PDD/ AUTISM SPECTRUM DISORDER PARENT SUPPORT GROUP
NORTH CENTRAL IOWA
RESOURCE LIST - Updated 2/2010

This list compiles all of the positive ASD/PDD resources in the North Central Iowa area (within a 2 hour radius of Mason City), utilized by one or more families in our support group.

"Touchstones" of this group:
1. Provide a nurturing, supportive environment for parents and families.
2. Stay Positive
3. No gossiping
4. Do what works and do no harm
5. Share your resources and experiences, but do not "push" them on others.
6. Each family has different dynamics and what works for one child may not work for another.
7. Each child is a unique, amazing gift from God.
8. Confidentiality is a must!

SPECIAL NEEDS FAMILY ACTIVITIES (SNFA) Mason City Area
Contact: Diana Sherman 424-4346
E-mail: wind_decor@yahoo.com
Website:
http://specialneedsfamilyac.tripod.com
Yahoo Group:
specialneedsfamilyactivities@yahoogroups.com

CEDAR FALLS/WATERLOO PARENT SUPPORT GROUP WEBSITE –
http://www.autismiowa.com

Autism Society of Iowa (ASI)
Provides **free autism packet** to families who are newly diagnosed.
515-327-9075
1-888-722-4799
www.autismia.org
autism50ia@aol.com

Autism Society of America
1-800-3autism
301-657-0881
www.autism-society.org

Autism Research Institute
www.autism.com
866-366-3361

IOWA AUTISM SERVICES CONSULTANT
Sue Baker M.S.
100 Hawkins Drive, Rm 239
Iowa City, IA 52252-1011
Phone – 319-356-4619
sue-baker@uiowa.edu

RASP – Regional Autism Services Program
http://www.medicine.uiowa.edu/autismservices/

This site provides many important links to Iowa autism services. PARENTS, please try to be familiar with this site and use this as a reference and resource.

Specific "RED FLAGS" for ASD delays and free parent and professional autism "kits" for age's birth to age 6. Specific developmental milestone handouts and information-2005.
www.cdc.gov/actearly

Parents: Please make sure your child is tested for Fragile X along the way….this is a very commonly missed diagnosis. It is important to exclude with a blood test. There are certain reading and educational programs which work better for children with Fragile X verses ASD. Also, Fragile X can sometimes express more aggressive behaviors and different communication problems; thereby professionals use different, but more successful approaches to behavior modification and treatment. Many traits and characteristics of ASD can overlap, however.

Joan Sunde is president of NAMI- North Iowa
She is a wealth of information about counseling and resources in the North Central Iowa Area
(641) 357-0060

Julie Birkedal
Presents Visions for Tomorrow Programs in Mason City (parent education about autism, OCD, ODD, ADHD, bipolar, ect.)
420-1740

PSYCHIATRISTS AND PSYCHOLOGISTS
with experience in diagnosing and assessing ASD/PDD. Especially children who are **verbal** and fall into the Asperger/PDD-NOS category..

Grace Percival – Pediatric Psychologist
550 39th Street. Suite 100
Des Moines, IA 50312
515-274-4006

Dr Gaffney – Head of Autism Dept.
University of Iowa
Pediatric Psychiatry Dept.
319-356-1188

PSYCHOLOGICAL TESTING and/or
MR WAIVER TESTING
(MR stands for mental retardation – if child's IQ is below 70, they can qualify for this waiver)

Dr. Brent Seaton – Neuropsychologist
(Will evaluate children over the age of 6)
Mercy Behavioral Services
Mason City, Iowa
641-422-7797

Behavioral Services 422-7797
Jill Berkley – works with school system

Parents, your insurance or Medicaid should cover psych evals, speech, OT, therapy…. Legislation HR420 was passed in Iowa 2005. This bill provides that these types of services should be covered by major ins. Contact Karn (424-6917) if you have questions.
http://www.legis.state.ia.us/GA/81GA/Session.1/Summary/busi.htm#hf420

Parents: If your pediatrician is at all familiar with autism spectrum disorders, your child will be referred for competent, thorough language testing and sensory evaluations BEFORE you see a pediatric psychiatrist for the diagnosis. This must be done by professionals with specific training and experience in autism spectrum disorders. A diagnosis of PDD/ASD should not be made without these essential evaluations. Good pediatric psychiatrists know the value of these evaluations and use them to guide diagnosis and treatment recommendations.

