Note: Recent changes in the diagnosis of Autism have ignited passionate concern amongst many parents and professionals. Some argue that they are far too narrow. The following two articles look at this subject.

April is National Autism Awareness Month, a time when families, friends and advocates highlight the challenges of autism, a complex disorder of brain development characterized by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors.

According to the latest numbers from the U.S. Centers for Disease Control and Prevention (CDC), a whopping one in 88 children are on the autism spectrum — and it’s not just those afflicted who are affected.

Countless lives are impacted by the disorder, from parents and siblings to teachers and therapists. Nobody who loves somebody with autism is immune to the very real way it affects — and changes — their lives forever.

Back in January, an expert panel appointed by the American Psychiatric Association proposed changing the definition of autism by narrowing the criteria for diagnosis. The panel’s findings are preliminary, and a broader analysis will be released later this year, as the group works to complete the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders.

But that hasn’t stemmed outcry from the autism community, millions of whom rely on the social services and other health resources afforded those classified as being on the spectrum. Should the definition of autism change, so too would the right for innumerable families to receive the help they so desperately need, whether in the classroom, at the doctor’s office, or in the home.

Regardless of what has caused more than one million people in this country to be diagnosed with autism spectrum disorder, Asperger syndrome, or P.D.D.-N.O.S. (pervasive development disorder, not otherwise specified), the glaring truth is that more adults and children than at any other time in history are experiencing mental, emotional, and behavioral disabilities.

Whether somebody meets all the criteria for classification or just one or two, those one or two traits may be causing tremendous stress on an entire family — stress that could be relieved by providing a child on the spectrum with the therapies, interventions, and medical attention they need and deserve.

If a child’s diagnosis changes, so too might their school, their teacher, and their classmates. Change is unsettling for anyone, but is practically catastrophic for many children on the autism spectrum. Years of progress could be counteracted by the simplest change to their routine.

There is so much about autism that cannot be controlled, from how a child will react in certain settings to what they'll be willing to eat for dinner each night. One of the few things parents can control is who they let into their lives, and where they go for relief, help, and to be understood. The proposed changes to the definition of autism have cast a long shadow over the autism community. Despite the staggering new numbers indicating the prevalence of autism in this country, many parents — Continued from page 1 — still struggle to find
Stewards of Children is the only evidence-based child sexual abuse prevention training proven effective in educating adults to prevent, recognize, and react responsibly to child sexual abuse.

After training participants will:
* Understand the facts of child sexual abuse incidence rates and effects on individuals and society
* Understand how child sexual abuse happens
* Understand that adults are responsible for the protection of children
* Understand the importance of screening staff/volunteers who work with children and adolescents
* Understand the importance of a well conceived one-adult/one-child policy
* Have resources to react responsibly to incidents of child sexual abuse
* Understand the proactive role youth-serving organizations need to take to protect children and educate their communities about child sexual abuse

**TRAINING DATE:**

**Dates:**
* April 5
  Parent to Parent Network
  201 Miller Avenue
  402-379-2268
  6:00-8:30
* April 10
  Faith Regional Health Services Health Resource Center
  110 North 29th Street
  402-644-7348
  6:00-8:30
* April 11
  Educational Service Unit #1 Wakefield
  211 10th Street
  402-287-2061
  6:30-9:00
* April 12
  District #7 Probation Office
  602 Ironhorse Drive
  402-379-2026
  5:30 – 8:00

**Cost:**
$15.00
Parent to Parent Network

Children’s Mental Health Awareness
Summer Carnival & Pot Luck Picnic.

Come join us for an evening of outdoor fun!

*When:  Friday May 11, 2012 from 6:00 to 8:00 pm
*Where:  The Elkhorn Cabin at Ta-Ha Zouka Park in Norfolk

We will provide Drinks, & Sloppy Joes
Please bring a side dish or dessert.

Registration is Required!

Please Call:  1-877-379-9926 or 402-379-2268

RSVP by May 4th.
Hundreds of Nebraskans will be mounting their motorcycles to help bring awareness to children’s mental health issues.

- This is a statewide awareness and advocacy event that places a spotlight on the challenges faced by families with youth who have a behavioral health challenge. This year’s specific focus is on BULLYING!

- Journey begins with a kickoff celebration in Alliance and Scottsbluff, Nebraska on Thursday, May 31, 2012.
- Motorcyclists will travel across Nebraska collecting letters addressing bullying related to mental health from families. The parade will end at the steps of the capital the Pony Express handing the letters to the hands of the Youth to delivery to Governor Heineman in Lincoln on Saturday, June 2, 2012.

