PAPEI

Psychological Association
of Prince Edward Island

Private Practice Directory

The psychologists and psychological associates listed in this directory are PAPEI members who are also registered with the PEI Psychologists Registration Board, the regulatory authority governing psychological practice in this province. A complete listing of all registered psychologists in PEI is available at http://www.peipsychology.org/peiprb/.

The information in this directory is provided by PAPEI member psychologists. PAPEI makes no claim or guarantee about the services provided.

PAPEI's recommended private practice fee is $210 per hour for psychological services.

Kathren Allison, Psychologist
PEIPRB Registration #: 064

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	6 months
OFFICE ADDRESS	1 Rochford St., Charlottetown, PE C1A 9L2
TELEPHONE	(902) 314-111
EMAIL	kathy.allison@rogers.com
WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	Psycho-educational assessments for children and adults, ADHD and Adult ADHD, Cognitive and Intelligence, Learning Assessments, Learning Disabilities
AREAS OF PRACTICE	Learning Disabilities ADHD and Attention Problems
WORKS WITH	Individuals
AGE GROUPS SERVED	Children Adults

I am a registered psychologist who has been working full time in my own comprehensive private practice (assessment and treatment of anxiety, depression, PTSD, learning disabilities, ADHD, etc.) for over 10 years. I am now focusing exclusively on assessments for learning disabilities and attention problems/ADHD, for both children and adults.

Dr. Nancy Bartlett, Psychologist
PEIPRB Registration #: 088

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	
OFFICE ADDRESS	Suite 301, 129 Kent Street
TELEPHONE	(902) 367-5144
EMAIL	Drnancybartlett@gmail.com
WEBSITE	
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	No
AREAS OF PRACTICE	Abuse, Adoption Issues, Anger Management, Anxiety, Assertiveness, Attachment, Body Image, Depression, Dissociation, Grief and Loss and Bereavement, Health Issues, Loneliness, Obesity, Obsessive-Compulsive Disorder, Personality Disorders, Phobias, Fears, Panic, Post Traumatic Stress Disorder (PTSD), Trauma Psychotherapy, Relationship Issues, Self-Esteem, Separation / Divorce

WORKS WITH	Individuals
AGE GROUPS SERVED	Adults and Older Adults

I am a clinical psychologist with 20+ years of experience working in a private practice setting. I see adult clients who are simply looking for a compassionate and trained ear to help them navigate a current life challenge as well as those who are seeking to understand why they feel and behave the way they do and who wish to let go of patterns that are no longer serving them. I carefully tailor my treatment approach for each client with the goal of empowering them to create change that will be positive and meaningful in their lives. I am certified in EMDR Therapy.

Dr. Christine Beck, Psychologist
PEIPRB Registration#: 042

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	6 months
OFFICE ADDRESS	Suite 204, 51 University Avenue, Charlottetown, PE C1A 4K8
TELEPHONE	(902) 367-4446
EMAIL	drchristinebeck@gmail.com
WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	Behavioural, Emotional Cognitive, Intelligence Learning disability Neuropsychological
AREAS OF PRACTICE	Psychotherapy
WORKS WITH	Individuals Groups
AGE GROUPS SERVED	Adolescents Adults and Older Adults

Thank you for your interest in my private practice. I am a doctoral level Psychologist with training in adult and geriatric neuropsychology, adolescent and adult community mental health, educational assessment, health and rehabilitation psychology and psychotherapy with a variety of referral concerns. Please call my office to see if my services are appropriate for your needs.
Sincerely, Dr Christine Beck

Dr. Freda Burdett, Psychologist
PEIPRB Registration #: 081

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	
OFFICE ADDRESS	224 Queen Street, Charlottetown, PE C1A4B6
TELEPHONE	(506) 461-9959

EMAIL	drfredaburdett@gmail.com
WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	No
AREAS OF PRACTICE	Abuse, Addictions, Anxiety, Attachment Issues (Adult), Assertiveness Depression, Grief, Loss, Bereavement, Habit Change, Health Issues, Loneliness, Personal Growth And Wellness, Self- Esteem, Social Skills Obsessive-Compulsive Disorder, Phobias, Fears, Panic Personality Disorders, Post Traumatic Stress Disorder (PTSD), Trauma, Psychotherapy, Relationship Issues, Separation, Divorce, Sexual Issues Stress Management, Workplace Issues
WORKS WITH	Individuals
AGE GROUPS SERVED	Adolescents Adults

Dr. Burdett has a PhD in Clinical Psychology. Her primary area of focus has been on trauma assessment and treatment. She works with first responders, military members, and the general public; treating a wide range of clinical disorders, such as PTSD, anxiety, and depression (including post-partum depression). She has been trained in CBT, DBT, ACT, CPT, EMDR, and Prolonged Exposure. She welcomes you to contact her with any questions about her practice and availability.

Sarah Carr, Psychologist
PEIPRB Registration #: 068

CURRENTLY ACCEPTING CLIENTS	No
ESTIMATED WAIT TIME	8 – 10 weeks
OFFICE ADDRESS	53 Grafton Street, Charlottetown PEI C1A 1K8
TELEPHONE	(902) 367-4722
EMAIL	carrpsychological@gmail.com
WEBSITE	
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	No
AREAS OF PRACTICE	Abuse, ADHD and Attentional Problems, Anger Management, Behavioural Problems, Assertiveness, Conflict Resolution, Anxiety, Depression, Grief, Loss, Bereavement, Blended/Step-Family Issues, Family Therapy, Parenting, Obsessive-Compulsive Disorder, Personal Growth And Wellness, Self- Esteem, Post Traumatic Stress Disorder (PTSD), Trauma, Psychotherapy, Relationship Issues, Separation, Divorce , Stress Management, Workplace Issues
WORKS WITH	Individuals Couples Families Groups

AGE GROUPS SERVED	Pre-school Children School-aged Children Adolescents Adults and Older Adults

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Dr. Martha Giraldo-O'Meara, Psychologist
PEIPRB Registration #: 095

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	
OFFICE ADDRESS	Located in Charlottetown
TELEPHONE	(438) 522 4844
EMAIL	marthaomeara@gmail.com
WEBSITE	
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English Spanish
FORMAL ASSESSMENT SERVICES	No
AREAS OF PRACTICE	Anxiety Disorders Obsessive Compulsive Disorder Body Dysmorphic Disorder
WORKS WITH	Individuals
AGE GROUPS SERVED	Adults

I am a Registered Psychologist with the PEI Psychologists Registration Board, and l'Ordre des Psychologues du Québec. I am a psychology professor with expertise in the assessment and treatment of mood and anxiety disorders in adults. In my private practice, I specialize in cognitive-behavior therapy for anxiety disorders, obsessive-compulsive disorder (OCD), and body dysmorphic disorder (BDD). I work collaboratively with my clients to plan a treatment tailored to their unique goals, values, and difficulties.

Dr. Lee-Anne Greer, Psychologist
PEIPRB Registration #: 33

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	
OFFICE ADDRESS	Suite 2C, 126 Richmond Street, Charlottetown
TELEPHONE	(902) 620-9144
EMAIL	
WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	No
AREAS OF PRACTICE	Psychotherapy

WORKS WITH	Individuals
AGE GROUPS SERVED	Adults and Older Adults

Caroline LeBlanc, Psychologist
PEIPRB Registration #: 020

CURRENTLY ACCEPTING CLIENTS	No
ESTIMATED WAIT TIME	
OFFICE ADDRESS	174 Pickles Lane, Alexandra, PE
TELEPHONE	(902) 393-3829
EMAIL	caroline11leblanc@gmail.com
WEBSITE	www.sereneviewranch.com
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English French
FORMAL ASSESSMENT SERVICES	Work disability assessments
AREAS OF PRACTICE	Abuse, Anxiety, Depression, Health Issues, Loneliness, Obsessive-Compulsive Disorder, Personal Growth, Wellness, Personality Disorders, Phobias, Fears, Panic, Post Traumatic Stress Disorder (PTSD), Trauma, Psychotherapy, Rehabilitation, Relationship Issues, CISD, Equine Assisted Psychotherapy
WORKS WITH	Individuals Groups
AGE GROUPS SERVED	Adults and Older Adults

Caroline has been specializing in the area of trauma assessment and therapy for over 20 years. Her emphasis has been on helping first responders, military personnel and veterans deal with trauma and PTSD. Her approach to psychotherapy is based on the Cognitive Behavioural Model, Mindfulness, Equine Assisted Psychotherapy, and Sensorimotor Psychotherapy. Eight years ago, she became certified in Equine Assisted Psychotherapy. She also is trained in EMDR, an evidence-based approach for the treatment of trauma. Caroline operates a multidisciplinary mental health clinic that provides a full range of psychological assessments and treatment for children, adolescents and adults. The centre, Serene View Ranch, is located just outside of Charlottetown and overlooks Pownal Bay. Please visit the website at www.sereneviewranch.com

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Dr. George Mallia, Psychologist
PEIPRB Registration #: 040

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	12 months
OFFICE ADDRESS	51 University Avenue, Suite 204, Charlottetown, PE C1A 4K8
TELEPHONE	(902) 367-4446

EMAIL	drgeorgemallia@gmail.com
WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	ADHD, Adult ADHD, Behavioural, Emotional, Cognitive, Intelligence, Custody and Access, Learning Disability, Neuropsychological, Parental Capacity
AREAS OF PRACTICE	Abuse, Addictions, Adoption Issues, ADHD And Attentional Problems, Anger Management, Anxiety, Attachment Issues, Assertiveness, Autism Spectrum Disorder, Behavioural Problems, Blended/Step Family Issues, Body Image, Conflict Resolution, Depression, Disabilities, Eating Disorders, Family Therapy, Gifted/Talented Children, Grief, Loss, and Bereavement, Health Issues, Loneliness, Obesity, Obsessive- Compulsive Disorder, Pain Management, Parenting, Personality Disorders, Phobias/Fears/Panic, Post Traumatic Stress Disorder (PTSD), Trauma, Psychotherapy, Rehabilitation, Relationship Issues, Self-Esteem, Separation/Divorce, Sexual Issues, Sleep Disorders, Social Skills, Sports Psychology, Stress Management, Workplace Issues
WORKS WITH	Individuals Families
AGE GROUPS SERVED	School-aged Children Adolescents Adults

Dr. Brent Macdonald, Psychologist
PEIPRB Registration #: 072

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	Varies Assessment clinics run in 2-week cycles through the year
OFFICE ADDRESS	320, 1167 Kensington Cres. NW (Calgary) Local PEI office upon request
TELEPHONE	(403) 229-3455
EMAIL	brent@complexlearners.com
WEBSITE	complexlearners.com
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	ADHD, Adult ADHD, Behavioural and Emotional, Career and Vocational, Cognitive and Intelligence, Learning Disability
AREAS OF PRACTICE	ADHD, Attentional Problems, Anxiety, Autism Spectrum Disorder, Behavioural Problems, Depression, Disabilities, Gifted and Talented Children, Parenting
WORKS WITH	Individuals Families

AGE GROUPS SERVED	School-aged Children Adolescents Adults

While currently a resident of Calgary, Dr. Macdonald is a native Islander who maintains active registration and practice as a psychologist in his home province of PEI.
Dr. Macdonald provides psychoeducational assessments through ongoing 2 -week clinics on PEI, offered as needed. Once initiated, comprehensive psychoeducational assessments can be completed in a timely manner, allowing for fast and effective planning for students of a wide range of ages. Assessments focus on attention, learning, and social/emotional & behavioral issues, with a focus on providing practical and effective recommendations and strategies.
Since clinics run through the year, there is also the opportunity to follow-up and review the effectiveness of interventions, allowing Dr. Macdonald to maintain ongoing contact and support for his clients. Collaboration with schools, where possible, is also a service that can be incorporated into the assessment process. Learn more at complexlearners.com or contact Dr. Macdonald directly at brent@complexlearners.com.

Dr. Colleen Mac Dougall, Psychologist
PEIPRB Registration #: 098

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	2 days
OFFICE ADDRESS	55 Weymouth St., Charlottetown, PEI C1A 1E5
TELEPHONE	(819) 588-7525
EMAIL	soulcare@moderndigital.net
WEBSITE	www.soulofpeace.org www.beyondfear.org
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	Behavioural and Emotional, Career and Vocational, Insurance
AREAS OF PRACTICE	Abuse, Addictions, Attachment, Assertiveness, Blended/Stepfamily Issues, Body Image, Conflict Resolution, Couple Therapy, Depression, Eating Disorders, Family Therapy, Family Violence, Grief, Loss and Bereavement, Loneliness, Obesity, Personal Growth and Wellness, Personality Disorders, Relationship Issues, Self-Esteem, Separation and Divorce, Stress Management, Workplace Issues
WORKS WITH	Individuals Couples Families Groups
AGE GROUPS SERVED	Adolescents Adults and Older Adults

ORIENTATION: Companioning you in the realization of your aspirations and life purpose as you either choose different paths in your life or shifts are demanded because of illness, loss of capacity, deep soul wounds from war trauma, or other confrontations with painful work and life events. Use a positive lens to see into psychological disturbance.

AREAS OF PRACTICE: Life transitions; positive and deep soul healing for veterans that permeate deeper realms of spiritual healing; relational healing for veterans and their partners; maturity in personal and career shifts grounded in ancient wisdom and expansion of knowledge; redefining “work”; relationship therapy to deepen trust where betrayal or loss of connection has broken bonds.

SENIOR KNOWLEDGE AND SKILL: Deep insight into where you find yourself at this time in your life; compassion and care as you uncover what you may have been holding in fear or shame; depth therapist integrating psychospiritual skills to support and encourage you to process and move through what changes you are facing or choosing. Testimonial: "An iron fist in a velvet glove."

Dr. Neil McLure, Psychologist
PEIPRB Registration #: 009

CURRENTLY ACCEPTING CLIENTS	Yes, Assessments Only
ESTIMATED WAIT TIME	3 – 6 months
OFFICE ADDRESS	292 Water St., Summerside
TELEPHONE	(902) 432-3910
EMAIL	mclure@pei.sympatico.ca
WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	Neuropsychology Assessments, ADHD, Adult ADHD, Behavioural and Emotional, Cognitive and Intelligence, Insurance, Learning Disability, Legal, Pain Assessment
AREAS OF PRACTICE	Acquired Brain Injury, ADHD, Attentional Problems, Anxiety, Autism Spectrum Disorder, Behavioural Problems, Depression, Disabilities, Health Issues, Obsessive-Compulsive Disorder, Pain Management, Personality Disorders, Phobias, Fears, Panic, Post Traumatic Stress Disorder (PTSD), Trauma, Psychotherapy, Rehabilitation, Social Skills, Sports Psychology, Traumatic Brain Injury
WORKS WITH	Individuals Families
AGE GROUPS SERVED	School-aged Children Adolescents Adults and Older Adults

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Parise Nadeau, Psychologist
PEIPRB Registration #: 35

CURRENTLY ACCEPTING CLIENTS	No
ESTIMATED WAIT TIME	3 – 6 weeks
OFFICE ADDRESS	Summerside
TELEPHONE	(902) 438-1109
EMAIL	parisenadeau@gmail.com

WEBSITE	
TELEHEALTH	No
LANGUAGE(S) SPOKEN	English French
FORMAL ASSESSMENT SERVICES	ADHD, Adult ADHD, Behavioural and Emotional, Cognitive and Intelligence, Learning Disability
AREAS OF PRACTICE	ADHD, Attentional Problems, Anger Management, Anxiety, Assertiveness, Autism Spectrum Disorder, Behavioural Problems, Body Image, Depression, Gifted and Talented Children, Grief, Loss and Bereavement, Habit Change, Loneliness, Obesity, Obsessive-Compulsive Disorder, Pain Management, Parenting, Personal Growth and Wellness, Phobias, Fears, Panic, Psychotherapy, Self-Esteem, Social Skills, Stress Management
WORKS WITH	Individuals Families
AGE GROUPS SERVED	Pre-school Children School-aged Children Adolescents Adults

My main area of practice is with children, youth and families, providing support with parenting and behaviour management, as well direct individual therapy with children, youth and adults. I also offer mental health, behavioural and psycho -educational assessments. Bilingual service.

Ken Pierce, Psychologist
PEIPRB Registration #: 006

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	3-5 days
OFFICE ADDRESS	The Pierce Institute of Psychology Inc. 53 Mount Herbert Road, Stratford PE C1B 2S3
TELEPHONE	(902) 629-5474
EMAIL	contact@kenpiercepsychologist.com
WEBSITE	www.thepierceinstitute.com
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	Behavioural and Emotional, Career and Vocational, Custody and Access, Pain Assessment, Parental Capacity
AREAS OF PRACTICE	Abuse, Addictions, Adoption Issues, ADHD, Attentional Problems, Anger Management, Anxiety, Attachment Issues, Assertiveness, Autism Spectrum Disorder, Behavioural Problems, Blended/Step Family Issues, Body Image, Conflict Resolution, Couple Therapy, Depression, Disabilities, Eating Disorders, Family Therapy, Family Violence, Financial Loss, Gifted/Talented Children, Grief, Loss and Bereavement, Habit Change, Health Issues, Infatuations, Loneliness,

	Obesity, Obsessive- Compulsive Disorder, Pain Management, Parenting, Personal Growth and Wellness, Personality Disorders, Phobias, Fears, Panic, Post Traumatic Stress Disorder (PTSD), Trauma, Psychotherapy, Rehabilitation, Relationship Issues, Resentments, Self-Esteem, Separation/Divorce, Sexual Issues, Sleep Disorders, Social Skills, Spiritual, Sports Psychology, Stress Management, Workplace Issues
WORKS WITH	Individuals Couples Families Groups
AGE GROUPS SERVED	Pre-school Children School-aged Children Adolescents Adults and Older Adults

As a registered psychologist with over 40 years of experience, I have carried a variety of psychological roles including drug crisis, early childhood education, post-secondary education, corporate training, community development and private practice.

There are many, new, scientific-based, evolutionary tools available to assist others to evolve in the areas where they are challenged. The wisest and most effective professional helpers say very similar things including: that therapy is focused, accelerated learning; that since thinking determines feelings, talking mostly about feelings can distract from the learning process; that everyone is a survivor of their past, so no longer a victim of it, but rather, a victor over it; and while people do have losses, when they uncover the gains, they become more empowered, present and get on with their life.

I have the privilege of working with clients aged 3 to 83 years. I have assisted individuals and groups to move on from assault, abuse, addictions, ADHD, allergies, auto collisions, autoimmune diseases, bullying, bankruptcy, bipolar disorder, cancer, Crohn's, depression, divorce, grief, harassment, incest, injuries, job loss, learning disabilities, PTSD, workplace strikes and other traumatic events.

I have a special interest in working with couples and those struggling with bullying, depression and poor self-esteem.

Dr. Magdalena Pietruch, Psychologist
PEIPRB Registration #: 52

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	2 weeks
OFFICE ADDRESS	2C-126 Richmond Street, Charlottetown, PE C1A 1H9
TELEPHONE	(902) 916-2512
EMAIL	drmagdapietruch@gmail.com
WEBSITE	
TELEHEALTH	Yes
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	Adult ADHD, Behavioural and Emotional, Cognitive and Intelligence
AREAS OF PRACTICE	ADHD, Attentional Problems, Anxiety, Autism Spectrum Disorder, Behavioural Issues, Body Image, Depression, Habit Change, Obsessive-

	Compulsive Disorder, Personal Growth and Wellness, Phobias, Fears, Panic, Relationship Issues, Self-Esteem, Sleep Disorders, Social Skills, Stress Management, Workplace Issues
WORKS WITH	Individuals
AGE GROUPS SERVED	Adults and Older Adults

Please contact me by email if you have questions about my practice or would like to schedule an appointment.

Dr. Nancy Spitzack, Psychologist
PEIPRB Registration # 050

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	N/A
OFFICE ADDRESS	126 Richmond St., Suite 2C, Charlottetown, PE C1A 1H9
TELEPHONE	902-314-8817
EMAIL	nkayspitz@gmail.com
WEBSITE	
TELEHEALTH	Np
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	No
AREAS OF PRACTICE	Psychotherapy
WORKS WITH	Individuals
AGE GROUPS SERVED	Adolescents Adults and Older Adults

CURRENTLY ACCEPTING CLIENTS	Yes
ESTIMATED WAIT TIME	6 months
OFFICE ADDRESS	
TELEPHONE	
EMAIL	
WEBSITE	
TELEHEALTH	
LANGUAGE(S) SPOKEN	English
FORMAL ASSESSMENT SERVICES	
AREAS OF PRACTICE	
WORKS WITH	Individuals Groups
AGE GROUPS SERVED	Adolescents Adults and Older Adults

100 Day Kit

For Newly Diagnosed Families of Young Children

AUTISM SPEAKS® FAMILY SERVICES

JULY 2014

AUTISM SPEAKS®

It's time to listen.

A tool kit to assist families of young children in getting the critical information they need in the first 100 days after an autism diagnosis.

Autism Speaks does not provide medical or legal advice or services. Rather, Autism Speaks provides general information about autism as a service to the community. The information provided in this tool kit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. Autism Speaks has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request references when considering any resource associated with the provision of services related to autism.

About This Kit

The Autism Speaks 100 Day Kit is a tool designed to help assist families of children recently diagnosed with autism during the critical period following an autism diagnosis. The kit includes basic information about autism and its symptoms, tips for dealing with a child's diagnosis, information about therapies and treatments, forms to help parents get organized, a comprehensive list of resources and more.

The 100 Day Kit was released in 2008 and a second version was released in 2011. It was created by the **Autism Speaks Family Services** staff in conjunction with both a professional and parent advisory committee and the Family Services Committee.

Acknowledgements

Autism Speaks would like to extend special thanks to the Parent Advisory Committee for the time and effort that they put into reviewing the 100 Day Kit.

100 Day Kit Parent Advisory Committee

Stacy Crowe
Jill DiGiorgio
Rodney Goodman
Beth Hawes
Deborah Hilibrand
Dawn Itzkowitz
Lance Jeffreys
Stacy Karger
Marjorie Madfis
Donna Ross-Jones
Betsy Spalla
Judith Ursitti
Meredith Weiss
Marcy Wenning

With gratitude, we thank the 100 Day Kit Professional Advisory Committee for generously donating their time and experience to this project.

100 Day Kit Professional Advisory Committee

Geraldine Dawson, Ph.D.
Professor, Department of Psychiatry and Behavioral Sciences, Duke University Medical Center

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Director of Clinical Programs
M.I.N.D. Institute/U.C.Davis

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Director, Melmed Center
Medical Director, SARRC

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Staff Clinician
Pediatrics and Developmental Neuropsychiatry Branch
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Vanderbilt Kennedy Center
Treatment and Research Institute for Autism Spectrum Disorders

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Staff Psychologist Division of Developmental and Behavioral Pediatrics, Cincinnati Children's Hospital

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Cincinnati Children's Hospital Medical Center

Rebekah Ridgeway PsyD
Staff Psychologist, Kelly O'Leary Center for Autism Spectrum Disorders

Emily Schreiber, MA.
Cincinnati Children's Hospital Medical Center

Autism Speaks Family Services Committee

Dan Aronson
Parent

Liz Bell
Parent

Sallie Bernard*
Parent, Executive Director, SafeMinds

Farah Chapes
Chief Administrative Officer, The Marcus Autism Center

Peter F. Gerhardt, Ed.D
Former President, Organization for Autism Research (OAR)

Mel Karmazin*
Grandparent

Brian Kelly * **
Parent

Artie Kempner*
Parent

Gary S. Mayerson*
Founding Attorney, Mayerson & Associates

Kevin Murray*
Parent

Linda Meyer, Ed.D
Executive Director, Autism New Jersey

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President and CEO, Southwest Autism Research and Resource Center (SARRC)

Valerie Paradiz, PhD
Director, Valerie Paradiz, LLC
Director Autistic Global Initiative
Parent and self-advocate

Stuart Savitz*
Parent

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Leader, AJ Drexel Autism Institute Research Program Area on Life Course Outcomes

Stephen Shore, EdD
Assistant Professor, Special Education, Adelphi University, Self-advocate

Michelle Smigel
Parent

*Autism Speaks board member
**Chairperson – Family Services Committee
Parent – indicates a parent of a child with autism

Autism Speaks thanks the following supporters whose generous contributions have helped to fund this 100 Day Kit for Newly Diagnosed Families.

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Child Welfare Foundation
CWF

The Karma Foundation

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FOUNDATION
BREAKING THE BARRIERS OF AUTISM

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JEWISH COMMUNITY FOUNDATION
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JUST CABINETS®
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Director, Melmed Center
Medical Director, SARRC

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USC Keck School of Medicine

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Pediatrics and Developmental Neuropsychiatry Branch
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Vanderbilt Kennedy Center
Treatment and Research Institute for Autism Spectrum Disorders

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Director, Ascent Psychological Services

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About Autism

Why Was My Child Diagnosed with Autism? And What Does It Mean?

Your child has been diagnosed with autism spectrum disorder and you have asked for help. This is an important turning point in a long journey. For some families, it may be the point when, after a long search for answers, you now have a name for something you didn't know what to call, but you knew existed. Perhaps you suspected autism, but held out hope that an evaluation would prove otherwise. Many families report mixed feelings of sadness and relief when their child is diagnosed. You may feel completely overwhelmed. You may also feel relieved to know that the concerns you have had for your child are valid. Whatever it is you feel, know that thousands of parents share this journey. You are not alone. There is reason to hope. There is help. Now that you have the diagnosis, the question is, where do you go from here? The **Autism Speaks 100 Day Kit** was created to help you make the best possible use of the next 100 days in the life of your child. It contains information and advice collected from trusted and respected experts on autism and parents like you.

Why Does My Child Need a Diagnosis of Autism?

Parents are usually the first to notice the early signs of autism. You probably noticed that your child was developing differently from his or her peers. The differences may have existed from birth or may have become more noticeable later. Sometimes, the differences are severe and obvious to everyone. In other cases, they are more subtle and are first recognized by a daycare provider or preschool teacher. Those differences, the symptoms of autism, have led thousands of parents like you to seek answers that have resulted in a diagnosis of autism. You may wonder: *Why does my child need a diagnosis of autism?* That's a fair question to ask - especially when right now, no one is able to offer you a cure. Autism Speaks is dedicated to funding global biomedical research into the causes, prevention, treatments and a possible cure for autism. Great strides have been made and the current state of progress is a far cry from the time when parents were given no hope for their children. Some of the most brilliant minds of our time have turned their attention toward this disorder.

> It is important to remember that your child is the same unique, lovable, wonderful person he or she was before the diagnosis.

There are, however, several reasons why having a diagnosis is important for your child. A thorough and detailed diagnosis provides important information about your child's behavior and development. It can help create a roadmap for treatment by identifying your child's specific strengths and challenges and providing useful information about which needs and skills should be targeted for effective intervention. A diagnosis is often required to access autism-specific services through early intervention programs or your local school district.

How is Autism Diagnosed?

Presently, we don't have a medical test that can diagnose autism. As the symptoms of autism vary, so do the routes to obtaining a diagnosis. You may have raised questions with your pediatrician. Some children are identified as having developmental delays before obtaining a diagnosis of autism and may already receive some **Early Intervention** or **Special Education** services. Unfortunately, parents' concerns are sometimes not taken seriously by their doctor and as a result, a diagnosis is delayed. Autism Speaks and other autism-related organizations are working hard to educate parents and physicians, so that children with autism are identified as early as possible.

Your child may have been diagnosed by a **developmental pediatrician**, a **neurologist**, a **psychiatrist** or a **psychologist.** In some cases, a team of specialists may have evaluated your child and provided recommendations for treatment. The team may have included an **audiologist** to rule out hearing loss, a **speech & language therapist** to determine language skills and needs and an **occupational therapist** to evaluate physical and motor skills. A multi-disciplinary evaluation is important for diagnosing autism and other challenges that often accompany autism, such as delays in motor skills. If your child has not been evaluated by a multi-disciplinary team, you will want to make sure further evaluations are conducted so that you can learn as much as possible about your child's individual strengths and needs.

For more information, visit the Autism Speaks Autism Treatment Network at autismspeaks.org/atn.

Once you have received a formal diagnosis, it is important to make sure that you ask for a comprehensive report that includes the diagnosis in writing, as well as recommendations for treatment. The doctor may not be able to provide this for you at the appointment, as it may take some time to compile, but be sure to follow up and pick up this helpful necessary report as soon as it's available.

What is Autism?

Autism spectrum disorder (ASD) and **autism** are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the fifth edition of the ***American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders*** (commonly referred to as the DSM-5), all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, **childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS)** and **Asperger Syndrome.** The DSM is the main diagnostic reference used by mental health professionals and insurance providers in the United States.

You may also hear the terms Classic Autism or Kanner's Autism (named after the first psychiatrist to describe autism) used to describe the most severe form of the disorder. Under the current DSM-5, the diagnosis of autism requires that at least six developmental and behavioral characteristics are observed, that problems are present before the age of three and that there is no evidence of certain other conditions that are similar.

There are two domains where people with ASD must show persistent deficits:

1) persistent social communication and social interaction

2) restricted and repetitive patterns of behavior

More specifically, people with ASD must demonstrate (either in the past or in the present) deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used for social interaction and deficits in developing, maintaining and understanding relationships. In addition, they must show at least two types of repetitive patterns of behavior, including stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests, hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Symptoms can be currently present or reported in past history.
In addition to the diagnosis, each person evaluated will also be described in terms of any known genetic cause (e.g. Fragile X syndrome, Rett syndrome), level of language and intellectual disability and presence of medical conditions such as seizures, anxiety, depression and/or gastrointestinal (GI) problems.

The DSM-5 has an additional category called **Social Communication Disorder (SCD).** This allows for a diagnosis of disabilities in social communication, without the presence of repetitive behavior. SCD is a new diagnosis and much more research and information is needed. There are currently few guidelines for the treatment of SCD. Until such guidelines become available, treatments that target social-communication, including many autism-specific interventions, should be provided to individuals with SCD.

To read the whole DSM-5 criteria, please visit autismspeaks.org/dsm-5.

How Common is Autism?

Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) released in March 2014 identify around 1 in 68 American children as on the autism spectrum – a ten-fold increase in prevalence in 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls. An estimated 1 out of 42 boys and 1 in 189 girls are diagnosed with autism in the United States.

ASD affects over 2 million individuals in the U.S. and tens of millions worldwide. Moreover, government autism statistics suggest that prevalence rates have increased 10% to 17% annually in recent years. There is no established explanation for this continuing increase, although improved diagnosis and environmental influences are two reasons often considered.

What Causes Autism?

Not long ago, the answer to this question would have been “we have no idea.” Research is now delivering the answers. First and foremost, we now know that there is no one cause of autism, just as there is no one type of autism. Over the last five years, scientists have identified a number of rare gene changes or mutations associated with autism. Research has identified more than 100 autism risk genes. In around 15% of cases, a specific genetic cause of a person’s autism can be identified. However, most cases involve a complex and variable combination of genetic risk and environmental factors that influence early brain development.

In other words, in the presence of a genetic predisposition to autism, a number of non-genetic or environmental influences further increase a child’s risk. The clearest evidence of these environmental risk factors involves events before and during birth. They include advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy, extreme prematurity, very low birth weight and certain difficulties during birth, particularly those involving periods of oxygen deprivation to the baby’s brain. Mothers exposed to high levels of pesticides and air pollution may also be at higher risk of having a child with ASD. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk.

A small but growing body of research suggests that autism risk is lower among children whose mothers took prenatal vitamins (containing folic acid) in the months before and after conception.

Increasingly, researchers are looking at the role of the immune system in autism. Autism Speaks is working to increase awareness and investigation of these and other issues where further research has the potential to improve the lives of those who struggle with autism.

While the causes of autism are complex, it is abundantly clear that it is not caused by bad parenting. Dr. Leo Kanner, the psychiatrist who first described autism as a unique condition in 1943, believed that it was caused by cold, unloving mothers. Bruno Bettelheim, a renowned professor of child development, perpetuated this misinterpretation of autism. Their promotion of the idea that unloving mothers caused their children’s autism created a generation of parents who carried the tremendous burden of guilt for their child’s disability. In the 1960s and 70s, Dr. Bernard Rimland, the father of a son with autism who later founded the Autism Society of America and the Autism Research Institute, helped the medical community understand that autism is a biological disorder and is not caused by cold parents.

More Information about Symptoms of Autism

Autism affects the way an individual perceives the world and makes communication and social interaction difficult. Autism spectrum disorders (ASD) are characterized by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these three core areas. Taken together, they may result in relatively mild challenges for someone on the high functioning end of the autism spectrum. For others, symptoms may be more severe, as when repetitive behaviors and lack of spoken language interfere with everyday life.

> It is sometimes said that if you know one person with autism, you know one person with autism.

While autism is usually a life long condition, all children and adults benefit from interventions, or therapies, that can reduce symptoms and increase skills and abilities. Although it is best to begin intervention as soon as possible, the benefits of therapy can continue throughout life. The long term outcome is highly variable. A small percentage of children lose their diagnosis over time, while others remain severely affected. Many have normal **cognitive skills**, despite challenges in social and language abilities. Many individuals with autism develop speech and learn to communicate with others. Early intervention can make extraordinary differences in your child's development. How your child is functioning now may be very different from how he or she will function later on in life.

The information following on the social symptoms, communication disorders and repetitive behaviors associated with autism is partially taken from the National Institute of Mental Health (NIMH) website.

Social symptoms

Typically developing infants are social by nature. They gaze at faces, turn toward voices, grasp a finger and even smile by 2 to 3 months of age. By contrast, most children who develop autism have difficulty engaging in the give-and-take of everyday human interactions. By 8 to 10 months of age, many infants who go on to develop autism are showing some symptoms such as failure to respond to their names, reduced interest in people and delayed babbling. By toddlerhood, many children with autism have difficulty playing social games, don't imitate the actions of others and prefer to play alone. They may fail to seek comfort or respond to parents' displays of anger or affection in typical ways.

Research suggests that children with autism are attached to their parents. However, the way they express this attachment can be unusual. To parents, it may seem as if their child is disconnected. Both children and adults with autism also tend to have difficulty interpreting what others are thinking and feeling. Subtle social cues such as a smile, wave or grimace may convey little meaning. To a person who misses these social cues, a statement like "Come here!" may mean the same thing, regardless of whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world can seem bewildering.

Many people with autism have similar difficulty seeing things from another person's perspective. Most five-year-olds understand that other people have different thoughts, feelings and goals than they have. A person with autism may lack such understanding. This, in turn, can interfere with the ability to predict or understand another person's actions.

It is common – but not universal – for those with autism to have difficulty regulating emotions. This can take the form of seemingly "immature" behavior such as crying or having outbursts in inappropriate situations. It can also lead to disruptive and physically aggressive behavior. The tendency to "lose control" may be particularly pronounced in unfamiliar, overwhelming or frustrating situations. Frustration can also result in self-injurious behaviors such as head banging, hair pulling or self-biting.

Fortunately, children with autism can be taught how to socially interact, use gestures and recognize facial expressions. Also, there are many strategies that can be used to help the child with autism deal with frustration so that he or she doesn't have to resort to challenging behaviors. We will discuss this later.

Communication difficulties

Young children with autism tend to be delayed in babbling, speaking and learning to use gestures. Some infants who later develop autism coo and babble during the first few months of life before losing these communicative behaviors. Others experience significant language delays and don't begin to speak until much later. With therapy, however, most people with autism do learn to use spoken language and all can learn to communicate.

Many nonverbal or nearly nonverbal children and adults learn to use communication systems such as pictures, sign language, electronic word processors or even speech-generating devices.

When language begins to develop, people with autism may use speech in unusual ways. Some have difficulty combining words into meaningful sentences. They may speak only single words or repeat the same phrase over and over. Some go through a stage where they repeat what they hear verbatim (echolalia).

Many parents assume difficulties expressing language automatically mean their child isn't able to understand the language of others, but this is not always the case. It is important to distinguish between expressive language and receptive language. Children with difficulties in expressive language are often unable to express what they are thinking through language, whereas children with difficulties in receptive language are often unable to understand what others are saying. Therefore, the fact that your child may seem unable to express him or herself through language does not necessarily mean he or she is unable to comprehend the language of others. Be sure to talk to your doctor or look for signs that your child is able to interpret language, as this important distinction will affect the way you communicate with him or her.

It is important to understand the importance of pragmatics when looking to improve and expand upon your child's communication skills. **Pragmatics** are social rules for using language in a meaningful context or conversation. While it is important that your child learns how to communicate through words or sentences, it is also key to emphasize both when and where the specific message should be conveyed. Challenges in pragmatics are a common feature of spoken language difficulties in children with autism. These challenges may become more apparent as your child gets older.

Some mildly affected children exhibit only slight delays in language or even develop precocious language and unusually large vocabularies – yet have difficulty sustaining a conversation. Some children and adults with autism tend to carry on monologues on a favorite subject, giving others little chance to comment. In other words, the ordinary "give-and-take" of conversation proves difficult. Some children with ASD with superior language skills tend to speak like little professors, failing to pick up on the "kid-speak" that's common among their peers.

Another common difficulty is the inability to understand body language, tone of voice and expressions that aren't meant to be taken literally. For example, even an adult with autism might interpret a sarcastic "Oh, that's just great!" as meaning it really is great.

Conversely, individuals affected by autism may not exhibit typical body language. Facial expressions, movements and gestures may not match what they are saying. Their tone of voice may fail to reflect their feelings. Some use a high-pitched sing-song or a flat, robot-like voice. This can make it difficult for others to know what they want and need. This failed communication, in turn, can lead to frustration and inappropriate behavior (such as screaming or grabbing) on the part of the person with autism. Fortunately, there are proven methods for helping children and adults with autism learn better ways to express their needs. As the person with autism learns to communicate what he or she wants, challenging behaviors often subside.

Children with autism often have difficulty letting others know what they want or need until they are taught how to communicate through speech, gestures or other means.

Repetitive behaviors

Unusual repetitive behaviors and/or a tendency to engage in a restricted range of activities are another core symptom of autism. Common repetitive behaviors include hand-flapping, rocking, jumping and twirling, arranging and rearranging objects and repeating sounds, words or phrases. Sometimes the repetitive behavior is self-stimulating, such as wiggling fingers in front of the eyes.

The tendency to engage in a restricted range of activities can be seen in the way that many children with autism play with toys. Some spend hours lining up toys in a specific way instead of using them for pretend play. Similarly, some adults are preoccupied with having household or other objects in a fixed order or place. It can prove extremely upsetting if someone or something disrupts the order. Along these lines, many children and adults with autism need and demand extreme consistency in their environment and daily routine. Slight changes can be extremely stressful and lead to outbursts.

Repetitive behaviors can take the form of intense preoccupations or obsessions. These extreme interests can prove all the more unusual for their content (e.g. fans, vacuum cleaners or toilets) or depth of knowledge (e.g. knowing and repeating astonishingly detailed information about Thomas the Tank Engine or astronomy). Older children and adults with autism may develop tremendous interest in numbers, symbols, dates or science topics.

Many children with autism need and demand absolute consistency in their environment.

Unique Abilities that May Accompany Autism

Along with the challenges that autism involves, you may have noticed that your child also exhibits areas of strength. Although not all children have special talents, it is not uncommon for individuals with autism to have exceptional skills in math, music, art and reading, among others. These areas of expertise can provide great satisfaction and pride for the child with autism. If possible, incorporate your child's areas of expertise into his or her everyday activities and use them whenever possible as a way for him or her to learn and excel.

The following is adapted from Sally Ozonoff, Geraldine Dawson and James McPartland's *A Parent's Guide to Asperger's Syndrome and High-Functioning Autism.*

Just as individuals with autism have a variety of difficulties, they also have some distinctive strengths. Some of the strengths that individuals with autism have may include:

- ***Ability to understand concrete concepts, rules and sequences***
- ***Strong long term memory skills***
- ***Math skills***
- ***Computer skills***
- ***Musical ability***
- ***Artistic ability***
- ***Ability to think in a visual way***
- ***Ability to decode written language at an early age (This ability is called Hyperlexia – some children with autism can decode written language earlier than they can comprehend written language.)***
- ***Honesty – sometimes to a fault***
- ***Ability to be extremely focused – if they are working on a preferred activity***
- ***Excellent sense of direction***

"How Can My Child Have Autism When He Seems So Smart?"

From *Does My Child Have Autism?* by Wendy Stone

Right now you might be thinking about all the things your child with autism learned at a much younger age than other children you know. And yes, you are right: there are also things that children with autism learn on their own much faster than their typically developing peers or siblings. For example, they can be very good at learning to pick out their favorite DVD from a stack, even when it's not in its case. They may learn at a very young age how to operate the remote controls to the TV and DVD player so that they can rewind their videos to their favorite parts (or fast forward through the parts they don't like). They can be very creative in figuring out ways to climb up on the counter to reach a cabinet that has their favorite cereal or even how to use the key to unlock the dead bolt on the back door so they can go outside to play on the swing. Clearly, these are not behaviors that you would even think about trying to teach a two-year-old child. And yet some children with autism somehow manage to acquire these skills on their own. How can we understand this inconsistency between the things children with autism do and don't learn? How can a child who can't put different shapes into a shape sorter learn to turn on the TV and DVD player, put a DVD in and push the play button? How can a child who can't understand a simple direction like "get your coat" figure out how to unlock a door to get outside?

What accounts for this unique learning style? In a word: *motivation.* We all pay attention better to the things that interest us, so we become much more proficient at learning them. Understanding what is motivating to your child (all children are different) will be one of the keys to increasing their learning and their skills. Your child's special talents may be part of his unique and inherent learning style and nature.

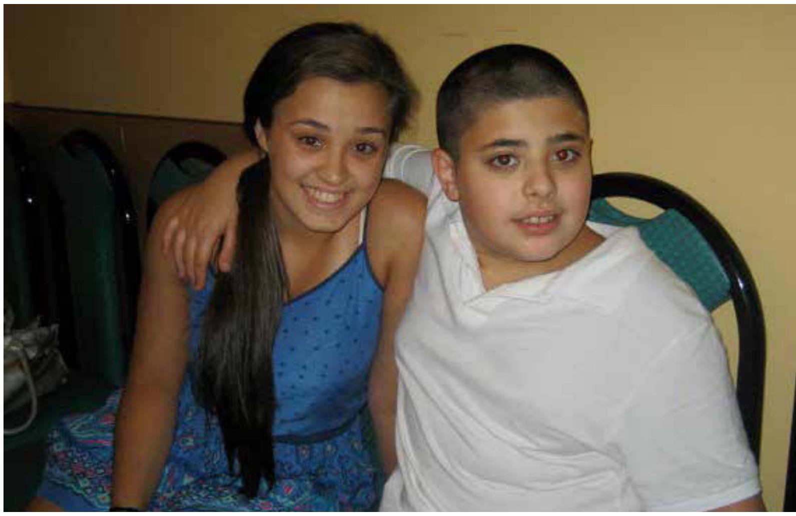
Physical and Medical Issues that May Accompany Autism

Seizure disorders

Seizure Disorder, also called **epilepsy**, occurs in as many as one third of individuals with autism spectrum disorder. Epilepsy is a brain disorder marked by recurring seizures or convulsions. Experts propose that some of the brain abnormalities that are associated with autism may contribute to seizures. These abnormalities can cause changes in brain activity by disrupting neurons in the brain. Neurons are cells in the brain that process and transmit information and send signals to the rest of the body. Overloads or disturbances in the activity of these neurons can result in imbalances that cause seizures.

Epilepsy is more common in children who also have **cognitive** deficits. Some researchers have suggested that seizure disorder is more common when the child has shown a regression or loss of skills. There are different types and subtypes of seizures and a child with autism may experience more than one type. The easiest to recognize are large "grand mal" (or **tonic-clonic**) seizures. Others include "petit mal" (or **absence**) seizures and **subclinical seizures**, which may only be apparent in an **EEG** (electroencephalogram). It is not clear whether subclinical seizures have effects on language, cognition and behavior. The seizures associated with autism usually start either early in childhood or during adolescence, but may occur at any time. If you are concerned that your child may be having seizures, you should see a neurologist. The neurologist may order tests that may include an **EEG**, an **MRI** (Magnetic Resonance Imaging), a **CT** (Computed Axial Tomography) and a **CBC** (Complete Blood Count). Children and adults with epilepsy are typically treated with **anticonvulsants** or seizure medicines to reduce or eliminate occurrences. If your child has epilepsy, you will work closely with a neurologist to find the medicine (or combination of medicines) that works the best with the fewest side effects and to learn the best ways to ensure your child's safety during a seizure.

You can find more information about autism and epilepsy at autismspeaks.org/family-services/epilepsy.



Genetic disorders

Some children with autism have an identifiable genetic condition that affects brain development. These genetic disorders include Fragile X syndrome, Angelman syndrome, tuberous sclerosis, chromosome 15 duplication syndrome and other single-gene and chromosomal disorders. While further study is needed, single gene disorders appear to affect 15 to 20% of those with ASD. Some of these syndromes have characteristic features or family histories, the presence of which may prompt your doctor to refer your child to a geneticist or neurologist for further testing. The results can help increase awareness of associated medical issues and guide treatment and life planning.

Gastrointestinal (GI) disorders

Many parents report **gastrointestinal (GI)** problems in their children with autism. The exact prevalence of gastrointestinal problems such as **gastritis, chronic constipation, colitis** and **esophagitis** in individuals with autism is unknown. Surveys have suggested that between 46 and 85% of children with autism have problems such as chronic constipation or diarrhea. One study identified a history of gastrointestinal symptoms (such as abnormal pattern of bowel movements, frequent constipation, frequent vomiting and frequent abdominal pain) in 70% of the children with autism. If your child has similar symptoms, you will want to consult a **gastroenterologist**, preferably one who works with people with autism. Your child's physician may be able to help you find an appropriate specialist. Pain caused by GI issues is sometimes recognized because of a change in a child's behavior, such as an increase in self-soothing behaviors like rocking or outbursts of aggression or self-injury. Bear in mind that your child may not have the language skills to communicate the pain caused by GI issues. Treating GI problems may result in improvement in your child's behavior. Anecdotal evidence suggests that some children may be helped by dietary intervention for GI issues, including the elimination of dairy and gluten containing foods. *(For more information, see Gluten Free Casein Free diet in the treatment section of this kit.)* As with any treatment, it is best to consult your child's physician to develop a comprehensive plan. In January 2010, Autism Speaks initiated a campaign to inform pediatricians about the diagnosis and treatment of GI problems associated with autism.

For additional information from the Official Journal of American Academy of Pediatrics, go to: pediatrics.aappublications.org/cgi/content/full/125/Supplement_1/S1.

For information that can be shared with your child's doctor, go to: autismspeaks.org/press/gastrointestinal_treatment_guidelines.php.

Sleep dysfunction

Is your child having trouble getting to sleep or sleeping through the night? Sleep problems are common in children and adolescents with autism. Having a child with sleep problems can affect the whole family. It can also have an impact on the ability of your child to benefit from therapy. Sometimes sleep issues may be caused by medical issues such as **obstructive sleep apnea** or **gastroesophageal reflux** and addressing the medical issues may solve the problem. In other cases, when there is no medical cause, sleep issues may be managed with behavioral interventions including **"sleep-hygiene"** measures, such as limiting the amount of sleep during the day and establishing regular bedtime routines. There is some evidence of abnormality of **melatonin** regulation in children with autism. While melatonin may be effective for improving the ability of children with autism to fall asleep, more research is needed. Melatonin or sleep aids of any kind should not be given without first consulting with your child's physician.

For additional information on sleep issues visit: autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit.