OTHER PROFESSIONALS WHO HAVE SPECIFIC TRAINING, EXPERIENCE AND WORK WELL WITH PDD/ASD TRAITS IN CHILDREN:

SPEECH PATHOLOGISTS-

Becky Vilda SLP
University of Iowa
Pediatric Psychiatry Dept.
Educational Services
319-356-0445
319-356-1188

Wendy Yonker SLP
Jeri Bartolow SLP
Mercy – Chelsea Creek
Mason City
641-422-7611
Also provides summer speech program for **social skills called Small Talk**.

Specific PDD/ASD language tests to help confirm or rule out ASD diagnosis (including Aspergers):

Language Processing Test
CLEF – (for preschoolers)
Test of Pragmatic Language
Test of Problem Solving (TOPS) –
(starting at age 6)

OCCUPATIONAL THERAPY - SENSORY INTEGRATION

The Therapy Place
Pediatric Occupational Therapists
Sensory Integration Therapy
900 West 94th Street
Bloomington, MN 55420
952-885-0418
www.thetherapyplace.net

Healing Thresholds
Online Community and Science Connection
http://autism.healingthresholds.com/

Local Counselors for parents and siblings.
http://autism.healingthresholds.com/therapist/us/iowa/mason-city/ia/all/25

HORSE THERAPY
No specific "qualified" resources (with liability ins and specific training) that I am aware of at this time in this area.

CHIROPRACTORS
(Some moms use these chiropractors and highly recommend them for helping to improve behaviors – such as meltdowns, self-injury behaviors, hyperactivity)

Jeannie Staudt
Rockford
641-756-3740

Slinger Chiropractor Clinic
Charles City
228-3142

Aaron Street
Osage
641-732-4665

Jean Westendorf - NP
Child Health Specialty Clinic
Mason City
641-422-7388

PEDIATRIC DENTIST
Dr. Hoeppner
Children's Dental Center of **Mason City**
615 South Illinois
641-424-0060

Other Dentists recommended by moms:
Barb Boeding in New Hampton
Kyle Bobinet in Osage

OPTOMETRISTS
Dr. Karen Anderson
Clear Lake Optometry
14 N 18th St., Clear Lake
She is also **a DAN! trained**
641-357-2020

ABA THERAPY (Applied Behavioral Analysis**)- I am not aware of any specific professional resource in Northern Iowa. You would need to contact Opportunity Village and be on a waiver to consider this…at this time…However the new health care bill that congress just passed REQUIRES insurance companies to pay for ABA specifically, so hopefully, we will see some more locally trained resources that are more readily available SOON!! You will need to advocate and work hard to get this resource for your child. Iowa is very behind Minn. and Wis. regarding access to this resource. I'm telling you this to prepare you, not to dissuade or anger you!!**

Minnesota:
This center uses ABA therapy.
Jon Sailer is a therapist who can teach ABA therapy to school staff and/or parents needing it for a child.
Rochester Center for Autism
Jon Sailer, ABA Therapist
1220 4th Ave SW
Rochester, MN 55902
507-282-4134

Partners in Excellence
Barnesville, MN
Contact - Debbie Thomas
952-746-5350
fax 952-746-6131
e-mail: www.pieofmn.com
or www.debthomas@pieofmn.com
This center has an intensive ABA program 30-40 hours per week.

Wisconsin:
WEAP (Wis. Early Autism Program)
Dr. Sallows
Google this for more info.

