru]. Spanish language film with English subtitles.

Books

Beytien, A. (2011). *Autism every day: over 150 strategies lived and learned by a professional autism consultant with 3 sons on the spectrum*. Arlington, TX: Future Horizons.

Klein, S. D. & Schive, K. (2001). *You will dream new dreams: inspiring personal stories by parents of children with disabilities*. New York, NY: Kensington Publishing Group.

Snow, K. (2001). *Disability is natural: revolutionary common sense for raising successful children with disabilities*. Woodland Park, CO : BraveHeart Press.

Winter, J. (2006). *Breakthrough parenting for children with special needs: raising the bar of expectations*. San Francisco, CA: Jossey-Bass.

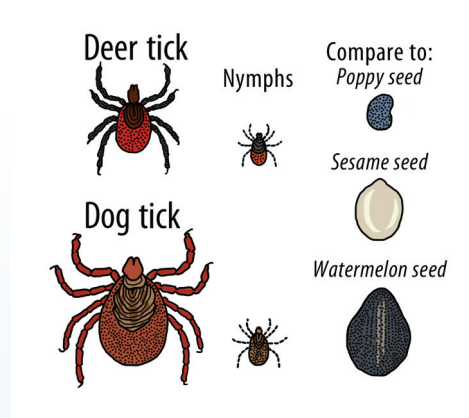
Articles

Christen, A. & Stanberry, K. "Talking with family about your child's learning disability" = "Hablando con su familia sobre la discapacidad de aprendizaje de su niño." *GreatSchools*. GreatSchools Inc., [2013.] Web. 28 April 2014.

Becker, A. J. "How to talk to kids (and parents) about disability." *PBSparents*. Public Broadcasting Service, [2013.] Web. 28 April 2014.

Summer means bugs, bugs, bugs

Warmer weather goes hand-in-hand with bugs. Mosquitoes and ticks can spread a number of diseases. You can reduce your risk by taking steps to prevent bug bites. Some mosquitoes in the US can carry West Nile virus or St. Louis encephalitis. Ticks can spread Lyme disease, human babesiosis, and Rocky Mountain spotted fever. The first line of defense is using repellent.



What type of insect repellent should I use?

Consumer Reports Health issued a new ranking of the repellents it says are best to ward off mosquitoes and deer ticks. They tested 10 insect repellents. Six of them earned a "recommended" rating from Consumer Reports. They are:

- **Off Deep Woods Sportsmen II**; 30% DEET
- **Cutter Backwoods Unscented**; 23% DEET
- **Off Family Care Smooth & Dry**; 15% DEET
- **3M Ultrathon Insect Repellent 8**; 25% DEET
- **Repel Plant Based Lemon Eucalyptus**; active ingredient oil of lemon eucalyptus
- **Natrapel 8-Hour with picaridin**; 20% picaridin

Both the American Academy of Pediatrics and the Environmental Protection Agency (EPA) have judged DEET to be safe when used as directed. It has caused rare toxic reactions when not used as instructed. The EPA also says DEET should **not** be applied to babies less than 2 months old. No one, children or adults, should use DEET in concentrations higher than 30%.

Always follow product directions and reapply as directed. If you are also using sunscreen, apply sunscreen first and insect repellent second. **The CDC recommends that people avoid products that are both sunscreen and DEET insect repellent combined.** Generally we apply a lot more sunscreen and that is probably too much DEET. Follow package directions when applying repellent on children. Avoid applying repellent to their hands, eyes, and mouth. Use your hands to apply the repellent to your face.

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Though the labels of some repellents suggest they can be used on clothes, most of those listed above damaged leather and vinyl, and some stained synthetic fabrics.

If you're going to be out for long periods, consider using permethrin-treated clothing and gear (such as boots, pants, socks, and tents). You can buy pre-treated clothing and gear or treat them yourself. Treated clothing remains protective after multiple washings. See the product information to find out how long the protection will last. If you treat items yourself, follow the product instructions carefully. Do not use permethrin directly on the skin.

What other steps should I take to prevent bug bites?

