

Autism Spectrum Disorder (ASD*) : So You Have a Diagnosis, Now What?

CHECKLIST [November 2005]

by Mary Beth Steinfeld, MD, Lynne Weissmann, Connie Ajay

- Attend a local support group meeting (see Reading List)
- Apply to regional center for services
- Request, in writing, that your child be evaluated for special education services in his/her school district (3 years and older)
- Obtain a copy of the recommendations section of the book Educating Children with Autism, <http://books.nap.edu/catalog/10017.html>. Published in 2001 by the National Research Council, it summarizes an expert panel's literature review regarding evidence based treatments. The recommendations in chapter 16, are very specific.
- Contact Families for Early Autism Treatment (FEAT), www.feat.org, and request their new parent packet which includes their parent handbook with community resource lists and contact information for families with newly diagnosed children, including parent support groups and parent advocates. Sign-up for their free mail list and newsletter. Print out and read "Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders": <http://www.feat.org/docs/cabestpr.pdf>
- Request specific comprehensive evaluations/assessments in areas of need for your child to establish baseline functioning and identify appropriate services:
 - Communication-expressive/receptive and pragmatic language
 - Behavior
 - Occupational Therapy/Sensory Integration (OT/SI) – including handwriting
 - Academic – including visual-auditory processing
 - Social-emotional functioning
 - Play skills
 - Adaptive behavior – including daily living/ self-help skills
 - Executive Function
- Know your rights before attending IEP meetings with the school district and intake meeting at the regional center. Obtain and read (see Reading List):
 - Special Education: Rights & Responsibilities
 - Wrightslaw: Special Education Law and From Emotions to Advocacy
 - Lanterman Developmental Disabilities Services Act
 - Autistic Spectrum Disorders – Best Practice Guidelines for Screening, Diagnosis and Assessment
- Obtain California Special Education Programs: A Composite of Laws. Parents of children with a disability can receive one free copy per year. Call 1-800-995-4099 and be sure to state that your child has a disability and you'd like to obtain a free copy.
- Set up a binder with diagnosis, assessments/evaluations, copies of correspondence, log of all conversations, meeting notes, IEPs/IPP, etc.
- Continue to read and learn about your child's diagnosis and specific areas of need (refer to Reading List). Attend support meetings, conferences and workshops. Keeping planning and looking ahead, ask: what's next?

*ASDs include: autism, Asperger Syndrome, PDD-NOS, High Functioning Autism

***Autism Spectrum Disorder (ASD) : So You Have a Diagnosis, Now What?**
Reading List

General/Diagnosis

Facing Autism, Giving Parents Reasons for Hope and Guidance for Help
Lynn M. Hamilton, Bernard Rimland
Waterbrook Press

Asperger's Syndrome: A Guide for Parents and Professionals
Tony Attwood
Jessica Kingsley Publications

Autistic Spectrum Disorders – Best Practice Guidelines for Screening, Diagnosis and Assessment
California Department of Developmental Services
A printed copy can be obtained for no charge at: <http://www.ddhealthinfo.org>

Autism Spectrum Disorders: A Research Review for Practitioners
Sally Ozonoff, Sally J. Rogers, Robert Hendren
Amer Psychiatric Pr

A Parent's Guide to Asperger's Syndrome and High Functioning Autism: How to Meet the Challenges and Help Your Child Thrive
Sally Ozonoff, Geraldine Dawson, James McPartland
Guilford Press

Asperger's: "What Does it Mean to Me?"
Catherine Faherty
Future Horizons

Treatment/Education

Educating Children with Autism
National Research Council
National Academy Press

Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders
Sponsored by the California Departments of Education and Developmental Services
Download and print out: <http://www.feat.org/docs/cabestpr.pdf>

Teaching Children with Autism: Strategies to Enhance Communication and Socialization
Kathleen Ann Quill
Singular Publishing

How To Be a Para Pro: A Comprehensive Training Manual for Paraprofessionals
Diane Twachtman-Cullen
Starfish Specialty Press

A Treasure Chest of Behavioral Strategies for Individuals with Autism

Beth Fouse
Future Horizons

The Power of Positive Parenting: A Wonderful Way to Raise Children
Glenn I. Latham
P & T Ink

More Than Words: Helping Parents Promote Communication and Social Skills in Children
with Autism Spectrum Disorder
Fern Sussman
Hanan Centre

The Hidden Curriculum: Practical Solution for Understanding Unstated Rules in Social
Situations
Brenda Smith Myles, Melissa L. Trautman, Ronda L. Schelvan
Autism Asperger Publishing Company

The New Social Story Book
Carol Gray
Future Horizons

Navigating the Social World - A Curriculum for Individuals with Asperger's Syndrome, High
Functioning Autism and Related Disorders
Jeanette Mc Afee
Future Horizons