Sensory Integration Dysfunction

Many children with autism experience unusual responses to **sensory stimuli** or input. These responses are due to difficulty in processing and integrating sensory information. Vision, hearing, touch, smell, taste, the sense of movement **(vestibular system)** and the sense of position **(proprioception)** can all be affected. This means that while information is sensed normally, it may be perceived much differently. Sometimes stimuli that seem "normal" to others can be experienced as painful, unpleasant or confusing by a child with **Sensory Integration Dysfunction (SID)**, the clinical term for this characteristic. (SID may also be called Sensory Processing Disorder or Sensory Integration Disorder.) SIDs can involve hypersensitivity (also known as **sensory defensiveness**) or hyposensitivity. An example of hypersensitivity would be an inability to tolerate wearing clothing, being touched or being in a room with normal lighting. **Hyposensitivity** might be apparent in a child's increased tolerance for pain or a constant need for sensory stimulation. Treatment for Sensory Integration Dysfunction is usually addressed with occupational therapy and/or sensory integration therapy.

Pica

Pica is an eating disorder involving eating things that are not food. Children between 18 and 24 months of age often eat nonfood items, but this is typically a normal part of development. Some children with autism and other developmental disabilities persist beyond the developmentally typical timeframe and continue to eat items such as dirt, clay, chalk or paint chips. Children showing signs of persistent mouthing of fingers or objects, including toys, should be tested for elevated blood levels of lead, especially if there is a known potential for environmental exposure to lead. You should speak to your doctor about these concerns so he or she can help you with treatment. Your child's doctor will help you to assess if your child needs a behavioral intervention or if it is something that can be managed at home.

Visit the Autism Speaks Tool Kits page to download tool kits with information and resources related to pica for both parents and professionals at autismspeaks.org/family-services/tool-kits.

Mental health

Oftentimes a child diagnosed with ASD may receive an additional diagnosis such as **Attention Deficit Hyperactivity Disorder (ADHD). ADHD** and anxiety are quite common and addressing these diagnoses properly can help your child make great strides. Recent studies suggest that 1 in 5 children on the autism spectrum also has ADHD and 30% struggle with an **anxiety disorder** such as social phobia, separation anxiety, panic disorder and specific phobias. The classic symptoms of ADHD include chronic problems with inattention, impulsivity and hyperactivity. However, these or similar symptoms can likewise result from autism. For this reason, it is important that evaluation be made by someone with expertise in both disorders. A recent study found that just 1 in 10 children with autism and ADHD was receiving medication to relieve the ADHD symptoms.

In regards to anxiety, children with autism express anxiety or nervousness in many of the same ways as typically developing children. Understandably, many individuals with ASD have trouble communicating how they feel. Outward manifestations may be the best clues. In fact, some experts suspect that outward symptoms of anxiety – such as sweating and acting out – may be especially prominent among those with ASD. This can include a racing heart, muscular tensions and stomachaches. It is important for your child to be evaluated by a professional who has expertise in both autism and anxiety so he or she can provide the best treatment options for your child.

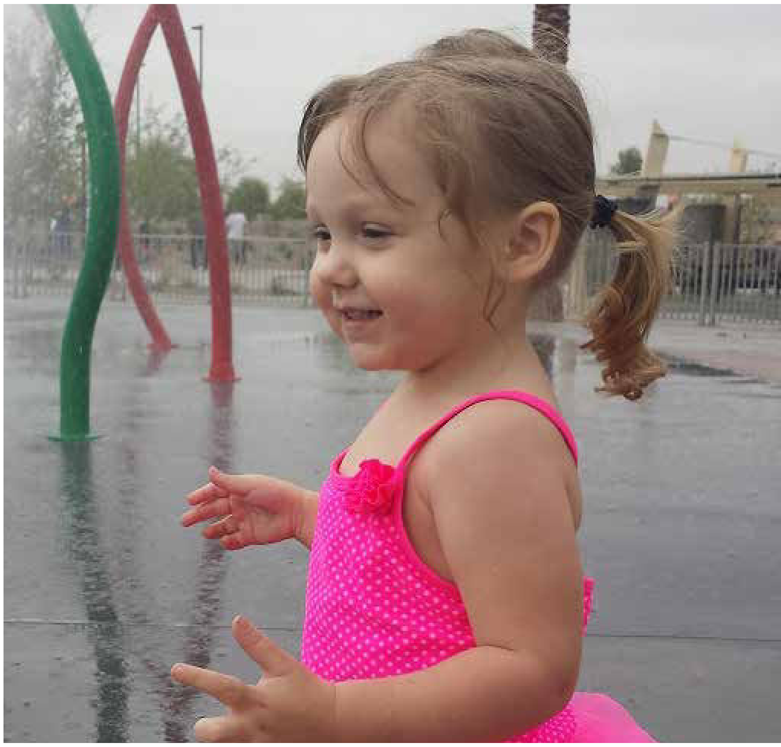
You, Your Family and Autism

How Will I Deal with This Diagnosis?

You are never prepared for a diagnosis of autism. It is likely that you will experience a range of emotions. It is painful to love so much, to want something so much and not quite get it. You want your child to get better so badly that you may feel some of the stages commonly associated with grieving. You may "revisit" these feelings from time to time in the future. Part of moving forward is dealing with your own needs and emotions along the way.

Stages associated with grieving

Elisabeth Kübler-Ross, M.D., a Swiss-American psychiatrist, outlined five stages in the grief process. Grief does not progress in an orderly way that follows a predictable path. It is normal to move forwards and backwards among the five stages, skip a stage or be stuck in one. Her five stages are outlined here.



Denial

You may go through periods of refusing to believe what is happening to your child. You don't consciously choose this reaction; it just happens. During this time, you may not be able to hear the facts as they relate to your child's diagnosis. Don't be critical of yourself for reacting this way. Denial is a way of coping. It may be what gets you through a particularly difficult period. You must, however, be aware that you are in denial, so that it doesn't cause you to lose focus on your child's treatment. Try not to "shoot the messenger." When a professional, a therapist or a teacher tells you something that is hard to hear about your child, consider that he or she is trying to help you so that you can address the problem. It is important not to alienate people who can give you helpful feedback and help monitor your child's progress. Whether you agree or not, try to thank them for the information. If you are upset, try considering the information when you have had a chance to calm down.

Anger

With time, your denial may give way to anger. Although anger is a natural part of the process, you may find that it's directed at those closest to you – your child, your spouse, your friend or at the world in general. You may also feel resentment toward parents of typical children. Your anger may come out in different ways – snapping at people, overreacting to small things, even screaming and yelling. Anger is normal. It is a healthy and expected reaction to feelings of loss and stress that come with this diagnosis. Expressing your anger releases tension. It is an attempt to tell the people around you that you hurt and are outraged that this diagnosis has happened to your child.

"I felt angry when a child at my son's school was diagnosed with Leukemia around the time our son was diagnosed with autism. Everyone sent cards and cooked dinners for them. They didn't know I needed that kind of help too. When I let people know I needed help they came through for me."

Bargaining

This stage involves the hope that the diagnosis can be undone. The feeling of helplessness you may be experiencing might create a need to regain control of the situation. Many parents will ask themselves questions like: What if we had gotten our child in to the doctor earlier? What if it was caused by something we did? You may also question the diagnosis or search for another doctor hoping that he or she might tell you something different.

Sadness or Grief

Many parents must mourn the loss of some of the hopes and dreams they had for their child before they can move on. There will probably be many times when you feel extremely sad. Friends may refer to this as being "depressed," which can sound frightening. There is, however, a difference between sadness and depression. Depression often stands in the way of moving forward. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable. Crying can help release some of the tension that builds up when you try to hold in sadness. A good cry can get you over one hurdle and help you face the next. If you find that your sadness is interfering with your ability to cope or you show other symptoms of depression, such as weight loss, social withdrawal, suicidal thoughts, sleep difficulties, low self-esteem or loss of interest in daily activities, consult your family physician who can recommend treatment.

"My husband had a harder time accepting our son's diagnosis at first. When Max began making progress in his ABA program, everything changed for the better. For a while, I was the one holding everything together for all of us."

Acceptance

Ultimately, you may feel a sense of acceptance. It's helpful to distinguish between accepting that your child has been diagnosed with autism and accepting autism. Accepting the diagnosis simply means that you are ready to advocate for your child. The period following an autism diagnosis can be very challenging, even for the most harmonious families. Although the child with autism may never experience the negative emotions associated with the diagnosis, parents, siblings and extended family members may each process the diagnosis in different ways, and at different rates. Give yourself time to adjust. Be patient with yourself. It will take some time to understand your child's disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than you had planned. But you will also experience feelings of hope as your child begins to make progress.

Caring for the Caregiver

Changing the course of the life of your child with autism can be a very rewarding experience. You are making an enormous difference in his or her life. To make it happen, you need to take care of yourself. Take a moment to answer these questions: *Where does your support and strength come from? How are you really doing? Do you need to cry? Complain? Scream? Would you like some help but don't know who to ask?*

> Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself.

Parents often fail to evaluate their own sources of strength, coping skills or emotional attitudes. You may be so busy meeting the needs of your child that you don't allow yourself time to relax, cry or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is not helping you or your family. You may feel that your child needs you right now, more than ever. Your "to do" list may be what is driving you forward right now. You may feel completely overwhelmed and not know where to start. There is no single way to cope. Each family is unique and deals with stressful situations differently. Getting your child started in treatment will help you feel better. Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead. Autism is a pervasive, multi-faceted disorder. It will not only change the way that you look at your child, it will change the way you look at the world. Maintaining open and honest communication with your partner and family as well as discussing your fears and concerns will help you to deal with the many changes in your life. As some parents may tell you, you may be a better person for it. The love and hope that you have for your child make you stronger than you realize.

Here are some tips from parents who have experienced what you are going through:

Get going.

Getting your child started in treatment will help. There are many details you will be managing in an intensive treatment program, especially if it is based in your home. If you know your child is engaged in meaningful activities, you will be more able to focus on moving forward. It may also free up some of your time so you can educate yourself, advocate for your child and take care of yourself.

Ask for help.

Asking for help can be very difficult, especially at first. Don't hesitate to use whatever support is available to you. People around you may want to help, but may not know how. Is there someone who can take your other kids somewhere for an afternoon? Or cook dinner for your family one night so that you can spend the time learning? Can someone pick a few things up for you at the store or do a load of laundry? Or let other people know you are going through a difficult time and could use a hand?

Talk to someone.

Everyone needs someone to talk to. Let someone know what you are going through and how you feel. Someone who just listens can be a great source of strength. If you can't get out of the house, use the phone to call a friend.

Consider joining a support group.

It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources of information about what services are available in your area and who provides them. You may have to try more than one to find a group that feels right to you. You may find you aren't a "support group kind of person." For many parents in your situation, support groups provide valuable hope, comfort and encouragement.

You may also want to consider attending a recreational program for children with autism. This may be a good way to meet other parents just like you.

One study from Vanderbilt University, a part of the Autism Speaks Autism Treatment Network, found that mothers of children with autism benefit significantly from weekly stress-reduction classes led by other mothers. The classes reduced previously high levels of personal stress, anxiety and depression and improved the mom's interactions with their children.

> "At my support group I met a group of women who were juggling the same things I was. It felt so good not to feel like I was from another planet!"

You may find a listing of support groups in the Autism Speaks Resource Guide at autismspeaks.org/resource-guide. Another avenue is through the local SEPTA (Special Education Parent Teacher Association) in your school district or online through the Autism Speaks Facebook page at facebook.com/autismspeaks.

My Autism Team, the social network for parents of kids with autism, is another great resource. On this site, parents of children with autism share their experiences, including their reviews of local service providers, to help inform the parents in their communities. Visit the site at myautismteam.com.

Try to take a break.

If you can, allow yourself to take some time away, even if it is only a few minutes to take a walk. If it's possible, getting out to a movie, going shopping or visiting a friend can make a world of difference. If you feel guilty about taking a break, try to remind yourself that this break will help you feel renewed for the things you need to do when you get back. Try to get some rest. If you are getting regular sleep, you will be better prepared to make good decisions, be more patient with your child and more able to deal with the stress in your life.

Consider keeping a journal.

Louise DeSalvo, in *Writing as a Way of Healing*, notes that studies have shown that: "Writing that describes traumatic events and our deepest thoughts and feelings about them is linked with improved immune function, improved emotional and physical health, and positive behavioral changes." Some parents have found a journal to be a helpful tool for keeping track of their child's progress, what is working and what isn't.
Be mindful of the time you spend on the internet. The internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child.
Unfortunately, there is more information on the web than any of us have time to read in a lifetime. There may also be a lot of misinformation.

As a parent, always remember to trust your gut.

There are many paths to take, treatment options and opinions. You know your child best. Work with your child's treatment team to find what works best for your child and your family.

Right now, while you are trying to make the most of every minute, keep an eye on the clock and frequently ask yourself these important questions:

Is what I'm reading right now very likely to be relevant to my child?

Is it new information?

Is it helpful?

Is it from a reliable source?

Sometimes, the time you spend on the internet will be incredibly valuable. Other times, it may be better for you and your child if you use that time to take care of yourself.

> The internet will be one of the most important tools you have for learning what you need to know about autism and how to help your child.

Becoming Resilient During Times of Adversity

by Dr. Peter Faustino, school psychologist, state delegate to the National Association of School Psychologists (NASP) and member of the Autism Speaks Family Services Committee

Resiliency, or finding ways to properly adapt to challenges or stress in your life, is a process, not a character trait. Research has revealed several key elements in fostering resilience and by considering the following, you will find you are not only helping your child but yourself and your entire family.

Connectedness: One of the strongest pillars in resilience is having positive relationships or feeling connected to others. While the diagnosis of autism may be extraordinary at first, it no longer is synonymous with being alone or having few places to turn for help. This tool kit is only one example of the ways in which Autism Speaks can lend support. Regional chapters of Autism Speaks all across the country can open up doors to other parents, families and communities who have experience with navigating the autism diagnosis. When relationships with friends, neighbors and family are based on mutual, reciprocal support and care, they can bolster resiliency.

Competence: Whenever a challenge presents itself, individuals can feel a loss of control over the situation and their lives. Competence or at this early stage learning about autism and then taking action on realistic goals will help you gain a sense of control. Having trustworthy information and feeling more competent (not only about autism but in other aspects of your life) can be critical in maintaining a hopeful outlook.

Care: Eventually, your journey will lead to a place where you can balance negative emotions with positive ones. Taking care to avoid seeing an event as unbearable or unchangeable versus looking for opportunities and considering the event in a broader context can be an important factor to resilience. Positive attitudes such as encouraging yourself to try, being determined to persevere until success is attained, applying a problem solving approach to difficult situations and fostering feelings of determination or grit are critical. Care also refers to parents attending to their own mind and body, exercising regularly, as well paying attention to basic needs and feelings.

Resilience is the result of individuals being able to interact with their environments and the processes that either promote wellbeing or protect them against overwhelming influence of risk factors. In many cases, adversity can act as a spring board for growth and success, not only in our children, but in ourselves as well.

"Is Your Son On the Spectrum?"

**In her own words,
Alysia K. Butler, who has a recently diagnosed son, describes her experience being part of the autism community.**

The question was slightly jarring to me. My son and I had just walked into a gymnastics class for kids with autism. We had received his diagnosis only three weeks before and we hadn't shared our news with anyone except for close friends and family. It was the first time we had been anywhere that was just for kids like mine and I wasn't really ready to talk to a total stranger about it.

"Yes," I answered, trying to keep the conversation short.

"Hi and welcome! That's my son over there and my name is Sandy. How old is your son? Do you live in town? How long have you known your son was on the spectrum? What was his diagnosis?" I really didn't want to answer her. I wasn't even sure we belonged at this class and all I wanted to do was pay attention to my son to see how he was responding to the class. I watched the other kids as they came in – six boys and one girl – and my first instinct was that we were in the wrong place. One little boy was crying, another was spinning in circles and another one was running in all different directions. My son's not like that, I thought to myself. This isn't us.

And then I looked at my Henry. I watched him hold tightly to his one-on-one helper's hand as they walked on a low balance beam, but he wouldn't look her in the eye when she talked to him. I watched him try to run away to jump into the comfort of the sensory foam blocks and become so focused on that foam pit that he couldn't move on to anything else. I listened to him babble while he swayed back and forth on the rings and saw the terror in his face when the noise level got up too high. The tears welled up in my eyes. We did belong here. This was the right place for him. We had found a safe place for him to exercise and develop his muscles in an environment that understood his special needs. For so long we had avoided the "regular" gym classes, music classes and playgroups because of his behavior. No one here was giving me the usual disapproving looks we get when we're out places and Henry starts to act up. I took a deep breath and turned to the mom.

"Hi! My son Henry was diagnosed with PDD-NOS a few weeks ago. We do live in town. In fact, I've seen your son at the preschool that my son attends. How long has your son attended classes here?"

It took everything I had to have that conversation, but it was such a relief. This other mom was reaching out to make a connection – to find someone else who struggles on a daily basis like she does – something I myself had been desperate to do for weeks and months. I was instantly welcomed into a community of people who "get it." No one batted an eye when Henry buried himself under the foam blocks at the end of class so he didn't have to leave. I got comforting looks of understanding from all the parents and teachers when he had a major meltdown leaving the gym and big thumbs up from everyone when we finally got our shoes on and went out the door. These were moms and dads who shared my daily difficulties of just getting out of the house. Finally, we were somewhere that felt like we belonged.

"Will we see you next week?" asked the mom.

"Absolutely," I replied.

What Should We Know About our Younger or Future Children?

As discussed below, genetic risk factors contribute to autism. If you are expecting another child or have plans to expand your family in the future, you may be concerned about the development of any younger siblings of your child with autism. Studies show that if you have a child diagnosed with an autism spectrum disorder, the risk of the next child also being diagnosed with an ASD is between 10 and 20%. The risk for ASD is higher for boys than girls and for baby siblings who have more than one older sibling with ASD. However, statistics are changing and there are several ongoing research studies that are studying the recurrence rate or likelihood that autism will be diagnosed in a second or third child. For the most recent findings and updated research on the rate of recurrence and susceptibility of autism in siblings, please visit **earlistudy.org.** The **EARLI** study is a nationwide effort to investigate the genetic and environmental contributions to autism in a high risk group, that is, younger siblings of children who have received a diagnosis.

More recent evidence has suggests that distinct early signs of autism may be seen in some children as young as 8 to 10 months of age. For example, infants who later develop autism may be more passive, more difficult to soothe or may fail to orient when their name is called. Some of these early signs may be noticed by parents, others may only be observed with the help of a trained clinician. These signs become more pronounced by 18 to 24 months.

Through a joint venture between Autism Speaks and the National Institute of Child Health and Human Development, research on the early signs and symptoms of autism has been accelerated. Called the **High Risk Baby Siblings Research Consortium (BSRC)**, the goal is to improve the lives of individuals affected with ASD by making discoveries that will help researchers develop new ways to treat or even prevent some debilitating symptoms by intervening at an early age. The pace of this research has grown exponentially over the past decade, supported by the formation of the consortium, which has enabled researchers from around the world to meet and share their ideas, methods and data. Consortium members carry out their own studies focusing primarily on younger siblings of children with ASD or other high risk infants. Each member is supported by public, private or foundation funding. The group collaborates on studies and publications, pooling collective data and knowledge to enhance the ability to contribute to this important area of research and provide help to families.

In 2007, a group of researchers within the BSRC, together with psychologists from around the U.S., formed the **Autism Speaks Toddler Treatment Network (TTN).** The goal of the network is to determine whether intervention between the ages of 18 to 24 months affects developmental outcomes at an age when autism can be more reliably diagnosed. Today, the network involves more than 60 investigators from around the world studying the effectiveness of early intervention and the utility of parent-mediated approaches. They have begun to shift their focus from research in the clinic to implementation in "real life" community settings, so more people can benefit from them.

If you are interested in participating in a research project studying the earliest signs of autism, visit AutismSpeaks.org/science/research-initiatives/high-risk-baby-sibs or find a research project in your area at autismspeaks.org/science/participate-in-research.

These studies provide intense observation, documentation and feedback by experts in the field on the development of your child with autism and any other children at risk for autism.

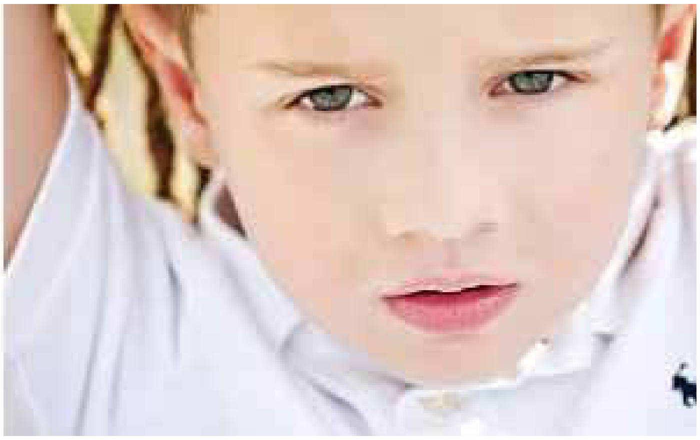
If you are interested in other intervention programs that are not part of these studies, visit the Resource Guide on the Autism Speaks website to help find an early intervention program in your area. autismspeaks.org/resource-guide.

How Will This Affect Our Family?

Even though it is your child who has the diagnosis, it is important to acknowledge that autism affects the whole family. This section of your tool kit may help you anticipate some of the emotions you and other people in your family will experience.

The article below, adapted from *Does My Child Have Autism?* by Wendy L. Stone, Ph.D., provides some helpful information for talking to your parents and close family members about the diagnosis.

Breaking the news



Sometimes telling your parents about your child's diagnosis can be extremely difficult, especially with your own emotions running so high. It's hard to know what to expect; I've seen that parental reactions to this news can vary dramatically. One young mother told me, "My mother-in-law told us that we shouldn't bring my son to family gatherings until he grows up. It's heartbreaking to hear her say that she would rather not see any of us for years instead of trying to understand her own grandson." But then I've also been told, "We were very touched by how our family reacted to my son's diagnosis. Everyone asked what they could do to help and they showed us so much support. I know his grandparents read books and articles on the disorder so they could better understand him. My mother even quit her job to help me through this very difficult time." Yes, reactions vary widely. But whatever reaction you get, it will be very important to educate your parents about the nature of autism after you have told them about the diagnosis. To begin your discussion, you might talk about specific behaviors. For example: "You know those behaviors we've been confused about for so long? Well, now we have a name for them and an explanation for why they occur. Howie doesn't act the way he does because he's spoiled or because he's shy or because he doesn't like us – he acts that way because he has autism. Autism explains why he doesn't speak or use gestures and why he doesn't seem to understand what we say. It explains why he's not as interested in interacting with us as the other children in the family have been and why he plays with spoons and bottles instead of toys. I know this is upsetting news for all of us. But the good news is that the disorder has been diagnosed early and there are a lot of things we can do to help him. He'll be starting some therapies soon and I'll be learning about things I can do to help him at home. I know that you will need some time to think about all of this. But if you have any questions as we begin his therapy, I'll be glad to try my best to answer them. I know we're all hoping for the best outcome possible." After the initial conversation about this diagnosis, continue to keep your other children and your extended family in the information loop.

Autism doesn't affect only one child. It affects the entire family.

Sharing Your Struggle with Family and Friends

The following excerpt from the book *Overcoming Autism*, by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, offers suggestions for how to tell people and explains why, for some people, it can make life easier for you and your friends.

You should, you know. Tell people. You don't have to walk up to strangers on the street or anything, but confide in the people who love you. That was one thing we did right: we told our families and our friends right away. First we called them, and then we copied a good comprehensive article someone wrote about autism and annotated it with specifics about Andrew, and we mailed it out to everyone we knew. (You could do the same things with sections from this book, by the way.) None of our good friends pulled away from us because our kid had autism. Just the opposite – our friends and families rallied around us in amazing ways and have continued to cheer Andrew's progress on year after year. In all honesty, telling people what we were going through only made our lives easier. Before then, we worried that Andrew's occasionally aberrant behavior was off-putting. But once he had a formal diagnosis, everyone cut us a lot of slack, and instead of wondering what the hell was wrong with us as parents, most people we knew admitted to a newfound respect for us for dealing with so much. Real friends don't love you more for being successful or less for having problems. If anything, it works the opposite way – we're all so busy that sometimes we forget to stay in touch with friends when everything's fine for them, but we rush forward when they need us. Now is the time to take advantage of that. Talk your friends' ears off, complain, bitch and moan to them. You're dealing with a huge challenge, take advantage of every minor plus it has to offer.

Some families have downloaded this Autism Speaks 100 Day Kit and sent it to their family members and close friends to provide more information about autism and what their family may be going through. The kit can be downloaded at autismspeaks.org/family-services/tool-kits/100-day-kit.

15 Tips for Your Family

As a result of her work with many families who deal so gracefully with the challenges of autism, family therapist Kathryn Smerling, Ph.D., offers five tips for parents, five for siblings and five for extended family members:

5 tips for parents

1. Learn to be the best advocate you can be for your child. Be informed. Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.

2. Don't push your feelings away. Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's okay to feel conflicting emotions.

3. Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is the autism that has you so upset and angry. Try to have some semblance of an adult life. Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse and refrain from constantly talking about autism. Everyone in your family needs support and to be happy despite the circumstances.

4. Appreciate the small victories your child may achieve. Love your child and take great pride in each small accomplishment. Focus on what he or she can do instead of making comparisons with a typically developing child. Love your child for who he or she is.

5. Get involved with the autism community. Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything yourself. Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

> "Learning more about my child's unique needs and abilities along with reaching out for support has enabled my husband and me to be better parents to our son and better partners for each other on this journey."

5 tips for brothers and sisters

1. Remember that you are not alone! Every family is confronted with life's challenges… and yes, autism is challenging…but, if you look closely, nearly everyone has something difficult to face in their families.

2. Be proud of your brother or sister. Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic…they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister and sometimes you may not like him or her. It's okay to feel your feelings. And often it's easier when you have a professional counselor to help you understand them – someone special who is here just for you! Love your brother or sister the way he or she is!

3. While it is okay to be sad that you have a brother or sister affected by autism, it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.

4. Spend time with your parents alone. Doing things together as a family with and without your brother or sister strengthens your family bond. It's okay for you to want alone time. Having a family member with autism can often be very time-consuming and attention-grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.

"At first I felt lost and confused about my brother but now that my parents have helped to explain things to me, I can be a better big brother and help my brother when he needs it."

5. Find an activity you can do with your brother or sister. You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired he or she may be, doing something together creates a closeness. Your brother or sister will look forward to these shared activities and greet you with a special smile.

5 tips for grandparents and extended family members

__1.__ Family members have a lot to offer. Each family member is able to offer the things he or she learned to do best over time. Ask how you can be helpful to your family. Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner or raising money for the special school that helps the child. Organize a lunch, a theatre benefit, a carnival or a card game. It will warm your family's hearts to know that you are pitching in to create support and closeness.

__2.__ Seek out your own support. If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that kind of support, so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face. Be open and honest about the disorder. The more you talk about the matter, the better you will feel. Your friends and family can become your support system…but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on, it will be easier. In the end, your experience with autism will end up teaching you and your family profound life lessons.

__3.__ Put judgment aside. Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options and are typically coming to well thought out conclusions. Try not to compare children. (This goes for typically developing kids as well.) Children with autism can be brought up to achieve their personal best.

__4.__ Learn more about autism. It affects people of all social and economic statuses. There is promising research, with many possibilities for the future. Share that sense of hope with your family, while educating yourself about the best ways to help manage this disorder.

__5.__ Carve out special time for each child. You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different, but all of the children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for 15 minutes. If you go to the same park every week, chances are over time that activity will become easier and easier…it just takes time and patience. If you are having a difficult time trying to determine what you can do, ask your family. They will sincerely appreciate the effort that you are making.

There are also specialized tool kits for specific people in your life. To access them visit: autismspeaks.org/family-services/tool-kits/family-support-tool-kits.

"Talking to other grandparents helped me to feel part of a bigger community and to learn more about my granddaughter. I am now able to help my family the best I can and spend quality time with each of my grandchildren."

Developmental Milestones: Understanding Your Child's Behavior

When a child is diagnosed with ASD, it can be difficult to figure out which symptoms are a result of autism and which are just typical for development. The information below from Ashley Murray, Psy.M., Emily Schreiber, M.A. and Rebekah Ridgeway, Psy.D. can help parents to navigate these behaviors.

Some parents express difficulty in understanding whether their child's behavior is developmentally appropriate or related to his or her diagnosis of an autism spectrum disorder. This can lead to increased frustration and uncertainty of how to respond to specific behaviors. Based on a child's developmental level, parents are able to better assess whether their child's behavior is developmentally appropriate or warrants further discussion with their pediatrician. For example, it can be helpful for parents to know that it is developmentally appropriate for a two-year-old child to begin testing his or her parents' limits and having temper tantrums (e.g., dropping to the floor, crying, pounding fists). However, this behavior is not considered developmentally appropriate if your child is in his or her middle school years. Additionally, in terms of social interaction, it is considered developmentally appropriate for one-year-olds to enjoy playing by themselves with toys. However, by preschool age, children should be engaging in cooperative play with others.

Oftentimes parents of children with autism spectrum disorders have the most difficulty determining if their child's social and emotional development is appropriate for his or her age or if the child's behaviors are related to the diagnosis. To help make this distinction, understanding developmental milestones for these two areas can be useful. The following chart presents social and emotional developmental milestones and is separated by the child's age. Having resources to identify developmental milestones can aid parents in assessing their child's behavior and determining if they should seek additional support for their concerns.

If your child is demonstrating behavior that you believe is not developmentally appropriate, it is always important to discuss this with your pediatrician and other members of the treatment team. Your team may be able to make suggestions on how best to address these concerns and make referrals as needed for additional evaluations. Additionally, if you have concerns regarding other areas of your child's development, your treatment team can provide you with expected milestones in all areas of development.

Birth to 6 Months

- *Shows excitement by waving arms, kicking and wiggling*
- *Fears loud or unexpected noise, strange objects, sudden movements and pain*
- *Imitates smiles, other's movements*
- *Enjoys interactions (e.g., smiles, tickles, being held) with others*
- *Laughs out loud and smiles socially*
- *Plays peek-a-boo*
- *May enjoy looking at themselves in the mirror*
- *Responds to other people's emotions*

6 Months to 1 Year

- *Becomes unhappy when the primary caregiver leaves*
- *Withdraws from strangers*
- *Enjoys being held and cuddled*
- *Begins to imitate behaviors of others*
- *May push, pull or poke other children*
- *Is able to distinguish familiar people from strangers*
- *When loses a toy, may display a reaction*

1 Year to 2 Years

- *Seeks out attention of his or her primary caregiver or an adult he or she feels comfortable with*
- *Begins to develop a level of trust in others*
- *Has temper tantrums*
- *Is generally in a happy mood, but may become angry when others interfere with his or her activities*
- *May become frustrated due to not being able to fully verbalize his or her thoughts and wants*
- *May be possessive of toys and enjoy playing alone*
- *Enjoys interacting with familiar adults*

2 Years to 3 Years

- *Begins to develop a sense of independence*
- *Enjoys praise*
- *Tests parental limits and has an increased level of emotion (e.g., laughing, temper tantrums, crying)*
- *Is fearful of loud noises, quick movements, large animals and separation from caregiver*
- *Tries to "help" adults with actions (e.g., washing dishes, vacuuming, hammering)*
- *Plays with objects in symbolic play (e.g., playing house, using toy tools to "make repairs")*

3 Years to 4 Years

- *Begins to develop more independence and self-reliance*
- *May be fearful of strangers, animals and the dark*
- *Has a desire to please adults*
- *Shows a wide range of emotions*
- *May become upset with major changes in routine*
- *Begins to enjoy playing in groups*
- *Becomes more interested in others*
- *With prompting, begins to share and take turns*
- *May pretend to act out scenes from movies or beginning dramatic play (e.g., pretending to be animals)*

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Getting Your Child Services

How Do I Get the Help My Child Needs?

The road ahead will be bumpy. There will be times when your progress stalls or takes an unexpected turn. When it does, try to remind yourself that these are speed bumps, not roadblocks. Take them one at a time. It is important that you start now. There are a variety of services available to treat and educate your child. The article below, from *Does My Child Have Autism?* by Wendy L. Stone, PhD, with Theresa Foy DiGeromino, MEd, explains why:

Early Intervention will improve the outcome for your child.

There is no debate or doubt: early intervention is your child's best hope for the future. Early attention to improving the core behavioral symptoms of autism will give your child – and the rest of the family – several important benefits that you will not gain if you take a wait-and-see approach until your child enters school at age four or five. A good early intervention program has at least four benefits:

1. *It will provide your child with instruction that will build on his or her strengths to teach new skills, improve behaviors and remediate areas of weakness.*

2. *It will provide you with information that will help you better understand your child's behavior and needs.*

3. *It will offer resources, support and training that will enable you to work and play with your child more effectively.*

4. *It will improve the outcome for your child.*

For these reasons, an intervention program for your child should be implemented as soon as possible after he or she receives a diagnosis. However, as you probably know by now, it can be very challenging to teach young children with autism. They have a unique profile of strengths and needs and require intervention services and teaching approaches that are sensitive to these needs. That's why strategies that worked for teaching your other children to remain seated at the dinner table, to play appropriately with a toy or to say words simply don't work as well for your child with autism. In the same way, intervention programs that are generic – rather than autism-specialized – are less likely to be effective for your child. That's why as you begin your exploration of early intervention, you must keep in mind that not all interventions are equal.

Accessing Services: Your Child's Rights to Public Education

Every child has the right to a free appropriate education. The **Individuals with Disabilities Education Act (IDEA)**, enacted in 1975, mandates a public education for all eligible children and makes the schools responsible for providing the supports and services that will allow this to happen. IDEA was most recently revised in 2004 (and, in fact, renamed the Individuals with Disabilities Education Improvement Act, but most people still refer to it as IDEA). The law mandates that the state provide an eligible child with a free appropriate public education that meets his or her unique individual needs.

IDEA specifies that children with various disabilities, including autism, are entitled to early intervention services and special education. In addition, the IDEA legislation has established an important team approach and a role for parents as equal partners in the planning for an individual child and promotes an education in the least restrictive environment. You, as a parent, are entitled to be treated as an equal partner with the school district in deciding on an education plan for your child and his or her individual needs. This enables you to be a powerful advocate for your child. It also means that you must be an informed, active participant in planning and monitoring your child's unique program and legal rights.

In addition to the IDEA stipulations, the Americans with Disabilities Act of 1990 (ADA) sets forth, as a civil right, protections and provisions for equal access to education for anyone with a disability. Section 504 of the Rehabilitation Act of 1973 is another civil rights law that prohibits discrimination on the basis of disability in programs and activities, public and private, that receive federal financial assistance. Generally, the individuals protected by these laws include anyone with a physical or mental impairment that substantially limits one or more life activities.

Advocating for your child's education is a very important role and at times can seem overwhelming and confusing. Two books that may be helpful are:

Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide
by Pam Wright and Pete Wright

How to Compromise with Your School District Without Compromising Your Child
by Gary Mayerson

You will also find additional books and websites at the end of this kit that will be helpful in this process. You, as a parent, are entitled to be treated as an equal partner with the school district in deciding on an education plan for your child.

What is a "Free and Appropriate Public Education" (FAPE)?

As described previously, IDEA provides for a "free and appropriate education" for all children with disabilities. Each word in this phrase is important, but "appropriate" is the one that relates specifically to your special needs child. Your child is entitled to an education that is tailored to his or her special needs and a placement that will allow him or her to make educational progress.

Although you and your child's teachers or therapists may want to provide your child with the best and optimal programs and services, the school district is simply required to provide an appropriate education. One of the challenges here is working with the school district to determine what is appropriate and therefore what will be provided for your child. This is a collaborative process and may require considerable negotiation in order to secure the appropriate services from the school.

What is "Least Restrictive Environment" (LRE)?

As specified in the IDEA, your child is entitled to experience the **"least restrictive environment"** in schools. This means that your child should be placed in the environment in which he or she has the greatest possible opportunity to interact with children who do not have a disability and to participate in the general education curriculum. The child must be educated in the school he or she would attend if not disabled to the maximum extent appropriate and supported with the aids and services required to make this possible. This does not mean that every student has to be in a general education classroom, but the objective is to place the student in as natural a learning environment as possible, within his or her home community. This decision is made by the members of the Individualized Education Program (IEP) team, with consideration of the myriad of issues related to appropriate environment and supports for the student. Placements and the LRE for a particular student may change over time.

The participation of children with disabilities in the general education environment is often referred to as **"mainstreaming"** or **"inclusion"**. Inclusion does not mean that a child with special needs should be placed into a general education setting just like a typical learner; a variety of special education supports should be provided in order to create a successful environment and positive experience for everyone involved. Careful planning and training are essential to providing modifications or accommodations and to successfully situating a child with a disability in the least restrictive setting. These supports might include providing a specially trained classroom or one-on-one paraprofessional, altering testing environments or expectations, adapting curriculum, providing visual supports or adaptive equipment, etc. The special education department should provide training, strategies and support for general education staff and others in the general school community who may interact with students with special needs. It is important to note that philosophies about inclusion vary considerably among school districts, staff and parents of students with and without special needs.

IDEA provides for a team approach to planning so that the objectives of all members of the team can be considered and the necessary supports can be put in place to maximize inclusion. Not all parents will feel that a mainstream environment will enhance the growth and development of their student with special needs and allowances need to be made to accommodate various perspectives. Additionally, not all students will be ready for full inclusion all of the time. The anxiety and sensory issues related to inclusion may mean that efforts should begin with small steps that can generate ongoing success and increase participation within the local student body and community.

Early Intervention Services (EI) for Children Under the Age of Three

The IDEA provides states with federal grants to institute **Early Intervention** programs. Any child younger than age three who has a developmental delay or a physical or mental condition likely to result in a developmental delay is eligible to receive early intervention services through these programs. EI services can vary widely from state to state and region to region. However, the services should address your child's unique needs and should not be limited to what is currently available or customary in your region.

The document that spells out your child's needs and the services that will be provided is the **Individual Family Service Program (IFSP)**. The IFSP should be based on a comprehensive evaluation of your child. It should describe your child's current levels of functioning and the anticipated goals. It should also list the specific services that will be provided to your child and your family. EI services are aimed at minimizing the impact of disabilities on the development of your child. Services for your child may include, but are not limited to, speech and language instruction, occupational therapy, physical therapy, Applied Behavior Analysis (ABA) and psychological evaluation. Services for families may include training to help reinforce the affected child's new skills and counseling to help the family adapt.

Information about the Legal Rights and Procedures for Early Intervention in your state can be found in the Autism Speaks Resource Guide at autismspeaks.org/resource-guide.

Click on your state and you will find the information under Early Intervention/State Information.

In this same section of the Autism Speaks Resource Guide you will also find state specific information on the process of transitioning from Early Intervention Services to Special Education Services.

You can learn more about early intervention at: autismspeaks.org/blog/2012/10/26/evaluating-early-interventions.

Special Education Services for Children Ages 3 - 22

Special Education services pick up where early intervention services leave off, at age three. Your local school district provides these services through their special education department. The focus of special education is different from that of early intervention. While early intervention services address your child's overall development, special education focuses on providing your child with an education, regardless of disabilities or special needs.

The document that spells out your child's needs and how these needs will be met is the **Individualized Education Program (IEP)**. Like the IFSP, the IEP describes your child's strengths and weaknesses, sets goals and objectives and details how these can be met. Unlike the IFSP, the IEP is almost entirely related to how the needs of your child will be met within the context of the school district and inside school walls.

Information about the Legal Rights and Procedures for Special Education Services can be found in *Individualized Education Plan (IEP): Summary, Process and Practical Tips*, a guide created by law firm Goodwin Procter LLP on the Autism Speaks website at autismspeaks.org/family-services/tool-kits/iep-guide.

There are IEP forms from the guide included at the end of this kit.

You can also read more about legal information in your state by visiting the Autism Speaks Resource Guide at autismspeaks.org/resource-guide.

Click on your state and you will find the information under Preschool Age or School Age Services/State Information.

You can also view the Autism Speaks School Community Tool Kit at autismspeaks.org/school.

Extended School Year (ESY) Services

If there is evidence that your child experiences a substantial regression in skills during school vacations, he or she may be entitled to **Extended School Year (ESY)** services. These services would be provided over long breaks from school (such as summer vacation) to prevent substantial regression, but not to acquire new skills. It is important for the family to remain involved in determining appropriate goals, communicating with the educational team about your child's progress and working to provide consistency between home and school life.

How Do I Get Services Started for My Child?

If your child is under the age of three, call your local Early Intervention agency. In most states, Early Intervention is provided by the Department of Health. Contact information is included in the Autism Speaks Resource Guide. If your child is three or older, contact your local school district, more specifically the Office of Special Education within the school district. In some cases, you may need to put the request in writing that you would like your child evaluated for special education services. Refer to "Assembling Your Team" in this kit for more information. You'll find more in the Action Plan section of this kit.

Before services can be provided, it may be necessary to complete further assessments and evaluations. These may include:

An unstructured diagnostic play session

A developmental evaluation

A speech-language assessment

A parent interview

An evaluation of current behavior

An evaluation of adaptive or real life skills

You may find yourself spending some time in waiting rooms with your child when you are completing additional evaluations. You have probably already figured out how helpful it is to bring some snacks for your child, his or her favorite toy or some other form of entertainment to help pass the time. Waiting for the completion of these additional evaluations, which may be required by the school district or early intervention services, may be frustrating. There are sometimes waiting lists, so it is important to start the process as soon as possible. The additional evaluations will provide much more in-depth information about your child's symptoms, strengths and needs and will be helpful for accessing and planning therapy services in the long run.

> "I was overwhelmed in the beginning by all the evaluations and paperwork. But watching the changes in Samantha as she learns and grows, we know our efforts are paying off."

The purpose of the evaluations is to understand your child's challenges so that he or she can get the appropriate services that he or she needs. The Organization for Autism Research's *A Parent's Guide to Assessment* can be helpful in explaining the results of the evaluations and what they mean for your child. The guide can be found at **researchautism.org/resources/reading/documents/AssessmentGuide.pdf.**

If you find you are spinning your wheels waiting for the results, there are things you can be doing in the meantime. Talk to other parents about what services have been helpful for their children. Investigate the therapies outlined in this kit. Start reading about autism. There is a list of suggested books and websites at the end of this kit, as well as in the Autism Speaks Resource Library at **autismspeaks.org/family-services/resource-library.**

Autism and Insurance

While there are effective treatment options for autism, these services are not consistently covered by health insurance. Since 2007, Autism Speaks has focused its state advocacy efforts on passage of meaningful autism insurance reform. As of May 2014, 37 states have enacted laws that require certain health insurance plans to cover the treatment of autism, including Applied Behavior Analysis (ABA). These states appear in green on our state initiatives map at **autismspeaks.org/advocacy.**

Unfortunately, determining whether your insurance plan includes a meaningful autism benefit is not as easy as looking at a map. Not all plan types are subject to state law. Additionally, many state autism insurance laws further exclude certain plan types or impose age caps that may adversely affect your coverage.

It can sometimes be difficult to read some of the evaluations about your child's strengths and challenges. It's helpful to remember that your child is the same child as before the diagnosis and all of the evaluations.

Autism Speaks Insurance Link was developed to help families navigate the complexities of health insurance for autism. By answering a short series of questions, this online application will help parents determine whether their dependent is entitled to autism benefits under their health insurance plan. If not covered, Autism Speaks Insurance Link will provide parents with the tools to effectively advocate for meaningful coverage for the treatment of autism.

For more information about Autism Speaks efforts related to health insurance for autism, please email advocacy@autismspeaks.org.

And to access the Autism Speaks Insurance Link please visit autismspeaks.org/advocacy/insurancelink.

"While we were waiting for EI to complete the 'evals', my husband and I picked up two copies of the same book about autism and raced each other through it. By the time the tests were done, we'd learned a lot!"

How is Autism Treated?

Each child or adult with autism is unique and as a result, each autism intervention plan should be tailored to address specific needs. Treatment for autism is usually a very intensive, comprehensive undertaking that involves the child's entire family and a team of professionals. Some programs may take place in your home. These may be based in your home with professional specialists and trained therapists or may include training for you to serve as a therapist for your child under the supervision of a professional. Some programs are delivered in a specialized center, classroom or preschool. It is not unusual for a family to choose to combine more than one treatment method.

The terms "treatment" and "therapy" may be used interchangeably. The word "intervention" may also be used to describe a treatment or therapy.

We've provided an overview of many different treatment methods for autism in this section of your tool kit. The descriptions are meant to give you general information. Your pediatrician, developmental pediatrician or a social worker who specializes in the treatment of children with autism can make suggestions or help you prioritize therapies based on the strengths and challenges detailed in your child's comprehensive evaluation. Once you have narrowed down some choices of appropriate therapies for your child, you will want to explore more information before making a commitment to one. For many children, autism is complicated by medical conditions, biological issues and symptoms that are not exclusive to autism.

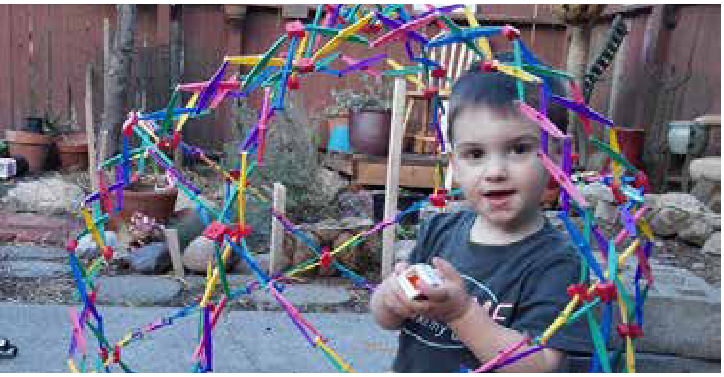
Treatments for associated symptoms address challenges commonly associated with autism, but not specific to the disorder. If your child has biological or medical conditions such as allergies, food intolerances, gastrointestinal issues or sleep disturbances, these will need to be treated too. Treatment programs may combine therapies for both core symptoms and associated symptoms. Your child's treatment program will depend on his or her needs and strengths. Some of these therapies may be used together. For example, if medical causes for sleep disturbances are ruled out, a behavioral intervention might be used to address them. Occupational therapy or speech-language therapy are often integrated into one of the intensive therapy programs described here as core symptom therapies.

Therapies include a wide range of tools, services and teaching methods that you may choose to use to help your child reach his or her potential. The recommended number of hours of structured intervention ranges from 25 to 40 hours per week during the preschool period.

Many of the therapy methods described here are very complex and will require more research on your part before you get started. Whenever possible, observe the therapies in action. Talk to experienced parents and make sure you have a thorough understanding of what is involved before beginning any therapy for your child.

Treatment for the Core Symptoms of Autism

Most families use one type of intensive intervention that best meets the needs of their child and their parenting style. The intensive interventions described here require multiple hours per week of therapy and address behavioral, developmental and/or educational goals. They are developed specifically to treat autism. During the course of treatment, it may be necessary to reevaluate which method is best for your child.



Therapies are not always delivered in a "pure format." Some intervention providers who work primarily in one format may use successful techniques from another format.

Before we get into the types of therapies available, it is helpful to take a step back and look at the bigger picture. Although research and experience have revealed many of the mysteries surrounding autism, it remains a complex disorder that impacts each child differently. However, many children with autism have made remarkable breakthroughs with the right combination of therapies and interventions. Most parents would welcome a cure for their child or a therapy that would alleviate all of the symptoms and challenges that make life difficult. Just as your child's challenges can't be summed up in one word, they can't be remedied with one therapy. Each challenge must be addressed with an appropriate therapy. No single therapy works for every child. What works for one child may not work for another. What works for one child for a period of time may stop working. Some therapies are supported by research that shows their efficacy, while others are not. The skill, experience and style of the therapist are critical to the effectiveness of the intervention.