- Cover exposed skin by wearing light-colored clothing, including long-sleeved shirts, pants, and hats
- Avoid wooded and brushy areas with high grass, brush, and leaves
- Walk in the center of hiking trails
- If you do walk in high grass or woods, tuck your pants into socks and wear closed shoes not sandals
- Avoid scented products when outdoors, especially from dusk to dawn (peak feeding time for mosquitoes)
- Stay and sleep in screened or air-conditioned rooms
- Use a bed net if the area where you are sleeping is exposed to the outdoors
- Remove areas of standing water near your house where mosquitoes like to breed

What should I do if I am bitten by bugs?

- Bathe or shower as soon as possible after coming indoors
- Find and remove ticks from your body
- Check your entire body (under your arms, in and around your ears, in your belly button, behind your knees, between your legs, around your waist, and especially in your hair). Use a hand-held or full-length mirror to view all parts of your body
- Be sure to remove ticks properly
- Avoid scratching mosquito bites
- Apply hydrocortisone cream or calamine lotion to reduce itching
- Check children for ticks
- Check your pets and belongings (ticks can be on outdoor equipment and clothes)



Join us for Superhero Summer Fun!

Who can come?

Any child with a disability, ages 5-12, who wants to...

- Dance, sing, draw, craft/create
- Build self-esteem and confidence
- Be social and have FUN!

Therapists will guide all activities.

These therapists will be from speech, music, art, and physical therapy.

When, where, cost?

- We will meet from 8:30 to 11:30 am
- Monday through Friday
- at the Center for Disabilities and Development, Room 102
- There are two sessions:
Session 1: June 16th – 20th / **Session 2:** June 23rd – 27th
- Cost: \$150 per week
- **Sign-Up Soon! – Limited Space Available!**
- **Register by June 2, 2014**

For more information...

Please contact either Deanna or Jennifer to get a registration form.

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Jennifer Fitzpatrick

319-467-6013

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14 Weeks to a Healthier YOU!

Looking for a fun, new program to help you get moving and make healthy choices? Check out the National Center on Health, Physical Activity, and Disability (NCHPAD). They are inviting people with mobility issues, chronic health problems, and disabilities to join in this web-based program. You can do it from home and you don't have to buy any equipment.

The program offers:

- Weekly exercises
- Physical activity and nutrition tips
- Resources
- Weekly recipes
- Ways to track your activity and what you eat
- Reminders and alerts
- Ways to connect to others
- 14-Week coaches

Sign up at:
www.nchpad.org/14weeks/

Did you know...?

In March of this year, the Center for Disease Control (CDC) came out with some new information on autism spectrum disorders (ASD). They now say that 1 in 68 children have ASD. This is according to the Autism and Developmental Disabilities Monitoring (ADDM) Network. Some other facts about ASD are that:

- It occurs in all racial, ethnic, and socioeconomic groups
- It is almost 5 times more common among boys (1 in 42) than among girls (1 in 189)
- About 1 in 6 children in the United States has a developmental disability ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism
- It can be diagnosed at age 2 but on average, children with ASD are not diagnosed until after age 4
- Studies have shown that parents of children with ASD notice a developmental problem before their child's first birthday
- Concerns about vision and hearing may occur in the first year, and differences in social, communication, and fine motor skills are evident from 6 months of age

More people than ever before are being diagnosed with ASD. It is unclear how much of this increase is due to a broader definition of ASD and better efforts in diagnosis.

The ADDM Network is a group of programs funded by CDC to estimate the number of children with ASD and other developmental disabilities living in different areas of the United States.

Autism rates climbed nearly 30% between 2008 and 2010 and have more than doubled since the turn of the century, according to a new study from the U.S. Centers for Disease Control and Prevention. In 2012, it was one in 88.

That means virtually every grade in every elementary school potentially has at least one child with autism – a seemingly astonishing rise for a condition that was nearly unheard of a generation ago.

At the Center for Disabilities and Development we offer an early screening for ASD. We are also part of the University of Iowa Children's Hospital Autism Center. For more information or to make an appointment please contact us at 877-686-0031 or email us at **cdd-scheduling@uiowa.edu**.

CenterLines

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Centerlines for Families is published quarterly. CDD encourages subscribers to read partner newsletters **Iowa COMPASS News** and **Possibilities in Education and Training**. You can find them all by going to our website at **www.uichildrens.org/cdd** and then clicking on the link for newsletters on the right.

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

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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.