Wanna be a *pony express* rider? Please do, your involvement would be so appreciated.
Contact Sarah @ 308-995-6531 swonder@nefamilies4kids.org
A day in the life of a family advocate is many things, but boring is never one of them! I cannot even tell you about a typical day, because there is no such thing.

My day might begin at 8 am and not end until 8 pm or later; a 12 hour day is not unusual. I might have bankers’ hours or only 200 miles in a day, or never meet with families when I see or speak to them, and some days only one family. Half a dozen agencies in the area have a dozen agencies in the assistance and resources clients need. I might travel 200 miles in a day, or never leave the office. There are days when I see or speak to nearly every one of my families, and some days only one or two. Sometimes I contact a dozen agencies in the area hoping to locate the assistance and resources clients need. But some days are spent going from meeting to meeting.

We have days of victory, and defeat. There is nothing like sitting in a juvenile courtroom and realizing that the judge recognizes all the progress a child has made. That child will go home to make further progress, partly because of the supports Parent to Parent has helped put into place. When I sit in a family team meeting and hear how well the month has gone for a family, I feel proud to have played a small part—and when a family has been reunited: Priceless!

But there are also heart wrenching moments too. I’ve sat behind the glass of the county jail and spoken with a hurting client. I’ve had to call DHHS to report suspected abuse. Sometimes, I just pass the tissues and lend a listening ear. But fortunately, those days are far fewer than those of victory.

Of course there is paperwork. Files and files of paperwork! But I also teach classes, plan events and celebrations, attend trainings, frequent the schools, encourage the discouraged, and network with some amazing people in Nebraska. Occasionally I go home feeling tired and defeated, but mostly I go home tired and satisfied.

Being a family advocate is a job like no other.

Editors Note: Tonda Cranor is a Family Advocate with Parent to Parent Network, having started her work here in June of 2011. She taught for many years; has a B.S. in Elementary Education, and is the mother of a child with behavioral health challenges. She and her family came to Nebraska from Indiana.
Child Welfare Bill Advances

Lawmakers amended and advanced three bills from select file March 7 that are part of a package of measures intended to provide legislative oversight to the state’s child welfare reform initiative. Under LB820, introduced by the Health and Human Services Committee, the state Department of Health and Human Services (DHHS) would be required to apply for a federal waiver for a foster care demonstration project by Sept. 30, 2013.

The bill also would require DHHS to create a Foster Care Reimbursement Committee that would develop a statewide standard rate structure for children in foster care and require licensure of all foster parents not related to a child by blood, marriage or adoption.

The bill was amended on general file to provide a $3.10 rate increase for foster parents starting July 1, 2013.

A select file amendment offered by Lincoln Sen. Kathy Campbell and adopted 33-0 clarified that a 25 cent administrative fee authorized in the bill for foster care agencies would be in addition to the foster parent payment increase, rather than deducted from it.

LB949, introduced by the Legislative Performance Audit Committee, would tighten budgeting standards for the state’s child welfare system.

Among other provisions, LB949 would require DHHS’s division of children and family services to include a strategic plan in its budget request to the Legislature for the next two budget cycles. The plan must identify the main purpose of each program in the division, goals for measuring progress and benchmarks and time frames for meeting those goals.

The division also would be required to provide quarterly updates to the Legislature’s Health and Human Services and Appropriations committees, beginning in October 2012, on any transfer of funds greater than $250,000 into the child welfare subprogram from other budget programs.

Appropriation of funds for child welfare would be designated as a separate budget program beginning with the biennium budget ending June 30, 2015.

Sen. Bob Krist of Omaha offered an amendment on select file, adopted 29-0, which changed the deadline for designating a separate child welfare budget to July 1, 2012.

A second amendment, offered by Omaha Sen. Heath Mello and adopted 27-0, added a provision requiring DHHS to provide the Appropriations Committee with information regarding outcomes related to funds appropriated to the children and family services division.

Mello said the department should be accountable for outcomes as well as expenditures.

Finally, LB1160, introduced by the Health and Human Services Committee, would require DHHS to develop and implement a web-based, statewide automated information system to integrate child welfare data.

The bill also would require the department to obtain an evaluation of the state’s child welfare system by a nationally recognized entity. The department would be required to report to the Legislature regarding the completed evaluation and plans for the new data system by Dec. 1, 2012.