Before you choose an intervention, you will need to investigate the claims of each therapy so that you understand the possible risks and benefits for your child. At first, all of these techniques – ABA, VB, PRT, DTT, ESDM, among others – may seem like alphabet soup to you. You may be confused now, but you will be surprised at how quickly you become "fluent" in the terminology of autism therapies.

For information on different treatment options, turn to the glossary in this kit or visit AutismSpeaks.org and view the National Standards Project produced by the National Autism Center at nationalautismcenter.org/about/national.php.

To view different treatments in video format please visit the Autism Speaks Autism Video Glossary at autismspeaks.org/what-autism/video-glossary.

You should also see your pediatrician for more information, so that you can be confident you are making informed choices as you begin to narrow down your options.

What is Applied Behavioral Analysis?

Behavior analysis was originally described by B.F. Skinner in the 1930s. You may have learned about Skinner and "operant conditioning" when you studied science in school. The principles and methods of behavior analysis have been applied effectively in many circumstances to develop a wide range of skills in learners with and without disabilities.

Behavior analysis is a scientifically validated approach to understanding behavior and how it is affected by the environment. In this context, "behavior" refers to actions and skills. "Environment" includes any influence – physical or social – that might change or be changed by one's behavior. On a practical level, the principles and methods of behavior analysis have helped many different kinds of learners acquire many different skills – from healthier lifestyles to the mastery of a new language.

Behavior analysis focuses on the principles that explain how learning takes place. Positive reinforcement is one such principle. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning.

Applied Behavior Analysis (ABA) is the use of these techniques and principles to bring about meaningful and positive change in behavior.

Since the early 1960s, ABA has been used by thousands of therapists to teach communication, play, social, academic, self-care, work and community living skills and to reduce problem behaviors in learners with autism. There is a great deal of research that has demonstrated that ABA is effective for improving children's outcomes, especially their cognitive and language abilities. Over the past several decades, different models using ABA have emerged, all of which use behavioral teaching. They all use strategies that are based on Skinner's work.

ABA is often difficult to understand until you see it in action. It may be helpful to start by describing what all of the different methods of ABA have in common. ABA methods use the following three step process to teach:

An ***antecedent****, which is a verbal or physical stimulus such as a command or request. This may come from the environment or from another person or be internal to the subject;*

A resulting ***behavior****, which is the subject's (or in this case, the child's) response or lack of response to the antecedent;*

A ***consequence****, which depends on the behavior, can include positive reinforcement of the desired behavior or no reaction for incorrect responses.*

ABA targets the learning of skills and the reduction of challenging behaviors. Most ABA programs are highly structured. Targeted skills and behaviors are based on an established curriculum. Each skill is broken down into small steps and taught using prompts that are gradually eliminated as the steps are mastered. The child is given repeated opportunities to learn and practice each step in a variety of settings. Each time the child achieves the desired result, he or she receives positive reinforcement, such as verbal praise or something else that the child finds to be highly motivating, like a small piece of candy. ABA programs often include support for the child in a school setting with a one-on-one aide to target the systemic transfer of skills to a typical school environment. Skills are broken down into manageable pieces and built upon so that a child learns how to learn in a natural environment. Facilitated play with peers is often part of the intervention. Success is measured by direct observation and data collection and analysis – all critical components of ABA. If the child isn't making satisfactory progress, adjustments are made.

One type of ABA intervention is **Discrete Trial Teaching** (also referred to as DTT, "traditional ABA" or the Lovaas Model, for its pioneer, Dr. Ivar Lovaas). DTT involves teaching individual skills one at a time using several repeated teaching trials and reinforcers that may or may not be intrinsically related to the skill that is being taught.

Who provides traditional ABA or DTT?

A Board Certified Behavior Analyst (BCBA) specializing in autism will write, implement and monitor the child's individualized program. Individual therapists, often called "trainers," (not necessarily board certified) will work directly with the child on a day-to-day basis.

What is a typical ABA therapy session like?

Sessions are typically two to three hours long, consisting of short periods of structured time devoted to a task, usually lasting three to five minutes. 10 to 15 minute breaks are often taken at the end of every hour. Free play and breaks are used for incidental teaching or practicing skills in new environments. Effective ABA intervention for autism is not a "one size fits all" approach and should never be viewed as a "canned" set of programs or drills. On the contrary, a skilled therapist customizes the intervention to each learner's skills, needs, interests, preferences and family situation. For those reasons, an ABA program for one learner might look somewhat different from a program for another learner. An ABA program will also change as the needs and functioning of the learner change.

What is the intensity of most ABA programs?

Most ABA programs consist of 25 to 40 hours per week of therapy. Families are also encouraged to use ABA principles in their daily lives.

To find more information on ABA, go to the Association for Behavior Analysis International website at ABAinternational.org

or the Behavior Analyst Certification Board website at BACB.com.

What is Verbal Behavior?

Verbal Behavior therapy teaches communication using the principles of Applied Behavior Analysis and the theories of behaviorist B.F. Skinner. By design, **Verbal Behavior** therapy motivates a child, adolescent or adult to learn language by connecting words with their purposes. The student learns that words can help obtain desired objects or other results.

Verbal Behavior therapy avoids focusing on words as mere labels (cat, car, etc.). Rather, the student learns how to use language to make requests and communicate ideas. To put it another way, this intervention focuses on understanding why we use words.

In his book *Verbal Behavior*, Skinner classified language into types, or "operants." Each has a different function. Verbal Behavior therapy focuses on four word types. They are:

Mand: *A request, such as "Cookie," to ask for a cookie*

Tact: *A comment used to share an experience or draw attention, such as "airplane" to point out an airplane*

Intraverbal: *A word used to answer a question or otherwise respond, such as "Where do you go to school?" "Castle Park Elementary"*

Echoic: *A repeated, or echoed, word, such as "Cookie?" "Cookie!" (important as the student needs to imitate to learn)*

Verbal Behavior therapy begins by teaching mands or requests as the most basic type of language. For example, the individual with autism learns that saying "cookie" can produce a cookie. Immediately after the student makes such a request, the therapist reinforces the lesson by repeating the word and presenting the requested item. The therapist then uses the word again in the same or similar context.

Importantly, children don't have to say the actual word to receive the desired item. In the beginning, he or she simply needs to signal requests by any means. Pointing at the item represents a good start.

This helps the student understand that communicating produces positive results. The therapist builds on this understanding to help the student shape the communication toward saying or signing the actual word.

Verbal Behavior therapy uses "errorless learning." The therapist provides immediate and frequent prompts to help improve the student's communication. These prompts become less intrusive as quickly as possible, until the student no longer needs prompting. Take, for example, the student who wants a cookie. The therapist may hold the cookie in front of the student's face and say "cookie" to prompt a response from the child. Next, the therapist would hold up the cookie and make a "c" sound to prompt the response. After that, the therapist might simply hold a cookie in the child's line of sight and wait for the request. The ultimate goal, in this example, is for the student to say "cookie" when he or she wants a cookie – without any prompting.

VB and classic ABA use similar behavioral formats to work with children. VB is designed to motivate a child to learn language by developing a connection between a word and its value. VB may be used as an extension of the communication section of an ABA program.

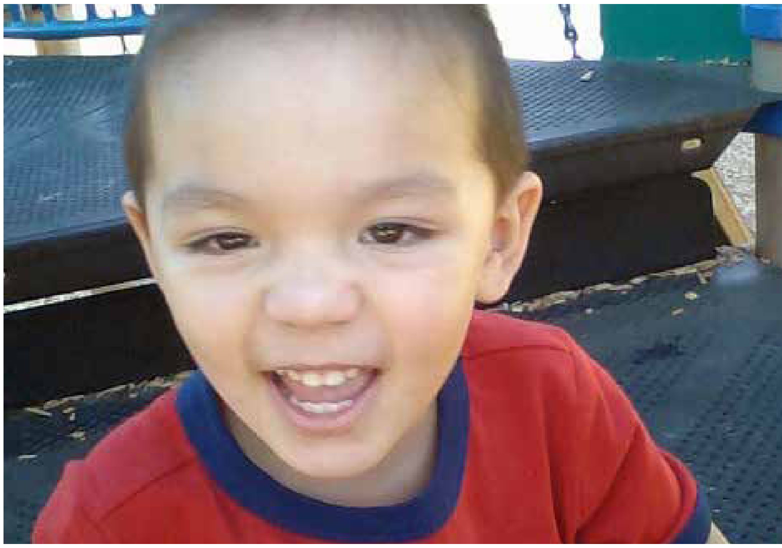
Who provides VB?

Verbal Behavior therapy is provided by VB-trained psychologists, special education teachers, speech therapists and other providers.

What is the intensity of most VB programs?

VB programs usually involve 30 or more hours per week of scheduled therapy. Families are encouraged to use VB principles in their daily lives.

For Information on VB, go to the Cambridge Center for Behavioral Studies website at behavior.org/vb.



What is Pivotal Response Treatment?

Pivotal Response Treatment, or PRT, was developed by Dr. Robert L. Koegel, Dr. Lynn Kern Koegel and Dr. Laura Shreibman at the University of California at Santa Barbara. PRT was previously called the Natural Language Paradigm (NLP), which has been in development since the 1970s. It is a behavioral intervention model based on the principles of ABA.

PRT is one of the best studied and validated behavioral treatments for autism. Derived from ABA, it is play-based and child-initiated. Its goals include the development of communication, language and positive social behaviors and relief from disruptive self-stimulatory behaviors.

Rather than target individual behaviors, the PRT therapist targets “pivotal” areas of a child’s development. These include motivation, response to multiple cues, self-management and the initiation of social interactions. The philosophy is that by targeting these critical areas, PRT will produce broad improvements across other areas of sociability, communication, behavior and academic skill building.

Motivation strategies are an important part of the PRT approach. These emphasize “natural” reinforcement. For example, if a child makes a meaningful attempt to request, say, a stuffed animal, the reward is the stuffed animal – not a candy or other unrelated reward.

Who provides PRT?

Some psychologists, special education teachers, speech therapists and other providers specifically are trained in PRT. The Koegel Autism Center offers a PRT Certification program.

What is a typical PRT therapy session like?

Each program is tailored to meet the goals and needs of the individual learner and his or her school and home routines. A session typically involves six segments during which language, play and social skills are targeted with both structured and unstructured interactions. As the child progresses, the focus of each session changes to accommodate more advanced goals and needs.

What is the intensity of a PRT program?

PRT programs usually involve 25 or more hours per week. Everyone involved in the child's life is encouraged to use PRT methods consistently in every part of his or her life. PRT has been described as a lifestyle adopted by the affected family.

For more information on PRT, visit the UCSB Koegel Autism Center website at Education.UCSB.edu/autism or the UCSD Autism Research Program website at psy3.ucsd.edu/~autism/prttraining.html.

What is the Early Start Denver Model (ESDM)?

The Early Start Denver Model (ESDM) is a comprehensive behavioral early intervention approach for children with autism, ages 12 to 48 months. The program encompasses a developmental curriculum that defines the skills to be taught at any given time and a set of teaching procedures used to deliver this content. It is not tied to a specific delivery setting, but can be delivered by therapy teams and/or parents in group programs or individual therapy sessions in either a clinic setting or the child's home.

Psychologists Sally Rogers, Ph.D., and Geraldine Dawson, Ph.D., developed the Early Start Denver Model as an early-age extension of the Denver Model, which Rogers and colleagues developed and refined. This early intervention program integrates a relationship-focused developmental model with the well-validated teaching practices of Applied Behavior Analysis (ABA). Its core features include the following:

Naturalistic applied behavioral analytic strategies

Sensitive to normal developmental sequence

Deep parental involvement

Focus on interpersonal exchange and positive affect

Shared engagement with joint activities

Language and communication taught inside a positive, affect-based relationship

The Early Start Denver Model is the only comprehensive early intervention model that has been validated in a randomized clinical trial for use with children with autism as young as 18 months of age. It has been found to be effective for children with autism across a wide range of learning styles and abilities.

Who provides ESDM?

An ESDM therapist may be a psychologist, behaviorist, occupational therapist, speech and language pathologist, early intervention specialist or developmental pediatrician. What's important is that the therapist has ESDM training and certification.

Parents can also be taught to use ESDM strategies. Parental involvement is a crucial part of the ESDM program. If your child is receiving ESDM therapy, the instructor will explain and model the strategies for you to use at home.

What is the intensity of most ESDM programs?

ESDM programs usually involve 20 to 25 or more hours per week of scheduled therapy. Families are encouraged to use ESDM strategies in their daily lives.

What is a typical ESDM session like?

ESDM is designed to be highly engaging and enjoyable for the child, while skills are systematically taught within a naturalistic, play-based interaction. Some skills are taught on the floor during interactive play while others are taught at the table, focusing on more structured activities. As the child develops social skills, peers or siblings are included in the therapy session to promote peer relationships. ESDM can be delivered in the home, the clinic or a birth-to-three or developmental preschool setting.

To find more information on ESDM, check out *Play and Engagement in Early Autism: The Early Start Denver Model* by Rogers, SJ., & Dawson, G. (2009) or the *ESDM Curriculum Checklist*, also from Rogers and Dawson. Information about training in the ESDM model can be found at ucdmc.ucdavis.edu/mindinstitute/research/esdm.

What is Floortime (DIR)?

Floortime is a specific therapeutic technique based on the **Developmental Individual Difference Relationship Model (DIR)** developed in the 1980s by Dr. Stanley Greenspan. The premise of Floortime is that an adult can help a child expand his or her circles of communication by meeting the child at his or her developmental level and building on his or her strengths. Therapy is often incorporated into play activities – on the floor. The goal of Floortime is to help the child reach six developmental milestones that contribute to emotional and intellectual growth:

Self regulation and interest in the world

Intimacy or a special love for the world of human relations

Two-way communication

Complex communication

Emotional ideas

Emotional thinking

In Floortime, the therapist or parent engages the child at a level the child currently enjoys, enters the child's activities and follows the child's lead. From a mutually shared engagement, the parent is instructed on how to move the child toward increasingly complex interactions, a process known as "opening and closing circles of communication."

Floortime does not separate and focus on speech, motor or cognitive skills but rather addresses these areas through a synthesized emphasis on emotional development. The intervention is called Floortime because the parent gets down on the floor with the child to engage the child at his or her level. Floortime is considered an alternative to and is sometimes delivered in combination with ABA therapies.

Who provides Floortime?

Parents and caregivers are trained to implement the approach. Floortime-trained psychologists, special education teachers, speech therapists or occupational therapists may also use Floortime techniques.

What is a typical Floortime therapy session like?

In Floortime, the parent or provider joins in the child's activities and follows the child's lead. The parent or provider then engages the child in increasingly complex interactions. During the preschool program, Floortime includes integration with typically developing peers. Ideally, Floortime takes place in a calm environment. This can be at home or in a professional setting. Floortime sessions emphasize back-and-forth play interactions. This establishes the foundation for shared attention, engagement and problem solving. Parents and therapists help the child maintain focus to sharpen interactions and abstract, logical thinking.

What is the intensity of most Floortime programs?

Floortime is usually delivered in a low stimulus environment, ranging from two to five hours a day. Families are encouraged to use the principles of Floortime in their day-to-day lives.

To find more information on Floortime, go to the Floortime Foundation website at Floortime.org,

Stanley Greenspan's website at StanleyGreenspan.com

or the Interdisciplinary Council on Developmental and Learning Disorders website at ICDL.com.

What is Relationship Development Intervention (RDI)?

Like other therapies described in this tool kit, **Relationship Development Intervention (RDI**) is a system of behavior modification through positive reinforcement. RDI was developed by Dr. Steven Gutstein as a family-based behavioral treatment using dynamic intelligence and addressing autism's core symptoms. RDI aims to help individuals with autism form personal relationships by gradually strengthening the building blocks of social connections. This includes the ability to form an emotional bond and share experiences.

The six objectives of RDI are:

Emotional Referencing: *the ability to use an emotional feedback system to learn from the subjective experiences of others*

Social Coordination: *the ability to observe and continually regulate one's behavior in order to participate in spontaneous relationships involving collaboration and exchange of emotions*

Declarative Language: *the ability to use language and non-verbal communication to express curiosity, invite others to interact, share perceptions and feelings and coordinate your actions with others*

Flexible Thinking: *the ability to rapidly adapt, change strategies and alter plans based upon changing circumstances*

Relational Information Processing: *the ability to obtain meaning based upon the larger context; solving problems that have no "right-and wrong" solutions*

Foresight and Hindsight: *the ability to reflect on past experiences and anticipate potential future scenarios in a productive manner*

The program involves a systematic approach to working on building motivation and teaching skills while focusing on the child's current developmental level of functioning. Children begin work in a one-on-one setting with a parent. When the child is ready, he or she is matched with a peer at a similar level of relationship development to form a "dyad." Gradually, additional children are added, as are the number of settings in which the children practice, in order to help the child form and maintain relationships in different contexts.

Who provides RDI?

Parents, teachers and other professionals can be trained to provide RDI. Parents may choose to work together with an RDI-certified consultant. RDI is somewhat unique because it is designed to be implemented by parents. Parents learn the program through training seminars, books and other materials and can collaborate with an RDI-certified consultant. Some specialized schools offer RDI in a private school setting.

What is a typical RDI therapy session like?

In RDI, the parent or provider uses a comprehensive set of step-by-step, developmentally appropriate objectives in everyday life situations, based on different levels or stages of ability. Spoken language may be limited in order to encourage eye contact and nonverbal communication. RDI may also be delivered in a specialized school setting.

What is the intensity of most RDI programs?

Families most often use the principles of RDI in their day-to-day lives. Each family will make choices based on their child.

Find more information on RDI on the Connections Center website at RDIconnect.com.

What is TEACCH?

The **TEACCH® Autism Program** is a clinical, training and research program based at the University of North Carolina – Chapel Hill. TEACCH, developed by Drs. Eric Schopler and Robert Reichler in the 1960s, was established as a statewide program by the North Carolina legislature in 1972 and has become a model for other programs around the world.

TEACCH developed the intervention approach called "Structured TEACCHing", an array of teaching or treatment principles and strategies based on the learning characteristics of individuals with ASD, including strengths in visual information processing and difficulties with social communication, attention and executive function. In response to this profile of strengths and challenges, Structured TEACCHing includes:

External organizational supports to address challenges with attention and executive function

Visual and/or written information to supplement verbal communication

Structured support for social communication

Structured TEACCHing is not a curriculum, but instead is a framework to support achievement of educational and therapeutic goals. This framework includes:

Physical organization

Individualized schedules

Work (Activity) systems

Visual structure of materials in tasks and activities

The goal of Structured TEACCHing is to promote meaningful engagement in activities, flexibility, independence and self-efficacy. Structured TEACCHing strategies are integrated into other evidenced-based practices.

What does TEACCH look like?

TEACCH programs are usually conducted in a classroom setting. TEACCH-based home programs are also available and are sometimes used in conjunction with a TEACCH-based classroom program. Parents work with professionals as co-therapists for their children so that TEACCH techniques can be continued in the home.

Who provides TEACCH?

TEACCH is available at the TEACCH centers in North Carolina and through TEACCH-trained psychologists, special education teachers, speech therapists and other providers in other areas of the country.

To find more information on TEACCH, go to the TEACCH Autism Program website at TEACCH.com.

What is Social Communication/Emotional Regulation/Transactional Supports (SCERTS)?

Social Communication/Emotional Regulation/Transactional Support (SCERTS) is an educational model developed by Barry Prizant, PhD, Amy Wetherby, PhD, Emily Rubin and Amy Laurant. SCERTS uses practices from other approaches including ABA (in the form of PRT), TEACCH, Floortime and RDI. The SCERTS Model differs most notably from the focus of “traditional” ABA by promoting child-initiated communication in everyday activities. SCERTS is most concerned with helping children with autism to achieve “Authentic Progress,” which is defined as the ability to learn and spontaneously apply functional and relevant skills in a variety of settings and with a variety of partners.

The acronym “SCERTS” refers to the focus on:

“SC” Social Communication: Development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults

“ER” Emotional Regulation: Development of the ability to maintain a well-regulated emotional state to cope with everyday stress and to be most available for learning and interacting

“TS” Transactional Support: Development and implementation of supports to help partners respond to the child’s needs and interests, modify and adapt the environment and provide tools to enhance learning (e.g., picture communication, written schedules, and sensory supports); specific plans are also developed to provide educational and emotional support to families and to foster teamwork among professionals

What does a SCERTS session look like?

The SCERTS model favors having children learn with and from other children who provide good social and language models in inclusive settings, as much as possible. SCERTS is implemented using transactional supports put in place by a team, such as environmental accommodations and learning supports like schedules or visual organizers.

Who provides SCERTS?

SCERTS is usually provided in a school setting by SCERTS-trained special education teachers or speech therapists.

For more information on SCERTS, visit SCERTS.com.

Treatment for Biological & Medical Conditions Associated with Autism

The next section of this tool kit covers a number of what are frequently called "related services." These services are therapies that address symptoms commonly associated with autism, but not specific to the disorder.

Speech-language therapy (SLT)

Most autism behavioral intensive therapy programs include **speech-language therapy.** With a variety of techniques, speech-language therapy addresses a range of challenges often faced by persons with autism. For instance, some individuals on the autism spectrum do not speak, while others love to talk but have difficulty using conversational speech and/or understanding the nuances of language and nonverbal cues when talking with others.

Speech-language therapy is designed to coordinate the mechanics of speech with the meaning and social use of language. Such a program begins with an individual evaluation by a speech-language pathologist to assess an individual's verbal aptitudes and challenges. From this evaluation, the pathologist sets goals that may include mastering spoken language and/or learning nonverbal communication skills such as signs or **gestures.** In each case, the goal is to help the person communicate in more useful and functional ways.

The speech language pathologist can provide therapy one-on-one, in a small group or in a classroom setting. Therapists who work with children have additional specialized training.

One approach used in speech-language therapy is **Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT)**. PROMPT is a physical-sensory approach to therapy in which a therapist uses touch and pressure to an individual's jaw, tongue and lips to help him or her develop motor control and the proper oral muscular movements to speak. Speech therapists need to be fully trained in order to provide PROMPT therapy. To learn more about PROMPT, visit **promptinstitute.com.**

Occupational therapy (OT)

Occupational therapy (OT) addresses a combination of cognitive, physical and motor skills. Its goals including helping a child or adult gain age-appropriate independence and participate more fully in life. For a person with autism, occupational therapy often focuses on skills for appropriate play or leisure skills, learning and self-care skills.

Therapy begins with a certified occupational therapist evaluating the person's developmental level as well as related learning styles, social abilities and environmental needs. Based on this evaluation, the therapist determines goals and selects strategies and tactics for enhancing key skills. For instance, goals may include independent dressing, feeding, grooming and use of the toilet, along with improved social, fine motor and visual perceptual skills. Typically, occupational therapy involves half-hour to one-hour sessions with a frequency determined by the individual's needs. In addition, the person with autism practices strategies and skills – with guidance – at home and in other settings including school. OT is provided by certified occupational therapists.

Sensory integration (SI) therapy

Many children and adults with autism have challenges in processing sensory information such as movement, touch, smell, sight and sound. **Sensory integration (SI) therapy** identifies such disruptions and uses a variety of techniques that improve how the brain interprets and integrates this information. Occupational therapy often includes sensory integration. Other times it is delivered as a stand-alone therapy.

Certified occupational and physical therapists provide sensory integration therapy. The therapist begins with an individual evaluation to determine a person's sensitivities. From this information, he or she plans an individualized program that matches sensory stimulation with physical movement to improve how the brain processes and organizes incoming information. As such, the therapy often includes equipment such as swings, trampolines and slides.

Sensory integration therapy can allow a child or adult with sensory integration difficulties to become more "available" for learning and social interactions. Family members and teachers often find that its techniques can help calm an affected child or adult, reinforce positive behavior and help with transitions between activities.

Physical therapy (PT)

Many children and adults with autism have challenges with motor skills such as sitting, walking, running and jumping. **Physical therapy (PT)** focuses on problems with movement that cause real-life limitations. In particular, physical therapy can improve poor muscle tone, balance and coordination.

Certified physical therapists deliver physical therapy beginning with an evaluation of a person's physical abilities and developmental level. They then design programs of activities that target areas of challenge. Typically therapy sessions run a half hour to an hour and include assisted movement, various forms of exercise and the use of orthopedic equipment. The needs of the child or adult receiving services should determine the frequency of these sessions.

Social skills

Individuals with autism have a great deal of difficulty with social interactions. In recent years, social skills training, in both one-on-one and peer group settings, has become a very common treatment for facing this particular challenge. Social skills taught during training sessions range from simple skills like eye contact to more difficult skills like inviting a peer for a playdate. Studies have shown that this type of intervention program can significantly improve social competence and social skill development. Though social skills training is not an official or certified form of therapy, professionals like social workers, speech therapists and psychologists often focus largely on improving social skills when treating both children and adults with autism. In addition, parents, family members and other caregivers can be taught effective ways to help improve the social skills of their loved ones with autism both inside and outside the home on a regular basis.

Picture Exchange Communication System (PECS)

Picture Exchange Communication System (PECS) is a learning system that allows children with little or no verbal ability to communicate using pictures. PECS can be used at home, in the classroom or in a variety of other settings. A therapist, teacher or parent helps the child to build a vocabulary and to articulate desires, observations or feelings by using pictures consistently.

The PECS program starts by teaching the child how to exchange a picture for an object. Eventually, the individual is shown how to distinguish between pictures and symbols and use them to form sentences. Although PECS is based on visual tools, verbal reinforcement is a major component and verbal communication is encouraged. Standard PECS pictures can be purchased as a part of a manual or pictures can be gathered from photos, newspapers, magazines or other books.

Auditory Integration Training

Auditory Integration Training (AIT), sometimes called sound therapy, is often used to treat children with difficulties in auditory processing or sound sensitivity. Treatment with AIT involves the patient listening to electronically modified music through headphones during multiple sessions. There are different methods of AIT, including the Tomatis and Berard methods. While some individuals have reported improvements in auditory processing as a result of AIT, there are no credible studies that demonstrate its effectiveness or support its use.

Gluten free, casein free diet (GFCF)

Much has been said about the **gluten** free, **casein** free (GFCF) diet and its use to help individuals with autism. Many families with children newly diagnosed with autism wonder if it's something their child should follow. The GFCF diet was first developed for people with celiac disease, a disorder that involves a severe reaction to gluten in the diet. Gluten is found in wheat products such as bread and other bakery goods but also in a wide variety of other food products. Casein is a protein most associated with dairy products and has potential to cause severe reactions in certain individuals. When used appropriately, the GFCF diet is safe and can help avoid these severe health problems.

The theory behind its use in autism is that if a person is having GI responses to these products, the resulting inflammation may damage the lining of the intestine and as a result lead to absorption of molecules that are not normally absorbed by healthy intestines. Some evidence suggests that these molecules or the inflammation they cause can interact with the brain in ways that cause problems such as anxiety, mood abnormalities, mental difficulties and perhaps worsen the behavioral symptoms of autism. That said, while the GFCF diet has been used in the autism community for a couple of decades, there is minimal evidence that it improves autism-related behaviors.

Families choosing a trial of dietary restriction should make sure their child is receiving adequate nutrition by consulting his or her pediatrician or a nutrition specialist. Dairy products are the most common source of calcium and Vitamin D for young children in the United States. Many young children depend on dairy products for a balanced, regular protein intake. Alternative sources of these nutrients require the substitution of other food and beverage products, with attention given to the nutritional content. Substitution of gluten-free products requires attention to the overall fiber and vitamin content of a child's diet. Vitamin supplements may have both benefits and side effects. Consultation with a dietician or physician is recommended for the healthy application of a GFCF diet. This may be especially true for children who are picky eaters.

What about other medical interventions?

Right now you are itching to do everything possible to help your child. Many parents in your position are eager to try new treatments, even those treatments that have not yet been scientifically proven to be effective. Your hopes for a cure for your child may make you more vulnerable to the lure of untested treatments.

It is important to remember that just as each child with autism is different, so is each child's response to treatments.

It may be helpful to collect information about a therapy that you are interested in trying and speak with your pediatrician, as well as your intervention team members, in order to discuss the potential risks/benefits and establish measurable outcomes and baseline data. Parents of older children with autism can provide you with a history of therapies and biomedical interventions that have been promised to be cures for autism over the years. Some of them may have been helpful to a small number of children. Upon further study, none of them, so far, has turned out to be a cure for the vast majority. We do know that many children get better with intensive behavioral therapy. There is a large body of scientific evidence to support this theory. It makes sense to focus on getting your child engaged in an intensive behavioral program before looking at other interventions.

Is There a Cure?

Is recovery possible? You may have heard about children who have recovered from autism. Although relatively rare, it is estimated that approximately 10% of children lose their diagnosis of autism. The factors that predict which children lose their diagnosis are unknown. Children initially diagnosed with autism who lose their diagnosis often have residual difficulties in the areas of hyperactivity, anxiety and depressive symptoms. Symptom reduction from autism is usually reported in connection with intensive early intervention, but it is unknown how much or which type of intervention works best or whether the recovery can be fully credited to the intervention. You may also hear about children who reach "best outcome" status, which means they score normally on tests for IQ, language, adaptive functioning, school placement and personality, but have mild symptoms on some personality and diagnostic tests. Recent epidemiology studies estimate that approximately 60% of children with autism have IQ's above 70 by age eight (70 is the cut-off point for developmental delay). Presently, there is no reliable way of predicting which children will have the best outcomes. In the absence of a cure or even an accurate prognosis of your child's future, do not be afraid to believe in your child's potential. All children with autism will benefit from intervention. All will make very significant, meaningful progress.

Making It Happen

How Do I Choose the Right Intervention?

Choosing a treatment path for your child may feel overwhelming. Remember to work closely with your child's treatment team and explore all of your options. The two articles that follow may provide helpful information for you as you choose between methods of therapies for your child.

"Alleviate Stress by Actively Pursuing the Right Intervention" from ***Overcoming Autism***
by Lynn Kern Koegel, PhD and Claire LaZebnik

It's scary to have to question your own child's potential, but the best way to relieve your fears is to take action with productive interventions. The first step is to be informed. Talk to people you trust - parents who've been there, experts in the field, doctors you have a relationship with and so on. There are a lot of fly-by-night procedures that prey on distraught parents who will do anything for their child. Make sure that the interventions you're using are scientifically sound and well documented. Make sure they've been tested with many children with autism and that they've been replicated by other experts and clinics. Also, make sure you understand their limitations – some interventions only work on a small number of symptoms or on a small subgroup of children with autism. If you're going to spend time and money for interventions, be informed about the degree and extent of the change they may bring about.

“Understanding Your Child’s Learning Style”
from ***Does My Child Have Autism?***
by Wendy Stone, PhD, and
Theresa Foy DiGeronimo, M.Ed

Finding the right intervention program begins with an understanding of your child’s learning style – which is quite different from the learning style of other children. You probably realize this as you’ve tried to get your child with autism to wave bye-bye using the same teaching strategies you used with your other children – that is, demonstrating the action, providing a verbal prompt by saying “wave bye-bye” and even moving his or her hand to demonstrate what to do. But when that approach didn’t seem to be working, you probably started to think that your child was being stubborn or uncooperative. After all, you’re teaching simple skills using methods that worked very well for your other children. But the reality is that your child isn’t being bad; he or she just has a different learning style from your other children. This difference in learning styles isn’t apparent only when you try to teach children with autism; it’s also evident in the way they learn (or don’t learn) on their own. There are lots of things that children without autism seem to learn effortlessly, without being taught, but that children with autism don’t pick up on as easily. For example, young children without autism somehow learn, without explicit teaching, how to use a pointing gesture to let you know what they want or to indicate where they want you to look. They learn to follow your point or eye gaze to figure out what you’re looking at or what you’re interested in. They figure out on their own how to use eye contact and facial expressions to convey their feelings-as well as to understand the meaning of your facial expressions and tone of voice. Social-communicative behaviors and skills like these just don’t come as naturally to young children with autism and often need to be taught explicitly.

Assembling Your Team

Your child’s team will consist of many different members. They will help you to address all areas of your child’s life and assist you in making decisions about your child’s treatment, education, recreation and health. Below is some helpful information on how to assemble this group of professionals.

Medical team

Your child should be supported by a pediatrician who understands developmental issues and who will serve as your child’s primary care provider. Depending on your child’s needs, other medical team members may include a neurologist, geneticist, developmental pediatrician, gastroenterologist, psychiatrist or nutritionist.

Intensive intervention team

ABA, ESDM, Floortime, PRT, RDI, SCERTS, TEACCH and VB are all intensive interventions. Depending on the intensity of the primary intervention, there may be an intervention leader and several providers or therapists involved in providing the treatment as structured by the leader.

Related services team

Speech and language therapy, occupational therapy, physical therapy, sensory integration therapy and social skills instruction are all related services. All therapists working with your child should be communicating frequently and using a consistent method of teaching.

Hiring therapists

For parents hiring new therapists, you may want to consider the candidate as you would any other job applicant and handle the situation accordingly. Ask for resumes.

Specific Things to Look for on the Resume:

- ***Past experience with children with autism approximately the same age as your child***
- ***Amount of experience the therapist has had***
- ***Kinds of experience the therapist has had, for example, whether he or she has worked in a school setting or in a private program***
- ***Educational background***
- ***Membership in professional autism organizations – if so, then he or she is most likely going to conferences, thus enhancing his or her skills in the profession***

Conducting interviews

Conduct a "hands on" interview, during which the potential therapist works with your child to implement a skill acquisition program. It is important to see how the potential therapist takes direction and to see how flexible he or she is about changing approaches in his or her teaching. You will want a therapist to potentially be open to new ideas in terms of teaching approaches. It's a good idea to have him or her bring video of a therapy session conducted with another child. This offers yet another view of his or her teaching skills. If possible, observe the therapist working with another child.

Check references. Be sure to talk to previous supervisors and other parents for whom the therapist has worked. They are often good sources for finding additional therapists.

Consider a probation period. The therapist should be hired for a probation period, during which sessions are videotaped or observed directly until you and/or the home coordinator feel comfortable with the therapist and confident in his or her abilities.

Check clearances. Anyone working with your child will need to provide background clearances from the state you live in to establish that he or she does not have a criminal record. If you have chosen a home-based intervention program for your child, you will probably be required to submit copies of those clearances to the state, county or local agency providing services.

"When to Be Concerned About a Therapist"
from ***Overcoming Autism*** by Lynn Kern Koegel, PhD and Claire LaZebnik

There's plenty of evidence showing that children with autism do better when parents are actively involved in the intervention and when programs are coordinated. Find programs that encourage you to be involved – you should be learning all the procedures and coordinating your child's program across every environment. You can't do that if you're being shut out. If a treatment provider tells you that you can't watch the sessions or that your child does better when you're not there, this is a RED FLAG. It may be reasonable for a therapist to request a few sessions alone to bond with the child, but more than that just doesn't make sense and the therapist needs to communicate fully with you so that you know exactly what's going on at all times. If a clinician tells you that she's not documenting any type of changes, be concerned – the only way to evaluate whether a treatment program is working is to analyze the changes your child is making. Also be wary of any therapist who says that he's working on the "parent-child bond," and that fixing your relationship with your child will improve her behavior. In other words, if your therapist is excluding you, blaming you or using techniques that do not have measurable outcomes, you should consider looking for another therapist or agency.

Managing your team

Participate in training. Be part of the team. Your participation in team training is vital so that you can increase your skills to successfully parent your child and understand the goals and techniques of his or her program. Knowing the techniques and objectives of your child's intervention program will allow you to closely monitor his or her progress and guide and evaluate the members of your team. Intensive intervention programs often start with a one or two day training course where individual therapists are trained by the primary intervention leader.

Establishing team communication

There are two important ways your team will communicate. One is through a notebook in which each therapist records information after his or her session with your child. Each therapist reads the information recorded since the previous session before the next session with your child. Parents and supervisors can add information to the notebook as needed. The other way is through team meetings. Team meetings are often held at the home of the child, especially in the case of intervention programs that are home-based. These meetings should include as many members of your team as possible. This will ensure that your therapists are up to date on every aspect of the program and that they are all working with your child in consistent ways. At team meetings, you will discuss what is working, as well as areas in which there have not been progress, so that you can determine whether to make changes and what those changes should be. Teams usually meet once a month, but may meet more or less often as needed. Many team meetings include time for therapists to observe each other in action with your child and receive feedback on their techniques.

"Making Therapies Work for the Entire Family" from ***Overcoming Autism*** by Lynn Kern Koegel, PhD and Claire LaZebnik

Always be sure you select interventionists who will view the family as teammates and will include you in the determination of target goals – your child needs to learn skills that will help the family function, fit into your lifestyle and be compatible with your cultural and religious values. For example, a clinician may feel that it's important to work on answering the phone, while the family may feel that toilet training is a much more pressing and immediate goal. Both goals may well be valid, but the family needs to have a say in prioritizing them. Similarly, studies show that families who are required to implement drill type interventions have greater stress than when less rigid interventions are incorporated into daily family routines. How well the family functions as a whole is just as important as how well the child with special needs is doing and it's your responsibility to work toward both kinds of success.

There are also currently apps and other technology resources out there that help parents manage their team and keep everyone informed and connected. One resource is My Autism Team (myautismteam.com), a social network that allows all professionals and family members involved in the care of an individual with autism to communicate and provide updates. Search the Autism Speaks Autism Apps database at autismspeaks.org/autism-apps for similar tools!

Technology and Autism

Technology such as iPads, computers and smart phones have become valuable tools in the treatment and daily lives of individuals with autism. These devices can assist in areas ranging from behavior tracking to communication and more. There are many options for how to use technology to benefit each individual. Discuss the use of technology for your child with your treatment team.

The Autism Speaks Autism Apps database contains hundreds of helpful apps divided by age, platform and category. Categories include behavioral intervention, communication, social skills, educational, functional skills and more. Search the database at **autismspeaks.org/autism-apps.** Many of these apps have been found to help individuals with autism make great strides in their communication skills and abilities to express themselves.

Additionally, technology has been very helpful in allowing families of individuals with autism and their team members to track the child's progress and remain up to date on his or her schedule, improvements, strengths and challenges following treatments and interventions. Examples include:

My Medical App

This app stores complete medical histories for as many people as you wish, helps you keep critical and hard-to-remember information on hand all the time and allows you to track and chart tests results and vital signs and send the records to your doctors with the click of a button.
mymedicalapp.com

TherapyConnectApp

This app was developed by a team of speech-language pathologists and behavioral consultants dedicated to the service of children with disabilities including autism. It is a tool for both therapists/service providers and families who wish to maintain consistent treatment plans that work for their children by allowing the user to monitor the child or client's treatment plan from any iPad.
truetherapydata.com

AutismTrack™

Autism Track is a portable, customizable data tracking tool that empowers caregivers of those with autism to easily track interventions, behaviors and symptoms. Checkboxes allow daily recording of any therapy, medicine or diet.
handholdadaptive.com/AutismTrack.html

You can find additional information on technology and the many ways it can assist individuals with autism at autismspeaks.org/family-services/technology.

Search the Autism Speaks Apps database for helpful apps for your child at autismspeaks.org/autism-apps.

Autism and Wandering

Safety is a critical part of all of our lives, whether we are at home or out in the community, alone or with loved ones. Being aware of our surroundings and taking precautions to stay safe is even more important for individuals with autism and their families. Wandering is an especially prominent issue in the autism community. A 2012 study from the Interactive Autism Network confirmed that nearly half of all children with autism have attempted to wander or bolt from a safe, supervised place. Given the frequency of this problem, here are some tips that have been adapted from Autism Wandering Awareness Alerts Response Education Coalition (AWAARE) on how to prevent wandering:

1. Secure Your Home

Consider contacting a professional locksmith, security company or home improvement professional to promote safety and prevention in your home. You may find it is necessary to prevent your loved one from slipping away unnoticed by installing secure dead bolt locks that require keys on both sides, a home security alarm system, inexpensive battery-operated alarms on doors, hook and eye locks on all doors above your child's reach, a fence around your yard, printable STOP SIGNS on doors, windows and other exits, etc.

2. Consider a Locating Device

Check with local law enforcement for Project Lifesaver or Lo Jack SafetyNet services. These locating devices are worn on the wrist or ankle and locate the individual through radio frequency. Various GPS systems are also available.

3. Consider an ID Bracelet

Medical ID bracelets will include your name, telephone number and other important information. They may also state that your child has autism and is nonverbal if applicable. If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information.

4. Teach Your Child to Swim

The leading cause of death of individuals with autism who wander is drowning. It is critical to teach your child both to swim and to understand the importance of water safety. Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes on. Remember that teaching your child how to swim does not mean your child is safe in water. If you own a pool, fence it. If neighbors have pools, let them know of these safety precautions and your child's tendency to wander. Remove all toys or items of interest from the pool when not in use.

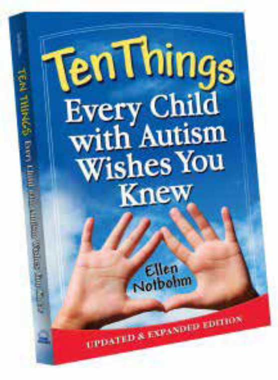
Autism Speaks has a grant program that awards funding to organizations providing scholarships for swimming and water safety lessons for financially disadvantaged individuals with autism. Learn more at **autismspeaks.org/family-services/grants/swimming.**

5. Alert Your Neighbors

It is recommended that caregivers plan a brief visit with neighbors to introduce their loved one or provide a photograph. Knowing your neighbors can help reduce the risks associated with wandering.

6. Alert First Responders

Providing first responders with key information before an incident occurs may improve response. Informational handouts should include all pertinent information and be copied and carried with caregivers at all times. Circulate the handout to family, neighbors, friends and co-workers, as well as first responders. Always make sure to work with your child's team to express any concerns about safety issues, so that you can work together on a safety plan best suited for your loved one. More information about safety and wandering can be found at: **awaare.org, autismspeaks.org/safety** and **autismspeaks.org/wandering-resources.**



Ten Things Every Child with Autism Wishes You Knew

by Ellen Notbohm

From the book Ten Things Every Child with Autism Wishes You Knew, 2nd edition (2012, Future Horizons, Inc.) Reprinted in its entirety with permission of author.

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute–the inconsistency. Autism can be baffling, even to those who spend their lives around it. The child who lives with autism may look "normal" but his behavior can be perplexing and downright difficult. Autism was once labeled an "incurable disorder," but that notion has crumbled in the face knowledge and understanding that increase even as you read this. Every day, individuals with autism show us that they can overcome, compensate for and otherwise manage many of autism's most challenging characteristics. Equipping those around our children with simple understanding of autism's basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is a complex disorder but for purposes of this article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly, every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am a child.

My autism is part of who I am, not all of who I am. Are you just one thing, or are you a person with thoughts, feelings, preferences, ideas, talents, and dreams? Are you fat (overweight), myopic (wear glasses) or klutzy (uncoordinated)? Those may be things that I see first when I meet you, but you're more than just that, aren't you?

As an adult, you have control over how you define yourself. If you want to single out one characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. If you think of me as just one thing, you run the danger of setting up an expectation that may be too low. And if I get a sense that you don't think I "can do it," my natural response will be, why try?

2. My senses are out of sync.

This means that ordinary sights, sounds, smells, tastes, and touches that you may not even notice can be downright painful for me. My environment often feels hostile. I may appear withdrawn or belligerent or mean to you, but I'm just trying to defend myself. Here's why a simple trip to the grocery store may be agonizing for me.

My hearing may be hyperacute. Dozens of people jabber at once. The loudspeaker booms today's special. Music blares from the sound system. Registers beep and cough, a coffee grinder chugs. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle three with ammonia. I feel like throwing up.

And there's so much hitting my eyes! The fluorescent light is not only too bright, it flickers. The space seems to be moving; the pulsating light bounces off everything and distorts what I am seeing. There are too many items for me to be able to focus (my brain may compensate with tunnel vision), swirling fans on the ceiling, so many bodies in constant motion. All this affects how I feel just standing there, and now I can't even tell where my body is in space.

3. Distinguish between won't (I choose not to) and can't (I am not able to).
It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, I hear "*&^%$#@, Jordan. #$%^*&^%$&*." Instead, come over to me, get my attention, and speak in plain words: "Jordan, put your book in your desk. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.20 21

4. I'm a concrete thinker. I interpret language literally.
You confuse me by saying, "Hold your horses, cowboy!" when what you mean is, "Stop running." Don't tell me something is "a piece of cake" when there's no dessert in sight and what you mean is, "This will be easy for you to do." When you say, "It's pouring cats and dogs," I see pets coming out of a pitcher. Tell me, "It's raining hard."
Idioms, puns, nuances, inferences, metaphors, allusions, and sarcasm are lost on me.

5. Listen to all the ways I'm trying to communicate.
It's hard for me to tell you what I need when I don't have a way to describe my feelings. I may be hungry, frustrated, frightened, or confused but right now I can't find those words. Be alert for body language, withdrawal, agitation or other signs that tell you something is wrong. They're there.

Or, you may hear me compensate for not having all the words I need by sounding like a little professor or movie star, rattling off words or whole scripts well beyond my developmental age. I've memorized these messages from the world around me because I know I am expected to speak when spoken to. They may come from books, television, or the speech of other people. Grown-ups call it echolalia. I may not understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Picture this! I'm visually oriented.
Show me how to do something rather than just telling me. And be prepared to show me many times. Lots of patient practice helps me learn.

Visual supports help me move through my day. They relieve me of the stress of having to remember what comes next, make for smooth transition between activities, and help me manage my time and meet your expectations.
I need to see something to learn it, because spoken words are like steam to me; they evaporate in an instant, before I have a chance to make sense of them. I don't have instant-processing skills. Instructions and information presented to me visually can stay in front of me for as long as I need, and will be just the same when I come back to them later. Without this, I live the constant frustration of knowing that I'm missing big blocks of information and expectations, and am helpless to do anything about it.

7. Focus and build on what I can do rather than what I can't do.
Like any person, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need fixing. I avoid trying anything new when I'm sure all I'll get is criticism, no matter how "constructive" you think you're being. Look for my strengths and you will find them. There is more than one right way to do most things.

8. Help me with social interactions.
It may look like I don't want to play with the other kids on the playground, but it may be that I simply do not know how to start a conversation or join their play. Teach me how to play with others. Encourage other children to invite me to play along. I might be delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to read facial expressions, body language, or the emotions of others. Coach me. If I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know what to say. Talk to me about Emily's feelings and teach me to ask, "Are you okay?"

9. Identify what triggers my meltdowns.
Meltdowns and blow-ups are more horrid for me than they are for you. They occur because one or more of my senses has gone into overload, or because I've been pushed past the limit of my social abilities. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, and activities. A pattern may emerge.

Remember that everything I do is a form of communication. It tells you, when my words cannot, how I'm reacting to what is happening around me. My behavior may have a physical cause. Food allergies and sensitivities sleep problems and gastrointestinal problems can all affect my behavior. Look for signs, because I may not be able to tell you about these things.

10. Love me unconditionally.
Throw away thoughts like, "If you would just—" and "Why can't you—?" You didn't fulfill every expectation your parents had for you and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's happening to me, not you. Without your support, my chances of growing up to be successful and independent are slim. With your support and guidance, the possibilities are broader than you might think.
Three words we both need to live by: Patience. Patience. Patience.

View my autism as a different ability rather than a disability. Look past what you may see as limitations and see my strengths. I may not be good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, or pass judgment on other people?
I rely on you. All that I might become won't happen without you as my foundation. Be my advocate, be my guide, love me for who I am, and we'll see how far I can go.