Holland Center
Excelsior, MN
Pediatric Mental Rehabilitation Program
Provides behavioral therapy for ASD children up to age 8. Goal is to become fully mainstreamed with minimal aide.
952-401-9359

AEA 267-- MASON CITY /CLEAR LAKE
Provides free and appropriate educational services for children with disabilities in Iowa. They can **NOT** make a **diagnosis,** but can help determine what supports a child may need to succeed in the educational setting.
1-800-392-6640
641-357-6125
Go to
http://www.aea267.k12.ia.us/autism/index.php

There is an **AUTISM RESOURCE TEAM** through the AEA. These specialized educators **need to be ASKED** to observe and evaluate your child in the classroom to "problem-solve" *The child's teacher must fill out a special form for the autism team to have contact with your child*.

Autism Resource Team – (Partial List)
Patricia Notestine - SLP
Jolene Euken – Early Childhood Ed.
Sara Jarnacin – Psychologist
Dea- Ellen Birtwistle – Social worker

Through your AEA and child's school teachers, you should be able to ask for help with specific picture schedules and social stories you need at home, to help connect what the child is learning at school, in the home too**. Don't feel like you have to do all of this yourself.** They are excellent resources for specific behavior modification ideas for your child. They will help us problem-solve disruptive or frustrating behaviors.

Ages 0-3 – Provides free screening and evaluations to help determine if developmental delays are present and begin speech, PT, OT therapies if indicated through the AEA. (Typically 40 minutes twice a month- in home; FYI- MN and WI provide over 30 - 40 hours a week in-home paid by the state)

Family-Educator coordinator
Clear Lake/ Mason City Region
Sandy Kraschel 1-800-392-6640
Email: skraschel@aea267.k12.ia.us
Sandy provides information, support and encouragement to families and educators of children and young adults with disabilities.

MR WAIVER INFORMATION
http://www.ime.state.ia.us/docs/MRPacket.doc

(If your child has also been diagnosed with mental retardation –(MR) – you will qualify for this waiver which includes **free medical coverage** and **respite services**) There are also other qualifications (adaptability) to get on a MR waiver besides mental retardation. You need to be an advocate for you and your child and keep asking for more info until you find a way to qualify – ask other moms and Drs and case managers until you get an answer. Don't give up if you want to get on a waiver! It will take some time and patience, but hang in there!

CONSUMER CHOICES'S is a new option under the MR waiver that some parents in our group are now in – this started Jan of 2007. Ask your case manager about this.

Your child may also/or qualify for other HCBS Waivers, such as the Ill and Handicap Waiver or the Children's Mental Health Wavier. Yes, these Waivers usually have waiting lists, but the sooner you get on the list the sooner you may receive a slot.
http://www.dhs.state.ia.us/dhs2005/dhs_homepage/medical_assistance/medical_insurance/help_ownhome.html
Each waiver has a different set of criteria for determining eligibility.

http://www.dhs.state.ia.us/dhs2005/dhs_homepage/children_family/getting_help/map_offices.html
And finally, this link will take you to find where your DHS office is located. They too, are a good place to call for questions regarding waivers and how to begin the process

*TO GET AN **APPLICATION** FOR MR WAIVER: Call the Department of Human Resources in your **county** and speak with a **case manager**.*

Cerro Gordo County –424-8641
Floyd County – 228-5713
Mitchell County – 585-3271
Worth County – 324-3209

RESPITE INFORMATION
For children without waivers, contact:

Iowa Respite & Crisis Care Coalition
Direct Family Access – Des Moines
(Respite Care Reimbursement)
www.irccc.com
1-877-255-3140
Contact: Terri
.
Private Pay Respite through Opportunity Village
$16.00 per hour
Contact: Elisha Payton
641-355-1248
epayton@oppvill.org

The Respite Connection Inc.
Natasha Eyerly- Service Supervisor
515-283-3867
neyerly@therespiteconnection.com

LEGAL SERVICES
Iowa Protection and Advocacy Services
950 Office Park Road, Suite 221
West Des Moines, IA 50265
515-278-2502
1-800-779-2502
This is an independent, non-profit agency, federally funded and serves people with developmental disabilities, mental illnesses and other disabilities. Problems dealt with include abuse, neglect, education, housing or denial of services.