A Campbell amendment, offered on select file and adopted 34-0, added several reporting requirements to the bill, including information on a new lead agency pilot project, non-court involved child welfare cases and cases involving children with co-occurring conditions.

The three bills were advanced to final reading by voice vote.

“Action expresses priorities.”

Mahatma Gandhi
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For more updates, visit the Nebraska Legislative Home Page: [http://update.legislature.ne.gov/](http://update.legislature.ne.gov/)
Parent to Parent Network is a private, non-profit, community based organization devoted to strengthening families in Nebraska. Organized in 1998, the program has grown substantially through the years, including outreach to several communities in Northeast Nebraska.

We hire people who are or have been primary care-givers for children with behavioral health, emotional, or school issues. Our Advocates are trained to help, but their strength lies in having “been there”, and having found ways to navigate the systems affecting their child.

We charge no fees for our services. We’re members of the Nebraska Federation of Families for Children’s Mental Health and the National Federation with the same name.

Services are provided confidentially. You determine what services you want. We may make suggestions, but you have the final say!

Advocacy on behalf of the families we serve is an integral part of the services we provide. We look upon those to whom we advocate as being partners rather than opponents. We prefer what we call collaborative advocacy. We know that our families are best served when we make and strengthen partnerships with other helping organizations. Our advocacy is done with regard for one overriding principle: that the family voice be heard.

Our Web Address Is: www.parent-parent.org

Staff:
Robert Gereaux, Executive Director
Teri Jarecki-Schlecht, Services Supervisor
JoAnn Pieper, Office Manager
Cliff Hogancamp, Information Systems Specialist
Kimberly Dye, Family Advocate
Andrea Prior, Family Advocate
Tonda Cranor, Family Advocate
James Horn, Family Advocate
support and services for their child within their local communities, Just because criteria changes does not mean passion has to. I encourage the caretakers of children on the autism spectrum to continue communicating with one another, advocating for what’s right, and staying vigilant in the face of potentially life-altering changes to the definition of the disorder. It is through their strong, tireless work that so much attention has already been given to this unbelievably pressing issue, and it is by those same means that real, tangible progress will eventually be made against the ravages of autism.

———From Fox News.Com by Deidre Imus

Deirdre Imus: Founder of the site devoted to environmental health, dienviro.org, is President and Founder of The Deirdre Imus Environmental Health Center™ at Hackensack University Medical Center and Co-Founder/Director of the Imus Cattle Ranch for Kids with Cancer. She is a New York Times best-selling author and a frequent contributor to FoxNewsHealth.com.

People have been arguing about autism for a long time—about what causes it, how to treat it and whether it qualifies as a mental disorder. The controversial idea that childhood vaccines trigger autism also persists, despite the fact that study after study has failed to find any evidence of such a link. Now, psychiatrists and members of the autistic community are embroiled in a more legitimate kerfuffle that centers on the definition of autism and how clinicians diagnose the disorder. The debate is not pointless semantics. In many cases, the type and number of symptoms clinicians look for when diagnosing autism determines how easy or difficult it is for autistic people to access medical, social and educational services.

The controversy remains front and center because the American Psychiatric Association (APA) has almost finished redefining autism, along with all other mental disorders, in an overhaul of a hefty tome dubbed the Diagnostic and Statistical Manual of Mental Disorders (DSM)—the essential reference guide that clinicians use when evaluating their patients. The newest edition of the manual, the DSM-5, is slated for publication in May 2013. Psychiatrists and parents have voiced concerns that the new definition of autism in the DSM-5 will exclude many people from both a diagnosis and state services that depend on a diagnosis.

The devilish confusion is in the details. When the APA publishes the DSM-5, people who have already met the criteria for autism in the current DSM-IV will not suddenly lose their current diagnosis as some parents have feared, nor will they lose state services. But several studies recently published in child psychiatry journals suggest that it will be more difficult for new generations of high-functioning autistic people to receive a diagnosis because the DSM-5 criteria are too strict. Together, the studies conclude that the major changes to the definition of autism in the DSM-5 are well grounded in research and that the new criteria are more accurate than the current DSM-IV criteria. But in its efforts to make diagnosis more accurate, the APA may have raised the bar for autism a little too high, neglecting autistic people whose symptoms are not as severe as others. The studies also point out, however, that minor tweaks to the DSM-5 criteria would make a big difference, bringing autistic people with milder symptoms or sets of symptoms that differ from classic autism back into the spectrum.

———Reprinted from Scientific American, January 2012.