Award-winning author and mother of sons with ADHD and autism, Ellen Notbohm's books and articles have informed and delighted millions in more than nineteen languages. Her work has won a Silver Medal in the Independent Publishers Book Awards, a ForeWord Book of Year Honorable Mention and two finalist designations, a Mom's Choice Gold Award, Learning magazine's Teacher's Choice Award, two iParenting Media awards, and an Eric Hoffer Book Award finalist designation. She is a contributor to numerous publications, classrooms, conferences and websites worldwide.

Conclusion

The time after an autism diagnosis is likely a difficult time for you. It is important to remember that you are not alone. Others have gone down this road before you. You are stronger than you think. You will learn how to overcome challenges and best meet your child's needs so that he or she can live as full and independent of a life as possible. You will also begin to experience the world in a new way; your priorities may shift and you will meet some incredible people who are dedicated to helping those with autism to succeed. Keep in mind that great strides are being made every day in the field of autism research, including many studies looking into new treatments and interventions.

There are a multitude of resources and tool kits on the Autism Speaks website to help you navigate this journey with your child. The 100 Day Kit is only the beginning. In addition, the **Autism Response Team** is available to answer your questions and connect you with resources. Please call **888-288-4762 (en Español 888-772-9050)** or email familyservices@autismspeaks.org and they are happy to help you at every step of the way.

Please do not hesitate to reach out.

Your feedback is important to us. To share your comments on the kit - What was helpful? What additional information could be included? please email your comments to familyservices@AutismSpeaks.org with the word "feedback" in the subject line.

A Week by Week Plan for the Next 100 Days

Getting Organized

The first thing you will need to do is get yourself organized. You may already find you've accumulated a lot of paperwork about your child and about autism in general. Organizing the information and records that you collect for your child is an important part of managing his or her care and progress. If you set up a simple system, things will be much easier over time. You may need to stop by an office supply store to pick up a binder, dividers, some spiral notebooks, loose leaf paper or legal pads and pens.

The Binders

Many parents find that binders are a great tool for keeping the mountain of paperwork down to a more manageable, size and for sharing information. You may want to organize by subject or by year. In either case, here are some of the subjects that you are likely to want to have at your fingertips:

Contacts

A section for service providers, caregivers and others

Schedules

A section for therapy times, program start and end dates, deadlines

Diagnosis

A section for medical documents and any prescriptions

Therapy

A section for speech, occupation therapy, SI and so on (multiple or sub sections may be necessary)

Individualized Family Service Plan (IFSP)

A section for your child's IFSP and related documents (for children under three years of age)

Individualized Education Plan (IEP)

A section for your child's IEP and related documents (for children age three and older)

We've included a sample contact list, phone log and weekly planner in this kit so you can copy and use them as needed. You may also want to summarize your child's progress in therapy and at school with cover sheets in each section; sample summary sheets are also in the Resources section.

Using Your Weekly Planner

The timeframe and action items will vary depending on your child's symptoms, age, where you live and what you have already accomplished. Even if you are very on top of this, it may take a while to be able to access additional evaluations and the services that your child needs.

Start Now

Week 1

Complete Evaluations

If your child has not had a complete work up, schedule the remainder of necessary evaluations (see Getting Services below).

Getting Services

If your child is younger than three, you'll start with Early Intervention (EI) often through your state department of health. If your child is three or older, you'll start with your local school district. Call to begin the process of getting services. EI or your school district may want to conduct evaluations of your child (at their expense). This can be a long and time consuming process, but may be useful in further determining the services that are needed.

Keep a Phone Log

Try to set aside some time each day to make the phone calls necessary to set up the evaluations and to start the process of getting services. There may be a waiting list for services and evaluations, so make the calls as soon as possible and follow up as needed. Don't hesitate to put your name on multiple lists so you can get the earliest appointment possible. Some of the professionals who provide services through Early Intervention or Special Education may take a specified number of days to complete evaluations or begin services.

Start a Video Record

Try a variety of settings and show a range of behavior. Note both good and not-so-good behavior so that, in the future, you will be able to recognize where your child was at that point in time. Make a new recording every three months at home, in therapy sessions, wherever. These video "snapshots" can be used to track your child's progress and help show what effect a particular therapy or intervention may have had. Label the tapes or discs with your child's name and the dates they were recorded.

Week 2

Getting Support

Find a support group or a parent mentor. If your child is in school, you may also want to find out if your district has a Special Education Parent Teacher Association (SEPTA), which may offer informational meetings and parent outreach.

Getting Services (Follow Up)

Follow up on services. Continue to check status on waiting lists and available programs.

Research Treatment Options

Start to read material, join online groups and ask questions that will help you understand the treatment options that are available and what might be right for your child and your family.

Week 3

Getting Services (Continue to Follow Up)

Follow up on services. Continue to check status on waiting lists and available programs. Keep using your phone log to record the dates you contacted service providers and track when you may need to make another call.

Play with Your Child

Play with your child. Play is an important part of any child's development and is a critical part of learning socialization for a child with autism. We've included a very helpful article, *Ideas for Purposeful Play*, from the University of Washington's Autism Center that illustrates how to include useful play activities, to help your child learn.

Set Aside Sibling Time

The siblings of children with autism are affected by the diagnosis as well. Consider spending time talking together about their feelings. Start a "Joy Museum" together of happy memories. Talking about these times can help them remember that their lives involve a lot more than autism.

Play with Your Child

Ideas for purposeful play are included at the end of this section of your tool kit.

Week 4

Build Your Team

By this time, your child's team of therapists, educators and caregivers is probably taking shape. Continue to look for service providers and observe as many therapy sessions as possible to identify new recruits for your child's team. Talk to other parents who may know of therapists with time available for your child. You don't have to wait until every member of the team is in place before beginning therapy.

Create a Safety Plan

You may already have had to adapt your home because of your child's behaviors or needs. You've probably already read the section of this kit called Create a Safety Plan. If not, carve out some time to survey your home for possible problems and begin contacting local safety personnel to plan ahead to ensure your child's safety.

Plan Some Time Away

Plan some time away from your child. You will do a better job helping your family if you take care of yourself. Even if it's just going for a walk alone, you are going to need a break so that you can come back with a clear head.

Week 5

Continue Building Your Team

See Week 4.

Review Your Insurance

Investigate your insurance coverage to see what, if any, therapies are covered and make sure that you are getting the most from your provider. Your health insurance may cover therapies or services not covered by your child's IFSP or IEP. You may need to create a separate binder to keep track of insurance claims. Document everything.

Get to Know Your Child's Legal Rights

Familiarize yourself with your child's rights. There is a wealth of information available. You may find out your child is entitled to services you weren't aware of or hadn't considered.

Do Something for You

You've made it through a month, and it may have been one of the most challenging months of your life. Remember to take care of yourself. Remember who you were before the diagnosis. Spend some time on an activity that you enjoy. You will find it helps you face the challenges ahead. There are probably friends and family in your life who would love to help, but may not know what you need. Don't be afraid to ask for help.

Week 6

Continue to Research Treatment Options

Continue to research treatment options. If possible, go to a workshop or look for additional information online.

Connect with Other Parents

Go to a support group or spend some time with a parent who can help you along your journey. You'll learn a lot and being around people who know what you are going through will help you stay strong.

Find Childcare

Get a babysitter. Look into qualified babysitting services and respite care. Don't wait until you're desperate—find someone you're comfortable with and plan a night out. If you already have a great babysitter, invite her or him to spend some time with you and your child so he or she can adjust to the new techniques your family is using at home.

Build Your Team

Continue to follow up on services and research any new possible providers.

Schedule a Team Meeting

If you've built a team of therapists, you may want to call a meeting to establish procedures and goals and open lines of communication. You'll also want to continue observing therapy sessions and using what you learn at home. If it's difficult to schedule a time for the service providers to meet in person, you may want to schedule a conference call instead.

Week 7

Become Competent in the Intervention Methods You Have Chosen for Your Child

Take advantage of parent training. Therapists often provide parent training that will help bring the methods used at therapy into your home and help your child's progress.

Create a Schedule

Having a written weekly schedule for your child's therapy will help you see if you've scheduled your time as well. It will also help you plan for the other members of your household.

Continue Learning about Treatments and Services

Consult the Autism Speaks Resource Guide for contacts in your area.

Spend Some Time Organizing Your Paperwork

Organize any paperwork that may have piled up. Try to eliminate any materials you won't need.

Week 8

Check Your Progress

Look back through this action item list. Is there anything you started that needs follow up?

Investigate Recreational Activities for Your Child

Add a recreational activity, such as gymnastics or swimming, to broaden your child's development.

Plan More Sibling Time

Your typically-developing children will no doubt be richer for having a sibling with autism. But maintaining as much normalcy as possible will help them reach their potential too.

Make Contact with Friends and Family

Stay connected. Make contact with your friends and family and participate in community events. Keeping up your social life will help you safeguard against feelings of isolation.

Spend Time Alone with Your Spouse

Plan a relaxing and fun activity with your partner. After all, you've just made it through month two.

Week 9

Round Out Your Team

Continue to evaluate service providers and therapists.

Use the Internet

Get e-savvy. Spend time researching online resources that will keep you up-to-date. Add useful websites to your favorites, register for e-newsletters and join list servs where parents and professionals share information.

Continue to Connect with Other Parents

Stay active with a support group or, if possible, socialize with other parents of children with autism. Being around other adults who understand what your family is going through will help you stay strong.

Check in on Your Child's Sessions

Continue to observe your child's therapy sessions. Your child should be getting used to his or her therapy routine at this point.

Play with Your Child

Play with your child. Continue to use the strategies you've learned from parent training sessions and other resources.

Week 10

Schedule a Team Meeting

It's team meeting time again. Schedule a meeting to discuss progress and strategies. Stay involved with your team by continuing to attend as many sessions as possible.

Rally the Troops

Encourage your team. Let them know you appreciate everything they are doing for your child.

Plan a Family Outing

Schedule an activity designed to include your child with autism and utilize strategies you've picked up from therapy. Ask your child's therapist to help you with specific strategies to make the outing a success.

Brush Up on the Law

Continue to learn about your child's legal rights.

Week 11

Check Your Child's Progress

Look for progress. Hopefully, your child has been through a consistent month of therapy at this point. Review your binder and videos to see if you notice improvements. Continue to attend sessions too. Take notes on what you see. Keep a copy in your binder and bring them to your next team meeting.

Dig Deeper into Treatment Options

Set aside time to do some research and reading on additional treatments and therapies. Make notes and copy useful information to include in your binder.

Week 12

Reconnect with Your Spouse

Take some one-on-one time to enjoy each other's company. If communication has been difficult, consider scheduling time with a counselor to keep your relationship healthy.

Continue Connecting with Other Parents

Keep going to support groups. Parents are amazing resources and will help provide emotional and practical support. Look into additional groups in your area if you don't feel like you've found the right one for you.

Sign Up for More Training

Using the methods you are learning from your child's therapists will help create a productive environment at home so your child will have the best chance of obtaining his or her goals.

Week 13

Hold a Team Meeting

Check on progress again. You should continue to see progress after at least six weeks of consistent therapy. If there has been little or no progress, call another team meeting to brainstorm and make adjustments to your child's routine.

Continue Learning

Keep learning about autism. Books, seminars, movies, websites – all sorts of sources can help you deepen your understanding of autism and your child. See the Suggested Reading List in this kit for ideas.

Do Something for You

Enjoy some "me" time. Do something nice for yourself – you've made it through 100 days!

Ideas for Purposeful Play

From the University of Washington Autism Center Parent Care book
Imitation: Object and Motor

- Sing finger play songs such as the Itsy Bitsy Spider, 5 Little Monkeys, Zoom down the Freeway
- Utilize musical instruments: “Let’s make music”, play Simon Says, have a musical parade, slow down, speed up, “Follow Me Song”
- Figurines: know on barn door, follow the leader to the schoolhouse
- Block play: make identical block structures
- Painting and drawing similar pictures, strokes, circles, lines, dot art
- Dramatic play: feeding babies, pouring tea, driving cars or trains on tracks, hammering nails, stirring

Receptive and Expressive Labeling
Embed labeling into activities such as:

- House (cup, spoon, plate, door)
- Grocery store (orange, apple, banana)
- Dolls (body parts, brush, clothing)
- Barn (animals, tractor)
- Art: Colors, scissors, glue, markers, big crayons, little crayons
- Books: pointing and labeling objects, letters, numbers, shapes, etc.
- Sensory Table: put different colors of animals, shapes, sizes, common objects
- Park/Playground: slide, swing, ball
- Play Dough: use different colored play dough, animal shaped cookie cutters

Receptive Instructions

- Songs: “Simon Says” clap hands, tap legs, etc.
- Clean up time: put in garbage, put on shelf
- During activities request items, “Give me ___”
- Ask child to get their coat/backpack on the way outside or at the end of the day

Matching

- Lotto matching game
- Puzzles with pictures underneath
- Picture to object matching can be done as activity during play (have the child match the picture of a cow while playing with the barn)

Requesting

- Utilize motivating items (i.e. bubbles, juice, trains) to address requesting/communication
- Swing: wait to push until child makes the request
- Door: wait to open until child makes a request
- Lunch/Snack withhold until child makes request
- Art: child can request glitter, glue, stickers, paint, etc.

Comparing Treatment Methods & Providers

Adapted from: Does My Child Have Autism? By Wendy L. Stone, Ph.D. with Theresa Foy DiGeronimo

ABOUT THE PROGRAM

Name of Program/Provider	
Method	
Location	
Phone Number	
Email	
Website	
Hours per Week	
Cost	
Reimbursement	
Recommended by	

PROGRAM CONTENT

What are the developmental areas of focus? (language, communication, peer play, social interactions, behavior, pre-academic skills, parent training, etc.)	
How specific are the goals identified for each child?	
How are behaviors and skills prioritized?	
What kind of teaching is used?	
How are behaviors managed?	

MEASURING PROGRESS

How will I know if my child is making progress?	
How long will it be before I see changes?	
What types of improvements should I expect?	

How often will you assess progress and how is it measured?	
What will happen if my child doesn't make progress with this treatment?	

THERAPIST QUALIFICATIONS

How many children with autism have you worked with? What ages?	
Do you serve children over three years old?	
What are your qualifications? What type of training do you have?	
Do you have a professional degree or certificate? (Ask for details.)	
Are you affiliated with a professional organization? (Ask for details.)	
What do you see as your strongest skill in working with children with autism?	
Are there issues or problems you consider to be outside of your realm of expertise?	

SCIENTIFIC EVIDENCE OF EFFECTIVENESS

Is there research to support the effectiveness of this type of treatment? (Ask for details as well as copies of published articles.)	
Has research shown this treatment to be better than other types of treatment?	

PROFESSIONAL INVOLVEMENT

Who will be providing the direct intervention with my child?	
What type of training does he/she have?	
Who will be supervising him/her and how?	
How often will you see my child personally?	

PARENT INVOLVEMENT

Will I be able to participate in the treatment?	
Will you teach me how to work with my child? How?	
What skills will you teach me? (Ask for examples.)	

COMPATIBILITY WITH OTHER TREATMENTS

How many hours per week of your treatment will my child need?	
Is your treatment compatible with other interventions my child is participating in?	
How do you collaborate with other therapy providers on my child's team? (Get examples.)	

Service Provider Planner

Agency & Contact	Phone #	Date Called	Requested Services	Requested # of Sessions and Duration	Availability	Status	Follow-Up	Other Info

Service Provider Planner

Agency & Contact	Phone #	Date Called	Requested Services	Requested # of Sessions and Duration	Availability	Status	Follow-Up	Other Info

CONTACTS: MEDICAL

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
Address	
Email Address/ Website	

Specialty	
Name of Contact	
Name of Practice	
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CONTACTS: THERAPY

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PHONE LOG

NAME OF CONTACT: ___________________________________

PHONE NUMBER: _____________________________________

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

PHONE LOG

NAME OF CONTACT: ________________________________

PHONE NUMBER: __________________________________

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Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

PHONE LOG

NAME OF CONTACT: ________________________________

PHONE NUMBER: ________________________________

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

Date/Time	
Summary of Call	
Follow-up Required	

ASSESSMENT TRACKING

Type of Therapy ________________

Date	Test Administered	Evaluator	Standard Score	Age Equivalent	Change in Standard Score	Change in Age Equivalent

ASSESSMENT TRACKING

Type of Therapy ________________

Date	Test Administered	Evaluator	Standard Score	Age Equivalent	Change in Standard Score	Change in Age Equivalent

GOAL TRACKING: IFSP GOALS

Date Date	Comments Comments	Goals Mastered Goals Mastered	Goals Making Progress	Goals Just Started Goals Just Started	Goals Not Started Goals Not Started

GOAL TRACKING: IFSP GOALS

Date	Comments	Goals Mastered	Goals Making Progress	Goals Just Started	Goals Not Started

Safety Log

In the chart below, include any wandering incidents, attempts or interactions that put your child at risk. Keep track of what was going on before, during and after the incident to try and determine antecedents, triggers and possible prevention methods. Ask your child's behavioral team, teachers and other caregivers to complete the log as needed.

Date	Location	Description	Possible Triggers	Changes Noted	Suggested Next Steps

Glossary

Note: Visit the Autism Speaks Video Glossary at
AutismSpeaks.org/what-autism/video-glossary
to see video of the items in blue.

A

Absence Seizure, *see Seizures.*

Americans with Disabilities Act (ADA) is the US law that ensures rights of persons with disabilities with regard to employment and other issues.

Angelman Syndrome is a genetic disorder causing developmental delays and neurological problems, often accompanied by seizures. Children often display hyperactivity, small head size, sleep disorders and movement and balance disorders.

Anticonvulsant is a type of drug used to prevent or stop seizures or convulsions; also called antiepileptic.

Anxiety Disorder is a disorder that affects an estimated 30% of individuals with autism and includes social phobia, separation anxiety, panic disorder and specific phobias. An individual suffering from anxiety may experience strong internal sensations of tension such as a racing heart, muscular tensions and stomachache.

Applied Behavior Analysis (ABA) is a style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught to child through a system of reinforcement.

Asperger Syndrome is a developmental disorder on the Autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors, without a significant delay in language and cognitive development. The diagnosis is no longer used in DSM5, but DSM5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Attention Deficit Hyperactivity Disorder (ADHD) is a disorder that affects approximately 1 in 5 children with autism. Symptoms include chronic problems with inattention, impulsivity and hyperactivity.

Audiologist is a professional who diagnoses and treats individuals with hearing loss or balance problems.

Auditory Integration Training, or sound therapy, is used to treat children with difficulties in auditory processing or sound sensitivity and involves the individual listening to electronically modified music through headphones during multiple sessions.

Autism Diagnostic Observation Schedule (ADOS) is a test considered to be current gold standard for diagnosing ASD and, along with information from parents, should be incorporated into a child’s evaluation.

Autism Speaks Insurance Link is a tool to help families in the autism community determine whether an individual is entitled to coverage for the treatment of autism under their health insurance plan.

Autism Speaks Toddler Treatment Network (TTN) supports a consortium of research sites studying behavioral interventions appropriate for children under 18 months of age.

Autism Spectrum Disorder and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD.

B

C

Casein is protein found in milk, used in forming the basis of cheese and as a food additive.

Celiac Disease is a disease in which there is an immunological reaction within the inner lining of the small intestine to gluten, causing inflammation that destroys the lining and reduces the absorption of dietary nutrients. It can lead to symptoms of nutritional, vitamin and mineral deficiencies.

Childhood Disintegrative Disorder is a disorder in which development begins normally in all areas, physical and mental. At some point between 2 and 10 years of age, the child loses previously developed skills. The child may lose social and language skills and other functions, including bowel and bladder control. The diagnosis is no longer used in DSM5, but DSM5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Chronic Constipation is an ongoing condition of having fewer than three bowel movements per week.

Cognitive Skills are any mental skills that are used in the process of acquiring knowledge; these skills include reasoning, perception and judgment.

Colitis is inflammation of the large intestine.

Complete Blood Count (CBC) is a lab test reporting number of white blood cells, red blood cells, platelets, hemoglobin, hematocrit and other values reflecting overall blood health.

Compulsions are deliberate repetitive behaviors that follow specific rules, such as pertaining to cleaning, checking or counting. In young children, restricted patterns of interest may be early sign of compulsions.

Computed Axial Tomography (CT) examines organs by scanning with X rays and using computer to construct series of cross-sectional scans. Called “CAT” scan.

D

Declarative Language is used to communicate what the mind is producing. It is what is most common in conversation, whereas Imperative Language is used to ask questions, make commands or give instructions.

Developmental Disorder refers to several disorders that affect normal development. May affect single area of development (specific developmental disorders) or several (pervasive developmental disorders).

Developmental Individual Difference Relationship (DIR) is a type of therapy, known as Floortime, that seeks to move the child toward increasingly complex interactions through mutually shared engagement.

Developmental Milestones are skills or behaviors that most children can do by a certain age that enable the monitoring of learning, behavior and development.

Developmental Pediatrician is a medical doctor who is board-accredited and has received sub-specialty training in developmental-behavioral pediatrics.

Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is the official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association in 2013 that, among other changes, established new criteria for an autism diagnosis, eliminated the previously separate subcategories on the autism spectrum, including Asperger Syndrome, PDD-NOS, Childhood Disintegrative Disorder and Autistic Disorder and added a new category called Social Communication Disorder (SCD).

Discrete Trial Training (DTT) is a technique incorporating principles of ABA, including positive reinforcement used to teach behaviors in one-to-one setting. Concepts are broken down into small parts.

E

Early Autism Risk Longitudinal Investigation (EARLI) is a network of research sites that enrolls and follows a large group of mothers of children with autism at the start of another pregnancy and documents the newborn child's development through three years of age.

Early Intervention (EI) is a state-funded program designed to identify and treat developmental problems or other disabilities as early as possible. Eligibility for EI is from birth to three years of age.

Early Start Denver Model (ESDM) is a comprehensive behavioral early intervention approach for children with autism, ages 12 to 48 months, that uses a developmental curriculum that defines the skills to be taught at any given time and a set of teaching procedures used to deliver this content.

Echolalia is repeating words or phrases heard previously, either immediately after hearing word or phrase or much later. Delayed echolalia occurs days or weeks later. Functional echolalia is using quoted phrase in a way that has shared meaning, for example, saying "carry you" to ask to be carried.

Electroencephalogram (EEG) is a test using electrodes on scalp to record electrical brain activity. For diagnoses of seizure disorder or abnormal brain wave patterns.

Epilepsy (seizure disorder) is a pattern of repeated seizures, causes include head injury, brain tumor, lead poisoning, genetic and infectious illnesses. Cause is unknown in 50% of cases.

Esophagitis is inflammation of the esophagus, the soft tube-like portion of the digestive tract connecting the pharynx with the stomach.

Expressive Labeling is the communication of a name for an object or person, see expressive language.

Expressive Language is communication of intentions, desires or ideas to others, through speech or printed words and includes gestures, signing, communication board and other forms of expression.

Extended School Year (ESY) Services are provided during breaks from school, such as during summer vacation, for students who experience substantial regression in skills during school vacations.

F

Free Appropriate Public Education (FAPE) means that education must be provided to all children ages three to twenty-one at public expense.

Floortime is a developmental intervention for children with autism involving meeting a child at his current developmental level and building upon a particular set of strengths.

Fragile X syndrome is a genetic disorder that shares many of the characteristics of autism. Individuals may be tested for Fragile X.

G

Gastritis is inflammation of the stomach.

Gastroenterologist is a doctor specializing in diagnosis and treatment of disorders of GI tract, including esophagus, stomach, small intestine, large intestine, pancreas, liver, gallbladder and biliary system.

Gastroesophageal Reflux is the return of stomach contents back up into the esophagus which frequently causes heartburn due to irritation of the esophagus by stomach acid.

Gastrointestinal pertains to the digestive tract, including the mouth, throat, esophagus, stomach, small intestine, large intestine and rectum.

Geneticist refers to a medical doctor who specializes in genetic problems. Genes are the unit in the chromosome that contain the blueprint for the transmission of inherited characteristics.

Gestures are hand and head movements, used to signal to someone else, such as a give, reach, wave, point or head shake. They convey information or express emotions without the use of words.

Global Developmental Delay is diagnosis in children younger than 5, characterized by delay in two or more developmental domains, sometimes associated with mental retardation.

Gluten is a protein present in wheat, rye and barley.

Grand mal seizure, see Seizures.

H

High Risk Baby Siblings Research Consortium (BSRC) is a joint venture between Autism Speaks and the National Institute of Child Health and Human Development that is focused on making discoveries that will help researchers develop new ways to treat or even prevent debilitating symptoms by intervening at an early age.

Hyperlexia is the ability to read at an early age. To be hyperlexic, a child does not need to understand what he or she is reading.

Hyperresponsiveness*, hypersensitivity, see Sensory Defensiveness.*

Hyporesponsiveness, hyposensitivity, is abnormal insensitivity to sensory input. Could be exhibited by a child who appears to be deaf, whose hearing is normal, is under reactive to sensory input, may have a high tolerance to pain, may be clumsy, sensation seeking and may act aggressively.

I

Incidental Teaching teaches a child new skills while in their home or community, in natural context or "in the moment," to help make sense of what they learn during formal instruction and generalize new skills.

Individual Family Service Plan (IFSP) is developed by a multidisciplinary team including family as primary participant. Describes child's level of development in all areas; family's resources, priorities and concerns, services to be received and the frequency, intensity and method of delivery. Must state natural environments in which services will occur.

Individualized Education Plan (IEP) identifies student's specific learning expectations, how school will address them with appropriate services and methods to review progress. For students 14 and older, must contain plan to transition to postsecondary education or the workplace or to help the student live as independently as possible in the community.

Individuals with Disabilities Education Act (IDEA) is the US law mandating the "Free and Public Education" of all persons with disabilities between ages 3 and 21.

Inclusion involves educating all children in regular classrooms, regardless of degree or severity of disability. Effective inclusion takes place with planned system of training and supports; involves collaboration of multidisciplinary team including regular and special educators.

J

Joint Attention is the process of sharing one's experience of observing an object or event, by following gaze or pointing gestures. Critical for social development, language acquisition, cognitive development. Impairment in joint attention is a core deficit of ASD.

K

L

Least Restrictive Environment (LRE) is setting that least restricts opportunities for child with disabilities to be with peers without disabilities. The law mandates that every child with a disability be educated in a Least Restrictive Environment.

M

Magnetic Resonance Imaging (MRI) is a diagnostic technique using powerful electromagnets, radio frequency waves and a computer to produce well defined images of the body's internal structures.

Mainstreaming is where students are expected to participate in existing regular ed classes, whereas in an inclusive program classes are designed for all students. May be gradual, partial or part-time process (e.g., student may attend separate classes within regular school or participate in regular gym and lunch only).

Melatonin is a hormone produced by pineal gland, involved in regulating sleeping and waking cycles. Sometimes used for chronic insomnia. Consult your child's physician before giving melatonin; it is not recommended for all patients with sleep problems.

Modified Checklist of Autism in Toddlers (MCHAT) is a screening tool for identifying young children who may be referred to specialist for further evaluation and possible Autism Spectrum Disorder diagnosis.

Motor deficits are physical skills that a person cannot perform or has difficulty performing.

Motor function (or motor skills) is the ability to move and control movements.

N

Neurologist refers to a doctor specializing in medical problems associated with the nervous system, specifically the brain and spinal cord.

Nonverbal Behaviors are things people do to convey information or express emotions without words, including eye gaze, facial expressions, body postures and gestures.

O

Obsessions are persistent and intrusive repetitive thoughts. Preoccupations with specific kinds of objects or actions may be an early sign of obsessions.

Obstructive Sleep Apnea breathing disorder interrupting breathing during sleep when air flow cannot flow through the nose or mouth although efforts to breathe continue. Throat collapses during sleep causing snorting and gasping for breath. May cause daytime sleepiness. May increase risk of hypertension and heart problems.

Occupational Therapy assists development of fine motor skills that aid in daily living. May focus on sensory issues, coordination of movement, balance and self-help skills such as dressing, eating with a fork, grooming, etc. May address visual perception and hand-eye coordination.

Occupational Therapist helps minimize impact of disability on independence in daily living by adapting child's environment and teaching sub-skills of the missing developmental components.

Operant Conditioning is the modification of behavior through positive and/or negative reinforcement.

P

Perseveration is repetitive movement or speech or sticking to one idea or task, that has a compulsive quality to it.

Pervasive Developmental Disorders (PDD) is group of conditions involving delays in development of many basic skills, including ability to socialize with others, to communicate and use imagination. Includes Autism, Asperger Syndrome, Childhood Disintegrative Disorder, Rett Syndrome and Pervasive Developmental Disorder - Not Otherwise Specified. Persuasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) a category of PDD referring to children having significant problems with communication and playand some difficulty interacting with others ,but are too social for diagnosis of autism. The diagnosis is no longer used in

DSM5, but DSM5 indicates that individuals with a “well-established diagnosis” of these conditions “should be given the diagnosis of autism spectrum disorder.”

Petit Mal Seizure, *see Seizures.*

Physical Therapy uses specially designed exercises and equipment to help patients regain or improve their physical abilities.

Physical Therapist designs and implements physical therapy programs and may work within a hospital or clinic, in a school or as an independent practitioner.

Pica is persistent eating or mouthing of non-nutritive substances for at least 1 month when behavior is developmentally inappropriate (older than 18-24 months). Substances may include items such as clay, dirt, sand, stones, pebbles, hair, feces, lead, laundry starch, wood, plastic and more.

Picture Exchange Communication System (PECS) is an alternative communication system using picture symbols taught in phases starting with simple exchange of symbol for desired item. Individuals learn to use picture symbols to construct complete sentences, initiate communication and answer questions.

Pivotal Response Treatment (PRT) is a therapeutic teaching method using incidental teaching opportunities to target and modify key behaviors related to communication, behavior and social skills.

Pragmatics are social rules for using functional spoken language in a meaningful context or conversation. Challenges in pragmatics are a common feature of spoken language difficulties in children with ASD.

Prevalence is the current number of people in a given population who have a specific diagnosis at a specified point in time. As of May 2014, the U.S. Centers for Disease Control and Prevention estimated autism prevalence as 1 in 68 children, including 1 in 42 boys and 1 in 189 girls.

Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) is an approach used in speech-language therapy that manually guides an individual’s jaw, tongue and lips through a targeted word, phrase or sentence to develop motor control and proper oral muscular movements, while eliminating unnecessary muscle movements such as jaw sliding.

Proprioception is the receiving of stimuli originating in muscles, tendons and other internal tissues.

Prosody is the rhythm and melody of spoken language expressed through rate, pitch, stress, inflection or intonation. Some children with ASD have unusual intonation (flat, monotonous, stiff or “sing songy” without emphasis on the important words).

Psychiatrist is a doctor specializing in prevention, diagnosis and treatment of mental illness who has received additional training and completed a supervised residency in specialty. May have additional training in specialty, such as child psychiatry or neuropsychiatry and can prescribe medication, which psychologists cannot do.

Psychologist is a professional who diagnoses and treats diseases of the brain, emotional disturbance and behavior problems. May have a master’s degree (M.A.) or doctorate (Ph.D.) in psychology. May have other qualifications, including Board Certification and additional training in a specific type of therapy.

Q

R

Receptive Labeling, *see receptive language.*

Receptive Language is the ability to comprehend words and sentences and begins as early as birth and increases with each stage in development. By 12 months of age, a child begins to understand words and responds to his or her name and may respond to familiar words in context. By 18 to 20 months, a child identifies familiar people by looking when named (e.g., Where's mommy?), gives familiar objects when named (e.g., Where's the ball?) and points to a few body parts (e.g., Where's your nose?). These skills commonly emerge slightly ahead of expressive language skills.

Reinforcement or reinforcer, is any object or event following a response, increasing or maintaining the rate of responding. Positive reinforcer may be produced by or added after a response.

Relationship Development Intervention (RDI) is a therapeutic teaching method based on building intelligence competencies of social connection – such as referencing, emotion sharing, coregulation and experience sharing – that normally develop in infancy and early childhood.

Respite Care is temporary, short-term care provided to individuals with disabilities, delivered in the home for a few short hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue.

Rett Syndrome is a very rare disorder in which patients have symptoms associated with PDD along with problems with physical development. They generally lose many motor or movement skills – such as walking and use of hands – and develop poor coordination. The condition has been linked to a defect on the X chromosome and as a result, almost always affects girls.

S

Seizure refers to uncontrolled electrical activity in the brain, which may produce a physical convulsion, minor physical signs, thought disturbances or a combination of symptoms.

Seizure, absence, takes the form of a staring spell as the person suddenly seems "absent" and has a brief loss of awareness. May be accompanied by blinking or mouth twitching. Absence seizures have very characteristic appearance on EEG. Also called a petit mal seizure.

Seizure, atonic, is a seizure marked by the person losing muscle tone and strength and unless supported, falls down. Atonic means lack of muscle tone and strength.

Seizure, subclinical (Electrographic Seizures) are visible on the EEG, but the patient does not exhibit clinical symptoms. Electroencephalography often detects subclinical seizures during sleep.

Seizure, tonic clonic, involves two phases – tonic phase when body becomes rigid and clonic phase of uncontrolled jerking. May be preceded by aura and is often followed by headache, confusion and sleep. May last for seconds or continue for several minutes.

Self-Regulation and self-control are related but not the same. Self-regulation refers to both conscious and unconscious processes that have an impact on self-control, but regulatory activities take place more or less constantly to allow us to participate in society, work and family life. Self-control is a conscious activity.

Sensory Defensiveness is a tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others. Also called hypersensitivity.

Sensory Input*, see sensory stimuli.*

Sensory Integration is the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

Sensory Integration Dysfunction a neurological disorder causing difficulties processing information from the five classic senses (vision, hearing, touch, smelland taste), sense of movement (vestibular system)and positional sense (proprioception). Sensory information is sensed normally, but perceived abnormally. May be a disorder on its own or with other neurological conditions.

Sensory Integration Therapy is used to improve ability to use incoming sensory information appropriately and encourage tolerance of a variety of sensory inputs.

Sensory Stimulus Agent, action or condition, internal (e.g., heart rate, temperature) or external (e.g., sights, sounds, tastes, smells, touchand balance) that elicits physiological or psychological response. Response depends on ability to regulate and understand stimuli and adjust emotions to demands of surroundings.

Sleep Hygiene a set of practices, habits and environmental factors critically important for sound sleep, such as minimizing noise, light and temperature extremes and avoiding naps and caffeine.

Social Communication Disorder (SCD) is a new diagnostic category established in the DSM-5 that applies to individuals who have deficits in the social use of language, but do not have the restricted interests or repetitive behavior you see in those with autism spectrum disorders.

Social Communication/Emotional Regulation/Transactional Support (SCERTS) is an educational model of treatment that differs notably from the focus of “traditional” ABA by promoting child-initiated communication in everyday activities.

Social Reciprocity is back-and-forth flow of social interaction. How behavior of one person influences and is influenced by behavior of another and vice versa.

Social Stories, developed by Carol Gray, are simple stories that describe social events and situations that are difficult for a child with a PDD to understand. For example, a social story might be written about birthday parties if the child appears to have a difficult time understanding what is expected of him or how he is supposed to behave at a birthday party.

Social Worker is a trained specialist in the social, emotional and financial needs of families and patients. Social workers often help families and patients obtain the services they have been prescribed.

Special Education is specially designed instruction, at no cost to families, to meet unique needs of child with disability, including instruction conducted in the classroom, in the home, in hospitals and institutions and in other settings and instruction in physical education.

Speech-Language Therapist or Speech Language Pathologist, specializes in human communication. The focus is on communication, not speech, to increase child's ability to impact and understand their environment.

Speech-Language Therapy is provided with the goal of improving an individual's ability to communicate. This includes verbal and nonverbal communication. The treatment is specific to the individual's need.

Spoken Language (also referred to as expressive and receptive language) is the use of verbal behavior or speech, to communicate thoughts, ideas and feelings with others. Involves learning many levels of rules - combining sounds to make words, using conventional meanings of words, combining words into sentences and using words and sentences in following rules of conversation.

Stereotyped Behaviors refer to an abnormal or excessive repetition of an action carried out in the same way over time. May include repetitive movements or posturing of the body or objects.

Stereotyped Patterns of Interest or restricted patterns of interest refer to a pattern of preoccupation with a narrow range of interests and activities.

Stimming or "self-stimulating" behaviors, are stereotyped or repetitive movements or posturing of the body that stimulate ones senses. Some "stims" may serve a regulatory function (calming, increasing concentration or shutting out an overwhelming sound).

Subclinical Seizure, *see Seizures.*

Symbolic Play is where children pretend to do things and to be something or someone else. Typically develops between the ages of 2 and 3 years. Also called make believe or pretend play.

Syndrome is a set of signs and symptoms that collectively define or characterize a disease, disorder or condition.

T

Tactile Defensiveness is a strong negative response to a sensation that would not ordinarily be upsetting, such as touching something sticky or gooey or the feeling of soft foods in the mouth. Specific to touch.

TEACCH is a therapeutic approach broadly based on the idea that individuals with autism more effectively use and understand visual cues.

Tonic-clonic seizure, *see Seizures*

Typical Development (or healthy development) describes physical, mental and social development of a child who is acquiring or achieving skills according to expected time frame. Child developing in a healthy way pays attention to voices, faces and actions of others, showing and sharing pleasure during interactions and engaging in verbal and nonverbal back-and-forth communication.

U

V

Verbal Behavior is a method of Applied Behavioral Analysis (ABA) for teaching children with autism, based on B.F. Skinner's description of the system of language.

Vestibular System refers to the body's system for maintaining equilibrium.

W

X

Y

Z

Resources

Different books and websites resonate with different families. Here are some that parents have recommended. For a more complete list of books and web sites, as well as magazines, products, and DVDs, please visit our ***Resource Library*** on the Autism Speaks web site, **AutismSpeaks.org**.

BOOKS

1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorder
by Veronica Zysk and Ellen Notbohm

Activity Schedules for Children with Autism: Teaching Independent Behavior
by Lynn E., McClannahan, Ph.D. and Patricia J. Krantz, PhD

Autism Solutions
by Ricki Robinson, MD

The Autism Sourcebook
by Karen Siff Exkorn

Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder and Other ASDs
by Chantal Sicile-Kira

Autism Spectrum Disorders: What Every Parent Needs to Know
from the *American Academy of Pediatrics*, edited by Alan I. Rosenblatt and Paul S. Carbone

Changing the Course of Autism: A Scientific Approach for Parents and Physicians
by Brian Jepson, M.D. and Jane Johnson

Children with Autism: A Parent's Guide
by Michael D. Powers

Could it be Autism? A Parent's Guide to the First Signs and Next Steps
by Nancy Wiseman

Does My Child Have Autism? A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders
by Wendy L. Stone, Ph.D. and Theresa Foy Digeronimo, MEd

Facing Autism: Giving Parents Reasons for Hope and Guidance for Help
by Lynn M. Hamilton

Let Me Hear Your Voice: A Family's Triumph over Autism
by Catherine Maurice

Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts
by Susan Senator

Not My Boy!: A Father, A Son, and One Family's Journey with Autism
by Rodney Peete

Nourishing Hope
by Julie Matthews

Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life
by Lynn Kern Koegel, PhD Claire LaZebnik

Playing, Laughing and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Caregivers
by Julia Moor

Play and Engagement in Early Autism: The Early Start Denver Model
by Sally Rogers, PhD and Geraldine Dawson, PhD

A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know
by Fred R. Volkmar and Lisa A. Wiesner

Siblings of Children with Autism: A Guide for Families
by Sandra L. Harris, PhD and Beth A. Glasberg, PhD

Special Diets for Special People: Understanding and Implementing a Gluten-Free and Casein-Free Diet to Aid in the Treatment of Autism and Related Developmental Disorders
by Lisa S. Lewis

Ten Things Every Child with Autism Wishes You Knew
by Ellen Notbohm

Thinking in Pictures, Expanded Edition: My Life with Autism
by Temple Grandin, PhD

Understanding Autism For Dummies
by Stephen Shore and Linda G. Rastelli

WEBSITES

Autism Speaks
AutismSpeaks.org

Autism Research Institute
Autism.com

Autism Society
Autism-Society.org

AWAARE: Autism Wandering Awareness Alerts Response and Education Collaboration
awaare.org

Center for Autism & Related Disorders
centerforautism.com

Interactive Autism Network
ianproject.org

OCALI: Ohio Center for Autism and Low Incidence
ocali.org

Organization for Autism Research
ResearchAutism.org

Have more questions or need assistance? Please contact the Autism Response Team for information, resources and tools.

TOLL FREE: 888-AUTISM2 (288-4762)
EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG
WWW.AUTISMSPEAKS.ORG
Text ART to 30644

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Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed more than $500 million to its mission, the majority in science and medical research. Each year Walk Now for Autism Speaks events are held in more than 100 cities across North America. On the global front, Autism Speaks has established partnerships in more than 40 countries on five continents to foster international research, services and awareness.

To learn more about Autism Speaks, please visit AutismSpeaks.org.

ACCESS 2

An Easter Seals Canada Program

Easter Seals Timbres de Pâques Canada

Access 2 Card Application Form

Instructions

1. Read this document carefully. If you have any questions, please visit www.access2card.ca
2. If this is your first Access 2 Card, print, complete and submit sections B (Applicant Information), C (Health Care Professional Authorization) and D (Administration Fee Payment) – along with the administrative fee.
3. If you are renewing an expired card or replacing a lost card, submit only sections B and D - along with the administrative fee.
4. Mail, fax, or email completed Sections B and/or C and D to Easter Seals Canada.
5. Include administration fee: by cheque or money order (payable to "Easter Seals Canada") or online payment (credit card, Visa debit, or PayPal - payable at www.access2card.ca). Paying online is highly recommended as you will receive your card faster. See section D for payment details.
6. Keep a copy of the application form for your records.

Important: You may only purchase one Access 2 Card per individual who has a disability.

Program Overview

The Access 2 Card is for people of all ages and types of **permanent** disabilities who require the assistance of a support person. When a cardholder presents the Access 2 Card at a participating movie theatre or selected attraction across Canada, the support person is then given one free or discounted admission. The person with the disability pays regular admission price. **For a full list of participating venues, visit**: www.access2card.ca.

Persons with a permanent disability who require a support person when attending a movie theatre or attraction are eligible for the Access 2 Card. The applicant must agree to follow the terms and conditions for use of the card (see next page).

A support person is an individual who accompanies a person with a disability to provide those services that are not provided by the participating theatre/attraction employees, such as assisting the person with eating, administering medication, communication and use of the facilities.

There is a $20 (3-year valid card) or a $30 (5-year valid card) fee to acquire the Access 2 Card. The card will be valid for either 3 or 5 years and can be used at all Access 2 Card participating venues.

Terms and Conditions

1. The application form must be submitted by a person with a disability or a legal guardian on his or her behalf. If the applicant is unable to sign, a legal guardian can sign on their behalf.

2. The applicant must be identified as having a disability that requires a support person/attendant while attending an entertainment, cultural, recreation or attraction. This must be verified by a registered health care professional or a recognized service provider (see section C for a complete list of regulated health care professionals).

3. The applicant must be a client of the authorizing health care professional/service provider. The authorized health care provider signing section C must **NOT** be related to the applicant. We do **NOT** accept medical or diagnosis letters.

4. If the applicant has a CNIB ID card, a photocopy of the card can be submitted in place of the Section C. In this case, you do not have to complete section C. DO NOT SEND ORIGINALS OF THE CNIB CARD.

5. This card is valid for a period of **3 or 5 years** from date of issue after which a renewal application form must be filed with Easter Seals Canada. **$20 for a 3-year card or $30 for a 5-year card**.

6. The applicant must present the Access 2 Card at the movie theatre or selected attraction or venue's box office when purchasing his or her own ticket. The Access 2 card cannot be used in such way where two free entries are granted. One individual must pay admission, regardless of other promotions. An attendant is defined as an adult who is 18 years or older. Photo Identification is not necessary; however, the theatre or attraction may ask to see a second piece of photo identification.

7. Prices may vary by participating venue. No advanced tickets or admissions can be obtained with this card. For theatres: admission tickets can only be issued on the day of the selected movie.

8. Tickets can only be purchased in person together with a support person attending the same attraction. Under no circumstances are tickets to be resold.

9. This program is administrated by Easter Seals Canada on behalf of the Access 2 Card partners. Upon submission of your complete application please allow 4-6 weeks for processing of your application and delivery of your Access 2 Card.

10. There is a $20 or $30 (see no. 5) replacement fee for a lost or stolen card. Send a cheque made out to Easter Seals Canada to 40 Holly St. Suite 401, Toronto, ON, M4S 3C3 - or pay online. Paying online is highly recommended-as you will receive your card faster.

11. Applications that are incomplete or improperly completed will not be processed. The applicant will be notified and asked to resubmit a complete and corrected application.

12. Misuse or abuse of this card could result in the termination of the card and its privileges.

13. These terms and conditions are subject to change without notice.

ACCESS 2
An Easter Seals Canada Program

Easter Seals Timbres de Pâques Canada

Access 2 Card Application Form

Section B – Applicant Information

***Select the type of card you are applying for by checking off a box**:

(Only select “new card” if this is your first Access 2 Card)

☐ **New Card** ☐ **Renewal/Expired Card** ☐ **Lost Card**

If you have had a card in the past, write the barcode below (if known):

___ ___ ___ ___ - ___ ___ ___ ___ ___ ___ **Preferred Language**: ☐ English ☐ French

***Applicant Name (Person with the Permanent Disability)**

First Name: ______________________________ Last Name: __________________________________

***Date of Birth** (dd/mm/yyyy): _______ / _______ / ______________

***Mailing Address**: ____ **Unit #**: ___________

***City**: ______________________________ ***Province**: _____________ ***Postal Code**: ________________

***Phone**: (___________) - ___________ - ______________

***E-mail**: ____

I certify that I understand the terms and conditions as set forth in this application.

➡ ***Applicant or Guardian’s Signature**: ____________________________________ **Date**: _________________

*Only “*new*” card applicants are required to complete and submit *Section C – Health Care Professional Authorization* of this application.

*All applicants (New, Renewal/Expired, Lost) must pay the administration fee for the Access 2 card. Please ensure to also complete and submit *Section D – Administration Fee Payment* of this application.

Easter Seals Canada is committed to protecting the privacy, confidentiality and security of any personal information we collect, use, and retain.

I wish to receive email communications about the Access 2 Card Program and other information about Easter Seals Canada, check this box: ☐

Section C – Health Care Professional Authorization

Section C must be filled out by one of the authorized health care practitioners*.

IMPORTANT: This section *only* needs to be completed for **New Access 2 card** applicants. **Renewal/Expired** and **Lost card** applicants do *not* need to have it completed. New applicants with a **CNIB ID card** do *not* need to have this section completed (simply provide a photocopy of your CNIB card with your application).

***Type of Accepted Health Care Professional (select one)**:

☐ Physician	☐ Speech Language Pathologist
☐ Nurse	☐ Occupational Therapist
☐ Social Worker (RSW)	☐ Audiologist
☐ Physiotherapist	☐ Psychiatrist
☐ Behaviour Analyst (BCBA)	☐ Recreational Therapist
☐ Psychologist	☐ Éducateur/trice (QC only)
☐ Executive Director of a Disability Services Provider *Organization Name: ________________________________	

Professional Stamp (if available)

> *I certify that the applicant, who is a client/patient of mine, is a person with a* ***PERMANENT disability*** *who, due to the disability,* ***needs to be accompanied by a support person*** *to assist with communication, mobility, personal/medical needs or with access to goods, services or facilities. I certify further that the information I have provided in this application is accurate and complete to the best of my knowledge.*

Patient's name (Access 2 Card Applicant): ____

Name of Health Care Professional OR Executive Director: ____

Professional Registration Number: ____

Practice/Service Address: ____ **Unit #**: __________

City: ___________________________________ **Province**: ___________ **Postal Code**: ___________________

Phone: (______) - _______ - __________ x. ______**E-mail**: ____

➡ **Health Care Professional OR Executive Director Signature**: ____

Date: ____________________________

-Signatures from other types of health care professionals not included on the list above will **NOT** be accepted;
-**NO OTHER** forms or letters will be accepted in place of this section – e.g. diagnosis letters;
-Easter Seals Canada is committed to protecting the privacy, confidentiality and security of any personal information we collect, use, and retain.