CURT SYTSMA
Des Moines
Special Education Lawyer
Experience with Autism Spectrum Disorders
Phone 515-282-2747
1961 Arlington Ave
Des Moines, IA

FINANCIAL SUPPORT
Family Support Subsidy Program through Iowa Department of Human Services
Contact: Marion Kresse – Manager
515-281-4522
(annual income <40,000 to qualify)

Modest Needs resource
http://www.modestneeds.org/

CAMP SUNNYSIDE – Des Moines
Easter Seals camp for ASD/PDD
401 NE 66th Ave
Des Moines, Ia 50313
clecroy@eastersealsia.org
515.309.2376
515.289.1281 FAX

MISCELLANEOUS sites which have been helpful to different families in this support group.

Free visual schedules to print out.
www.dotolearn.com

Visual Schedules/ Special Ed info
http://www.specialed.us/autism/index2.htm

Sensory items (chewies, ect.)
Pocket Full of Therapy
www.pfot.com/about.htm

Visual Time Timers
http://www.timetimer.com/

ASA "Safe and Sound" window decal and "Personal Information Record".

http://www.autism-society.org/site/PageServer?pagename=research_safeandsound

WALLET CARDS
http://www.autism-society.org/site/PageServer?pagename=research_safeandsound_firstresponders

Fast ForWord is a computer program designed by a neurologist. This program helps improve comprehension and auditory processing later on, even if they do poorly on it now. It costs over $4000 and can be covered by educational grants.
http://www.scilearn.com/

Schafer Autism Report (SAR)
!international, daily news reports on Advocacy, Education, Research, Political, Legal, ect issues on Autism Spectrum Disorders. $30/yr
http://www.sarnet.org or
mailto:subs@doitnow.com

Educational Websites for ASD children
www.kidspsych.org/index2.html

ADHD info
www.brainplace.com

C.A.R.D.
CENTER FOR AUTISM AND RELATED DISORDERS, INC

www.centerforautism.com

This organization has most of it's centers on the East and West Coasts. But they can provide services anywhere. CARD supervisors develop and oversee a child's comprehensive treatment, behavioral and educational program for up to 4 years.

HOMEOPATHIC MEDICINE

www.homeopathyhouston.com

The Homeopathy Center in Houston is very experienced in treating autism. Contact Karn with questions or local recommendations if you are interested in this form of therapy. Some moms use this solely or in addition to prescription medication as an adjunct therapy. There are two kinds of homeopathy- sequential (several remedies used at a time) and constitutional (one remedy used at a time).

BIOMEDICAL INTERVENTIONS

There are huge debates and controversies surrounding ASD/PDD. Instead of ASD being considered a psychiatric/developmental delay disorder, many argue that ASD is an underlying immunologic, metabolic disorder with psychiatric manifestations; which has been "triggered or aggravated" by environmental toxins, (ie heavy metal toxicity – not just thimerosal)

Recommended Reading explaining treatment protocols:
CHANGING THE COURSE OF AUTISM:
A SCIENTIFIC APPROACH FOR PARENTS AND PHYSICIANS
BY: BRYAN JEPSON MD

Autism Research Institute
Main autism/biomedical website with many helpful links. They have a quarterly e-mail newsletter you can subscribe to with current research and updates.
www.autism.com

Updated DAN! Dr. List 2009
http://autism.com/dan/index.htm#practlist

DAN (Defeat Autism Now) These are physicians who have taken additional training through the Autism Research Institute and usually have a child, grandchild or close relative who has ASD/PDD which motivated their interest in the treatment and knowledge of autism.

Free webcasts of DAN! Conferences:
http://autism.com/danwebcast/index.htm

Parent Funded Informational Website
www.generationrescue.org
Find "rescue angels" and "action plans" to help you start the biomedical process.