Inside Out: What Make the Person with Social Cognitive Deficits Tick?
-and-

Thinking About You, Thinking About Me: Philosophy and Strategies for Facilitating the
Development of Perspective Taking for Students with Social Cognitive Deficits
Michelle G. Winner

Autism/Aspergers: Solving the Relationship Puzzle
Stephen E. Gutstein
Future Horizons

Relationship Development Intervention with Young Children: Social and Emotional
Development Activities for Asperger Syndrome, Autism, PDD, and NLD
-and-

Relationship Development Intervention with Children, Adolescents and Adults: Social and
Emotional Development Activities for Asperger Syndrome, Autism, PDD, and NLD
Stephen E. Gutstein, Rachelle K. Sheely
Jessica Kingsley Publications

Incorporating Social Goals in the Classroom - A Guide for Teachers and Parents of Children
with High Functioning Autism and Asperger's
Rebecca A. Moyes, Susan J. Moreno
Jessica Kingsley Publications

The Affect-Based Curriculum: An Intensive Program for Families, Therapists and Teachers
Stanley I. Greenspan and Diane Lewis
ICDL Publication
<http://icdl.com/icdlpubs.htm>

Learning the R.O.P.E.S. for Improved Executive Function: A Cognitive-Behavioral Approach
for Individuals with High Functioning Autism and Other Behavioral Disorders
Patricia Schetter, MA
Website orders: <http://www.autismandbehavior.com/services.htm>

Asperger Syndrome and Psychotherapy
Jessica Kingsley Publications
Paula Jacobsen

Exploring Feelings – Anger
Exploring Feelings – Anxiety
Tony Attwood, PhD
Future Horizons

The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction
Carol Stock Kranowitz
Perigee

The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated,
Chronically Inflexible Children
Ross W. Greene
Harper Collins

Special Education/Advocacy

1) *Special Education: Rights and Responsibilities*
VERY HIGHLY RECOMMENDED – order form on last page of this document – note that \$20
is *suggested* donation to cover their copying costs
– also -

2) Lanterman Developmental Disabilities Services Act
Community Alliance for Special Education (CASE)
Protection and Advocacy (PAI)
1-800-776-5746 or 916-488-9955

Wrightslaw: Special Education Law
–and–

Wrightslaw: From Emotions to Advocacy – The Special Education Survival Guide
Pamela Darr Wright, Peter W. Wright
Harbor House Law Press

The Complete IEP Guide: How to Advocate for Your Special Ed Child
Lawrence Siegel
Nolo Press

How to Compromise with Your School District without Compromising Your Child: A Field
Guide for Getting Effective Services for Children with Special Needs
Gary Mayerson
Drl Books Inc.

How Well Does Your IEP Measure Up? Quality Indicators for Effective Service Delivery
Diane Twachtman-Cullen, Jennifer Twachtman-Reilly
Starfish Specialty Products

How to Argue and Win Everytime: At Home, in Court, Everywhere, Everyday
Gerry Spence
St. Martin's Griffin

Support

Nobody's Perfect: Living and Growing with Children Who Have Special Needs
–and–
Everybody's Different: Understanding and Changing Our Reactions to Disabilities
Nancy B. Miller
Paul H. Brookes Publishing Co

From the Heart: On Being the Mother of a Child with Special Needs
Jayne B. Marsh
Woodbine House

Siblings of Children with Autism: A Guide for Families
Sandra L. Harris
Woodbine House

Transition/Adult Issues

Ask and Tell: Self Advocacy and Disclosure for People on the Autism Spectrum
Ruth Elaine Joyner Hane, et al
Autism Asperger Publishing Company

The Other Half of Asperger Syndrome
Maxine Aston
National Autistic Society

Autism and Asperger Syndrome: Preparing for Adulthood
Patricia Howlin
Routledge

Support Groups

Families for Early Autism Treatment (FEAT) Parent Resource Meeting

www.feat.org, 916-843-1536

Sacramento Asperger Syndrome Information & Support (Sacramento AS IS)

Lynne Weissmann, 916-682-1740, LWeissmann@aol.com, www.sacramentoasis.com

FEAT Family Empowerment Forum

Connie Ajay, 916-683-5652, BELT3@aol.com

Davis Area Asperger Syndrome Parent Support Group

Robin Dewey, 530-753-8649, rdewey@uclink4.berkeley.edu or

DeDe Douglass, 530-759-8817, dededouglass@yahoo.com

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*Special Education Rights & Responsibilities is a highly recommended, easy-to-understand publication written in question and answer format that answers many special education questions. Excellent for families newly entering the special education system.

Protection & Advocacy, Sacramento Legal Unit

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