Section D – Administration Fee Payment

IMPORTANT: The administration fee must be paid BEFORE we can process your application. Payment must be made for all applications (New, Renewal/Expired, Lost).

- If you are paying by cheque or money order (payable to "Easter Seals Canada"), please mail it along with your application.

- If you are paying online with a credit card, Visa debit card or PayPal account, you must submit your application after payment. Pay online at www.access2card.ca. Paying online results in the fastest turn-around time.

*Select Your Access 2 Card Type:

☐ **3-Year Valid Card ($20)**

☐ **5-Year Valid Card ($30)**

*Select Your Payment Method:

☐ **Online Payment**
(Pay at www.access2card.ca)

*Name of credit card holder:

____

*Name of Access 2 Card Applicant:

____

*Transaction Confirmation Code
(sent by e-mail after online payment is complete):

ESC - ______________________________

The charge on your account statement will appear as being paid to "Easter Seals Canada".

☐ **Cheque or Money Order**
(send with completed application)

Please ensure that the cheque/money order is:

- ○ Payable to "Easter Seals Canada"
- ○ Dated within the last 6 months
- ○ Signed

Application Checklist (For Your Reference)

- ☐ Complete Section B (Applicant Information)
- ☐ Complete Section C (Health Care Professional Authorization) – New applicants ONLY
- ☐ Complete Section D (Administration Fee Payment)
- ☐ Pay online or enclose the administration fee made payable to Easter Seals Canada
- ☐ Enclose a self-addressed, stamped, return envelope (mailed-in applications only)*
- ☐ Only submit Sections B, C, and D – and not this entire package.

*Please make sure the envelope is at least "standard business" size as we are mailing you your card.

Submitting Your Application

There are three ways to submit your application: by mail, fax, or e-mail.
Payment must be made prior to submitting your application.

Mailing Address:

Access 2 Program
40 Holly Street, Suite 401
Toronto, ON
M4S 3C3

Fax:

416-932-9844

E-Mail (Scanned):

access2card@easterseals.ca

If you have any questions, please contact us by:

- E-Mail: access2card@easterseals.ca
- Phone: 1-877-376-6362 (Toll-Free) or 416-932-8382

Allow four to six weeks for your Access 2 card to be delivered. Please refrain from contacting us to check the status of your application for at least four weeks after it has been submitted.

AccessAbility Supports

The Disability Support Program has expanded and is now called **AccessAbility Supports.** New supports offer more and better assistance to Islanders living with disabilities.

Disabilities may include physical, intellectual, neurological, sensory and mental disabilities.

New or Enhanced Supports

Our government wants to ensure Islanders living with disabilities can access the tools they need to reach their full potential and contribute to society as fully as possible. These improvements mean supports will be more personalized and focus on empowering individuals and their families.

Some of the new or enhanced supports include:

- support for all disabilities including physical, intellectual, neurological, sensory and mental, based on an assessment;
- a new assessment tool to help better understand how the disability affects activities of daily living to ensure appropriate support is provided;
- a supports coordinator to navigate all available support services and develop a personalized plan to meet individual needs;
- increased supports for finding or keeping a job including coaching and skills training;
- increased financial help for home and vehicle modifications required because of a disability - $10,000 every 10 years for home (was $2,000 in a lifetime) and $6,000 every 8 years for a vehicle (was $2,000 in a lifetime); and
- a single point of contact by calling a toll-free number for easier access to support.

How can I get support?

You will meet with a staff person who will conduct an assessment to determine how disability affects your daily life and how AccessAbility Supports can help meet your needs.

If you are a current disability support client, you will be automatically enrolled in AccessAbility Supports.

What type of support is available?

Help is available under five areas of support, as follows:

Personal Supports

Personal Supports help with personal daily living assistance such as:

- life skills training in areas like meal preparation, budgeting, grocery shopping, recreational activities;
- technical aids and assistive devices such as a wheel chair; and
- supports that enable an individual to be self-sufficient and live independently such as in-home supports or personal care workers.

Housing Supports

Housing Supports help with independent living and may include assistance such as:

- financial assistance for a caregiver to provide daily supervision and guidance in a community-based residential setting; and
- financial help for required home and vehicle modifications - $10,000 every 10 years for home modifications and $6,000 every eight years for a vehicle.

Community Supports

Community Supports help increase active participation in the community and may include:

- assistance with finding or keeping a job including coaching, skills training, and supports for youth transitioning from the education system to the workforce; and
- supports to enable active participate in the community such as day programming, personal aid or specialized transportation.

Caregiver Supports

Caregiver Supports help family members or caregivers and may include:

- respite for caregivers to allow for time for breaks to recharge; and
- support to provide supervision for adults who are unable to stay home alone safely so that caregivers can go to work or school.

Financial Supports

Financial Supports help with basic living expenses, if needed, and may include:

- assistance for basic needs such as food, clothing, shelter, household and personal supplies through what is called Assured Income.

Questions?

Call toll-free in Prince Edward Island:

1-877-569-0546

Published date:
October 8, 2020

An assessment will determine how **AccessAbility Supports** can help meet your indivdual needs

Help is available under five areas of support

My *Personal* Supports helps with personal daily living, which may include:

- life skills training in areas like meal preparation, budgeting, grocery shopping, recreational activities
- technical aids and assistive devices such as a wheel chair
- supports that enable an individual to be self-sufficient and live independently such as in-home supports or personal care workers

My *Housing* Supports helps with independent living, which may include:

- financial assistance to provide daily supervision and guidance in a community residential setting
- financial help for required home and vehicle modifications

My *Community* Supports helps increase active participation in the community and may include:

- assistance with finding or keeping a job including coaching, skills training and supports for youth transitioning from the education system to the workforce
- supports to enable active participation in the community such as day programming, personal aid or specialized transportation

My *Caregiver* Supports to help family members or caregivers may include:

- respite for caregivers to allow them time to have a break and recharge
- support to provide supervision for adults who are unable to safely be left home alone so that care givers can go to work or school

My *Financial* Supports helps with basic living expenses if needed and may include:

- assistance for basic needs such as food, clothing, shelter, household and personal supplies through what is called Assured Income

PrinceEdwardIsland.ca/accessability-supports

Prince Edward Island
CANADA

GOVERNMENT OF PRINCE EDWARD ISLAND
WWW.PRINCEEDWARDISLAND.CA
P.O. BOX 2000, CHARLOTTETOWN, PE
CANADA C1A 7N8

Questions? Call:

Prince Edward Island
CANADA

AccessAbility Supports

Formerly the disability support program, **AccessAbility Supports** will ensure more Islanders get the help they need to reach their full potential.

New or enhanced services include:

Support for **all disabilities** including *physical, intellectual, neurological, sensory and mental based on assessment*

A supports coordinator will navigate **all available support services** and develop a *personalized plan to meet individual needs*

Increased supports for **finding or keeping a job** including *coaching, skills training and supports for youth transitioning* from the education system to the workforce

Increased financial help for home and vehicle modifications required because of a disability -**$10,000 every 10 years for home** *(was $2,000 in a lifetime)* and **$6,000 every 8 years for a vehicle** *(was $2,000 in a lifetime)*

A new assessment tool for **children, youth and adults** will help us to better understand *how the disability affects activities of daily living*

New Community Connector positions will focus on *improving people's independence* and more *active participation in community living*

Easy Access

A single point of contact by calling

1-877-569-0546

toll-free makes it easier to access support

Prince Edward Island
CANADA

These improvements mean supports will be **more personalized** *and focus on* **empowering individuals and their families.**

Islanders currently participating in the Disability Support Program will be automatically enrolled for services through **AccessAbility Supports.**

Please call **1-877-569-0546** for more information or if you have questions.

PrinceEdwardIsland.ca/accessability-supports

The Autism Society of PEI

Navigation Handout

There are many different programs and services on Prince Edward Island for both individuals and their families touched by Autism.

Please note:

Many programs require documentation of the disability in order to access the provided services. If your documentation is in a language other than English or French you may want to pursue getting it translated by a health care professional and signed off on to diminish wait times of translating the document.

A Provincial Health Card will be required as well to access services. After arriving to PEI, you may apply for the health card. Provincial Health Card information can be found at:
https://www.princeedwardisland.ca/en/information/health-pei/pei-health-card

1. **Accessibility Supports Program**
   Funding based on a Needs Assessment done by a support worker. The amount allotted is based on the assessed need. For example, Respite care needs, incontinence supplies, safety locks, etc.

2. **School Aged Funding**
   $6,600 is allotted each year to every school aged individual who has been diagnosed with Autism. This funding supports community support workers to help with social skills, or funding for tutors. To access school age autism funding speak to your Accessability supports worker.

3. **Disability Tax Credit (Federal)**
   The Disability Tax Credit (DTC) is a non-refundable tax credit that assists persons with disabilities or their supporting persons reduce the amount of income tax they have to pay. Their website is: The Form can be located at:
   https://www.canada.ca/content/dam/cra-arc/formspubs/pbg/t2201/t2201-18e.pdf

4. **RDSP (Registered Disability Savings Plan)**
   If the individual qualifies for the DTC (Disability Tax Credit) they will also qualify for the RDSP. More information regarding RDSP's can be found at:
   https://www.canada.ca/en/employment-social-development/programs/disability/savings/rdsp.html

Here are some additional Services provided through community organizations similar to the Autism Society. They include:

Stars For Life Foundation for Autism

Stars For Life work with students on the Autism Spectrum who are over the age of 18 with a focus on education, housing, day programing, and employment services. You can locate their website at:
https://starsforlife.com/

Serene View Ranch

Serene View Ranch is a team of health professionals dedicated to supporting mental health challenges, especially those that are trauma based. Their website can be found at:
https://www.sereneviewranch.com/

Sylvan Learning Centre

Sylvan Learning offers a variety of services including personalized tutoring, Test Prep, Academic Coaching and much more. Their website is located at:
https://www.sylvanlearning.com/

Project LifeSaver PEI INC

Project LifeSaver provides timely responses to save lives and reduce potential injury for adults and children who wander due to Alzheimer's, autism, and other related disorders or conditions. Their website is located at:
https://www.projectlifesaverpei.ca/

Triple P Parenting

Triple P uses simple, positive tips to help Islanders and caregivers face typical challenges or raising children and teens. The Positive Parenting Program offers various levels of support to parents including a stay positive public awareness campaign, large group parent seminars, parenting skills and supports along with intensive family interventions. More information about Triple P Parenting supports can be located at their website:
https://www.princeedwardisland.ca/en/information/social-development-and-housing/triple-p-positive-parenting-program

The Island Helpline (Canadian Mental Health)

1-800-218-2885 or visit their website at:
https://www.theislandhelpline.com/

PEI 211

Connect with Social, Government, and non-urgent free and confidential health services 24 hours a day 7 days a week. Text or Call 2-1-1 via phone or visit their webpage at:
https://www.princeedwardisland.ca/en/information/211-pei

Social ABC’s

The Social ABC’s program is a structured, evidence-based early intervention program for children identified as possibly having autism spectrum disorder (ASD), providing families with intervention support at the first signs of concern, even before diagnosis. Parents will play a major role in the program.
The website for Social ABC’s is: https://www.socialabcs.com/

autism speaks | ATN
AUTISM TREATMENT NETWORK

AIR-P
Autism Intervention Research Network on Physical Health

How to Use Sleep Strategies to Help Your Child with Autism

DISCLAIMER: This summary provides overall strategies you can use to help your child. For more details, it may be helpful to read the Strategies to Improve Sleep Tool Kit and to communicate with your child's clinician about your concerns.

Who would benefit from the Autism Learning Health Network Sleep Tip Sheet?

If your child has trouble falling asleep, sleeping through the night, waking during the night and waking too early, these tips may help.

How to select a sleep program for your child:

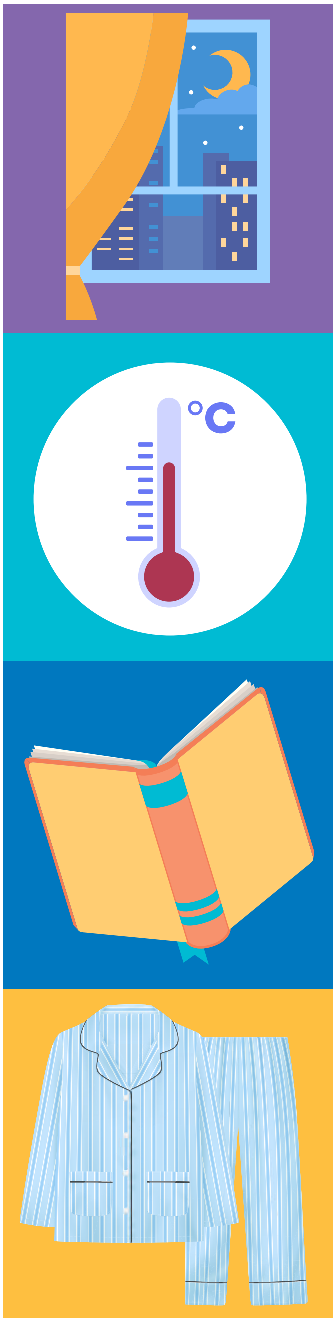
- **Choose ideas** that work well with your family's lifestyle.
- **Begin a new sleep program** only when you have time and energy to see if it will work.
- **Try one small change** at first and slowly incorporate additional changes one at a time.
- **Be patient** – it can take weeks or months of carrying out strategies to see a change.

How to keep a regular routine and daytime habits:

- **Keep the same wake time** and bedtime seven days a week, as much as possible.
- **Choose a bedtime** when your child is likely to be tired.
- For young children, **identify a regular nap schedule**, with naps ending no later than 4 p.m. Try to avoid "unplanned" naps.
- **Avoid heavy meals or snacks** before bed. A light snack with carbohydrates, such as cheese and crackers, may help your child sleep.
- **Expose your child to natural light** when your child wakes up – for example, open the curtains in their bedroom. Dim the lights in the house in the hours before bed.
- **Promote exercise** during the day, but not during the two to three hours before bedtime.
- **Avoid all caffeine products**, such as chocolate, soda, tea or coffee. Their stimulating effects can last up to 12 hours.
- **Reduce and/or avoid daytime bedroom use** for things like homework, playing or time out.

How to Use Sleep Strategies to Help Your Child with Autism

How to establish a regular bedtime routine:



- **Start a short and predictable routine** 15 to 30 minutes before bedtime. Use the same order every night to help your child relax and get ready for sleep.
- **Place calm, soothing activities** at the end of the routine, like reading a book with dimmed lights.
- **Avoid stimulating activities,** such as watching movies, playing video games or other screen time activities as part of the routine. Try to avoid physical activities like running or jumping 30 minutes before bedtime.
- **Consider creating visual supports,** like a chart with pictures of your child's bedtime routine, to support and communicate your expectations around bedtime.

How to create a comfortable and consistent sleep environment:

- Make sure your child's **sleeping space is not too hot or cold** and keep the room quiet and dark. Consider adding white noise if needed throughout the night.
- **Caregivers can add a night light** if your child needs one, but leave the night light on all night.
- Consider adding **heavy window coverings** to block outside light.
- Use **materials for bedding and sleep clothes** that work for your child's preferences.

How to teach your child to fall asleep alone:

- Caregivers should **gradually fade out of the room.** Try sitting on a chair by your child's bed instead of lying in the bed. Gradually move the chair further away from the bed every few nights, with the ultimate goal to move the chair completely out of the room.
- **Keep all interactions with your child brief** and boring if you need to go back in the room. For example, you can say, "You are ok, go to sleep," and leave again.
- Try to wait longer between each visit to the room.
- Consider using a bedtime pass, which your child can exchange for one visit from caregiver, a drink of water, or an extra hug or kiss.
- You can also use these same strategies if your child calls out in the night for you.

For more information:

Visit **autismspeaks.org/tool-kit** to find all of our tool kits, including
ATN/AIR-P Strategies to Improve Sleep in Children with Autism.

Toilet Training

A Parent's Guide

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital.

Toileting training can be challenging for children with autism spectrum disorders (ASD). There are many reasons why it can take a long time. Many children with ASD learn to use the toilet at a late age. Most children with ASD learn to urinate and have bowel movements in the toilet later than other children (Tsai, Stewart, & August, 1981).

Each child with an ASD is different. Children with ASD have some common problems that can make toileting hard. Knowing about these problems can help you come up with different ways to meet your child's needs. Here are some ideas to think about:

Physical: There may be a physical or medical reason for toileting difficulties. Discuss these issues with your child's pediatrician.

Language: Children with ASD have trouble understanding and using language. Do not expect a child with autism to ask to use the toilet.

Dressing: Some children with ASD have difficulty pulling their pants down or pulling them back up.

Fears: Some children with ASD are afraid of sitting on toilet seats or hearing toilets flush. Getting used to the toilet by using a visual schedule and making it part of the routine can make it less scary.

Body cues: Some children with ASD may not be aware that they need to go or that their clothes are wet or soiled.

Need for sameness ***(aka routine)***: Many children with ASD already have their own ways of urinating and having bowel movements. Learning new ways to toilet may be hard.

Using different toilets: Some children with ASD learn a toileting routine at home or school, but have a hard time going in other places such as public restrooms.

"It's a marathon, not a sprint." - Gary Heffner

A study by Dalrymple and Ruble (1992) found that, on average, children with ASD require 1.6 years of toilet training to stay dry during the day and sometimes more than 2 years to achieve bowel control.

It can be a few years journey but to achieve a lifetime of toileting independence is worth the wait!

Never Give Up!

The ideas included in this handout may help teach toileting skills to young children, teenagers and adults with ASD. While the problems listed above may make you unsure about how to start toilet training, it is a task within your control; ***there is always something a child with autism can do to become more independent in toileting***. Just remember that toilet training tips for typically developing children often need to be changed for children with ASD.

WHERE DO I START?

"Trip Training" or "Schedule Training" helps children learn toileting skills without placing other demands on them. Adults set the schedule and help train the child's body to follow the schedule.

☑ **Sit for 6.** Set a goal for 6 toilet sits per day. At first, trips will be short (as little as 5 seconds per trip), with one longer trip each day to work on bowel movements. Over time, toilet sits can be long (e.g., up to 10 minutes). Setting a timer can be a helpful way to let your child know when the toilet sit can end. Your child also is allowed to get up from the toilet immediately if s/he urinates or has a bowel movement. Boys are taught to sit on the toilet to urinate until they regularly have bowel movements on the toilet.

☑ **Don't Ask. Tell.** Do not wait for children to tell you they need to use the bathroom or to say "yes" when asked if they need to go. Tell them it is time for a toilet trip.

☑ **Schedule.** Make toilet trips part of your everyday life. Plan toilet trips around your usual routine. Stick with the same times of the day or the same daily activities.

☑ **Communicate.** Use the same simple words, signs or pictures during each trip. This helps a child learn toileting language.

☑ **Keep Trying.** They say it takes 3 weeks to make a habit. Once you outline the routine and methods, keep working towards the same goal for 3 weeks.

☑ **Make a Visual Schedule.** Pictures may help your child know what to expect during toilet trips (see Appendix 2: Example Visual Schedule on page 9). Take pictures of items in your bathroom (e.g., toilet, toilet paper). Place the pictures in order on a piece of paper to show your child each step of the toilet trip. There also are websites with toileting pictures that you can print out. Please see page 7 for the website information. If your child does not yet understand pictures, you may show your child actual objects (e.g., a roll of toilet paper) for each step.

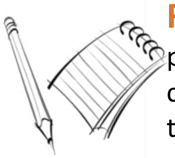
Quick Points to Practice…

- ✓ **Be Supportive.** Use encouraging language whenever you are talking with children about toileting. Use positive words if they are nearby.
- ✓ **Praise your child's** effort and cooperation-no matter how large or small.
- ✓ Be **calm and "matter of fact"** when you approach toilet training.
- ✓ **Stick to a schedule**. Establish a time when toileting is practiced both in and outside of the home.
- ✓ Use the **same words** about toileting.
- ✓ **Make sure *everyone* is using the same plan**. Talk with other people who work with your child. Share the toileting plan with them and request they stick to the same routine and language.

☑ **Identify Rewards.** Make a list of your child's favorite things, like foods, toys, and videos. Think of which ones will be easiest to give your child as soon as he/she urinates or has a bowel movement in the toilet. A small food item (e.g., fruit snack, cracker, chocolate chip) often works well. In addition to giving a reward for "going" in the toilet, you also can give your child time to do a favorite activity (e.g., watch a video, play with a toy) after the toilet trip is over.

The Key to Success: Keep language simple and keep toileting routines the same.

TIPS TO INCREASE TOILETING SUCCESS!



For 3- "typical" days, document your child's routine. To help you write your child's toileting program, track how long it takes between when your child drinks and when he or she is wet. Checking your child's diaper frequently for wetness (e.g., every 15 minutes) will help you decide when to schedule toilet trips.

Consider your child's diet. Dietary changes, such as increasing the fluids and fiber your child eats and drinks, may help your child feel the urge to use the toilet.

Make small changes in daily habits. Dress your child in easy-to-remove clothing. Change your child as soon as he or she becomes wet or soiled. Change diapers in or near the bathroom. Involve your child in the cleanup process.

Have your child put waste from the diaper in the toilet when possible. This will also help your child understand that waste goes in the toilet. Have your child flush the toilet and wash hands after each diaper change.

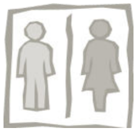
Make sure toilet trips are comfortable. Your child should be comfortable while sitting on the toilet. Use a smaller potty seat and/or provide a footstool. If your child will not sit on the toilet, work on sitting before beginning a toilet training program.

Think about your child's sensory needs. If your child does not like certain sounds, smells, or things he or she touches in the bathroom, change these as much as you can.

Have many pairs of underwear ready. During toilet training it is important for children to wear underwear during the day. They need to feel when they are wet. Your child may wear rubber pants or a pull-up over underwear if necessary. Diapers or pull-ups may be used when your child is sleeping or is away from the home.

Use a visual schedule. Pictures showing each step of the "potty routine" may help your child learn the routine and know what will happen. During toilet trips, show your child the visual schedule you have created. Label each step as you go along (see Appendix 2: Example Visual Schedule on page 9).

Use rewards. Give your child a reward *immediately* after he or she urinates or has a bowel movement in the toilet. The more quickly you reward a behavior, the more likely that behavior will increase. Toileting rewards are special. Rewards used for toileting should *only* be used for toileting.



Practice in different bathrooms. Using different bathrooms helps your child know he or she can use different toilets in different places.

CREATING YOUR CHILD'S TOILETING PLAN

Many different people may help your child with toileting. Different family members, teachers, aids, and day program staff may help. Everyone working with your child should use the same language and the same routine. This will help make toilet training a success.

A written toileting plan may help your child with ASD make progress. If it is in writing, everyone will be able to use the same language and the same routine. Toileting plans may include these details:

Goals:

- ✓ Let your child's helper know your goals. Outline for the helper, *what* it is you are trying to achieve for the given period of time. For example, "The goal is to have Tommy visit the restroom 15 minutes after the meal and sit on the toilet for 5 seconds."

Routine:

- ✓ **How often?** Include how often or what time the child should visit the rest room. Some examples include, "every hour on the hour" or "15 minutes after drinking / meals."
- ✓ **For how long?** Be sure to include how long your child is able to tolerate the bathroom trips-it may start with only 5 seconds.

Language:

- ✓ **Words**: Use words that work for your child. For example, are there any "code" words that you use for urination? What words do you use to tell your child to go to the bathroom?

Places:

- ✓ **Where?** Where does your child go to the bathroom?
- ✓ **What?** Think about the lights, are they bright or dim? How does light affect your child? What about noises in the bathroom (e.g., a fan)? What about the type of toilet paper? Should the door be open or closed?
- ✓ **Who?** Who goes with your child to the bathroom? Is someone with your child or just nearby?

Tools:

- ✓ What tools are you using? Do you use a visual schedule? Does your child like to listen to music or read a book?

Rewards:

- ✓ What activities earn a reward? What activities do not?
- ✓ How do you reward your child for a job well done? What happens if your child does not earn a reward?

FREQUENTLY ASKED QUESTIONS FROM PARENTS

Q♦ ***Our child will use the potty at school, but he refuses to use it at home. What should we do?***

A♦ Something your son with a diagnosis of ASD learns to do at school may be hard for him to do at home. It might help to have your son learn to use different bathrooms at school. Use the words and ideas that his teachers use at school. You may need to start with simple steps at home. Start by walking into the bathroom. Add steps one at a time until he is using the toilet at home. Practice potty trips in different bathrooms. Use the bathroom in stores and other people’s houses.

Q♦ ***We thought we had a good toileting program for our daughter, but it isn’t working. What are our next steps?***

A♦ There are a number of steps you may want to take. (1) Be sure there is not a medical reason. Talk with your daughter’s doctor to see if she is constipated or to get ideas about changes in diet. (2) Look at your daughter’s toileting schedule and make sure you are taking her when she is likely to urinate or have a bowel movement. (3) Think about changing rewards. Make sure your daughter likes the reward. It is often helpful to think about what type of reward you are using at least every 3 months, but you may have to do so more often.

Q♦ ***I worked on toileting all weekend with my son, but we didn’t make any progress. How long should the process take?***

A♦ Toileting takes a long time for many people. It helps to be relaxed and have patience. There isn’t a deadline for toileting. Toilet training should be a small part of your life. You can take a break and try again when you have more energy or when your son seems ready. Remember that it can be hard to learn to go to the toilet. Practice toileting when it is a good time for you and your family. That way you will have the energy to work on this important skill over the long haul.

Q♦ ***Our family has tried to help our son become toilet trained, but he is still wearing diapers. What should we do?***

A♦ It may be time to seek help from someone who has special training. There are physicians, psychologists, special educators, speech/language pathologists, behavioral analysts / specialists, and occupational therapists that can help children with ASD become toilet trained. These professionals may be able to help your family in intensive toilet training. This is a method that may work well for children diagnosed with ASD, but needs to be monitored by a professional. Remember that it can take a long time to learn this complicated and important skill.

Please see Appendix 2 on page 8 for an Example Toileting Plan that you can print and complete.

RESOURCES

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism www.autismspeaks.org/family-services. If you are interested in speaking with a member of the Autism Speaks Family Services Team contact the Autism Response Team (ART) at 888-AUTISM2 (288-4762), or by email at familyservices@autismspeaks.org. ART En Español al 888-772-9050

References

1. Dalrymple, N.J. & Ruble, L.A. (1992). Toilet training and behaviors of people with autism: Parent views. Journal of Autism and Developmental Disorders, 22 (2), 265-275
2. Tsai, L., Stewart, M.A., & August, G. (1981). Implication of sex differences in the familial transmission of infantile autism. Journal of Autism and Developmental Disorders, 11(2), 165-173.

Websites

- The National Autistic Society: Toilet Training: www.autism.org.uk/living-with-autism/understanding-behaviour/toilet-training.aspx
- www.do2learn.com/picturecards/printcards/selfhelp_toileting.htm is a great resource for picture schedules
- Tips for Daily Life—Toilet Training: www.theautismprogram.org/wp-content/uploads/toileting-tips.pdf
- Bright Tots: Toilet Training and Autism: www.brighttots.com/Toilet_training_and_autism.html

DVDs

- Potty Power
- Elmo's Potty Time

Books

- *Self-help Skills for People with Autism: A Systematic Teaching Approach* by Anderson, S.R., Jablonski, A.L., Thomeer, M.S., & Knapp, M. (2007).
- *The Potty Journey: Guide to Toilet Training Children with Special Needs, Including Autism and Related Disorders* by Coucouvanis, J. (2008).
- *Toilet Training for Children with Special Needs* by Hepburn, S. (2009).
- *Toilet Training for Individuals with Autism or other Developmental Issues: A Comprehensive Guide for Parents and Teachers* by Wheeler, M. (2007).
- *Once Upon a Potty* by Frankel, A. (2007).
- *Going to the Potty* by Rogers, F. (1997).

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APPENDIX 1: EXAMPLE TOILETING PLAN

Goal: “The goal is to have Tommy visit the restroom 15 minutes after the meal and sit on the toilet for 5 seconds.”	
Routine: **How often?** Tommy goes to the restroom 15 minutes after every meal and drink.	
How long doing what behavior? Tommy visits the restroom for 5 seconds. He sits on the toilet.	
Language: “Now we go to the bathroom”; “Pee-Pee” = urinate.	
Place: Helper stands outside the door. Door is open. Lights and fan on.	
Tools: Tommy reads *Where the Wild Things Are* in the bathroom.	
Rewards: Tommy receives 5 minutes of iPad time for every visit to the bathroom	

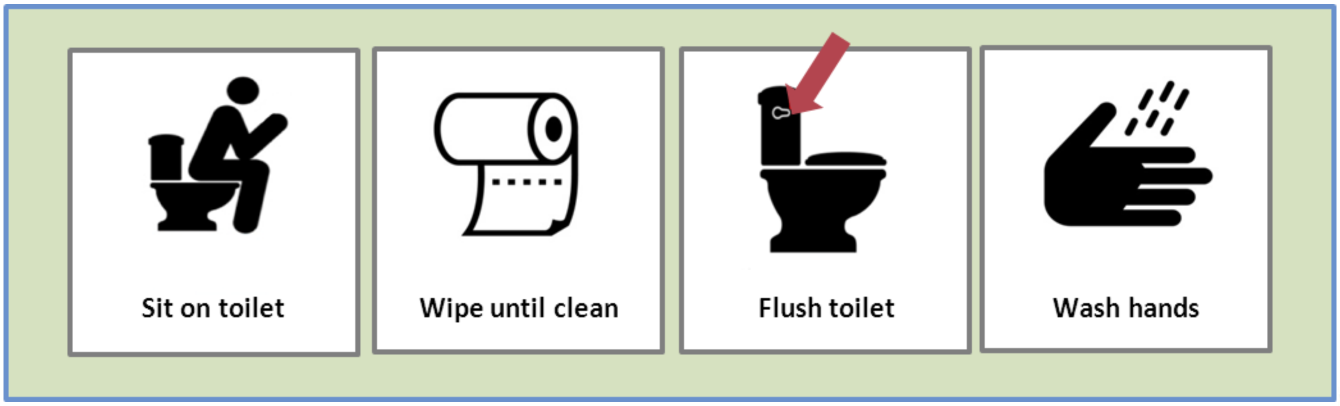
APPENDIX 2: EXAMPLE VISUAL SCHEDULE

Visual Schedule

A visual schedule is a display of what is going to happen throughout the day or during an activity. A visual schedule is helpful during toilet trips to decrease anxiety and difficulty with transitions by clearly letting your child know when certain activities will occur.

1) **Decide the activities that you will put on the schedule**. Try to mix in preferred activities with non-preferred ones.
2) **Put the visuals that stand for the activities** that you have identified on a portable schedule (on a binder or clipboard). The schedule should be available to your child from the beginning of the first activity. It should continue to be visible through all of the activities.
3) **When it is time for an activity on the schedule to occur**, let your child know with a brief verbal instruction before the next activity begins. When that task is completed, give your child praise. Then refer to the schedule and label the next activity.
4) **Provide praise and/or other rewards** for following the schedule and completing the activities. Put a preferred activity at the end of the schedule to give your child something positive to look forward to after completing all the items on the schedule.

VISUAL SCHEDULE



autism speaks

Successful Dental Visits for Children with Autism

Getting Started at Home

Oral health is a very important component of healthy daily living. But for some children with autism, oral health habits can be challenging. Our hope is that this guide will provide information for families to help begin a lifetime of good oral care.

To get started, you and your child should pick out the right toothbrush. There are many colors, styles, and types available. It is important that the brush is the right size for your child's mouth and that it has soft bristles.

For some children with autism, brushing teeth can be difficult. The sensation can be uncomfortable at first, and the child may need to be desensitized. You may want to start by using the toothbrush to touch your child's lips or just inside the mouth. You may also want to teach your child to "open wide," so that this direction is understood. Showing your child how you brush your own teeth may also be helpful.

Brushing and Flossing

Brushing Your Child's Teeth

- Stand behind your child with their head on your chest.
- Put a pea size amount of toothpaste on the center of the brush.
- Guide the brush as if you were brushing your own teeth.
- There are six steps to brushing:
    1. Brush the outside, inside and tops of the bottom back teeth on one side of the mouth five times.
    2. Move up and brush the inside, outside and chewing surfaces of the top teeth five times.
    3. Brush the bottom front teeth outside and inside five times.
    4. Move to the opposite side and brush the bottom teeth outside and inside five times.
    5. Brush the top front teeth inside, outside, and chewing surfaces five times.
    6. Brush the opposite top back teeth inside, outside, and chewing surfaces five times.

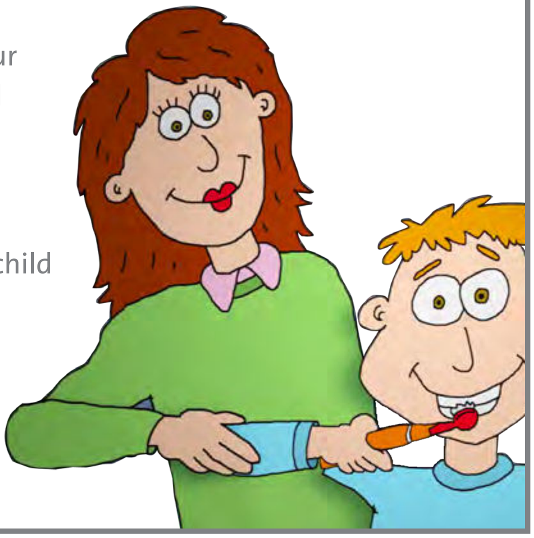
Although most people brush their teeth in the bathroom, in order to accommodate your child and get them accustomed to brushing their teeth, you may want to do this on the couch or in another part of your home where they may feel more comfortable. The ultimate goal is for your child to brush their teeth as independently as possible.

Flossing

Another important oral health skill that should be mastered is flossing. Just like brushing, this should be introduced as soon as possible in small steps, while building upon each success.

- The same technique is used in putting your child's head on your chest and flossing as you would your own teeth.
- Floss one tooth at a time.

Again, the goal is always for your child to achieve independence in this task.



Other Tips

Other Tips That May Be Helpful

- Some families find it useful to use a timer so that the individual with an autism spectrum disorder (ASD) can see when the task will be over.

- Some individuals with autism benefit from visual supports and schedules. A visual schedule can be created by taking photographs of the steps outlined on the previous page.
  - Families can then print the pictures and create visual schedules for their child. Some families may print the page and check off the activities as they occur. The pages can be laminated and a dry erase marker can be used to check off each activity, this way the page can be reused.
  - Others may cut out the photos and laminate them, and place Velcro on the back of each photo. The photos are arranged in chronological order on a board, and as each step is completed, the corresponding picture is removed.

- Another option is to photograph each step of the teeth brushing process, load the pictures on to a digital picture frame and program it so that each photo is displayed for 10 second intervals. This can be used in the bathroom as they are brushing their teeth so that they have a visual prompt when it is time to move on to the next step.*

- Some individuals need to be reinforced with verbal praise or a reward after each step. Others may be able to complete some, many, or all of the steps before verbal praise or a treat is needed. Each child will need to work at their own pace to achieve the skills necessary to brush their teeth.

  Once a manual toothbrush has been mastered, then a power brush can be introduced. The power brush is slightly different in that the brush does the work, so the individual no longer needs to do the "brushing."

  In all cases, the ultimate goal is for the individual with autism to brush their teeth as independently as possible.

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*This type of visual support was developed by Gloria Satriale, Executive Director of PAAL (Preparing Adolescents for Adult Life).

Preparing for the Dental Visit

Finding the Right Dental Office

It is important to find a dentist that works successfully with individuals with autism. You may find a dentist in your local area in the Autism Speaks Resource Guide. (*www.AutismSpeaks.org/community/resources*)

You may want to find out if the dentist has a questionnaire that you can fill out before your appointment. If not, you can use the one provided in this guide.

Speak with the dentist before the appointment.

- Let the dentist know what time of day works best for your child.
- Describe any concerns or challenges that may present themselves during the visit.
- See if they have pictures of the office so you can review them with your child before the appointment.

Preparing for the Dental Visit

You may want to prepare your child before going to the dentist. For some children, a visual schedule can be helpful to let them know what will happen throughout the visit. *You can find information about visual schedules on page 6, and you can find an actual visual schedule on page 7 of this Guide.* You can also practice having your child sit in a reclining chair. You may have to teach each of the following steps so that they understand the directions from the dental professional.

- Putting their hands on their stomach
- Putting their feet out straight
- Opening wide
- Holding their mouth open
- Counting their teeth
- Cleaning with a power brush
- Taking X-Rays
- Spitting into the sink

Each step may need to be mastered individually. Many of the instruments used at a dental visit can be bought at a drugstore. These would include:

- Small flashlight
- Dental mirror
- Rubber-tipped gum massager

You may also be able to get some dental bite wings from their dentist in advance of the visit, so that your child may practice biting down on the dental bite wings when they need to have X-Rays taken.

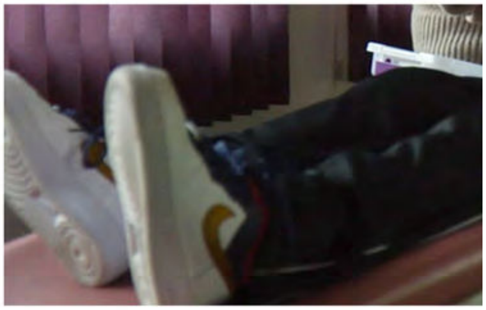
Visual Schedule

Individuals with autism often benefit from visual supports and schedules. The following visual schedule outlines the steps necessary for a dental visit. Families are welcome to print the pictures and create a visual schedule for their child. Some families may print the page and check off the activities as they occur. The pages can be laminated and a dry erase marker can be used to check off each activity, this way the page can be reused for each visit. Others may cut out the photos and laminate them, and place Velcro on the back of each photo. The photos are arranged in chronological order on a board, as each step is completed the picture is removed.

Some children may need to be reinforced with verbal praise, a preferred item, or a reward after each step. Others may be able to complete some, many or all of the steps before verbal praise or a reward is given. Each child will need to work at their own pace to achieve the skills necessary for a dental visit.

Visual Schedule for a Dentist Visit


1 Put hands on stomach ☐


2 Feet out straight ☐


3 Open mouth wide ☐


4 Hold mouth open ☐


5 Count teeth ☐

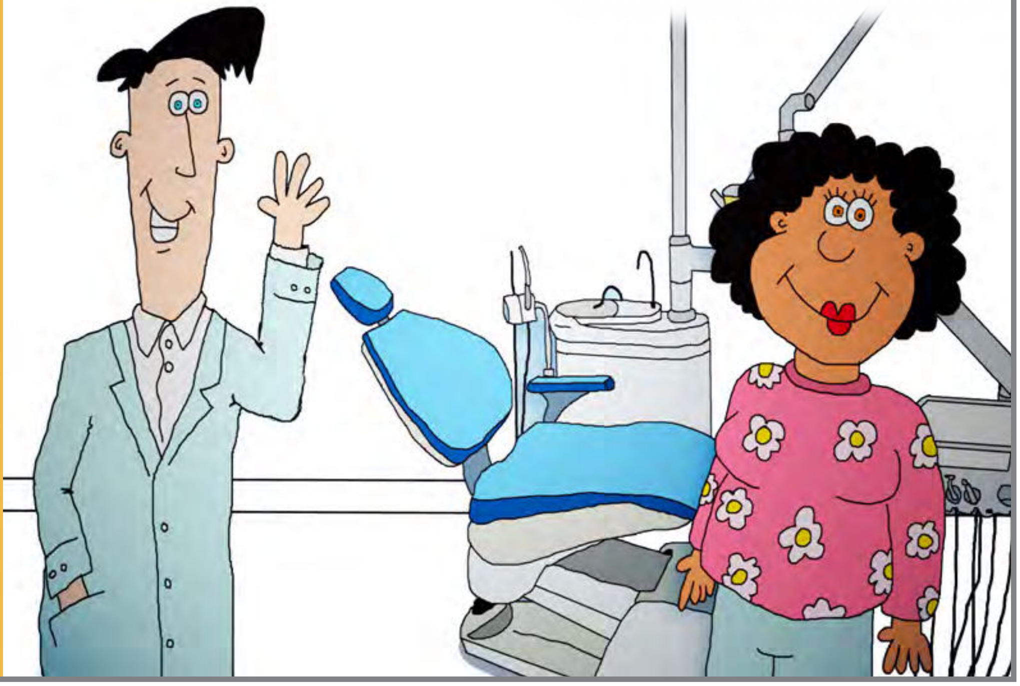

6 Take X-Rays ☐


7 Clean teeth ☐


8 Spit into sink ☐

Meeting the Dentist

Your child will most likely meet the dentist in the waiting area. You may want to call ahead to see if the dentist is running on time. If they are delayed and you think that your child may be anxious in the waiting area, you may want to ask the receptionist if you could wait in the car, and ask them to call you on your cell phone when the dentist is ready. Bring a favorite toy or reward for a job well done. You may also want to bring a family member, teacher, or autism expert to help make the visit a success.



For the Dentist

What is Autism?

Autism, or autism spectrum disorder (ASD), refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication. We now know that there is not one autism but many subtypes, and each person with autism can have unique strengths and challenges. A combination of genetic and environmental factors influence the development of autism, and autism often is accompanied by medical issues such as GI disorders, seizures and sleep disturbances. **Autism affects an estimated 1 in 59 children.**

Individuals with ASD have difficulties with:

- Social Interactions
- Communication
- Difficulty relating or participating in a back-and-forth conversation or interaction
- Repetitive or stereotypical behavior
- Individuals with ASD may also be hypersensitive or hyposensitive to light, sound, touch, smell, or taste.

Advice for Dental Experts

- Develop a relationship with your patient with autism.
- Speak in a calm and soothing voice.
- Get down to the child's level and be confident and reassuring.
- Do not ask the child if they want to come with you, but rather gently tell the child what you are doing next.
- Be consistent.

For the Dentist

Getting Your Office Ready

Since each child with autism is different, some suggestions may work for one patient with autism, but not for another. Ask the parent first if there are often suggestions that may better meet the needs of your patient with an ASD.

- Dim the lights if necessary.
- Turn down loud noises.
- Turn on instruments so that the child can see them before the instruments go in their mouths.
- Remove the clutter in your office that may distract the child or make them anxious.
- Let the child know what you will be doing. You may want to show the child on their hand how you will be counting their teeth so that they know what is going to happen.
- Make sure to provide clear and accurate information when speaking to the child.
- End each visit on a positive note, so that you and your patient can build upon your success.

Sometimes it may take several visits in order to complete a dental exam. If you work with the family on this process, you will build a relationship together that will result in a life time of good dental health for children with autism.

GETTING YOUR OFFICE
READY
FOR THE FIRST VISIT

#1
Dentist

Joseph Tuoti

About Us

About Autism Speaks

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. Through partnerships and collaboration, we are committed to:

- Increasing global understanding and acceptance of people with autism
- Being a catalyst for research breakthroughs
- Increasing early childhood screening and timely interventions
- Improving the transition to adulthood
- Ensuring access to reliable information and services throughout the life span

To find resources, join a fundraising walk or make a donation, go to **www.AutismSpeaks.org**.

CONNECT WITH US

Credits

Illustrations by: Joe Shea

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NSSA
Nassau Suffolk Services for Autism
www.nssa.net

kiddsmiles
pediatric dentistry
www.kiddsmiles.com

AUTISM SPEAKS®

Dental Form for Your Dentist Visit

MEDICAL INFORMATION

Patient Name:______________________ Parent/Guardian:______________________

Phone Number:_____________________ Parent/Guardian:______________________

Describe the nature of your child's disability:

Are they currently taking any medications? YES NO
If yes, what medications:

Has your child ever had seizures? YES NO
If YES, date of last seizure:

Describe the type of seizure:

Do you have any allergies? YES NO
If yes, please list:

Does your child wear a hearing aid? YES NO
If YES, please explain:

Does your child have any other physical challenges that the dental team should be aware of?

ORAL CARE

Has your child visited the dentist before? YES NO
If yes, please describe:

Please describe your child's at-home dental care:

Does your child use a powered toothbrush or a manual toothbrush? YES NO

Does your child floss? YES NO

Does your child brush independently or with parent/guardian's assistance? YES NO

What are your dental health goals?

How often does your child snack during the day and on what types of foods?

COMMUNICATION & BEHAVIOR

Is your child able to communicate verbally? YES NO

Are there certain cues that might help the dental team?

Are there any useful phrases or words that work best with your child?

Does your child use non-verbal communication? YES NO

Please check any of the following that your child uses:

- ○ Mayer Johnson Symbols
- ○ Sign Language
- ○ Picture Exchange Communication System (PECS)
- ○ Sentence Board or Gestures

Will you be bringing a communication system with you? YES NO

Are there any symbols/signs that we can have available to assist with communication?

BEHAVIOR/EMOTIONS

Are there any specific behavioral challenges that you would like the dental team to be aware of?

SENSORY ISSUES

Are there any sounds that your child is very sensitive to?

Does your child prefer the quiet? YES NO

Is your child more comfortable in a dimly lit room? YES NO

Is your child sensitive to motion and moving (i.e., the dental chair moving up and down or to a reclining position)?

Does your child have any specific oral sensitivities (gagging, gum sensitivities, etc.)?

Do certain tastes bother your child?

Is your child more comfortable in a clutter-free environment? YES NO

Please provide us with any additional information that may help us to prepare for a successful dental experience:

Diagnosing Autism Spectrum Disorder in PEI

Autism Spectrum Disorder (ASD) presents itself in a variety of ways and ranges from mild to severe. In PEI, a child may be identified with signs of autism at a very young age through a Public Health Nursing screening program. Public Health Nursing offers pre-school health clinics throughout the province and can assess your child's development in areas such as vision and hearing, growth and nutrition, speech and communication, and personal/social development. Find more information at Pre-School Health.

Because Autism Spectrum is a social-communication disorder, a child needing professional help developing speech and language abilities may be identified with signs of ASD through Speech Language Pathology.

If you suspect your child may have ASD, you should mention this to the public health nurse during your child's screening clinic or to the speech language pathologist, if your child is receiving SLP services. This is also a concern you should discuss with a family doctor or nurse practitioner. Any of these experienced health professionals will be able to help you decide if your child should begin the process for diagnostic assessment.

What if my child is identified with signs of Autism Spectrum Disorder?

1. If your child is identified with signs of ASD, the process for diagnostic assessment begins. It's common for families to have to wait for a diagnostic assessment.
2. A family doctor or nurse practitioner must issue a referral for your child to access pediatrician services. Find more information at Pediatrician Outpatient Services.
3. The pediatric office will contact you with an appointment and have you complete paperwork about your child to help the pediatrician better prepare for the appointment.
4. The pediatrician may refer your child for a diagnostic assessment from Pediatric Psychology Services.
5. Pediatric Psychology Services provides free diagnostic assessments for children up to age 5. A referral from a pediatrician is required to access these services.

What if my child receives an autism diagnosis?

After receiving your child's autism diagnosis, an assessment may indicate that your child needs support with skill development. You can:

- Build a support team tailored to your child's needs – it might include health professionals, therapists, care providers, educators and support workers;
- Apply for autism funding and grants to help cover the costs of support that will help them reach their development goals;

- Reach out for community support through the PEI Autism Society(link is external) and the PEI Association for Community Living(link is external); and
- Connect to community services and programs through 211PEI online at: https://pe.211.ca/(link is external) or by phone: 211

Published date:
May 4, 2021

Clear Data

Canada Revenue Agency   Agence du revenu du Canada

Protected B when completed

Disability Tax Credit Certificate

Help
canada.ca/disability-tax-credit
1-800-959-8281

The information provided in this form will be used by the Canada Revenue Agency (CRA) to determine the eligibility of the individual applying for the disability tax credit (DTC). For more information, see the general information on page 16.