Other helpful sites:
Neuroimmune Dysfunction Syndrome
www.nids.net
(Dr. Michael Goldberg)

Talk About Curing Autism (**TACA**)
http://www.talkaboutcuringautism.org/index.htm

SAMPLE - "TO DO CHECKLIST"
3 YEAR GUIDE – CAN START AT ANY AGE TO BEGIN ADDRESSING UNDERLYING METABOLIC, IMMUNE AND NUTRITIONAL DISORDERS/DEFICIENCIES WHICH CAN, IN TURN, IMPROVE THE CHILD'S HEALTH, COGNITION AND FUNCTIONING. Use this as a guide to help you see what options are out there. Yes, this is overwhelming, but it is also overwhelming living with uncontrolled autistic behaviors. Yes, you can use prescription medications along with these therapies. Yes, you will need to fight and go out of state for some of these resources if you chose to do so. Yes, it can be expensive, but safe, highly skilled long term care is expensive also. Make sure you have a positive support system set up for you and your family before you begin this path. Not every child will respond and again, each child is different just as each child responds differently to certain medications.
http://www.talkaboutcuringautism.org/new-parents/sample_checklist.htm

I tend to use the term "manage" instead of "cure". Using the analogy of managing uncontrolled asthma with meds, environmental changes and allergy therapies…..or managing diabetes with nutrition, diet, exercise, and meds. These interventions improve long-term outcomes, health and functioning of the individual.

National Autism Association
http://www.nationalautismassociation.org/

Autism ONE- free webcasts of past conferences
www.autismone.org

Parents, some insurances will cover biomedical lab testing and allergy testing. Medicaid will also cover some testing and eval. Contact Karn at 424-6917 with questions.

DIETS

Some parents prefer to have food allergy testing done before starting a diet . Know that there are many "false positives and false negatives "with IgM and IgG allergy testing. If you want to spend money on them to "prove" that you should remove this food from the diet, that's fine. But know that just trying the elimination diet will give you the answers you are looking for – the child's behavior is the "best test" indicator. Read about the different diets on the sites previously listed.

Gluten-Free, Casein Free Diet
Some "big" DAN Drs (the ones who see ASD patients all day, every day) will not see a child unless they are on a 100% GFCF diet. Within days, some parents note marked improvement in behavior, language, and bowel movements (meaning improvement of diarrhea or constipation), as well as decreased hyperactivity and stimming. However, some need to be on it for a few weeks or at least 3-6 months to start seeing the full benefits for the child.
www.gfcfdiet.com

Feingold Diet

Eliminates synthetic (artificial) colors and flavors (ie. Vanillin); 3 preservatives (BHA,BHT, TBHQ) and Aspartame (NutraSweet, Equal). Foods high in salicylates are also removed from the diet for 4-6 weeks and then slowly reintroduced.
www.feingold.org

Other families have used low sugar/carbohydrate and caffeine free diets with positive results. Also removing vegetable oils have helped some families.

HBOT (Hyperbaric Oxygen Therapy)
Softside Chamber – Viterus 320
Note: this is NOT "oxygen" therapy
Wellness Center –
Mankato, MN
507-388-8883
$100/hour
Never pay more than $4000/40 dives- . The cheapest I have seen is $50/ dive. Hardside chambers may possibly be more beneficial – some controversy. Many studies are currently being completed. Research this at www.danwebcast.com before you commit. Be educated and informed about it. Contact me with questions. There is an option for rental in this area thru a trained DAN! Physician. Contact me with questions. Read about mitochondrial disorders.

ATEC - Autism Treatment Evaluation Checklist - http://www.autismeval.com/ari-atec/

The ATEC can help you track specific symptoms you are trying to help - with any form of treatment – medication, specific behavior modification, specific supplement, ect.

Please understand that "biomedical" does NOT mean "anti-vaccine and anti-medication" . I feel there are different kinds of autism and different causes. Please keep an open mind and heart.

Only a parent knows what is best for their child- trust your instincts- your child's behavior will guide you as to if a therapy, diet, treatment, medication, ect is working or not.

AUTISM IS A PUZZLE – EACH CHILD HAS DIFFERENT PIECES THAT WILL WORK BEST FOR HIM OR HER– MEDICATIONS, VISUAL SCHEDULES, BEHAVIORAL MODIFICATIONS, SENSORY ITEMS, SPECIFIC FOOD ELIMINATIONS, SPECIFIC SUPPLEMENTS, ECT ECT….