Part A – Individual's section

1) Tell us about **the person with the disability**

First name: ____________________

Last name: ____________________

Social insurance number: ☐☐☐ ☐☐☐ ☐☐☐

Mailing address: ____________________

City: ____________________

Province or territory: ____________________

Postal code: ☐☐☐ ☐☐☐

Date of birth: ☐☐☐☐ ☐☐ ☐☐ (Year Month Day)

2) Tell us about **the person claiming the disability amount**

☐ The person with the disability is claiming the disability amount

or

☐ A supporting family member is claiming the disability amount (the spouse or common-law partner of the person with the disability, or a parent, grandparent, child, grandchild, brother, sister, uncle, aunt, nephew, or niece of that person or their spouse or common-law partner).

First name: ____________________

Last name: ____________________

Relationship: ____________________

Social insurance number: ☐☐☐ ☐☐☐ ☐☐☐

Does the person with the disability live with you? ☐ Yes ☐ No

Indicate which of the basic necessities of life have been regularly and consistently provided to the person with the disability, and the years for which it was provided:

☐ Food ____________ Year(s)   ☐ Shelter ____________ Year(s)   ☐ Clothing ____________ Year(s)

Provide details regarding the support you provide to the person with the disability (regularity of the support, proof of dependency, if the person lives with you, etc.):

If you want to provide more information than the space allows, use a separate sheet of paper, sign it, and attach it to this form. Make sure to include the name of the person with the disability.

As the supporting family member claiming the disability amount, I confirm that the information provided is accurate.

Signature: ____________________

Canada

Part A – Individual's section (continued)

3) Previous tax return adjustments

Are you the person with the disability or their legal representative, or if the person is under 18, their legal guardian?

☐ Yes ☐ No

If eligibility for the disability tax credit is approved, would you like the CRA to apply the credit to your previous tax returns?

☐ Yes, adjust my previous tax returns for all applicable years.

☐ No, do not adjust my previous tax returns at this time.

4) Individual's authorization

As the person with the disability or their legal representative:

- I certify that the above information is correct.
- I give permission for my medical practitioner(s) to provide the CRA with information from their medical records in order for the CRA to determine my eligibility.
- I authorize the CRA to adjust my returns, as applicable, if I opted to do so in question 3.

Signature: ____________________

Telephone number: ____________________

Date: Year Month Day

Personal information (including the SIN) is collected to administer or enforce the Income Tax Act and related programs and activities including administering tax, benefits, audit, compliance, and collection. The information collected may be used or disclosed for purposes of other federal acts that provide for the imposition and collection of a tax or duty. It may also be disclosed to other federal, provincial, territorial, or foreign government institutions to the extent authorized by law. Failure to provide this information may result in paying interest or penalties, or in other actions. Under the Privacy Act, individuals have a right of protection, access to and correction of their personal information, or to file a complaint with the Privacy Commissioner of Canada regarding the handling of their personal information. Refer to Personal Information Bank CRA PPU 218 on Info Source at **canada.ca/cra-info-source**.

This marks the end of the individual's section of the form. Ask a medical practitioner to fill out Part B (pages 3-16). Once the medical practitioner certifies the form, it is ready to be submitted to the CRA for assessment.

Next steps:

Step 1 – Ask your medical practitioner(s) to fill out the remaining pages of this form.

Note
Your medical practitioner provides the CRA with your medical information but does not determine your eligibility for the DTC.

Step 2 – Make a copy of the filled out form for your own records.

Step 3 – Refer to page 16 for instructions on how to submit your form to the CRA.

Clear Data

Part B – Medical practitioner's section

If you would like to use the digital application for medical practitioners to fill out your section of the T2201, it can be found at **canada.ca/dtc-digital-application**.

Important notes on patient eligibility

- Eligibility for the DTC is not based solely on the presence of a medical condition. It is based on the impairment resulting from a condition and the effects of that impairment on the patient. Eligibility, however, is not based on the patient's ability to work, to do housekeeping activities, or to engage in recreational activities.
- A person may be eligible for the DTC if they have a severe and prolonged impairment in physical or mental functions resulting in a marked restriction. A marked restriction means that, even with appropriate therapy, devices, and medication, they are unable or take an inordinate amount of time in one impairment category, **all or substantially all** (generally interpreted as 90% or more) of the time. If their limitations do not meet the criteria for one impairment category alone, they may still be eligible if they experience significant limitations in two or more categories.

For more information about the DTC, including examples and eligibility criteria, see Guide RC4064, Disability-Related Information, or go to **canada.ca/disability-tax-credit**.

Next steps

Step 1 – Fill out the sections of the form on pages 4-15 that are applicable to your patient.

When considering your patient’s limitations, assess them compared to someone of similar age who does not have an impairment in that particular category. If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section on page 14.

If you want to provide more information than the space allows, use a separate sheet of paper, sign it, and attach it to this form. Make sure to include the name of the patient at the top of all pages.

Step 2 – Fill out the "Certification" section on page 16 and sign the form.

Step 3 – You or your patient can send this form to the CRA when both Part A and Part B are filled out and signed (refer to page 16 for instructions).

The CRA will review the information provided to determine your patient's eligibility and advise your patient of our decision. If more information is needed, the CRA may contact you.

Clear Data

Patient's name: ______________________________

Protected B when completed

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner ______ optometrist

Vision

1) Indicate the aspect of vision that is impaired in each eye (visual acuity, field of vision, or both):

Left eye after correction	**Right eye** after correction
Visual acuity	**Visual acuity**
☐ Measurable on the Snellen chart (provide acuity)	☐ Measurable on the Snellen chart (provide acuity)
____ / ____ Example: 20/200, 6/60	____ / ____ Example: 20/200, 6/60
☐ Count fingers (CF)	☐ Count fingers (CF)
☐ No light perception (NLP)	☐ No light perception (NLP)
☐ Light perception (LP)	☐ Light perception (LP)
☐ Hand motion (HM)	☐ Hand motion (HM)
Field of vision (provide greatest diameter)	**Field of vision** (provide greatest diameter)
______ degrees	______ degrees

2) Is the patient considered blind in both eyes according to at least one of the following criteria:

- The visual acuity is 20/200 (6/60) or less on the Snellen Chart (or an equivalent).
- The greatest diameter of the field of vision is 20 degrees or less.

☐ Yes (provide the year they became blind) |_|_|_|_| Year

or

☐ No (provide the year the vision limitations began) |_|_|_|_| Year

Medical doctors and nurse practitioners only: If your patient experiences limitations in more than one category, tell us more about the patient's limitations in vision. They may be eligible under the "Cumulative effect of significant limitations" section on page 14.

Provide examples of how their limited vision impacts other activities of daily living (for example, walking, feeding). Also provide any other relevant details such as devices the patient uses to aid their vision (for example, cane, magnifier, service animal).

3) Has the patient's impairment in vision lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

4) Has the patient's impairment in vision improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) |_|_|_|_| Year ☐ No ☐ Unsure

Clear Data

Patient's name: ______________________________ **Protected B** when completed

Initial your designation if this category is applicable to your patient:

Speaking

______ medical doctor ______ nurse practitioner ______ speech-language pathologist

1) List any medical conditions that impact the patient's ability to speak so as to be understood and provide the year of diagnosis (if available):

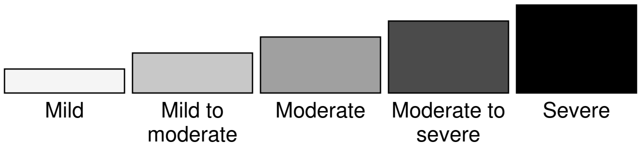
2) Does the patient take medication that aids their speaking limitations?

☐ Yes ☐ No ☐ Unsure

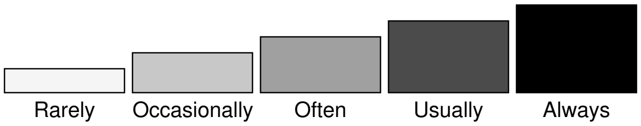
3) Describe if the patient uses any devices or therapy to aid their speaking limitations (for example, voice amplifier, behavioural therapy):

4) Provide examples of the factors that limit the patient's ability to speak using the severity and frequency scales provided as a guide (for example, they often require repetition to be understood, always experience mild difficulty with articulation, selective mutism, they use sign language as their primary means of communicating):

Severity



Frequency



5) Tell us in the table below about the patient's ability to speak so as to be understood by a familiar person in a quiet setting (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to speak so as to be understood when using the medication, devices, and therapy listed above, if applicable.

	Limitations in speaking	**Is this the case all or substantially all of the time (see page 3)?**	**Year this began**
☐	The patient is unable to speak or takes an inordinate amount of time to speak so as to be understood (at least three times longer than someone of similar age without a speech impairment) by a familiar person in a quiet setting.	☐ Yes ☐ No	
☐	The patient has difficulty, but does not take an inordinate amount of time to speak so as to be understood by a familiar person in a quiet setting.[1]	☐ Yes ☐ No	

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations section" on page 14.

6) Has the patient's impairment in speaking lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

7) Has the patient's impairment in speaking improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) ____ Year ☐ No ☐ Unsure

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner ______ audiologist

Hearing

1) Indicate the option that best describes the patient's level of hearing loss in each ear with any applicable devices (normal: 0-25dB, mild: 26-40dB, moderate: 41-55dB, moderate-to-severe: 56-70dB, severe: 71-90dB, profound: 91dB+, or unknown):

Left ear ______________________

Right ear ______________________

2) Provide the patient's overall word discrimination score in both ears:

______ % ☐ Unknown

3) Describe if the patient uses any devices to aid their hearing (for example, cochlear implant, hearing aid):

4) Provide the medical condition causing hearing loss and examples of the impacts of hearing loss on your patient using the severity and frequency scales as a guide (for example, they often require the use of repetition, lip-reading or sign-language to understand verbal communication, they have severely impaired awareness of risks to personal safety):

Severity

Mild	Mild to moderate	Moderate	Moderate to severe	Severe

Frequency

Rarely	Occasionally	Often	Usually	Always

5) Tell us in the table below about the patient's ability to hear so as to understand a familiar person in a quiet setting (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to hear when using the devices listed above, if applicable.

	Limitations in hearing	**Is this the case all or substantially all of the time (see page 3)?**	**Year this began**
☐	The patient is unable to hear or takes an inordinate amount of time to hear so as to understand (at least three times longer than someone of similar age without a hearing impairment) a familiar person in a quiet setting.	☐ Yes ☐ No	
☐	The patient has difficulty, but does not take an inordinate amount of time to hear so as to understand a familiar person in a quiet setting.[1]	☐ Yes ☐ No	

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section on page 14.

6) Has the patient's impairment in hearing lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

7) Has the patient's impairment in hearing improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) ________ ☐ No ☐ Unsure
Year

Clear Data

Protected B when completed

Patient's name: ______________________________

Initial your designation if this category is applicable to your patient:

Walking

______ medical doctor ______ nurse practitioner ______ occupational therapist ______ physiotherapist

1) List any medical conditions that impact the patient's ability to walk and provide the year of diagnosis (if available):

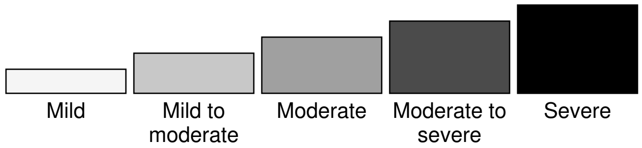
2) Does the patient take medication to aid their limitations in walking?

☐ Yes ☐ No ☐ Unsure

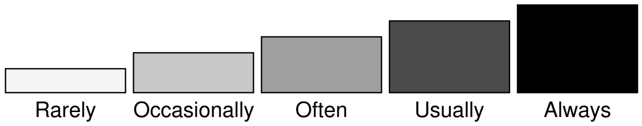
3) Describe if the patient uses any devices or therapy to aid their limitation in walking (for example: cane, occupational therapy):

4) Provide examples of the factors that limit the patient's ability to walk using the severity and frequency scales provided as a guide (for example, they have severe pain in their legs, they often have moderately impaired balance, they experience shortness of breath upon mild exertion):

Severity



Frequency



5) Tell us in the table below about the patient's ability to walk, for example, a short distance such as 100 metres (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to walk when using the devices and therapy listed above, if applicable.

Limitations in walking	Is this the case all or substantially all of the time (see page 3)?	Year this began
☐ The patient is unable or takes an inordinate amount of time to walk (at least three times longer than someone of a similar age without an impairment in walking).	☐ Yes ☐ No	|_|_|_|_|
☐ The patient has difficulty, but does not take an inordinate amount of time to walk.[1]	☐ Yes ☐ No	|_|_|_|_|

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section on page 14.

6) Has the patient's impairment in walking lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

7) Has the patient's impairment in walking improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) |_|_|_|_| Year ☐ No ☐ Unsure

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner

Eliminating

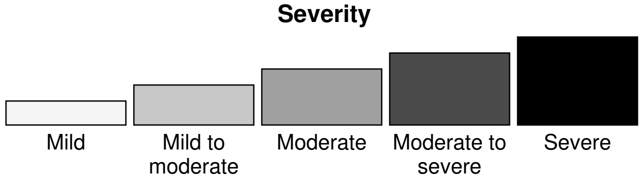
1) List any medical conditions that impact the patient's ability to personally manage bowel or bladder functions and provide the year of diagnosis (if available):

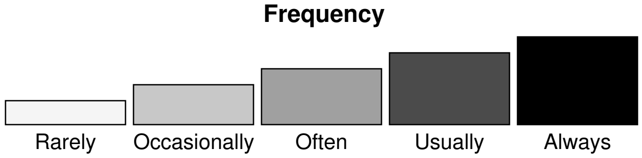
2) Does the patient take medication to aid their limitations in bowel or bladder functions?

☐ Yes ☐ No ☐ Unsure

3) Describe if the patient uses any devices or therapy to aid their limitations in bowel or bladder functions (for example, ostomy, biological therapy):

4) Provide examples of the factors that limit the patient's ability to personally manage their bowel or bladder functions using the severity and frequency scales provided as a guide (for example, they always require assistance from another person to manage bowel or bladder functions, they have chronic constipation or diarrhea, they often have fecal or urinary incontinence, they usually require intermittent catheterization):





5) Tell us in the table below about the patient's ability to personally manage their bowel or bladder functions (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to personally manage bowel or bladder functions when using the medication, devices, and therapy listed above, if applicable.

Limitations in eliminating	Is this the case all or substantially all of the time (see page 3)?	Year this began
☐ The patient is unable or takes an inordinate amount of time to personally manage bowel or bladder functions (at least three times longer than someone of similar age without an impairment in these functions).	☐ Yes ☐ No	
☐ The patient has difficulty, but does not take an inordinate amount of time to personally manage bowel or bladder functions.[1]	☐ Yes ☐ No	

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section on page 14.

6) Has the patient's impairment in bowel or bladder functions lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

7) Has the patient's impairment in bowel or bladder functions improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) ________ ☐ No ☐ Unsure
Year

Clear Data

Patient's name: ______________________________

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner ______ occupational therapist

Feeding

This impairment category includes the acts of feeding oneself as well as preparing food, except when the time spent on food preparation is related to a dietary restriction or regime. It does not include identifying, finding, shopping for, or obtaining food.

1) List any medical conditions that impact the patient's ability to feed themselves and provide the year of diagnosis (if available):

2) Does the patient take medication to aid their limitations in feeding themselves?

☐ Yes ☐ No ☐ Unsure

3) Describe if the patient uses any devices or therapy to aid their limitations in feeding themselves (for example, assistive utensils, occupational therapy):

4) Provide examples of the factors that limit the patient's ability to feed themselves using the severity and frequency scales provided as a guide (for example, they often require assistance from another person to prepare their meals or feed themselves, their dexterity is always severely impaired, they have moderate tremors, they rely exclusively on tube feeding):

Severity

Mild · Mild to moderate · Moderate · Moderate to severe · Severe

Frequency

Rarely · Occasionally · Often · Usually · Always

5) Tell us in the table below about the patient's ability to feed themselves (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to feed themselves when using the medication, devices, and therapy listed above, if applicable.

Limitations in feeding oneself	Is this the case all or substantially all of the time (see page 3)?	Year this began
☐ The patient is unable or takes an inordinate amount of time to feed themselves (at least three times longer than someone of similar age without an impairment in that ability).	☐ Yes ☐ No	
☐ The patient has difficulty, but does not take an inordinate amount of time to feed themselves.[1]	☐ Yes ☐ No	

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section on page 14.

6) Has the patient's impairment in feeding themselves lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

7) Has the patient's impairment in feeding themselves improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) ________ ☐ No ☐ Unsure
Year

Patient's name: ______________________________

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner ______ occupational therapist

Dressing

This impairment category does not include identifying, finding, shopping for, or obtaining clothing.

1) List any medical conditions that impact the patient's ability to dress themselves and provide the year of diagnosis (if available):

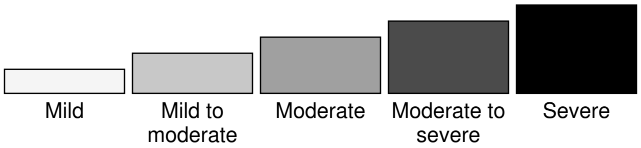
2) Does the patient take medication to aid their limitations in dressing?

☐ Yes ☐ No ☐ Unsure

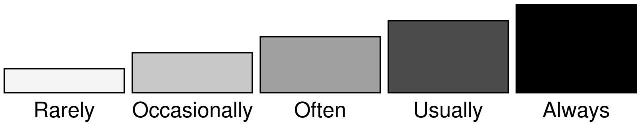
3) Describe if the patient uses any devices or therapy to aid their limitations in dressing themselves (for example, button hook, occupational therapy):

4) Provide examples of the factors that limit the patient's ability to dress themselves using the severity and frequency scales provided as a guide (for example, they often require assistance from another person to dress themselves, they have severe pain in their upper extremities, they often have moderately limited range of motion):

Severity



Frequency



5) Tell us in the table below about the patient's ability to dress themselves (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to dress themselves when using the medication, devices, and therapy listed above, if applicable.

Limitations in dressing oneself	Is this the case all or substantially all of the time (see page 3)?	Year this began
☐ The patient is unable or takes an inordinate amount of time to dress themselves (at least three times longer than someone of similar age without an impairment in that ability).	☐ Yes ☐ No	
☐ The patient has difficulty, but does not take an inordinate amount of time to dress themselves.[1]	☐ Yes ☐ No	

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section on page 14.

6) Has the patient's impairment in dressing themselves lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

7) Has the patient's impairment in dressing themselves improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) ______ ☐ No ☐ Unsure

Year

Clear Data

Patient's name: ______________________________

Protected B when completed

Mental functions necessary for everyday life

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner ______ psychologist

Mental functions necessary for everyday life include adaptive functioning, attention, concentration, goal-setting, judgment, memory, perception of reality, problem-solving, regulation of behaviour and emotions, and verbal and non-verbal comprehension.

1) List any medical conditions that impact the patient's ability to perform mental functions necessary for everyday life and provide the year of diagnosis (if available):

2) Does the patient take medication that aids their ability to perform mental functions necessary for everyday life?

☐ Yes ☐ No ☐ Unsure

Does the patient require supervision or reminders from another person to take their medication?
This question is not applicable to children.

☐ Yes ☐ No ☐ Unsure

Select the option that best describes how effectively the medication treats their condition:

☐ Effective ☐ Moderately effective ☐ Mildly effective ☐ Ineffective ☐ Unsure

3) Describe any devices or therapy the patient uses that aid their ability to perform mental functions necessary for everyday life (for example, memory aids, assistive technology, cognitive-behavioural therapy):

4) Does the patient have an impaired capacity to live independently (or to function at home or at school in the case of a child under 18) without daily supervision or support from others?

☐ No ☐ Yes

Select all types of support received by the adult or child under 18:

Adult

☐ Assisted living or long-term facility

☐ Community-based health services

☐ Hospitalization

☐ Support from family members

Child under 18

☐ Adult supervision at home beyond an age-appropriate level

☐ Additional support from educational staff at school

Provide additional details about support received (optional):

The Mental functions section continues on pages 12 and 13.

Patient's name: ____________________

Mental functions necessary for everyday life (continued)

5) Indicate the extent of the patient's limitations **compared to someone of similar age** without an impairment in mental functions:

Note: For a child, you can indicate either their current or anticipated limitations.

		No limitations	Some limitations	Very limited capacity
Adaptive functioning	Adapt to change	☐	☐	☐
	Express basic needs	☐	☐	☐
	Go out into the community	☐	☐	☐
	Initiate common, simple transactions	☐	☐	☐
	Perform basic hygiene or self-care activities	☐	☐	☐
	Perform necessary, everyday tasks	☐	☐	☐
	Other (optional):			
Attention	Demonstrate awareness of danger and risks to personal safety	☐	☐	☐
	Demonstrate basic impulse control	☐	☐	☐
	Other (optional):			
Concentration	Focus on a simple task for any length of time	☐	☐	☐
	Absorb and retrieve information in the short-term	☐	☐	☐
	Other (optional):			
Goal-setting	Make and carry out simple day-to-day plans	☐	☐	☐
	Self-direct to begin everyday tasks	☐	☐	☐
	Other (optional):			
Judgment	Choose weather-appropriate clothing	☐	☐	☐
	Make decisions about their own treatment and welfare	☐	☐	☐
	Recognize risk of being taken advantage of by others	☐	☐	☐
	Understand consequences of their actions or decisions	☐	☐	☐
	Other (optional):			
Memory	Remember basic personal information such as date of birth and address	☐	☐	☐
	Remember material of importance and interest to themselves	☐	☐	☐
	Remember simple instructions	☐	☐	☐
	Other (optional):			

The Mental functions section continues on page 13.

Clear Data

Patient's name: ______________________________ **Protected B** when completed

Mental functions necessary for everyday life (continued)

Note: For a child, you can indicate either their current or anticipated limitations.

		No limitations	Some limitations	Very limited capacity
Perception of reality	Demonstrate an accurate understanding of reality	☐	☐	☐
	Distinguish reality from delusions and hallucinations	☐	☐	☐
	Other (optional):			
Problem-solving	Identify everyday problems	☐	☐	☐
	Implement solutions to simple problems	☐	☐	☐
	Other (optional):			
Regulation of behaviour and emotions	Behave appropriately for the situation	☐	☐	☐
	Demonstrate appropriate emotional responses for the situation	☐	☐	☐
	Regulate mood to prevent risk of harm to self or others	☐	☐	☐
	Other (optional):			
Verbal and non-verbal comprehension	Understand and respond to non-verbal information or cues	☐	☐	☐
	Understand and respond to verbal information	☐	☐	☐
	Other (optional):			

6) Tell us in the table below about the patient's ability to perform mental functions necessary for everyday life (more than one answer may apply, given that the patient's ability may change over time). Evaluate their ability to perform mental functions when using the medication, devices, and therapy listed above, if applicable.

Mental functions	**Is this the case all or substantially all of the time (see page 3)?**	**Year this began**
☐ The patient is unable to perform these functions by themselves or takes an inordinate amount of time compared to someone of similar age without an impairment in mental functions.	☐ Yes ☐ No	
☐ The patient has difficulty performing these functions, but does not take an inordinate amount of time.[1]	☐ Yes ☐ No	

---

[1] If your patient experiences limitations in more than one category, they may be eligible under the "Cumulative effect of significant limitations" section.

7) Has the patient's impairment in performing mental functions necessary for everyday life lasted, or is it expected to last, for a continuous period of at least 12 months?

☐ Yes ☐ No

8) Has the patient's impairment in performing mental functions necessary for everyday life improved or is it likely to improve to such an extent that they would no longer be impaired?

☐ Yes (provide year) ________ ☐ No ☐ Unsure
Year

Clear Data

Patient's name: ______________________________

Protected B when completed

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner ______ occupational therapist[2]

Cumulative effect of significant limitations

[2] An occupational therapist can only certify limitations for walking, feeding, and dressing.

When a person's limitations in one category do not quite meet the criteria to qualify for the DTC, they may still qualify if they experience significant limitations in two or more categories.

1) Select all categories you completed in previous pages and in which your patient has significant limitations, even with therapy and the use of appropriate devices and medication:

☐ Vision
☐ Hearing
☐ Eliminating (bowel or bladder functions)
☐ Dressing
☐ Speaking
☐ Walking
☐ Feeding
☐ Mental functions necessary for everyday life

Important: If you checked a box for a particular category on this page but did not complete the corresponding section on the applicable page of this form, fill out that section prior to completing this page. The CRA will need that information to determine your patient's eligibility under the cumulative effect of significant limitations.

2) Do the patient's limitations in at least two of the categories selected above exist together all or substantially all of the time (see page 3)?

Note: Although a person may not engage in the activities simultaneously, "together" in this context means that they are affected by the limitations during the same period of time.

☐ Yes ☐ No

3) Is the cumulative effect of these limitations equivalent to being unable or taking an inordinate amount of time in one single category of impairment, all or substantially all of the time (see page 3)?

☐ Yes ☐ No

4) Provide the year the cumulative effect of the limitations described above began:

Year

Clear Data

Patient's name: ______________________________

Protected B when completed

Initial your designation if this category is applicable to your patient:

______ medical doctor ______ nurse practitioner

Life-sustaining therapy

Eligibility criteria for life-sustaining therapy are as follows:

- The therapy **supports a vital function**.
- The therapy is needed at least **2 times per week**.

  Note: For 2020 and previous years, the therapy had to be needed at least 3 times per week to be eligible.
- The therapy is needed for an average of at least **14 hours per week** including only the time that your patient or another person must dedicate to the therapy, that is, the time they spend on activities to administer the therapy requires them to take time away from normal everyday activities.

Refer to the following table as a guide for the types of activities to include in the 14-hour requirement.

Examples of eligible activities:	Examples of ineligible activities:
• Activities directly related to adjusting and administering dosage of medication or determining the amount of a compound that can be safely consumed • Maintaining a log related to the therapy • Managing dietary restrictions or regimes related to therapy requiring daily consumption of a medical food or formula to limit intake of a particular compound or requiring a regular dosage of medication that needs to be adjusted on a daily basis • Receiving life-sustaining therapy at home or at an appointment • Setting up and maintaining equipment used for the therapy	• Exercising • Managing dietary restrictions or regimes other than in the situations described in the eligible activities • Medical appointments that do not involve receiving the therapy or determining the daily dosage of medication, medical food, or medical formula • Obtaining medication • Recuperation after therapy (unless medically required) • Time a portable or implanted device takes to deliver therapy • Travel to receive therapy

1) Which type of life-sustaining therapy is your patient receiving?

Specify the life-sustaining therapy: ______________________________

Specify the medical condition: ______________________________

Note: If the life-sustaining therapy indicated is for type 1 diabetes and you are filing this form for 2021 or later years only, you may skip to question 6. Individuals in this case are deemed to have met the criteria for life-sustaining therapy.

2) List the eligible activities for which the patient or another person dedicates time to administer the life-sustaining therapy:

3) Does your patient need the therapy to support a vital function? ☐ Yes ☐ No

4) Provide the minimum number of times per week the patient needs to receive the life-sustaining therapy: __________ times per week

5) Provide the average number of hours per week the patient or another person needs to dedicate to activities in order to administer the life-sustaining therapy: __________ hours per week

6) Enter the year the patient began to meet the eligibility criteria at the top of the page:

Year ____ or ☐ Not applicable (provide the year life-sustaining therapy began) Year ____

7) Has the impairment that necessitated the life-sustaining therapy lasted, or is it expected to last, for a continuous period of at least 12 months? ☐ Yes ☐ No

8) Has the impairment that necessitated the life-sustaining therapy improved or is it likely to improve to such an extent that they would no longer be in need of the life-sustaining therapy?

☐ Yes (provide year) Year ____ ☐ No ☐ Unsure

Clear Data

Patient's name: ____________________

Protected B when completed

Certification – Mandatory

1) For which year(s) has the person with the disability been your patient? __________ to __________

2) Do you have medical information on file for all the year(s) you certified on this form? ☐ Yes ☐ No

Select the medical practitioner type that applies to you. Tick one box only:

☐ Medical doctor ☐ Nurse practitioner ☐ Optometrist ☐ Occupational therapist

☐ Audiologist ☐ Physiotherapist ☐ Psychologist ☐ Speech-language pathologist

As a **medical practitioner**, I certify that the information given in Part B of this form is correct and complete. I understand that this information will be used by the CRA to make a decision if my patient is eligible for the DTC.

Signature: ____________________

It is a serious offence to make a false statement.

Name (print): ____________________

Medical license or registration number (optional): ____________________

Telephone number: ____________________

Date: Year Month Day

Address

General information

Disability tax credit

The disability tax credit (DTC) is a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay.

For more information, go to **canada.ca/disability-tax-credit** or see Guide RC4064, Disability-Related Information.

Eligibility

A person with a severe and prolonged impairment in physical or mental functions **may be eligible** for the DTC. To find out if you may be eligible for the DTC, fill out the self-assessment questionnaire in Guide RC4064, Disability-Related Information.

After you send the form

Make sure to keep a copy of your application for your records. After we receive your application, we will review it and make a decision based on the information provided by your medical practitioner. We will then send you a notice of determination to inform you of our decision.

You are responsible for any fees that the medical practitioner charges to fill out this form or to give us more information. You may be able to claim these fees as medical expenses on line 33099 or line 33199 of your income tax and benefit return.

If you have questions or need help

If you need more information after reading this form, go to **canada.ca/disability-tax-credit** or call **1-800-959-8281**.

Forms and publications

To get our forms and publications, go to **canada.ca/cra-forms** or call **1-800-959-8281**.

How to send in your form

You can send your completed form at **any time** during the year online or by mail. Sending your form before you file your annual income tax and benefit return may help us assess your return faster.

Online

Submitting your form online is secure and efficient. You will get immediate confirmation that it has been received by the CRA. To submit online, scan your form and send it through the "Submit documents" service in My Account at **canada.ca/my-cra-account**. If you're a representative, you can access this service in Represent a Client at **canada.ca/taxes-representatives**.

By Mail

You can send your application to the tax centre closest to you:

Winnipeg Tax Centre
Post Office Box 14000, Station Main
Winnipeg MB R3C 3M2

Sudbury Tax Centre
Post Office Box 20000, Station A
Sudbury ON P3A 5C1

Jonquière Tax Centre
2251 René-Lévesque Blvd
Jonquière QC G7S 5J2

For internal use ____________

Validate and Print

Mailing Address:
Box 3243
Charlottetown, PE
C1A 8W5

Toll Free Phone 1-888-360-8681
Phone: 902-566-4844
Fax 1-902-368-8057
E-mail Nathalie@autismsociety.pe.ca

Autism Society of PEI

Family Membership Form 2025 – 2026 (Dates April 1st, 2025-March 31st, 2026)

Date: ______________________________

Individual or Family Name(s): ____

Mailing Address: ____

____

____

Email: ____________________________

Home Number: __________________ Work Number: ________________________________

Name of Family Member on Autism Spectrum ____

Age: _________

Additional Family Member on Autism Spectrum: ____

Age: __________

Additional Family Member on Autism Spectrum: ____

Age: __________

Family Membership fee is $50.00 per year and is inclusive of all members of the immediate family.

_____Cheque payable to "Autism Society of PEI"
_____Cash
_____ E-Transfer- Transfers sent to Nathalie@autismsociety.pe.ca
_____ Interac (We accept only debit tap at the Autism Society office for membership payments)

Additional Notes: Is there anything else the Autism Society can do to help you and your family?

Autism Society of PEI Photo Consent From

Throughout the year, the Autism Society of PEI hosts many family events, fundraisers, volunteer activities, programs and supports.

Occasionally at these events, we will have photographers taking event photos. By signing below, you are consenting to allow you and your family to be photographed at any Autism Society events throughout the 2025-2026 year.

I give my consent for my family to be photographed at Autism Society events and for these photo's to be used as promotional material through Autism Society promotional outlets.

________________________________ _______________________

Name (Signing on behalf of above family) **Date**

autism speaks

Successful Haircuts for Children with Autism

For Stylists

What is autism?

Autism is a neurological disorder that typically lasts throughout a person's lifetime. Autism affects the way an individual perceives the world, making communication and social interaction difficult. It may also result in repetitive behaviors or unusual or intense interests. The symptoms of autism, and their severity, can vary considerably in each individual on the autism spectrum. It is sometimes said: If you've seen one person with autism; you've seen one person with autism.

An individual with autism may display some or all of the following characteristics, which may represent challenges from a certain perspective, or strengths from another:

- Difficulty understanding language, gestures, and/or social cues
- Literal or excessive speech, often with a concentration on a particular topic
- Difficulty relating or participating in a back-and-forth conversation or interaction
- Social awkwardness
- Intense or unconventional interests
- Repetitive behaviors such as pacing or hand flapping or rocking
- More or less sensitivity to light, sound, smell, taste or touch than usual
- Anxiety, abnormal fears and/or lack of appropriate fear of real dangers
- Difficulty managing transitions, changes in routine, stress, frustration
- Strong visual skills
- Good rote and long term memory (facts, statistics, etc.)
- Adherence to rules, honesty
- Intense concentration or focus, especially on a preferred activity
- Understanding and retention of concrete concepts, patterns and rules
- Musical, mathematical, technological and/or artistic ability or interest

What can you do?

- Speak in a calm, low voice
- Do not surprise the child from behind
- Keep directions simple
- Wait for a response – some individuals with autism need time to process information and respond

For Parents & caregivers

Before your child's haircut you may want to think about the following:

- Speak with the salon manager about just coming in so that your child can be acquainted with the environment.
- Schedule an appointment during a time when the salon is not as crowded so there are less distractions for the child with autism.
- Speak with the stylist before hand about any particular sensitivities that your child may have.
- Identify reinforcers or preferred items that your child likes. For some children it's a favorite toy or book, for others it's a treat. Your child can earn the item as a result of successfully completing the steps requested of the child. For some children this may mean all the steps necessary for getting a haircut, for others it may mean to complete a predetermined number of steps. As these steps are mastered more steps can be added until the haircut is successfully completed. It is important that the child is successful and has earned the reward at the end of the sessions. This way the experience may be remembered as positive.
- Take a digital picture of the reinforcer or preferred item to remind the child what he is earning.
- Review the steps of getting a haircut with your child (see the visual schedule on page 5 of this pamphlet).
- Practice the steps of getting a haircut with your child at home before bring your child in for a haircut.

Visual Schedule

Individuals with autism often benefit from visual supports and schedules. The following visual schedule outlines the steps necessary to get a haircut. Families are welcome to print the pictures and create a visual schedule for their child. Some families may print the page and check off the activities as they occur. The pages can be laminated and a dry erase marker can be used to check off each activity, this way the page can be reused for each visit. Others may cut out the photos and laminate them, and place Velcro on the back of each photo. The photos are arranged in chronological order on a board, as each step is completed the picture is removed.

Some children may need to be reinforced with verbal praise, a preferred item, or a treat after each step. Others may be able to complete some, many or all of the steps before verbal praise or a treat is given. Each child will need to work at their own pace to achieve the skills necessary to get a haircut.

Print this page to create a visual schedule for your child.

1 Go to salon ☐

2 Check in ☐

3 Meet stylist ☐

4 Sit in chair ☐

5 Hands on lap ☐

6 Feet flat on the bar ☐

7 Spray comb with water ☐

8 Comb hair ☐

9 Trim hair ☐

10 Reward for a great job ☐

Home care & Grooming

To make home hair care enjoyable for your child, here are some tips to ensure the experience goes smoothly:

- Show the shampoo to the child. Let the child smell and touch the shampoo. If you are going to use conditioner repeat the same process.
- For shampoo and bath time you will want to make this time fun but quick. Let the child have a bath toy to play with for comfort. Some families use a shampoo and body wash combination product (for example one of our Snip-its Tearless Shampoo and Body Wash products). This will make the process easier, with one multi-purpose product.
- Rinse the shampoo until the water runs clear.
- If the child is sensitive to having their hair combed, use a leave-in spray detangler. Using a detangling product means there is nothing to rinse out of the child's hair and it will make combing the hair easier.
- Comb the child's hair with a wide tooth comb, this will create less tension on the child's hair and be more comfortable for the child.
- If you are going to apply a styling product on the hair, repeat the process of showing them the product, let them smell and touch it and then apply the product to the hair.
- To dry the child's hair, show the child the blow dryer, and turn the dryer on to a warm setting (not high/hot) with a lower speed. Blow some warm air on the child's hands or arms so they can feel that it's warm and will not hurt. If the child is comfortable with the blow dryer, proceed with drying the hair.
- If you want to use a brush to assist with the drying, use a paddle or vent brush. These types of brushes will not put added tension on the hair. Help your child to be involved in their hair care routine.
- While brushing or combing longer hair, start by coming out the ends of the hair first and then slowly work your way up towards the scalp. This will help to gently remove and tangles and pulling on the hair.

About Us

About Autism Speaks™

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. Through partnerships and collaboration, we are committed to:

- Increasing global understanding and acceptance of people with autism
- Being a catalyst for research breakthroughs
- Increasing early childhood screening and timely interventions
- Improving the transition to adulthood
- Ensuring access to reliable information and services throughout the life span

To learn more about Autism Speaks, please visit *www.autismspeaks.org*

About Us

About Snip-its®

Snip-its is an innovative hair care and branded entertainment concept designed specifically for kids. Snip-its salons feature colorful decor, a custom cast of animated cartoon characters, interactive computer game Play Stations, the 'Magic Box', and a complete line of hair care products specially formulated just for kids. Since 1995, Snip-its has changed the dynamic of children's hairdressing, turning what has been considered a traditionally mundane and often unpleasant experience into a fun-filled, animated adventure. Snip-its provides specialized training for all stylists to ensure top-quality haircuts, outstanding customer service, and a special certification program educating stylists to work with children who may have heightened sensitivity or anxiety toward haircuts.

For more information visit us at: ***www.snipits.com***

About Us

About Melmark®

Established in 1998, Melmark *New England* is a private, community-based 501(c)(3) organization in Andover, Massachusetts, dedicated to serving children and adolescents with autism spectrum disorder, acquired brain injury, neurological diseases and disorders, dual diagnosis and severe challenging behaviors. The program uses an interdisciplinary team approach based upon the science-based principles of Applied Behavior Analysis (ABA). Melmark *New England* provides educational, vocational, clinical, residential and consultative services, personally designed for each individual in an environment of warmth, care and respect. In close communication with families, Melmark *New England* works to develop and enhance the confidence and abilities of these students by providing a safe, motivating, challenging and nurturing environment that is clinically proficient and whose overriding goal is personal welfare of the students served. Melmark *New England's* parent organization, Melmark, Inc. in Berwyn, Pennsylvania, was established in 1966 by Paul and Mildred Krentel whose youngest daughter Melissa was born with Downs Syndrome. Melmark Inc. currently provides an extensive range of services to adults and children with Developmental Disabilities.

For more information visit us at: ***www.melmarkne.org***

List of Registered Occupational Therapists in PEI

Aguila, Sandra J. (# 199)

Amyotte, Bonnie L. (# 189)

Anand Toner, Alice (# 150)

Arsenault, Michelle (# 49)

Bernard, Monique M. (# 176)

Brine, Marie (# 57)

Bruce, Chloe (# 194)

Burchell , Felicia A. (# 185)

Butler, Selynn (# 197)

Callaghan, Cathy (# 44)

Carmichael, Shelley (# 39)

Clark, Julie (# 41)

Colter, Amanda S. (# 162)

Cooke, Nancy (# 37)

Cormier, Shianna (# 202)

Crawford, Karla M. (# 84)

Cutcliffe, Heather (# 18)

Deighan, MacKenzie A. (# 198)

Dennis, Julie H. (# 142)

Drake, Carrie E. (# 155)

Dykerman, Sarah (# 122)

Ellis, Lauren (# 180)

Findlay, Jessica R. (# 177)

Fitzpatrick, Rae E. (# 158)

Fullerton, Katie (# 192)

Gallant, Manon (# 104)

Gaudet, Kendra (# 72)

Gauthier, Gail (# 76)

Gauthier, Heather M. (# 78)

Giasson-Jean, Corinne (# 157)

Goodwin, Tanya M. (# 92)

Groeneweg, Charlotte L. (# 178)

Hackett, Marjorie J. (# 26)

Hann-Levy, Lorilei (# 60)

Higgins, Michelle (# 112)

Holland, Mark (# 82)

Hornby, Devin J. (# 171)

Horne , Jessica I. (# 144)

Hughes, Rachelle (# 81)

Jameson, Alicia (# 135)

Johnston, Christopher (# 109)

LeBlanc, Michael E. (# 140)

Love, Alida L. (# 77)

MacDonald, Sarah D. (# 145)

MacLauchlan, Nicole (# 173)

MacLean, Brittany (# 133)

Richard, Lloyd A. (# 116)

Robertson, Megan A. (# 149)

Ross, Daniel (# 191)

Saunders-Green, Lisa A. (# 159)

Sauve, Marla M. (# 175)

Schurman, Karen E. (# 48)

Shaw, Paula M. (# 188)

TeRaa, Tabatha (# 66)

Thompson, Derek J. (# 147)

Thompson, Yvonne (# 46)

Verhulst, Katie (# 108)

Watson, Joan R. (# 35)

Waugh, Sarah (# 195)

Woodside, Dawna L. (# 33)

Younie, Elizabeth M. (# 156)

List of Occupational Therapists with Special Registration for Telepractice in PEI during COVID19 Pandemic

MacMillan, Krista (# SR 2021-01 (Time-limited telepractice))

McCaskill, Pam (# SR 2021-02 (Time-limited telepractice))

Mercer, Jillian (# SR 2021-03 (Time-limited telepractice))

Thieu, Scott (# SR 2021-04 (Time-limited telepractice))

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Occupational Therapy (OT) for Preschool Children

Preschool occupational therapy is offered to children from infancy until entry into kindergarten. Occupational therapy services are often initiated by a referral from a health care professional. However, anyone may make a referral, including parents.

Occupational therapy services may be offered in a clinical setting, at home, in a child care centre or at school.

How do I know if my child needs occupational therapy?

A child's motor and sensory skills develop over time and children will reach motor and sensory milestones at his or her own rate. You can request occupational therapy services if you are concerned your child is late in reaching these motor and sensory milestones.

Preschool occupational therapists provide family-centered services to help children develop motor and sensory skills and independence in the areas of:

- **Self-care:** toileting, dressing, bathing, feeding self, eating, as well as following the home routine and completing simple chores
- **Play skills:** playing with a variety of toys and different textures/materials; taking turns and copying actions
- **Preschool readiness:** drawing, colouring, using scissors, building with blocks or puzzles
- **Exploring environment:** moving around environment safely; participating on playground equipment
- **Sensory input:** tolerating different sounds; also smells, tastes and textures

Occupational therapists may also recommend equipment, aids or adaptations so that children can be successful within the areas mentioned above.

How can I contact a preschool occupational therapist?

West Prince area

Home care O'Leary
Telephone: (902) 859-8730

Wellington and area

Evangeline Health Centre
Telephone: (902) 854-7259

Summerside and area

Prince County Hospital
Telephone: (902) 438-4480

Charlottetown and area

Queen Elizabeth Hospital
Telephone: (902) 894-2067

Montague and area

Home Care Montague
Telephone: (902) 838-0786

Souris and area

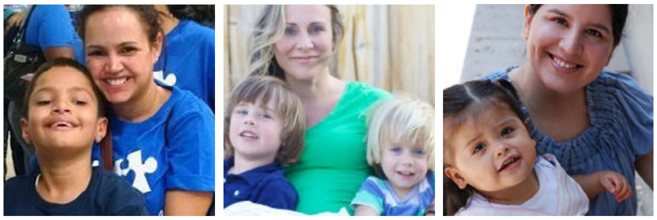
Home Care Souris
Telephone: (902) 687-7096

What if my child is school-aged?

Children who are in school may be eligible for school-based services. School-based occupational therapy can *only* be accessed through your child's school.

For more information, visit Occupational Therapy for School-Aged Children.

Published date:
October 3, 2019



autism speaks®

Parent's Guide to Autism

AUTISM SPEAKS®

Table of Contents

Introduction

If your child has recently been diagnosed with an autism spectrum disorder, you have come to the right place. ***A Parent's Guide to Autism*** was developed as part of Autism Speaks' series of *Family Support Tool Kits* to support you and promote a positive future for your child and family during an often challenging time. You are not alone in this journey and this guide is a step toward finding the help you need to travel the road to optimal outcomes for you, your child and your family.

The Autism Speaks 100 Day Kit for Newly Diagnosed Families (versions for both children under 5 and school age children) was designed to provide you with the information and tools you need to make the best possible use of the days following the diagnosis. It is a comprehensive tool filled with facts and resources such as information about symptoms, treatment, legal rights and advocacy. The *100 Day Kit* can be found at AutismSpeaks.org.

A Parent's Guide to Autism will help you:

- *Learn about how autism may impact your family.*
- *Find strategies and resources for raising a child with autism.*
- *Find support so you don't feel alone or isolated.*
- *Reduce the negative impact of the diagnosis on your family.*
- *Promote a positive future for your child and family.*

For additional guidance and support, the ***Autism Speaks Autism Response Team*** is here to help. The team is specially trained to connect you and your family to resources and information specific to your child's strengths and challenges.

Contact the team at
FamilyServices@AutismSpeaks.org
(888) 288-4762
(en Español 888-772-9050)

Response to the Diagnosis

Learning that your child has been diagnosed with autism is a powerful moment in your life. Suddenly your life may feel very different from what you expected it to be. You worry first about your child and what it will mean for his or her life experiences. You worry about how you and your family will adjust to this in the years ahead. You worry about the day-to-day challenges of caring for your child with autism.

This is an important turning point in your life as well as the lives of your child and other family members. Getting emotional support and factual information to help you cope and promote a positive future for your child and family will be critical during this period.

**For the purposes of this tool kit, the term "autism" will be used to describe children with all types of autism spectrum disorders, including Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)*

Common Reactions to the Diagnosis

Each family's reaction to the diagnosis will be different depending on many factors. When a child is diagnosed with autism, parents and other family members frequently experience a range of uncomfortable emotions. Whether or not you have suspected something for awhile or the diagnosis seems to have been out of the blue, many parents experience shock when they hear the words, "your child has autism."

You may go through periods of denial or refusing to believe this is happening to your child. During this time, you may not be able to hear the facts as they relate to your child. Denial is a way of coping. It may be what gets you through a particularly difficult period. It is important to be aware that you may be experiencing denial, so that it doesn't interfere with making good decisions about your child's treatment.

Some parents mourn some of the hopes and dreams they held for their child before they are able to move on. There will probably be times when you feel sad. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable. Anger is also a natural part of the process and you may find that it's directed at those closest to you. Anger is a healthy and expected reaction to the feelings of stress that come with your child's diagnosis. Expressing your anger is natural and at times healthy.

There are times you might feel isolated and lonely. These feelings come from a variety of sources when you experience a diagnosis or other significant life change. Loneliness may also come from the fact that you simply don't feel you have the time to contact friends or family for company. You may also feel that if you did reach out to others, they wouldn't understand or be supportive.

It's easy to become overwhelmed with your emotions and concerns about what the future may hold. Painful emotions are natural. If you accept your reactions and acknowledge your feelings, you will be able to move forward and begin advocating for your child. Emotions are powerful. If you deny your feelings or ignore them, they will often surface in unpleasant ways.

Ultimately, you will likely feel a sense of acceptance. Your life may not look like what you had planned and you may have to alter your expectations, but your goal remains the same: to help your child live a happy and fulfilling life. Once you accept the diagnosis, you will be ready to advocate for your child and start working toward a brighter future.

Common Areas of Concern

Like any stressful event in your life, learning your child has autism will affect everyone in your family and network of friends. It's probably not a surprise that your role as parent will change and you will go through many positive and negative experiences in your new role. Below are examples of new feelings you may encounter:

- *May feel burden with everyday responsibility of caring child with autism.*
- *May feel pressure to become an autism expert and learn everything overnight.*
- *May worry about child and family's future.*
- *May have difficulty finding balance and time to manage household tasks, other children, daily activities, etc.*
- *May be less inclined to share feelings.*
- *May become stressed about the family's finances and the unknowns of the situation.*
- *May develop other problems such as stress and anxiety that can affect work life.*

It is important to know that most families find a way to work together, grow stronger and learn ways to reduce the negative impact of the diagnosis and promote a positive future for their children and families.

When to Seek Professional Help

If you are experiencing several of the following signs and symptoms over a period of time, you may want to seek professional counseling:

- *You have trouble sleeping and don't feel rested when you do sleep.*
- *You can't control your negative thoughts, no matter how hard you try.*
- *You have lost your appetite or you can't stop eating.*
- *Others point out that you seem irritable, short-tempered or more aggressive than usual.*
- *You are consuming more alcohol than normal or engaging in other reckless behaviors.*
- *You have thoughts that life is not worth living.*

If you have trouble working through your emotions within a reasonable timeframe or you feel unable to function in your usual ways, it may be a good idea to seek professional help. Professional help can prevent serious problems from developing in the future. It can help to empower us to face challenges more effectively.

Your Role as a Parent

Your Child's Advocate

When your child is first diagnosed, you will likely find yourself fulfilling many roles: care coordinator, therapist, parent, teacher, etc. One of the most important roles you will have is serving as your child's advocate. Advocating for your child will be a lifelong journey that will require different skills depending on your child's needs.

In her book, *Everyday Advocate: Standing Up for Your Child with Autism*, Areva Martin describes seven principles that can be applied to serve as an effective advocate for your child:

1. ***Take Responsibility - Be a leader***
2. ***Learn - Be an expert***
3. ***Think Critically - Be discerning***
4. ***Speak with Authority- Be proactive***
5. ***Document - Be prepared***
6. ***Collaborate - Be a team builder***
7. ***Educate - Be a voice for your child***

Martin's book offers examples of each principle as it relates to real world activities that parents can do to advocate for their child with autism.

Supporting Your Other Children

Parents of children with autism can be under tremendous stress. It may seem like there is never enough time to do everything that needs to be done. So much focus and attention is placed on the child with autism, that it is common for parents to have little time or energy left to focus on their other children.

Brothers and sisters of children with autism frequently face their own challenges. Much more may be expected from these siblings. They often need help understanding the emotional reactions they are experiencing as a result of the many changes occurring in their lives. This support is essential to their future well-being.

Some things your other children may be struggling with:

Young children may not understand what is wrong with their brother or sister. *They may be confused and unable to fully comprehend the implications of diagnosis.*

They may have feelings of jealousy and resentment *if they see that their parents are spending less time with them compared to their brother or sister with autism.*

They may feel angry over unequal treatment *if their brother or sister is not disciplined in the same way they are or given similar chores to do.*

They may feel embarrassment *with friends or in community settings where strangers react negatively because of their sibling's unusual and sometimes aggressive behaviors.*

They are often frustrated *by the fact that they are not able to get their brother or sister to respond or interact with them in "normal" ways.*

Quietly, and sometimes secretly, siblings worry *about their brothers and sisters and their parents as everyone in a family is impacted by the disorder in some way.*

Many children are unable to express their feelings *so sometimes revert to "acting out" behaviors. For example, they may misbehave by defying their parents or getting into trouble at school.*

Strategies for supporting your other children:

It is important that your other children understand autism *and what is going on with their brother or sister. Talk with them early and often in age appropriate ways. Many books and other resources are available to help them to understand this diagnosis, some of which are listed on the Books page of the Autism Speaks Resource Library.*

Help your children learn how to play and form relationships *with their sibling with autism. There are a few simple things that you can do that will help with this, including teaching your other children how to get their sibling's attention and give simple instructions. It's also important to praise all your children when they play well together.*

Find sibling support groups *that can help them build friendships and relate to other peers who have a sibling with autism.*

Don't hesitate to consult a professional if you feel your child is internalizing most of his or her feelings or beginning to act out. The earlier you address this, the better. It is not a failure to ask for this type of help. Rather, it is a sign of strength and evidence of good parenting.

Ten Things a Parent Can Do to Help Their Child with Autism

This is a post by Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog about her two children with autism, at ***AutismMommyTherapist.Wordpress.com****. Her book "****Raising Autism****" is available on Amazon.*

Thirteen years ago this fall our beautiful son, Justin, was diagnosed with PDD at seventeen months of age. He would later go on to receive an "official" autism diagnosis, and would remain on the more severe end of the spectrum. I will never forget the day he was diagnosed – it was both comforting to put a name to something I'd suspected he'd had for a long time, and overwhelming because I just didn't know what to do next. I remember leaving the developmental pediatrician's office wishing someone had given me a checklist of things to accomplish which would help both him and our family in those early days post diagnosis.

Here are some things I did (and some things I wish I'd done) – I hope they are helpful to you and your family. Number ten is the most important!

1) No matter how exhausted you are, get your child out in the community. It was a struggle with us with Justin (I have the tiny little bitemarks on my body to prove it) but getting him out so he could have a repertoire of leisure activities was crucial to his happiness and to our family's. It set him up for a lifetime of being able to try different things, which will set him in good stead when I'm no longer here to take him places. Yes, I'm always planning.

2) If you haven't already done so, join a parent group and/or your school district's special education PTA. You will make invaluable connections at both. Try to find parents of kids with your kid's level of autism as you're making friends. These people will be a wealth of information for you and a lifeline.

3) If you can afford it, hire an advocate to check out your child's school program. A fresh set of eyes may see areas that need to improve, or may reassure you that they are doing all they can for your son or daughter. It's always good to know one in case you need an advocate at an IEP meeting. If you've already met, you won't be scrambling to find one.

4) If possible, volunteer at school functions or offer to be a class mom. This is a great way to get to know your child's teacher and your school's administrators better. You may also make friends with other parents too.

5) No matter how difficult your child can be, take any offer of babysitting you can and get out. You need a night off from autism once in a while. Even if it's for a few hours, a break will help.

6) Now that your child's program is set, tackle the big issues one at a time- perhaps it's sleeping, or eating, or potty training. If your child is in a private school there may be a BCBA on staff who can help you. If not and you can afford it, consider hiring a BCBA from an agency. Pick an issue and prioritize.

7) Educate your friends and family as to what's going on in your household. Perhaps you've been too tired up to this point to talk to people not in the "tribe" about what raising an autistic child is really like. It's time to tell them and ask for the support you need, even if it's just an ear to listen. My husband and I kept too much to ourselves, and if I could go back in time I'd be more open with everyone in our lives.

8) Make those doctor appointments for yourself that you've been putting off. Just do it.

9) Get involved in an autism walk in your community. It is so powerful to meet so many families like (and unlike) yours. It will give you strength.

10) I can't stress this one enough – take care of yourself, not just your kid. Autism is a marathon, not a sprint. You owe it to yourself and your child to be whole, healthy, and happy. Do whatever it takes to get there.

Building a Support Network

In today's world, there are a variety of family models and this can be especially true for parents or guardians of children with autism.

Whatever your family structure, you can expect you will need support and help at many times in your journey as a parent of a child with autism. It's important to remember to maintain relationships with your family, friends and community in order for your support network to be there when you need them the most.

Keeping your Marriage Strong

It is important to stay as connected as possible to your spouse and keep the lines of communication open. In addition to the normal demands of marriage, parents of a child with autism may also experience:

- *Additional stress from navigating the maze of agencies, funding sources and paperwork to help your child.*
- *Loss of income due to one parent not working in order to care for your child and the additional expense of hiring and managing specialized caretakers.*
- *Different points of view regarding your child's challenges and decisions about treatments and interventions.*
- *Loss of friendships or loss of time and energy to maintain outside friendships.*
- *Worries about the long-term future of your family.*
- *Changes in your retirement plans, your ability to take vacations or explore enrichment activities, etc.*

Tips to keep your marriage strong while dealing with the everyday challenges of living with autism:

- *Communicate! The more you can communicate in challenging times, the stronger you will be as a couple. You and your spouse may not react to your child's diagnosis in the same way, but try to explain how you feel and listen carefully as your spouse shares his or her feelings as well.*
- *Talk openly about problems as they occur.*
- *Be kind to yourself and your spouse during this difficult time.*
- *Work together to learn all that you can about autism.*
- *Help each other focus on the present and what you can do to make things better today.*
- *Spend time together. Plan some alone time, even if it is just a few hours a week, to relax and have fun together. Try and enjoy the leisure activities you did before your child was diagnosed with autism.*
- *Share the responsibilities at home when possible. Work together on chores, childcare, homework and other household tasks.*
- *Get help if you need it. A marriage counselor can help you and your spouse sort through your feelings and maintain a healthy marriage.*
- *Sort out what is important and what isn't important to the two of you. Take a close look at the best ways to make a good life for you and your family.*

Support for Single Parents

While stress affects all parents, single parents who have a child with autism may experience even more challenges. Single parents are often forced to take on several roles. They may be responsible for both the overall emotional and financial needs of their families while also caring for a child with special needs.

Come to an agreement that involves both parents. *If possible, start with your child's other parent and try to establish "agreements" that support everyone. The best situation is for your child to have frequent contact with the non-custodial parent so that your child will interact with both parents. This also gives the custodial parent a break or some down time.*

Build a support network of friends and relatives. *If you don't have family in your local community, you may want to consider moving closer to family or friends where you and your child will have a support network to fall back on.*

Take time for yourself. *If you can't depend on family or friends, find respite care in your area, so you can recharge and focus on yourself even for a short time each week.*

Social Networking – Find Support Online!

Many parents turn to the internet to avoid feeling isolated. Today's social networking sites will make it easy to seek out support from likeminded parents on the web. Social networking sites such as Facebook, Twitter and autism blogs will allow you to:

- *Connect with parents in similar situations, who are facing the same challenges.*
- *Ask specific question and get immediate feedback.*
- *Get support from other parents without having to travel or leave home.*
- *Read communications from trusted health organizations.*

Remember, your child with autism is part of a family and community. Family and friends are more likely to play a part in your support network if they understand your needs and the needs of your child. Do your best to keep family and friends informed and updated on your child's progress, as well as anything they might be able to do to help.

Taking Care of Yourself

Caring for a child with autism can be physically exhausting and emotionally draining. Parenting responsibilities can create extraordinary stress. Trying to balance your time and energy with the needs of your other children, the needs of your marriage and your own personal needs is not easy. It takes time to find a good balance and put it into practice.

What You Can Do for Yourself Right Now

Practice self-care.
Even if it is just for 15 minutes a day, take a breather. You need to take care of yourself in order to be able to take care of others. Take time to yourself so you can run errands, relax or enjoy time with your partner or other family members.

Acknowledge what you have accomplished.

It's easy at the end of the day to think about all the things you haven't been able to do that day. But this tends to discourage us from trying later. Instead, think about all that you did accomplish that day. You will be amazed at how long that list is, and you will feel better about getting started the next day.

Focus on the positive.

Nothing in life is perfect. Every situation has positive and negative aspects to it. Focusing on the positive, such as the progress your child is making or the amazing speech therapist you found, will give you the energy you need to move forward.

Continue family rituals.

When possible, continue your family routines or rituals. This will be helpful for your entire family. It may be a Friday night trip to the movies, or Sunday lunch in the park. Tradition and rituals give your family an increased sense of stability and create fun times to enjoy together and to remember.

Give yourself time to adjust.

Be patient with yourself. It will take some time to understand your child's disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than the one you had planned. Remember, you will also experience feelings of hope as your child begins to make progress.

Make time for your friends.

Many parents report that long-lasting friendships have given them the strength and comfort during the most difficult times. If you feel isolated, it's time to take action.

Explore creative interests outside of autism.

Try to exercise or explore some creative interests. Take the time to realize that you are important and are more than just the parent of a child with autism.

Get involved with the autism community!

Sometimes families of individuals with autism find themselves feeling isolated from others. It is important to connect with families that share similar experiences and seek the support of others. We encourage you to reach out and come together with other families at one of the many *Autism Speaks Walks* held around the country. For more info on how to get involved, visit AutismSpeaksWalk.org.

Respite Care

If you don't have a family member or friend to babysit, find respite care in your area so you can recharge and focus on yourself even for a short time each week. Building a relationship with a respite provider gives you a reliable caregiver for your child if there is a family emergency. Respite care allows you to take a break in order to relieve you and prevent stress and fatigue. When you are ready to interview respite care providers, keep in mind that the most important step is to observe how the respite worker interacts with your child with autism and your family. If possible, have the worker spend supervised time with your family member. Below is a checklist of what you will want to discuss with a potential respite worker:

- *Previous work experience with an individual with autism*
- *Background checks*
- *Training sessions*
- *Behavioral concerns*
- *Safety issues*
- *Availability and flexibility*
- *Work references*

To find respite care in your area, please look at our online *Resource Guide* for your state's information: AutismSpeaks.org/Resource-Guide.

How I Let Go of My Expectations and Learned Unconditional Love

Ths is a post from blogger Chrissy Kelly who has two sons on the autism spectrum.
Read more from Chrissy's blog, ***Life with Greyson + Parker****, at* ***LifewithGreyson.com****.*

With one final, excruciating push he flew into the world. All the pressure was released and for the first time in so long I am able to take in a deep inhale. In that same very instant a brick house of expectation was also born.

He was perfect. Ten fingers and toes and I sighed, and fell in love with every single blessed detail. Soaked him up and felt it - the sweetest, purest love. I didn't know it existed quite so lucidly. My expectations already had his life all planned out for him.

He will smile and sit and crawl and one day even walk. He will say Momma, and love ice cream. He will dress up for Halloween. He will love his birthday. He will say the funniest things. I will read him books at night and scare the monsters away from under his bed. He will ask for extra pancakes and wrap me around his currently teeny tiny finger.

He will go to school. He will be smart. I will help him with science projects and pretend to be annoyed but actually love it. He will play sports, and be a humble winner and the very best loser. He will be fast. He will be brave. He will be kind. He will go to college and get married and have babies.

I had great expectations. And then right before his third birthday, I heard the words, "Your son fits the diagnostic criteria for autism". In an instant, my boy's life vanished right before me.

I didn't realize at the time, but it was really just the death of expectation. You see, I confused the two; my real boy and the son I expected him to be. And mourning expectation is so very hard. Letting go of years worth of day dreams doesn›t happen in a day or a week. And like many before me, I deeply grieved the loss of that expectation. Some of what I expected for me. Some of what I expected for him. I ached for each and every single one of those experiences I might not ever have.

But the more I shed the pain of expectation, the better I got to know my boy.

The real one I got, not the made-up one I expected. He doesn't deserve to be expected to be anyone other than who he is, and who he is - is amazing. It took time and strength and a determination to willingly let my expectations go, without throwing hope out at the same time. To wake up every day still, and decide to let go again and again. And the truth is that my real boy is alive and better than any of my wildest expectations- in ways completely different than I could have even imagined.

And as far as his future - anything is still possible. I just don't need certain things to happen in certain order to be happy and to measure the worth of my parenting experience.

The truth is, for most of us, reality is nothing like we expected. It is only in the letting go of our expectations that we are able to realize that our reality may not be so bad at all. When you are living an unexpected life it is easy to focus what you don't have. But there is also incredible beauty, perspective, love and experiences that come with the unexpected. It's so important that we notice those gifts too.

Sometimes I have moments when I still focus on the death of the expected. But now I remind myself how awful it would feel if someone constantly expected me to be different - and to be someone I'm not.

I've learned the very definition of unconditional love is choosing to love someone exactly for who they are.

A love not based on expectations, but on reality. I've finally knocked down that brick house of expectations. Turns out it was hiding the most incredible view.

Frequently Asked Questions from Parents

Q: My daughter is 2 years old and was recently diagnosed with autism. I have some family members who keep insisting she's just delayed. Can you give me any suggestions for how to respond to them?

Your situation is very common in families of children diagnosed with special needs, most especially autism. There are so many emotional processes that are occurring for the family as a unit and for each family member individually after getting this diagnosis. Of course there is the initial shock that can send you spiraling into a true grieving process, and each of you in the family will work through this in your own time frame. Part of that process includes a stage of denial as particularly seen from family members who aren't living with your child day-to-day. It's probable that it will take them longer to come to terms with the diagnosis. In addition to everything else you are doing, you must also remain patient for this to happen. Family members who love your child will benefit most from learning about autism so they can adapt their interactions and expectations to more appropriate levels.

There are also professionals and effective support groups in your community who have a lot of experience and expertise in understanding this process. They may be able to provide you and your extended family with assistance.

Q: My husband refuses to accept the diagnosis and will not attend appointments with our doctor. What can I do?

This is not uncommon, where one parent accepts the diagnosis and the other is in denial. Denial happens both to fathers and mothers. As difficult as it may be for you at a time like this, you must be patient and supportive. Your spouse will eventually work through his or her denial. Meanwhile, you might try to recommend a book or share an article about autism, but be careful not to pressure. Most people need to do this on their own terms.

Q: Since my son was diagnosed, I've felt overwhelmed and I can't even bring myself to read anything about autism.

Being an advocate for your child with autism will most likely be a lifelong activity. Early on when faced with the diagnosis, parents are easily overwhelmed by the news. They feel confused, fearful and angry. Many tire easily as they try to cope. It is helpful to remember that you are not alone, that others are going through this so there is support available for you. Keep a folder of articles and other information material so that when you are able to read it, you will have it available. Pace yourself and in time you will do what needs to be done and your efforts over time will make a difference.

Q: My family's involvement in church is important to us. How do I get my church to be more accepting of my son?

For many people, including those members of your church, autism is not something they may have experience with or adequate information about, so you must help educate them. A good place to start is with your pastor or minister. See what he or she knows and offer information as needed. Sometimes a leader will incorporate the related issues into a sermon or lesson. He or she can also suggest folks who can be approached as more open to learning about autism. Then, suggest the church invite a professional to do a workshop on special needs children, with emphasis on the challenges associated with autism. Suggest the church develop a plan to accommodate special needs children in their various activities such as the Sunday school classes, the worship service, the choir, etc. At some point, it may be helpful to bring in a behavioral specialist to work with and train the staff. It may mean asking teachers, parents and other trained professionals in the church to volunteer time helping out in Sunday school, modifying the lessons, etc. Get your community involved and they will thank you later!

Once members of your congregation are given accurate information, they will become more open and supportive. You may have to suggest ways they can become involved with your child and with advocacy organizations. There are so many opportunities for the religious community to get involved and to partner with parents. As advocates, parents have a unique opportunity to lead the charge.

Q: How do I know everything possible is being done for my child? Sometimes it seems like not enough progress is being made.

Almost daily, every parent with a child with autism asks this question: is there more that can be done to help my child? We work as hard as we can, yet very often we feel as though we aren't doing enough. It is also easy for us to project this on to others involved in our child's life. In fact, historically, not enough has been done and in many ways, more should be done in today's world. This is what advocacy is all about. We must continue to push for the best treatments and services available.

Meanwhile, we must recognize that there are some limits that we have to accept. Treatments available today have limits. We are learning so much, but we have a long way to go. Government funding clearly has limits, especially in today's economy. Teachers are frequently overworked with too many students. Sometimes it does help to focus on what is being done and to acknowledge our efforts and the efforts of others. At the same time, as suggested above, parents must be their child's biggest advocates.

When you look at what you do each day, you may want to give yourself a compliment for what you have accomplished. Your child is doing the best he or she can given the many challenges he or she faces daily. Be kind to yourself and remember that your child with autism, like all children, is going to grow and develop at his or her own pace. While we may want to see our children go from one sentence to five paragraphs in a semester, we must accept and celebrate what they do accomplish and gently encourage them forward. Consulting with outside professionals, such as educational therapists, can also help you set goals and look at progress realistically. On this journey, we have to redefine success and progress. It has to be based on our own child's gifts, and nothing else!

Q: Is there any financial assistance available to assist in the care and education for our child with autism?

Financial difficulty is one of the biggest stressors that families with special needs children face. There seems to never be enough funding or financial help available and each family often finds that their own resources are stretched by providing for their child with little hope of reimbursement for all that gets spent.

The primary funding source for your child's services is mandated through a United States federal law, the Individuals with Disabilities Education Act (IDEA). IDEA governs how states and public agencies provide early intervention, special education and related services to children with disabilities.

In addition, your family's medical insurance may reimburse you for autism services, such as speech therapy or behavioral health treatment, such as Applied Behavior Analysis. Start by speaking with the human resources department where you or your spouse work, and inquire about insurance reimbursement for autism services. Many states now have government agencies monitoring the health insurance industry so this can be a back-up resource to explore benefits as needed.

Continuing to advocate for increased funding by the government and by the insurance industry is important. For more information about autism insurance reform in your state, visit the Autism Speaks website.

Q: My wife and I worry that over time our other children will develop deep resentments for all the attention and "special treatment" their brother gets and this could negatively impact their lives. Do you have any suggestions for raising our other children so they don't feel resentment?

Sibling rivalry occurs in all families with more than one child and it can be especially complex when it involves a child with special needs. There is no way to avoid giving some extra attention and treatment to a child with autism. For siblings of children with autism, these feelings may develop early because the children may be together all the time.

Constantly checking in with your other children about how they are doing, what they need, etc. is a good start. Finding time to be with each child individually also helps immensely, when possible. Involving grandparents, aunts, uncles, trusted neighbors, etc., may help as well.

Children at various ages have the capacity to understand the special needs of someone else if you take the time to explain in terms they will understand. Explain behaviors they see in their brother or sister and why you respond differently to deal with these situations. While you don't want them to become surrogate parents, they do need to know some basic explanations. Also, creating a safe space for them to talk about their feelings with you or with others can prevent later development of toxic resentments. Helping your other children find successful ways to play or interact with their brother or sister is powerful.

Siblings may sometimes feel guilty because they do feel resentment and anger, or even just because they are "normal" while their brother or sister is not. Guilt and resentment are normal growing up issues, made more complex often because of a special needs sibling. But like any feeling, they can be talked about and processed so that your other children move forward in their own emotional development and life journeys.

Resources

Autism Speaks Autism Response Team

*The **Autism Response Team (ART)** is specially trained to connect people with autism, their families and caregivers to information, tools, and resources. A team member can help you find resources to meet your family's specific needs.*

888-288-4762 (en Espanol 888-772-9050)

FamilyServices@AutismSpeaks.org

Autism Speaks 100 Day Kit for Newly Diagnosed Families

*The **100 Day Kit** was created to help families make the best possible use of the 100 days following an autism diagnosis. Important topics include understanding symptoms, accessing services, finding the right treatments and knowing your child's rights.*

AutismSpeaks.org/Family-Services/Tool-Kits/100-Day-Kit

Versions for both young children (under 5) and school age children (5-13)

Autism Speaks Tool Kits

Autism Speaks has developed nearly 50 tool kits for parents and caregivers of children and adults with autism on topics ranging from toilet training and challenging behaviors to housing and employment for adults. All tool kits are available free of charge.

AutismSpeaks.org/Family-Services/Tool-Kits

Find a Local Resource: Autism Speaks Resource Guide

*The **Resource Guide** contains tens of thousands of local resources including pediatricians, behavioral therapists, after school programs and more.*

AutismSpeaks.org/Resource-Guide

Autism Speaks Walk

*The **Autism Speaks Walk** is a great way to connect with families and services in your area. Autism Speaks Walk is the world's largest autism fundraising event dedicated to improving the lives of people with autism. Powered by the love of parents, grandparents, siblings, friends, relatives, and supporters, the funds raised help ensure people of all abilities have access to the tools needed to lead "their best lives".*

AutismSpeaksWalk.org

Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.

TOLL FREE: 888-AUTISM2 (288-4762)
EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG
AUTISMSPEAKS.ORG/ART

AUTISM
SPEAKS®

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

To learn more about Autism Speaks, please visit AutismSpeaks.org.

Pediatric Psychology Services

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Feedback

Psychological services can be an important part of the overall care for children and their families. If you have concerns regarding your toddler, preschool or kindergarten aged child's development, or if your child is experiencing behavioural or complex health issues, Pediatric Psychology Services may be appropriate. A comprehensive psychological assessment may assist in understanding your child's challenges in hopes of finding the right avenues for early intervention and/or consultation.

What services are offered?

- Comprehensive diagnostic assessments for children (referred prior to starting grade one) who are suspected of having Autism Spectrum Disorders;
- Psychological assessments for preschool children who are failing to meet developmental milestones and might present with complex health issues;
- Opportunities for parents of children assessed in the clinic to participate in Triple P programs.

Will my child need a referral?

Your child must be referred by a Pediatrician before he or she can be seen.

If you have concerns about your child and think he or she should see a Psychologist in this clinic, talk to your Family Doctor or Pediatrician.

What can I expect if I am referred to this clinic?

Pediatric Psychology assessments include:

- Interview with parents;
- Assessment and observation of child;
- Review of various records, including pediatrics, speech language pathology, occupational therapy, etc.;
- Conceptualization, feedback to parents, and written documentation; and
- Recommendations regarding interventions, supports and referrals indicated.

How can I contact Pediatric Psychology Services?

Pediatric Psychology Services
Sherwood Business Centre (2nd floor)
161 St. Peters Road
Charlottetown, PE   C1A7N8

Telephone: (902) 620-3789 (clinic administrative assistant)
Fax: (902) 620-3860

Email: pediatricpsychology@ihis.org(link sends e-mail)

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THE PEI HELPING TREE

The PEI Helping Tree is designed to inform Islanders of the many helping resources available on Prince Edward Island. If you or someone you care about is experiencing a problem in any of the areas listed, follow the arrows on the flow chart to find resources that may help. There are times in everyone's lives when we need to reach out to others - sometimes it's just a matter of knowing how to contact them. Note: unless indicated, you need to dial 902 for all local calls. **If you are still uncertain of where to turn, please call the Island Helpline at 1-800-218-2885, toll free 24/7.** **Emergency Call 9-1-1**

Extended Care Facilities
Deacon House.............. 368-4036
Lacey House (Women) . 368-4092
St. Eleanor's House...... 888-8386
Talbot House (Men)...... 368-4297

Other Addiction Supports
Al-Anon/Alateen 1-800-425-2666
Gambling Helpline:
.... 1-855-255-4255
Narcotics Anonymous Provincial Info Line 1-800-205-8402
Native Council of PEI ... 892-5314
Open Door (Women) 628-6826
Reach Foundation 620-6200
Smart Recovery PEI 330-4357
Smokers' Helpline:
.... 1-877-513-5333

AA-Alcoholics Anonymous
Charlottetown (All Addiction):
.... 892-2103
East Prince (24/7) 598-0001
Kings: Call Addiction Services Kings (below) for meeting info
Native Council of PEI .. 892-5314
Prince Co Central........ 436-7721
West Prince 856-0301

Provincial Addiction Facility
Toll Free, 24 hours:
1-888-299-8399
Family Program..... 368-4296
Gambling Prog....... 368-4273
Inpatient Detox 368-4048
Methadone Prog 368-4265
Outpatient Detox... 569-0524
Senior's Program... 368-4289
Transition Unit 368-4765

Addiction Services
Eastern Kings 687-7110
Queens.................. 368-4120
Southern Kings...... 838-0960
Summerside 888-8380
West Prince 853-0401
Youth Services....... 368-4273

CPP/Old Age Security Enquiries
1-800-277-9914

PEI Senior Citizens' Federation
For info on Local Seniors' Clubs, PEI Friendly Visitor Program & 55 Alive Driver Course:
(1-877)-368-9008

Seniors' Home Repair, Safe At Home and Home Renovation Programs
Ch'town.... 368-4889
& 1-855-374-7366

Housing Offices
Ch'town 368-5770
Montague ..838-0796
Souris 687-7098
S'Side.........888-8436

Home Care & Support
Lennox Island:
.... 831-2711
Montague:
.... 838-0786
Queens:
.... 368-4790
Souris... 687-7096
S'Side ... 888-8440
West Prince:
.... 859-8730

Senior's Independence Initiative
1-877-569-0546

Youth Programs
Adventure Group 628-8668
Big Brothers/Big Sisters..............569-5437
Ch'town Boys and Girls Club 892-1817
Ch'town Teen Zone 892-1719
LGBTQ Youth Groups...................566-2437
Montague Boys and Girls Club 838-2884
O'Leary Recreation Ctr 859-1464
Stratford Youth Centre.................569-1995
S'Side Boys and Girls Club 436-9403
S'Side Generation XX 436-7699
Wellington Boys and Girls Club....854-3174

Alzheimer Society of PEI
628-2257

Private Counselling
See Yellow Pages under 'Marriage, Family & Individual Counsellors'

Community Chaplains
PCH Spiritual Care...................438-4374
QEH Spiritual Care 894-2094
UPEI 894-2876

Life After Suicide Loss Program
368-4911

Hospice PEI Palliative Care & Grief Support Group Info
PEI 368-4498
Queens....368-4095
S. Kings ...838-2269
Souris 687-7150
S'Side.......438-4231
W. Prince .859-2870

Mi'kmaq Confederacy of PEI
Family Pride Prog. (Lennox & Abegweit) & Indian Residential School Supports
Toll Free
1-877-884-0808

Community Counselling Services
Catholic Family Services 894-3515
Family Service PEI:
Ch'town.................................892-2441
S'Side 436-9171
Farmer's Assistance Program...626-9787
Toll Free 24/7 1-800-736-8006

Family Ties Program
Charlottetown...........................368-4871
Montague 838-0715
O'Leary......................................859-8813
Souris 687-7014
Summerside 888-8480

Positive Parenting From Two Homes
Toll Free 1-877-203-8828

Strongest Families
1-866-833-5443

Triple P Parenting
438-4134

Crisis Help
Toll Free/24 hr.
Island Helpline:
....1-800-218-2885
Kids Help Phone:
....1-800-668-6868
Canada Suicide Prevention Service:
....1-833-456-4566
First Nations & Inuit Helpline:
....1-855-242-3310
Trans Lifeline Can:
....1-800-218-2885

Family Resource Centres
CAP Enfants:
.... 854-2123
CHANCES ... 892-8744
Families East:
.... 687-3928
Families First:
.... 838-4600
Family Place:
.... 436-1348
Kids West Inc:
.... 853-4066
Mi'kmaq 892-0928

Schizophrenia Society of PEI
368-5850

Canadian Mental Health Association
PEI Division.....566-3034
E. Prince 436-7399
W. Prince.........853-4180
Indiv., Family & Peer Supports........628-1648
Suicide Prevention (Non-crisis)....628-3669
Fitzroy Centre.566-5111
Hope Centre....853-3871
Notre Dame Place:
......................888-2237
Toll Free (non-crisis)
1-800-682-1648

Community Mental Health Services & Walk-In Clinics (WI)
Children's M.H. Services:
...........1-866-833-5443
Abegweit 676-3007
Alberton..........853-8670
Evangeline......854-7259
Lennox Island.831-2711
McGill Centre - WI:
.....................368-4911
Montague........838-0960
O'Leary...........853-8670
Richmond Centre - WI:
.....................368-4430
Souris.............687-7110
Summerside - WI:
.....................888-8180

Walk-In Clinics
Abegweit Wellness Centre..............676-3007
Ch'town (Boardwalk Ctr).................367-4444
Ch'town (Parkdale Med Ctr) 892-2111
Ch'town (Sherwood Med Ctr)...........628-8900
Crapaud (South Shore Health Ctr)....658-2212
Hunter River (Central Queens HCtr) 621-3050
Lennox Island Health Centre 831-2711
Morell (Fire Hall).............................620-3260
Souris (Eastern Kings Health Ctr)....687-7033
Stratford Medical Centre..................892-2111
Summerside (Central St Med. Ctr) ...724-3210

Women's Information
Aboriginal Women's Assoc...1-888-973-4292
Birthright National Helpline .1-800-550-4900
Ch'town...628-6028
East Prince Women's Info Centre ...436-9856
Island Pregnancy Centre......1-877-370-9711
The Moncton Hospital's Family Planning Clinic 1-844-806-9205
Women's Clinic (Dr. Hoffman).........367-3285
Women's Help Line 1-888-362-7373
Women's Network of PEI................368-5040
Women's Wellness Prog.......1-844-365-8258

Cancer Screening
Fit Kits & PEI PAP Screening 1-888-561-2233
Mammography 1-888-592-9888

PEI Needle Exchange
1-877-637-0333

Parents & Friends of Lesbians & Gays
569-3089

PEI Health Cards
1-800-321-5492

Pride PEI
pridepei.com

Family Doctor Registry
1-855-563-2101

PEI Trans Network
peitn@outlook.ca
& on Facebook

Health PEI Patient Navigator
1-844-882-3141

PEERS Alliance
Ch'town...... 566-2437
1-800-314-2437

Sexual Health Services & Walk-In Clinic
Toll Free 1-844-365-8258

Public Health Nursing
Abegweit......... 676-3007
Alberton 853-8601
Ch'town 368-4530
Evang./Well 854-7259
Kensington 888-8160
Lennox Island.. 831-2711
Montague 838-0762
O'Leary 859-8720
Souris 687-7049
S'Side.............. 888-8160
Tignish............ 882-7366
Tyne Valley...... 854-7259

Victim Services
Ch'town..... 368-4582
S'Side 888-8218

Adult Protection
Ch'town 368-4790
Montague .. 838-0786
O'Leary 859-8730
Souris 687-7096
S'Side 888-8440

Child Protection
During business hrs:
1-877-341-3101
After Hours Emerg:
1-800-341-6868

PEI Rape & Sexual Assault Centre
Office 566-1864
Therapy Requests:
... (1-888)-368-8055

Evangeline CCG
439-1147

Housing Programs
CMHA's 'My Place' Ch'town............. 628-3663
CMHA's 'My Place' S'Side 436-7399
CMHA's 'West Prince Housing Proj' .. 853-4180
John Howard's Rural Housing Prog.. 569-7764

Women's Shelter
Lennox Island 831-2332
or Toll Free........................... 1-855-297-2332

PEI Family Violence Prev. Services & Second Stage Housing
PEI Office... 894-3354
E. Prince 436-0517
W. Prince ... 859-8849
Kings 838-0795
Queens...... 566-1480

Anderson House
Women & Children
24hr: 1-800-240-9894
Ch'town.......892-0960
Office 368-8658

Food Banks
Alberton (St. Peter's Anglican Church):
.... Thurs. 10-12 noon
Bloomfield (St. Anthony's Parish Ctr):
.... Thurs. 10-12 noon
Montague ...838-3191
Salvation A. 892-8870
Souris 687-2996
S'Side SA.....888-3870
Tignish Parish Centre:
......Tuesdays 4-5 pm
Tyne Valley (Pres. Church Hall):
.... Thurs. 10-12 noon
Upper Room:
..................892-7092

Soup Kitchens
Ch'town..... 892-1995
S'Side 436-6044

Harvest House
894-5350

Provincial Housing Offices
Ch'town 368-5770
Montague .. 838-0796
Souris 687-7098
S'Side 888-8436

Men's Shelter
Ch'town ... 892-9242
Call after 4:30 pm

Red Cross Emergency & Disaster Services
1-800-222-9597

Habitat for Humanity
367-3559

Youth Justice Services
Ch'town 368-4587

Other Legal Supports
Community Legal Information Assoc.
Ch'town.......892-0853
Indigenous Justice Program......367-3681
or......1-800-240-9798
John Howard..566-5425
PEI Crime Stoppers:
..........1-800-222-8477

Mediation PEI
mediationpei.com

Family Law Centre
Children's Lawyer:
....................368-4631
Child Support Offices:
Ch'town......368-6220
S'Side 888-8188
Family Court Counsellors & Family Mediation 368-6928
Maintenance Enforcement 894-0383
Parent Education:
....................368-4333
Recalculation of Child Support 368-4109

Legal Aid: Criminal
Ch'town 368-6043
S'Side..........888-8219

Legal Aid: Family
Ch'town 368-6656
S'Side..........888-8066

Government of PEI General Inquiries
Ch'town 368-4000 / Toll Free 1-800-236-5196

Military & Veterans Supports
CF Member Assistance Program ..1-800-268-7708
Military Family Info Line 1-800-866-4546
Military Family Resource Centre............892-8999
Royal Can. Legion Service Officer..........892-2161
Veterans Affairs Canada..............1-866-522-2122

Newcomers Supports
C.I.F. (Cooperative for the integration of Francophones to PEI)..........................888-1687
PEI Assoc. for Newcomers to Canada .628-6009

PEI Council of People with Disabilities
Kings 838-5878
Prince.. 436-9259
Queens 892-9149

Student Financial Services
368-4640

Employment & Career Supports
E. Prince Youth Development Ctr... 436-2815
John Howard.. 566-5425
Mi'kmaq Confederacy:
.... 1-877-884-0808
Native Coun ... 892-5314
Newcomers.... 628-6009
Tremploy 892-5338
W. Prince Employment Centres 853-3715

Career Development Services
Bloomfield.... 859-2776
Ch'town 626-2014
Montague 838-5453
Souris 687-1526
S'Side 436-0706

Skills PEI
PEI Employment Programs:
1-877-491-4766
Employment Insurance Inquiries
1-800-206-7218

Atlantic Credit Counselling
1-888-753-2227

Credit Counselling PEI (Free)
Ch'town 892-2441
S'Side.........436-9171
1-866-892-2441

Emergency Home Heating Program
Prince Co ...436-6044
Queens/Kings Co:
..................892-8870

Drug Cost Assistance Support
Ch'town..... 368-4947
or 1-877-577-3737

Income Supports, AccessAbility Supports, Child Care Subsidies & Senior's Independence Programs
1-877-569-0546

Family Doctor / 811 (Health Care Info)/School Counsellor/Student Well-being Teams/Clergy/Employee Assistance Program/Campus Student Services

- Addictions
- Seniors
- End of Life Care / Grief
- Crisis/ Someone to Listen
- Help for Families
- Mental Health
- Physical Health
- Sexual Health, Pregnancy & Infant Care
- Violence & Sexual Assault
- Housing & Hunger
- Legal Issues
- Employment and/or Career
- Financial

YOU START HERE

Canadian Mental Health Association
Prince Edward Island

Réseau Santé
en français Î.-P.-É.

The Island Helpline
1-800-218-2885
Ligne d'écoute de l'Î.-P.-É.

The PEI Helping Tree was created by CMHA's Suicide Prevention Program. It is for informational purposes only and CMHA is not responsible for any acts or omissions of these organizations. To download a copy or to access a linked version go to www.pei.cmha.ca. For additional copies or to report changes, call (902) 628-3669. (September/2018)

THE PEI HELPING TREE

The PEI Helping Tree is designed to inform Islanders of the many helping resources available on Prince Edward Island. If you or someone you care about is experiencing a problem in any of the areas listed, follow the arrows on the flow chart to find resources that may help. There are times in everyone's lives when we need to reach out to others - sometimes it's just a matter of knowing how to contact them. Note: unless indicated, you need to dial 902 for all local calls. **If you are still uncertain of where to turn, please call the Island Helpline at 1-800-218-2885, toll free 24/7.** **Emergency Call 9-1-1**

Extended Care Facilities

Deacon House	368-4036
Lacey House (Women)	368-4092
St. Eleanor's House	888-8386
Talbot House (Men)	368-4297

Other Addiction Supports

Al-Anon/Alateen	1-800-425-2666
Gambling Helpline:	1-855-255-4255
Narcotics Anonymous Provincial Info Line	1-800-205-8402
Native Council of PEI	892-5314
Open Door (Women)	628-6826
Reach Foundation	620-6200
Smart Recovery PEI	330-4357
Smokers' Helpline:	1-877-513-5333

AA-Alcoholics Anonymous

Charlottetown (All Addiction):	892-2103
East Prince (24/7)	598-0001
Kings: Call Addiction Services Kings (below) for meeting info	
Native Council of PEI	892-5314
Prince Co Central	436-7721
West Prince	856-0301

Provincial Addiction Facility

Toll Free, 24 hours:
1-888-299-8399

Family Program	368-4296
Gambling Prog	368-4273
Inpatient Detox	368-4048
Methadone Prog	368-4265
Outpatient Detox	569-0524
Senior's Program	368-4289
Transition Unit	368-4765

Addiction Services

Eastern Kings	687-7110
Queens	368-4120
Southern Kings	838-0960
Summerside	888-8380
West Prince	853-0401
Youth Services	368-4273

CPP/Old Age Security Enquiries

1-800-277-9914

PEI Senior Citizens' Federation

For info on Local Seniors' Clubs, PEI Friendly Visitor Program & 55 Alive Driver Course:
(1-877)-368-9008

Alzheimer Society of PEI

628-2257

Seniors' Home Repair, Safe At Home and Home Renovation Programs

Ch'town 368-4889
& 1-855-374-7366

Housing Offices

Ch'town	368-5770
Montague	838-0796
Souris	687-7098
S'Side	888-8436

Home Care & Support

Lennox Island:	831-2711
Montague:	838-0786
Queens:	368-4790
Souris	687-7096
S'Side	888-8440
West Prince:	859-8730

Senior's Independence Initiative

1-877-569-0546

Private Counselling

See Yellow Pages under 'Marriage, Family & Individual Counsellors'

Community Chaplains

PCH Spiritual Care	438-4374
QEH Spiritual Care	894-2094
UPEI	894-2876

Life After Suicide Loss Program

368-4911

Hospice PEI Palliative Care & Grief Support Group Info

PEI	368-4498
Queens	368-4095
S. Kings	838-2269
Souris	687-7150
S'Side	438-4231
W. Prince	859-2870

Youth Programs

Adventure Group	628-8668
Big Brothers/Big Sisters	569-5437
Ch'town Boys and Girls Club	892-1817
Ch'town Teen Zone	892-1719
LGBTQ Youth Groups	566-2437
Montague Boys and Girls Club	838-2884
O'Leary Recreation Ctr	859-1464
Stratford Youth Centre	569-1995
S'Side Boys and Girls Club	436-9403
S'Side Generation XX	436-7699
Wellington Boys and Girls Club	854-3174

Mi'kmaq Confederacy of PEI

Family Pride Prog. (Lennox & Abegweit) & Indian Residential School Supports
Toll Free
1-877-884-0808

Community Counselling Services

Catholic Family Services	894-3515
Family Service PEI:	
Ch'town	892-2441
S'Side	436-9171
Farmer's Assistance Program	626-9787
Toll Free 24/7	1-800-736-8006

Family Ties Program

Charlottetown	368-4871
Montague	838-0715
O'Leary	859-8813
Souris	687-7014
Summerside	888-8480

Positive Parenting From Two Homes

Toll Free 1-877-203-8828

Strongest Families

1-866-833-5443

Triple P Parenting

438-4134

Crisis Help

Toll Free/24 hr.

Island Helpline:	1-800-218-2885
Kids Help Phone:	1-800-668-6868
Canada Suicide Prevention Service:	1-833-456-4566
First Nations & Inuit Helpline:	1-855-242-3310
Trans Lifeline Can:	1-800-218-2885

Family Resource Centres

CAP Enfants:	854-2123
CHANCES	892-8744
Families East:	687-3928
Families First:	838-4600
Family Place:	436-1348
Kids West Inc:	853-4066
Mi'kmaq	892-0928

Schizophrenia Society of PEI

368-5850

Canadian Mental Health Association

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W. Prince	853-4180
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Fitzroy Centre	566-5111
Hope Centre	853-3871
Notre Dame Place:	888-2237
Toll Free (non-crisis)	1-800-682-1648

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Children's M.H. Services:	1-866-833-5443
Abegweit	676-3007
Alberton	853-8670
Evangeline	854-7259
Lennox Island	831-2711
McGill Centre - WI:	368-4911
Montague	838-0960
O'Leary	853-8670
Richmond Centre - WI:	368-4430
Souris	687-7110
Summerside - WI:	888-8180

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Ch'town (Parkdale Med Ctr)	892-2111
Ch'town (Sherwood Med Ctr)	628-8900
Crapaud (South Shore Health Ctr)	658-2212
Hunter River (Central Queens HCtr)	621-3050
Lennox Island Health Centre	831-2711
Morell (Fire Hall)	620-3260
Souris (Eastern Kings Health Ctr)	687-7033
Stratford Medical Centre	892-2111
Summerside (Central St Med. Ctr)	724-3210

Women's Information

Aboriginal Women's Assoc	1-888-973-4292
Birthright National Helpline	1-800-550-4900
Ch'town	628-6028
East Prince Women's Info Centre	436-9856
Island Pregnancy Centre	1-877-370-9711
The Moncton Hospital's Family Planning Clinic	1-844-806-9205
Women's Clinic (Dr. Hoffman)	367-3285
Women's Help Line	1-888-362-7373
Women's Network of PEI	368-5040
Women's Wellness Prog	1-844-365-8258

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1-800-321-5492

Family Doctor Registry

1-855-563-2101

Health PEI Patient Navigator

1-844-882-3141

Parents & Friends of Lesbians & Gays

569-3089

Pride PEI

pridepei.com

PEI Trans Network

peitn@outlook.ca
& on Facebook

PEERS Alliance

Ch'town 566-2437
1-800-314-2437

Sexual Health Services & Walk-In Clinic

Toll Free 1-844-365-8258

Public Health Nursing

Abegweit	676-3007
Alberton	853-8601
Ch'town	368-4530
Evang./Well	854-7259
Kensington	888-8160
Lennox Island	831-2711
Montague	838-0762
O'Leary	859-8720
Souris	687-7049
S'Side	888-8160
Tignish	882-7366
Tyne Valley	854-7259

Victim Services

Ch'town	368-4582
S'Side	888-8218

Adult Protection

Ch'town	368-4790
Montague	838-0786
O'Leary	859-8730
Souris	687-7096
S'Side	888-8440

Child Protection

During business hrs:
1-877-341-3101
After Hours Emerg:
1-800-341-6868

PEI Rape & Sexual Assault Centre

Office	566-1864
Therapy Requests:	(1-888)-368-8055

Evangeline CCG

439-1147

Women's Shelter

Lennox Island	831-2332
or Toll Free	1-855-297-2332

PEI Family Violence Prev. Services & Second Stage Housing

PEI Office	894-3354
E. Prince	436-0517
W. Prince	859-8849
Kings	838-0795
Queens	566-1480

Anderson House

Women & Children
24hr: 1-800-240-9894
Ch'town 892-0960
Office 368-8658

Food Banks

Alberton (St. Peter's Anglican Church):	Thurs. 10-12 noon
Bloomfield (St. Anthony's Parish Ctr):	Thurs. 10-12 noon
Montague	838-3191
Salvation A.	892-8870
Souris	687-2996
S'Side SA	888-3870
Tignish Parish Centre:	Tuesdays 4-5 pm
Tyne Valley (Pres. Church Hall):	Thurs. 10-12 noon
Upper Room:	892-7092

Habitat for Humanity

367-3559

Soup Kitchens

Ch'town	892-1995
S'Side	436-6044

Harvest House

894-5350

Housing Programs

CMHA's 'My Place' Ch'town	628-3663
CMHA's 'My Place' S'Side	436-7399
CMHA's 'West Prince Housing Proj'	853-4180
John Howard's Rural Housing Prog	569-7764

Provincial Housing Offices

Ch'town	368-5770
Montague	838-0796
Souris	687-7098
S'Side	888-8436

Men's Shelter

Ch'town 892-9242
Call after 4:30 pm

Red Cross Emergency & Disaster Services

1-800-222-9597

Youth Justice Services

Ch'town 368-4587

Other Legal Supports

Community Legal Information Assoc. Ch'town	892-0853
Indigenous Justice Program	367-3681
or	1-800-240-9798
John Howard	566-5425
PEI Crime Stoppers:	1-800-222-8477

Mediation PEI

mediationpei.com

Family Law Centre

Children's Lawyer:	368-4631
Child Support Offices:	
Ch'town	368-6220
S'Side	888-8188
Family Court Counsellors & Family Mediation	368-6928
Maintenance Enforcement	894-0383
Parent Education:	368-4333
Recalculation of Child Support	368-4109

Legal Aid: Criminal

Ch'town	368-6043
S'Side	888-8219

Legal Aid: Family

Ch'town	368-6656
S'Side	888-8066

Government of PEI General Inquiries

Ch'town 368-4000 / Toll Free 1-800-236-5196

Military & Veterans Supports

CF Member Assistance Program	1-800-268-7708
Military Family Info Line	1-800-866-4546
Military Family Resource Centre	892-8999
Royal Can. Legion Service Officer	892-2161
Veterans Affairs Canada	1-866-522-2122

Newcomers Supports

C.I.F. (Cooperative for the integration of Francophones to PEI)	888-1687
PEI Assoc. for Newcomers to Canada	628-6009

PEI Council of People with Disabilities

Kings	838-5878
Prince	436-9259
Queens	892-9149

Student Financial Services

368-4640

Employment & Career Supports

E. Prince Youth Development Ctr	436-2815
John Howard	566-5425
Mi'kmaq Confederacy:	1-877-884-0808
Native Coun	892-5314
Newcomers	628-6009
Tremploy	892-5338
W. Prince Employment Centres	853-3715

Career Development Services

Bloomfield	859-2776
Ch'town	626-2014
Montague	838-5453
Souris	687-1526
S'Side	436-0706

Skills PEI

PEI Employment Programs:
1-877-491-4766

Employment Insurance Inquiries
1-800-206-7218

Atlantic Credit Counselling

1-888-753-2227

Credit Counselling PEI (Free)

Ch'town	892-2441
S'Side	436-9171
	1-866-892-2441

Emergency Home Heating Program

Prince Co	436-6044
Queens/Kings Co:	892-8870

Drug Cost Assistance Support

Ch'town 368-4947
or 1-877-577-3737

Income Supports, AccessAbility Supports, Child Care Subsidies & Senior's Independence Programs

1-877-569-0546

Family Doctor / 811 (Health Care Info)/School Counsellor/Student Well-being Teams/Clergy/Employee Assistance Program/Campus Student Services

Addictions | **Seniors** | **End of Life Care / Grief** | **Crisis/ Someone to Listen** | **Help for Families** | **Mental Health** | **Physical Health** | **Sexual Health, Pregnancy & Infant Care** | **Violence & Sexual Assault** | **Housing & Hunger** | **Legal Issues** | **Employment and/or Career** | **Financial**

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Canadian Mental Health Association
Prince Edward Island

Réseau Santé
en français Î.-P.-É.

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Ligne d'écoute de l'Î.-P.-É.

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Autism Services for Children and Youth

Autism services are offered to preschool and school-age children and youth in Prince Edward Island. Early Years Autism Specialists provide services to young children diagnosed with autism spectrum disorders before entering school. An integrated approach between professionals and the school boards ensures a smooth transition into the school system, where support continues with school-based Autism Consultants.

Supports for preschool children with autism spectrum disorders

Intensive Behavioural Intervention (I.B.I.)

I.B.I. often begins with one-on-one instruction and gradually moves into more natural settings as the child gains new skills. Your child may receive up to 25 hours of I.B.I. each week at home or in your child's early childhood centre, based on assessed needs. As your child progresses, fewer hours may be appropriate.

You or your child's centre hires the Autism Assistant to provide direct instruction. An Early Years Autism Specialist will supervise and monitor your child's program with additional clinical supervision by the Early Years Autism Coordinator.

How do I know if the I.B.I. program is right for my child?

Methods for assessment and instruction are grounded in Applied Behaviour Analysis (ABA). The primary assessment used to guide programming is the Verbal Behaviour Milestones Assessment and Placement Program (V.B.-M.A.P.P.). A variety of methods are used including (but not limited to) Analysis of Verbal Behaviour, Discrete Trial Instruction, Natural Environment and Activity Embedded Instruction.

What happens when my child enters school?

Planning begins six months before your child enters school to ease the transition from the preschool to the school environment. Family information meetings, case conferences, assessment and orientation activities for your child all contribute to the transition process. A school-based Autism Consultant will continue to monitor and assist during your child's school years.

What if my child needs more support in kindergarten?

Your child may need frequent and individualized instruction during this important first year of school. If this is the case, an Early Years Autism Specialist can provide regular support for both your child and the school staff. This **Intensive Kindergarten Support (I.K.S.)** includes weekly or biweekly consult visits to assist your child's teacher in individual programming, modifying curriculum, helping to address behavioural challenges, and participating in individual education plan (I.E.P.) development.   Your child will continue to receive support and assistance from a school-based Autism Consultant in Grades 1 to 12, based on your child's assessed needs.

Autism funding support

Parents and licensed early childhood centres can access preschool autism funding to hire an Autism Assistant for children receiving I.B.I. support. Parents and designated community-based organizations can access school-age autism funding to offset the costs of hiring one-on-one tutors and aides in home and group settings.

Who can I contact for more information?

Early Years Autism Coordinator
Education and Lifelong Learning
Early Childhood Development
Aubin Arsenault Building
3 Brighton Rd.
Charlottetown, PE C1A 8T6
Tel: (902) 368-4472
Fax: (902) 368-4622
Email: dmrochon@edu.pe.ca(link sends e-mail)
Published date:
February 18, 2020

Private Practice Directory

Psychological Association of Prince Edward Island
Updated November, 2022

Kathren Allison, Psychologist
PEIPRB Registration #: 064
Telephone: (902) 314-1113
Email: kathy.allison@rogers.com
Office address: 1 Rochford St., Charlottetown, PE C1A 9L2
Currently accepting referrals: Yes
Typical referral wait time: 6 months
Language in which service provided: English
Formal assessment services provided: Psycho-educational assessments for children and adults; ADHD; Adult ADHD; cognitive/intelligence; learning disability; learning assessments
Relevant areas of practice: Learning disabilities; ADHD/attention problems;
Services provided to: individuals
Age groups served: children; adults

I am a registered psychologist who has been working full time in my own comprehensive private practice (assessment and treatment of anxiety, depression, PTSD, learning disabilities, ADHD, etc.) for over 10 years. I am now focusing exclusively on assessments for learning disabilities and attention problems/ADHD, for both children and adults.

This entry last updated: 30 April, 2018

Dr. Christine Beck, Psychologist
PEIPRB Registration #: 042
Telephone: (902) 367-4446
Email: drchristinebeck@gmail.com
Office Address: 51 University Avenue, Suite 204, Charlottetown, PE C1A 4K8
Currently accepting referrals: Yes
Typical referral wait time: 6 months
Language in which service provided: English
Formal assessment services provided: behavioural / emotional; cognitive / intelligence; learning disability; neuropsychological

Relevant areas of practice: psychotherapy
Services provided to: individuals; groups
Age groups served: adolescents; adults; older adults

Thank you for your interest in my private practice. I am a doctoral level Psychologist with training in adult and geriatric neuropsychology, adolescent and adult community mental health, educational assessment, health and rehabilitation psychology and psychotherapy with a variety of referral concerns.

Please call my office to see if my services are appropriate for your needs.
Sincerely, Dr Christine Beck

This entry last updated: 23 April, 2016

Dr. Freda Burdett, Psychologist
PEIPRB Registration #: 081
Telephone: (506) 461-9959
Email: drfredaburdett@gmail.com
Office address: 224 Queen Street, Charlottetown, PE, C1A4B6
Currently accepting referrals: Yes
Typical referral wait time: New practice
Languages in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: Abuse; Addictions; Anxiety; Attachment issues (adult); Assertiveness; Depression; Grief / loss / bereavement; Habit change; Health issues; Loneliness; Obsessive-Compulsive Disorder; Personal growth / wellness; Personality Disorders; Phobias / fears / panic; Post Traumatic Stress Disorder (PTSD) / trauma; Psychotherapy; Relationship issues; Self-esteem; Separation / Divorce; Sexual issues; Social skills; Stress management; Workplace issues
Services provided to: individuals
Age-groups served: Adolescents and Adults

Dr. Burdett has a PhD in Clinical Psychology. Her primary area of focus has been on trauma assessment and treatment. She works with first responders, military members, and the general public; treating a wide range of clinical disorders, such as PTSD, anxiety, and depression (including post-partum depression). She has been trained in CBT, DBT, ACT, CPT, EMDR, and Prolonged Exposure. She welcomes you to contact her with any questions about her practice and availability.

This entry last updated: 02 August 2019

Sarah Carr, Psychologist
PEIPRB Registration #: 068
Telephone: (902) 367-4722
Email: carrpsychological@gmail.com
Office address: 53 Grafton street, Charlottetown PEI, C1A 1K8
Currently accepting referrals: No
Typical referral wait time: 8 – 10 weeks
Provides services through telehealth: Yes
Language in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: abuse; ADHD/attentional problems; anger management; anxiety; assertiveness; behavioural problems; blended/step family issues; conflict resolution; depression; family therapy; grief/loss/bereavement; obsessive-compulsive disorder; parenting; personal growth/wellness; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; relationship issues; self-esteem; separation/divorce; stress management; workplace issues
Services provided to: individuals; couples; families; groups
Age groups served: pre-school children; school-aged children; adolescents; adults; older adults
This entry last updated: May 3rd 2021.

Rebecca Deacon, Psychologist
PEIPRB Registration #: 051
Telephone: (902) 940-6157
Email: rjhooley@hotmail.com
Office Address: Suite 2C, 126 Richmond St, Charlottetown, PE C1A 1H9
Currently accepting assessment referrals: Yes
Currently accepting therapy referrals: No
Typical referral wait time: 3 - 6 months
Provides services through telehealth: Yes
Language(s) in which service provided: English

Formal assessment services provided: ADHD, behavioural/emotional; cognitive/intelligence; learning disability
Relevant areas of practice: ADHD/attentional problems; anger management; anxiety; behavioural problems; conflict resolution; depression; disabilities; family therapy; gifted/talented children; obsessive-compulsive disorder; parenting; phobias/fears/panic; psychotherapy; self-esteem; separation/divorce; social skills
Services provided to: individuals; families
Age groups served: pre-school children; school-aged children; adolescents

Rebecca Deacon's primary area of practice is in School Psychology and she has extensive experience in Psycho-Educational Assessment of School Aged Children, including the diagnosis and treatment of learning, behavioral, and social-emotional problems. Having worked within the school system for many years, Ms. Deacon is knowledgeable regarding evidence-based intervention, academic and behavioral program planning, and collaborating with families, schools, and other professionals. In addition to extensive assessment experience, Ms. Deacon has also treated a wide range of Anxiety Disorders in children and youth using a primarily Cognitive-Behavioral Approach, while also integrating other evidence-based strategies. Ms. Deacon also works with individuals and families to support the development of emotional and behavioral regulation, particularly as it relates to behavioral disorders such as ADHD.

This entry last updated: 27 March, 2020

Dr. Jason Doiron, Psychologist
PEIPRB Registration #: 038
Telephone: (902) 394-1249
Email: psychologist@pei.sympatico.ca
Office Address: 160 Belvedere Ave., Charlottetown, PE
Website: https://peipsychologist.wordpress.com/
Currently accepting referrals: Yes
Typical referral wait time: 2 months
Language(s) in which service provided: English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/ intelligence; learning disability
Relevant areas of practice: addictions; ADHD / attentional problems; anger management; anxiety; assertiveness; behavioural problems; conflict resolution; couple therapy; depression; grief/loss/bereavement; habit

change; loneliness; obsessive-compulsive disorder; parenting; personal growth / wellness; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; relationship issues; self-esteem; separation/divorce; sports psychology
Services provided to: individuals; couples; groups
Age-groups served: school-aged children; adolescents; adults

Following my undergraduate years at the University of Prince Edward Island I was trained as a clinical psychologist at the University of New Brunswick, where I obtained my PhD in 2005. My part-time private practice (I am a full time professor at UPEI) is best be described as relatively general in nature. Much of my clinical work presently involves the assessment of cognitive ability and academic skills, along with the diagnosis of learning disabilities and other conditions related to learning (e.g., ADHD) in children and adults. I also have a smaller caseload of individuals who work with me in a psychotherapy / counselling context. My therapeutic work with clients is usually shorter-term with the goal of achieving some improvement or growth within approximately 8-12 sessions of work together. I tend to view clinical issues (such as anxiety or depression) through the lens of cognitive behavioural theory while integrating ideas from other evidence-based approaches as well.

This entry last updated: 14 December, 2015

Dr. Lee-Anne Greer, Psychologist
PEIPRB Registration #: 33
Telephone: (902) 620-9144
Office Address: 126 Richmond Street, Suite 2C, Charlottetown
Currently accepting referrals: No
Typical referral wait time:
Language in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: psychotherapy
Services provided to: individuals
Age-groups served: adults; older adults
This entry last updated: 17 November, 2020

Barbara Jones, Psychologist
PEIPRB Registration #: 061
Telephone: (902) 393-3829

Email: windhorseps@gmail.com
Office address: 174 Pickles Lane, Alexandra, PE Box 24076, Stratford, PE C2B 2V5
Currently accepting referrals: Yes
Typical referral wait time: 5 – 6 months
Language in which service provided: English
Formal assessment services provided: behavioural / emotional
Relevant areas of practice: anger management; anxiety; attachment issues; assertiveness; depression; grief/loss/bereavement; habit change; health issues; loneliness; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; personality disorders; rehabilitation; relationship issues; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; stress management; workplace issues; mindfulness interventions
Services provided to: individuals; groups
Age-groups served: adults

Trained as a contemplative psychotherapist, mindfulness practices are embedded in all my work. My primary focus is PTSD I've worked extensively with first responders including veterans, police and fire fighters. I am working full-time at Serene View Ranch Psychological Services (www.sereneviewranch.com) where I offer individual therapy using mindfulness and CBT, psycho-educational and support groups as well as providing assessment services related to PTSD capacity and return-to-work.

This entry last updated: 15 December, 2018

Ruth Lacey, Psychologist
PEIPRB Registration #: 007
Telephone: (902) 675-4282
Email: rlacey688@gmail.com
Office mailing address: P.O. Box 512, Charlottetown, PE C1A 7L1
Currently accepting referrals: Yes
Typical referral wait time: 1 - 4 weeks
Languages in which service provided: English, Italian, Spanish
Formal assessment services provided: n/a
Relevant areas of practice: abuse; addictions; adoption issues; ADHD / attentional problems; anger management; anxiety; attachment issues;

assertiveness; autism spectrum disorder; behavioural problems; depression; family therapy; family violence; gifted/talented children; grief/loss/bereavement; health issues; loneliness; obsessive-compulsive disorder; pain management; parenting; Post Traumatic Stress Disorder (PTSD)/trauma; relationship issues; self-esteem; stress management; troubled children and youth; workplace issues
Services provided to: individuals; couples; families; groups
Age-groups served: pre-school children; school-aged children; adolescents; adults; older adults

I believe that education is important: people do the best they can and when they know better, they do better. I believe that people are inherently good. I believe that people need to be accountable, recognizing that they have choices and that they make their own decisions. I believe that every person who works on doing better benefits society. I have faith that with my experience and the client's desire to change, between us, solutions and better ways of doing things will emerge.

This entry last updated: 2 January, 2016

Caroline LeBlanc, Psychologist
PEIPRB Registration #: 020
Telephone: (902) 393-3829
Email: caroline11leblanc@gmail.com
Office address: 174 Pickles Lane, Alexandra, PE
Currently accepting referrals: No
Typical referral wait time: Not accepting referrals
Language in which service provided: French and English
Formal assessment services provided: Work disability assessments
Relevant areas of practice: abuse; anxiety; depression; health issues; loneliness; obsessive-compulsive disorder; personal growth / wellness; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD) / trauma; psychotherapy; rehabilitation; relationship issues; CISD; equine assisted psychotherapy
Services provided to: individuals; groups
Age-groups served: adults; older adults

Caroline has been specializing in the area of trauma assessment and therapy for over 20 years. Her emphasis has been on helping first responders, military personnel and veterans deal with trauma and PTSD. Her approach to psychotherapy is based on the

Cognitive Behavioural Model, Mindfulness, Equine Assisted Psychotherapy, and Sensorimotor Psychotherapy. Eight years ago, she became certified in Equine Assisted Psychotherapy. She also is trained in EMDR, an evidence-based approach for the treatment of trauma. Caroline operates a multidisciplinary mental health clinic that provides a full range of psychological assessments and treatment for children, adolescents and adults. The centre, Serene View Ranch, is located just outside of Charlottetown and overlooks Pownal Bay. Please visit the website at www.sereneviewranch.com
This entry last updated: 27 December, 2019

Dr. George Mallia, Psychologist
PEIPRB Registration #: 040
Telephone: (902) 367-4446
Email: drgeorgemallia@gmail.com
Office Address: 51 University Avenue, Suite 204, Charlottetown, PE C1A 4K8
Currently accepting referrals: Yes
Typical referral wait time: 1 year
Language(s) in which service provided: English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/ intelligence; custody / access; learning disability; neuropsychological; parental capacity
Relevant areas of practice: abuse; addictions; adoption issues; ADHD / attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; body image; conflict resolution; depression; disabilities; eating disorders; family therapy; gifted/talented children; grief/loss/bereavement; health issues; loneliness; obesity; obsessive-compulsive disorder; pain management; parenting; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; rehabilitation; relationship issues; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; sports psychology; stress management; workplace issues
Services provided to: individuals; families
Age-groups served: school-aged children; adolescents; adults
This entry last updated: 3 December, 2014

Dr. Brent Macdonald, Psychologist
PEIPRB Registration #: 072
Telephone: (403) 229-3455
Email: brent@complexlearners.com
Office Address: 320, 1167 Kensington Cres. NW (Calgary); local office on PEI upon request
Currently accepting referrals: Yes
Typical referral wait time: Varies; assessment clinics run in 2-week cycles through the year
Provides services through telehealth: Yes
Language(s) in which service provided: English
Formal assessment service provided:
ADHD; Adult ADHD; Behavioural / Emotional; Career / Vocational; Cognitive / intelligence; Learning disability
Relevant areas of practice: ADHD / attentional problems; Anxiety; Autism spectrum disorder; Behavioural problems; Depression; Disabilities; Gifted / talented children; Parenting
Services provided to: Individuals and Families
Age-groups served: School-aged children, Adolescents, and Adults

While currently a resident of Calgary, Dr. Macdonald is a native Islander who maintains active registration and practice as a psychologist in his home province of PEI. Dr. Macdonald provides psychoeducational assessments through ongoing 2-week clinics on PEI, offered as needed. Once initiated, comprehensive psychoeducational assessments can be completed in a timely manner, allowing for fast and effective planning for students of a wide range of ages. Assessments focus on attention, learning, and social/emotional & behavioral issues, with a focus on providing practical and effective recommendations and strategies.

Since clinics run through the year, there is also the opportunity to follow-up and review the effectiveness of interventions, allowing Dr. Macdonald to maintain ongoing contact and support for his clients. Collaboration with schools, where possible, is also a service that can be incorporated into the assessment process.

Learn more at complexlearners.com or contact Dr. Macdonald directly at brent@complexlearners.com.

This entry last updated: 27 March, 2020

Dr. Colleen Mac Dougall; Psychologist
PEIPRB Registration #: 098
Telephone: 819-588-7525
Email: soulcare@moderndigital.net,
Website: www.soulofpeace.org; www.beyondfear.org
Office Address: 55 Weymouth St., Charlottetown, PEI C1A 1E5
Currently accepting referrals: Yes
Typical referral wait time: 2 days
Provides services through telehealth: Yes
Language(s) in which service provided: English
Formal assessment services provided: Behavioural / Emotional, Career / Vocational, Insurance
Relevant areas of practice: Abuse, Addictions, Attachment, Assertiveness, Blended/stepfamily issues, Body image, Conflict resolution, Couple therapy, Depression, Eating disorders, Family therapy, Family violence, Grief / loss / bereavement, Loneliness, Obesity, Personal growth / wellness, Personality Disorders, Relationship issues, Self-esteem, Separation / Divorce, Stress management, Workplace issues
Services provided to: Individuals, Couples, Families, Groups
Age-groups served: Adolescents, Adults, Older adults

ORIENTATION: Companioning you in the realization of your aspirations and life purpose as you either choose different paths in your life or shifts are demanded because of illness, loss of capacity, deep soul wounds from war trauma, or other confrontations with painful work and life events. Use a positive lens to see into psychological disturbance.

AREAS OF PRACTICE: Life transitions; positive and deep soul healing for veterans that permeate deeper realms of spiritual healing; relational healing for veterans and their partners; maturity in personal and career shifts grounded in ancient wisdom and expansion of knowledge; redefining “work”; relationship therapy to deepen trust where betrayal or loss of connection has broken bonds.

SENIOR KNOWLEDGE AND SKILL: Deep insight into where you find yourself at this time in your life; compassion and care as you uncover what you may have been holding in fear or shame; depth therapist integrating psychospiritual skills to support and encourage you to process and move through what changes you are facing or choosing.

Testimonial: "An iron fist in a velvet glove."

This entry updated: 07 November, 2022

Dr. Wm. Neil McLure, Psychologist
PEIPRB Registration #: 009

Telephone: (902) 432-3910
Fax: (902) 432-3007
Email: mclure@pei.sympatico.ca
Office address: 292 Water St., Summerside
Currently accepting referrals: Yes, assessments only
Typical referral wait time: 3-6 months
Language in which service provided: English
Formal assessment services provided: Neuropsychology assessments, ADHD; Adult ADHD; behavioural/emotional; cognitive/ intelligence; insurance; learning disability; legal; pain assessment
Relevant areas of practice: acquired brain injury; ADHD / attentional problems; anxiety; autism spectrum disorder; behavioural problems; depression; disabilities; health issues; obsessive-compulsive disorder; pain management; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; rehabilitation; social skills; sports psychology; traumatic brain injury
Services provided to: individuals; families
Age-groups served: school-aged children; adolescents; adults; older adults
This entry last updated: 21 April 2022

Dr. Terry Mitchell, Psychologist
PEIPRB Registration #: 023
Telephone: (902) 394-0034
Email: mitchellcounselling.consulting@gmail.com
Office address: 75 Villa Ave., Charlottetown, PEI, C0A 2B2
Currently accepting referrals: Yes
Typical referral wait time: 1 week
Provides services through telehealth: Yes
Languages in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: anxiety; body image; colonial trauma, depression; eating disorders; grief/loss/bereavement; obsessive-compulsive disorder; pain management; parenting; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma;

relationship issues; sleep disorders; and stress management.
Services provided to: individuals

During this time of self-isolation and social distancing I am providing counselling services by telephone and video conferencing with pro-bono services for registered health professionals and front line workers. I am a psychology professor with many years of experience working with survivors of child sexual abuse and other forms of trauma. My counselling practice is based on a client-centred, feminist, psychodynamic approach using Mindfulness Practices, Cognitive Behaviour Therapy (CBT) and Dialectical Behavioural Therapy (DBT).

This entry last updated: April 23, 2020

Parise Nadeau, Psychologist
PEIPRB Registration #: 35
Telephone: (902) 438-1109
Email: parisenadeau@gmail.com
Office address: Summerside
Currently accepting referrals: No
Typical referral wait time: 3 - 6 weeks
Languages in which service provided: French; English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/intelligence; learning disability
Relevant areas of practice: ADHD/attentional problems; anger management; anxiety; assertiveness; autism spectrum disorder; behavioural problems; body image; depression; gifted/talented children; grief/loss/bereavement; habit change; loneliness; obesity; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; phobias/fears/panic; psychotherapy; self-esteem; social skills; stress management
Services provided to: individuals; families
Age-groups served: pre-school children; school-aged children; adolescents; adults

My main area of practice is with children, youth and families; providing support with parenting and behaviour management, as well direct individual therapy with children, youth and adults. I also offer mental health, behavioural and psycho-educational assessments. Bilingual service.

This entry last updated: May 3rd 2021

Ken Pierce, Psychologist
PEIPRB Registration #: 006
Telephone: 1-877-569-3710
Email: contact@kenpiercepsychologist.com
Website: www.kenpiercepsychologist.com
Office address: 549 North River Rd., Vision Care Building, 2nd floor, Charlottetown, PE C1E 1J6
Currently accepting referrals: Yes
Typical referral wait time: 5 - 7 days
Provides services through telehealth: Yes
Language in which service provided: English
Formal assessment services provided: behavioural/emotional; career/vocational; custody/access; pain assessment; parental capacity
Relevant areas of practice: abuse; addictions; adoption issues; ADHD/attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; body image; conflict resolution; couple therapy; depression; disabilities; eating disorders; family therapy; family violence; financial loss; gifted/talented children; grief/loss/bereavement; habit change; health issues; infatuations; loneliness; obesity; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; rehabilitation; relationship issues; resentments; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; spiritual; sports psychology; stress management; workplace issues
Services provided to: individuals; couples; families; groups
Age-groups served: pre-school children; school-aged children; adolescents; adults; older adults

I am a registered psychologist with over 30 years experience in a variety of roles including drug crisis, early childhood education, post secondary education, corporate training, community development and private practice.

There are many new science based tools available to assist others to evolve in the areas where they are challenged. The wisest professional helpers say similar things *including: therapy is 'focussed accelerated learning'; since thinking determines feelings talking mostly about feelings can distract from the learning process; everyone is a survivor of their past so no longer a victim of it; and while people do have losses when they uncover the gains they become more present and get on with their life.*

I have the privilege of working with clients aged 2 to 82 years. I have assisted individuals and groups to move on from: assault, abuse, addictions, ADHD, allergies, auto collisions, auto immune diseases, bullying, bankruptcy, bipolar disorder, cancer, Crohn's, death, depression, divorce, harassment, incest, injuries, job loss, learning disabilities, PTSD, workplace strikes and other traumatic events. I have a special interest in working with couples and those struggling with bulling, depression and self esteem.

This entry last updated: 27 March, 2020

Peter Joseph Pierre, Psychologist
PEIPRB Registration #: 044
Telephone: (902) 436-6799
Email: pjpierre@live.com
Office address: Suite 5, Granville Professional Centre, 500 Granville, Summerside, PE, C1N 5Y1
Currently accepting referrals: Yes
Typical referral wait time: less than 1 week
Language in which service provided: English
Formal assessment services provided: ADHD, adult ADHD, behavioural/emotional, career/vocational, cognitive/intelligence, learning disability
Relevant areas of practice: abuse; addictions; ADHD/attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; body image; conflict resolution; depression; disabilities; grief/loss/bereavement; habit change; health issues; loneliness; obsessive compulsive disorder; pain management; parenting; personal growth/wellness; phobias/fears/panic; post- traumatic stress disorder (PTSD)/trauma; psychotherapy; rehabilitation; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; stress management; workplace issues.
Services provided to: individuals; couples; families
Age-groups served: school-aged children; adolescents; adults

I practice cognitive behavioural therapy and emotion focused therapy.

This entry last updated: 21 May, 2015

Dr. Nancy Spitzack, Psychologist
PEIPRB Registration # 050
Telephone Number: 902-314-8817
Email: nkayspitz@gmail.com
Office Address: 126 Richmond St., Suite 2C, Charlottetown, PE C1A 1H9
Currently Accepting Referrals? Yes
Language in which service is provided: English
Relevant areas of practice: Psychotherapy
Services provided to: Individuals
Age groups served: Adults, Older Adults
This entry updated November 4, 2022

Find an Occupational Therapist IN THE PROVINCE OF PRINCE EDWARD ISLAND

Occupational therapists work in a variety of settings across all three counties in PEI. Some of these settings include:

- Acute care hospitals
- Rehabilitation programs
- Home care programs
- Long term care facilities
- Community mental health
- Private practice
- Administration
- Schools and/or early childcare centres
- Workplaces
- Workers Compensation Board

Referrals

Clients and their caregivers can self-refer to an Occupational Therapist in Prince Edward Island.

Current List of Private Practice Occupational Therapists Registered in PEI

Name	City / Town	Phone Number	Areas of Practice
Alice Anand Toner	Summerside	(902) 786-6156	-not specified-
Marie Brine	Cornwall	(902) 393-5151	Cognitive Rehab, Mental Health, Pain Management, School Age Services
Chloe Bruce	Souris West	(902) 327-0200	Pediatrics (ASD, Learning Disabilities, ADHD, Developmental Delays Physical Disabilities, Self-Regulation, Anxiety ,etc.), Mental Health, Chronic Pain Management, Return to Work, Home Assessments, Workplace Ergonomic Assessments
Felicia A. Burchell	Dartmouth	(902) 222-5022	Vocational rehab, career counselling, pain management counselling
Selynn Butler	Warren Grove	(902) 620-9136	Mental Health, Chronic Pain Management, Return to Work, Exposur Therapy
Shianna Cormier	Oyster Bed Bridge	(902) 940-0581	Mental Health Pediatrics
Karla M. Crawford	Little York	(902) 626-7591	Comprehensive Driving Evaluation
MacKenzie A. Deighan	Stratford	(902) 393-4564	general physical health, ergonomic assessments

Name	City / Town	Phone Number	Areas of Practice
Katie Fullerton	Cornwall	(902) 218-9678	Wheelchair Seating and Mobility; Home Assessments; Workplace Ergonomic Assessments
Marjorie J. Hackett	Stratford	(902) 626-8235	Mental Health, Home Care, Geriatrics, seating
Mark Holland	Stratford	(902) 628-1544	Office Ergonomics
Alicia Jameson	Cornwall	(902) 626-9591	Mental Health Pediatrics Sleep Independent Living Skills
Michael E. LeBlanc	Stratford	(902) 218-1301	-not specified-
Sarah MacKenzie	Charlottetown	(902) 629-1044	Vocational Rehabilitation, Brain Injury/Concussion Management, Pediatric (ASD, Learning Disabilities, ADHD, Developmental Delays, Physical Disabilities, Self-Regulation, Anxiety ,etc.), Functional Capacity Evaluations, Ergonomic Assessments, Stroke Rehabilitatio
Donna F. MacLeod	Stratford	(902) 394-3757	Mental Health/PTSD Home Assessments & Accessibility Chronic Pa PGAP Certified Brain Injury & Concussion
Grant MacLeod	Charlottetown	(902) 629-0235	1. Wheelchairs Seating and Mobility. 2. Long Term Care Occupation Therapy 3. Home Accessibility.
Jane P. MacNutt	Stratford	(902) 314-5190	Case management, worksite/ergonomic assessments, home assessments
Lauren W. Mood	Stratford	(902) 749-8377	-not specified-
Sherry L. Mourant	Moncton	(902) 229-0576	Concussion Management
Karen Nabuurs	Summerside	(403) 829-2086	Pediatric OT
Jennifer J. Neill	Grand Tracadie	(902) 314-3069	Sensory processing and emotional regulation Autism, ADHD, Learni Disability
Elizabeth Organ	Charlottetown	(709) 427-8474	-not specified-
Amanda K. Paynter	Springbrook	(902) 886-2529	Ergonomic Assessments
Jillian Paynter	Winsloe	(902) 213-0556	-not specified-
Rogan J. Power	Summerside	(506) 478-2231	- Home care - Long-Term Care - Seating/Surfaces
Shannon J. Reid	Charlottetown	(902) 316-0048	-not specified-
Lloyd A. Richard	Hammonds Plains	(902) 223-3561	Medicolegal Assessment
Lisa A. Saunders-Green	Harmony	(902) 449-7195	Medical Legal Consulting

Name	City / Town	Phone Number	Areas of Practice
Chelsey T. Walker	Summerside	(902) 432-4764	Workstation Ergonomics

Private Practice List

Speech Language Pathology

(Updated June 2020)

For a printer friendly version please click here: http://peispeechhearing.ca/printpg/private

Disclaimer: Please note that the "Private Practice List" is offered as a service to the public and members of our professions. The accuracy of the listings is the responsibility of the individuals listed. The Prince Edward Island Speech & Hearing Association (PEISHA) does not accept responsibility for its contents or the services provided by any individual listed.

Clinician Names & Contact Information	Areas of Specialty
Speech-Language Pathologists	
Jillian Arsenault 902-620-1109 jilarsenault@hotmail.com	Adolescents and Adults
Rick Burger, M.A. (SAC-cert) 902-940-5347 burgerrick@hotmail.com	Adults (Dysphagia)
Craig Cameron 902-218-5816 craigkcameron@gmail.com	Adults (Voice, Speech, Language, Stuttering, Swallowing)
Amber Ceretti 902-394-3079 aceretti@hotmail.com	Preschool Children, School Aged Children, and Adults
Jennifer Collings 902-393-0479 Jennifer_Collings@hotmail.com	Preschool and School Aged Children

Mary Anne Donovan (East Coast Speech) Clinic-based services available in Charlottetown and Summerside and in-home services available across PEI 902-786-8489 eastcoastspeechpei@gmail.com	Preschool Children, School Aged Children, and Adults
Leah Doyle 902-403-8187 doyleleahc@gmail.com	School Aged Children and Adults
Michele Moffat 902-388-1964 peislp@me.com www.speechstrength.com	Preschool, School Aged Children, Adolescents, and Adults
Jennifer Orlowski 902-626-5488 jenorlowski@hotmail.com	Preschool and School Aged Children
Dawn Riley 902-940-2562 dawnettariley@gmail.com	School Aged Children and Adults
Moira Shaw Shaw Speech Therapy Inc. Clinic based services in Western PEI 902-807-9358 shawspeechtherapyinc@gmail.com	Preschool and School Aged Children
Melissa Spidel, M.Sc. SLP-Reg, SLP(C) 902-394-3990 melissaspidel@yahoo.ca	Preschool and School Aged Speech and Language
Audiologists	
Peter Benstead PEI Audiology (Charlottetown) Midtown Plaza 39 Eden Street, Suite 6 Charlottetown, PE, C1A 2S2 Phone: 902-892-8060 Fax: 902-370-3039 hearing@peiaudiology.ca www.peiaudiology.ca	Clinical and Dispensing Audiologist
Krista Campbell Campbell Hearing	Clinical and Dispensing Audiologist

Kirkwood Mews 393 University Avenue Charlottetown, PE, C1A 4N4 Phone: 902-569-0101 Fax: 902-569-0304 hear@campbellhearing.ca www.campbellhearing.ca	
Charlotte Ellis Connect Hearing (Charlottetown and Summerside) C-614 North River Road Charlottetown, PE, C1E 1K2 902-892-6989 charlotte.ellis@connecthearing.ca	Clinical and Dispensing Audiologist
Pat Ellis Connect Hearing C-614 North River Road Charlottetown, PE, C1E 1K2 902-892-6989 pellis@connecthearing.ca	Clinical and Dispensing Audiologist
Chelsey Enman PEI Audiology (Summerside) Superstore 535 Granville Street, Upper Level Summerside, PE, C1N 3C4 Phone: 902-436-0074 Fax: 902-436-8072 hearing@peiaudiology.ca www.peiaudiology.ca	Clinical and Dispensing Audiologist
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IN A CHANGING WORLD

Registered Disability Savings Plans

Your guide to saving for a secure future

People with disabilities and their loved ones face a distinct set of financial challenges throughout their lives. To help address these challenges, in 2008 the Government of Canada introduced the Registered Disability Savings Plan (RDSP). Designed to help build long-term financial security for disabled persons, the RDSP makes it easier to accumulate funds by providing assisted savings and tax-deferred investment growth.

This brochure explains the main features of the RDSP and provides some examples to illustrate how the RDSP can best be used.

What is an RDSP?

The RDSP is a tax-deferred savings vehicle introduced by the Government of Canada to help parents and others save for the long-term financial security of a person with a severe disability.

Eligibility

A Canadian resident who is eligible for the Disability Tax Credit (DTC) is eligible for an RDSP until December 31st of the year they reach age 59.

The DTC is available to individuals who have mental or physical impairments that markedly restrict their ability to perform one or more of the basic activities of living (i.e., speaking, hearing or walking). The impairment must be expected to last a period of one or more years, and a physician or nurse practitioner must certify the extent of the disability. Individuals can apply to the Canada Revenue Agency (CRA) for the DTC using Form T2201.

To qualify for an RDSP, you must:

- Be eligible for the Disability Tax Credit
- Be a resident of Canada
- Be less than 60 years of age
- Have a valid SIN

Opening an RDSP account

Only one RDSP can be established per beneficiary. The plan must be established by the disabled individual, unless he or she is not legally competent to sign a contract (e.g., a minor or mentally impaired). When the beneficiary is not legally able to sign a contract, the person(s) legally authorized to act on behalf of the disabled individual can establish the plan.

A change was made in Budget 2012 and under the new rules a "qualifying family member" is allowed to establish an RDSP for a beneficiary who is not contractually competent. The definition of a qualifying family member is only a spouse, common-law partner or a parent. Otherwise, anyone other than the qualifying family member will still have to go through the formal process of being named a legal representative or guardian. This is a temporary change and applies from July 2012 to the end of 2023. Even though this is temporary, it is important to note that the account holder is able to remain as account holder beyond 2023. The temporary nature of the rule simply means that new accounts cannot be opened this way after 2023, unless the legislation is extended again.

The person who establishes the plan is referred to under the Income Tax Act (Canada) as the "holder" and has principal decision-making ability over the plan (e.g., directing investments and the amount and timing of withdrawals).

The Social Insurance Number (SIN) of the disabled individual is also required.

There can be more than one holder, but only one beneficiary per plan. A substitute beneficiary designation is not permitted.

An RDSP can be transferred from one financial institution to another as the holder and/or beneficiary wish.

To open an RDSP:

1. Determine if you are eligible for the disability tax credit. If so,
2. Get an application from Mackenzie Investments and fill it out. Your financial advisor can help you with this.

A car accident left 16-year-old Steve disabled. His father, Colin, decided to establish an RDSP on Steve's behalf. Because Steve qualifies for the disability tax credit, he is eligible for an RDSP. On setup, Colin becomes the holder of the plan (as Steve is a minor) and acquires decision-making authority over the plan. It is decided that once Steve reaches the age of majority, he will become a joint holder with his father.

Contributions

Once an RDSP is established, contributions can be made by anyone, with the holder's written consent or by giving the money to the holder to deposit. Written consent is required to ensure the holder of the plan is able to schedule contributions to maximize government grants (described later).

The maximum lifetime contribution is $200,000 per beneficiary. There is no annual contribution limit – $200,000 can be contributed in any one year, if so desired.

Contributions are not tax-deductible; however, the earnings on contributions grow tax-free while held in the plan.

Contributions must cease by the end of the year in which the beneficiary reaches age 59.

Once an RDSP is set up, there are five ways to put money in:

1. Contributions by the account holder
2. Contributions by people the account holder has authorized
3. Federal grants and bonds
4. Transfers from a qualified RRSP, RRIF or RPP
5. Transfers of the accumulated income from a Registered Education Savings Plan on which the beneficiary is on both RESP and RDSP

Jennifer, a widow and ailing mother was worried about who would care for her disabled daughter, Susan, following her death and decided to establish an RDSP for Susan with an initial contribution of $50,000. She then consulted her lawyer and revised her will to ensure an additional $150,000 would be contributed to the plan upon her death (provided Susan is age-eligible at that time, i.e., under 60). After Jennifer's death, $150,000 was contributed to the RDSP, thereby maximizing the amount available to Susan.

Government help: Taking advantage of grants and bonds

To assist in saving, the federal government offers Canada Disability Savings Grants (CDSGs) and Canada Disability Savings Bonds (CDSBs).

The RDSP is eligible for CDSGs and CDSBs until December 31 of the year the beneficiary turns 49.

Canada Disability Savings Grants (CDSGs)

CDSGs are matching grants that the Government will deposit into a beneficiary's RDSP to help accumulate savings. The Government provides matching grants of up to 300%, depending on the amount contributed and family net income.

The chart below outlines 2019 CDSG matching rates:

Family net income*	CDSG matching rates	Maximum annual CDSG
Up to or equal to $95,259	300% on first $500 200% on next $1,000	$3,500
Over $95,259	100% on first $1,000	$1,000

*2019 rates. For a minor beneficiary, the family net income is that of his or her parents. Where the beneficiary is over the age of majority, the family net income is that of the beneficiary and his or her spouse, if applicable. The income threshold is indexed annually to inflation.

Maximum grant

CDSGs are subject to a lifetime limit of $70,000 per beneficiary, and are payable until the end of the year in which the beneficiary reaches age 49 if the beneficiary remains a resident of Canada.

Unused grants

Beginning in 2011, you are allowed to carry forward unused grant and bond entitlements for a 10-year period.

The maximum CDSG that can be paid in any year is $10,500 and the maximum CDSB is $11,000.

Income thresholds for carry-forward will use the family net income applicable for each year used.

As part of a birthday gift, Meg and Allen agree to contribute $2,000 for each of the next five years to an RDSP for their disabled adult nephew, Tony. Because Tony is age of majority, his family income is used for CDSG purposes. Tony's family net income and grant allocation for the next five years is as follows:

	Family Net Income	Contribution	CDSG
Year 1	$44,500	$2,000	$3,500
Year 2	$48,350	$2,000	$3,500
Year 3	$50,000	$2,000	$3,500
Year 4	$75,000	$2,000	$3,500
Year 5	$100,000	$2,000	$1,000
Total	–	**$10,000**	**$15,000**

Since there are no annual contribution limits for RDSPs, contributions of up to $200,000 can be made in any given year. However, where a lump sum $200,000 contribution is made, no CDSG would be paid after the initial year. RDSP contributors should work with a financial advisor to determine whether lump sum or periodic contributions are the better option. Depending on expected rates of return, age of the RDSP beneficiary and cash flow needs, smaller annual contributions may be more suitable. Lump sum contributions would provide a longer period of tax-deferred growth, whereas annual contributions would maximize CDSGs.

RDSP lump sum or annual contributions: an example

Kevin, age 44, has $10,000 to contribute to his RDSP. He has a decision to make – contribute the full $10,000 upfront to maximize tax-deferred growth, or, because of annual cash flow needs contribute $2,000 for each of the next five years. Kevin speaks to his financial advisor, and the following potential outcomes are discussed (assuming a 6% rate of return and family net income of less than $95,259):

Option 1

Contribute $10,000 upfront

Total contribution: $10,000
CDSG: $3,500
RDSP value after five years: $18,066

Option 2

Contribute $2,000 per year for five years

Total contribution: $10,000
CDSG: $17,500
RDSP value after five years: $32,864

Kevin elects Option 2 as it is expected to provide a greater return and flexibility for annual cash flow needs. Also, his overall return may be enhanced if the excess amount each year (the amount that exceeds $2,000) is invested in a non-registered account.

If Kevin is receiving provincial disability support, there are limitations to the assets he can hold outside an RDSP. This could negatively impact his support.

Kim, age 44, receives an inheritance of $200,000. She, like Kevin, has a decision to make. Should she contribute the full $200,000 upfront, or contribute $40,000 each year for five years to allow cash flow flexibility? Kim speaks to her financial advisor and the following outcomes are discussed (assuming a 6% rate of return and family net income of less than $95,259):

Option 1

Contribute $200,000 as a lump sum

Total contribution: $200,000
CDSG: $3,500
RDSP value after five years: $272,329

Option 2

Contribute $40,000 per year for five years

Total contribution: $200,000
CDSG: $17,500
RDSP value after five years: $259,926

Unlike Kevin, Kim opts for Option 1. For her, a lump sum RDSP contribution will likely produce a better return despite forfeited grants. As well, if Kim chooses Option 2, deposits $40,000 to her RDSP and invests the remaining $160,000, she could lose part or all of her disability tax credit, as the value of tax credits decreases when income (from investments, employment, etc.) reaches a specified level. Kim contributes the full $200,000 upfront and considers other options for her annual cash flow needs. In addition, if Kim is receiving provincial disability support, there are limitations as to assets inherited as well as income that may negatively impact Kim's support unless the entire inheritance is contributed to her RDSP.

Canada Disability Savings Bonds (CDSBs)

In addition to CDSGs, lower income families have access to Canada Disability Savings Bonds (CDSBs). The Government may deposit up to $1,000 a year to the RDSP of a low income beneficiary, even if no contributions are made into the RDSP.

Family net income*	Maximum annual CDSB
Up to or equal to $31,120	$1,000
Between $31,120 and $47,630	$1,000 is reduced on a prorated basis (based on the formula in the Canada Disability Savings Act)
Over $47,630	No bond is paid

*2019 rates. For a minor beneficiary, the family net income is that of his or her parents. Where the beneficiary is over the age of majority, the family net income is that of the beneficiary and his or her spouse, if applicable.

CDSB payments are subject to a lifetime limit of $20,000 per beneficiary, and are payable until the end of the year in which the beneficiary reaches age 49 (if the beneficiary remains a resident of Canada).

Starting in 2011, you may carry forward unused grant and bond entitlement to future years. The carry forward is for a maximum period of 10 years.

Lower income families may qualify for up to a lifetime maximum of $20,000 from the Canada Disability Savings Bond (CDSB) program.

Victor and Shauna have a 16-year-old son, Mark, who requires regular life-sustaining therapy and have a family net income of $20,500. As Mark is eligible for the disability tax credit, he is also eligible for an RDSP. Although Victor and Shauna do not have funds to contribute to an RDSP for Mark, they can establish a plan and still receive CDSBs of $1,000 a year, since the Government does not require contributions to be made to be eligible for CDSBs.

Note: The Province of British Columbia also provides a one-time Disability Bond amount of $150 from the Endowment 150 Fund.

Repayment of CDSGs and CDSBs

When withdrawing funds from an RDSP, it is important to be aware of the 10-year rule. When a redemption is done the government will look to see if CDSGs or CDSBs were deposited to the account in the 10 years prior to the redemption. If the account did receive CDSGs or CDSBs, a repayment known as the Assistance Holdback Amount (AHA) will apply. This means for every $1 withdrawn, $3 worth of CDSGs or CDSBs must be repaid to the government.

The purpose of the Assistance Holdback Amount is to ensure that RDSPs are used for long-term savings, and also to ensure that government funds contributed are not withdrawn and used as leverage for matching grants in future years. The same rule applies to grants and bonds received in the 10-year period before death or the cessation of a disability. Grants and bonds received before the 10-year period do not have to be repaid.

Because of the repayment provisions, an RDSP might not be the best option for short-term expenses. The scenario below illustrates this.

Arnold, 35 and disabled, has an RDSP that his family has been contributing to for the past 10 years. Arnold wishes to withdraw $10,000 from his RDSP to purchase a car.

Details of his plans are as follows:

***Plan value:** $194,963*

***CDSGs (last 10 years):** $35,000*

***CDSBs (family income exceeds threshold):** $0*

Arnold's $10,000 redemption will result in repayment of $30,000 for CDSG for the 10-year period before the withdrawal. CDSGs received prior to the 10-year period are not subject to repayment, so if Arnold only contributed once and received CDSGs and CDSBs in Year 1, if this withdrawal is made after 10 years, no repayment would be required.

It is possible to *not* request grants or bonds for a period if there is a likelihood a Disability Assistance Payment will be required. Grants and bonds can be restarted after the payment.

The 10-year rule

Once a withdrawal of any amount is made, all federal grants and bonds paid into the RDSP in the previous 10 years have to be repaid to the federal government on a $3 for $1 basis.

Investment options

Qualified investments for RDSPs are generally the same as those for Registered Retirement Savings Plans (RRSPs) and Registered Education Savings Plans (RESPs) and include cash, stocks, bonds, GICs, mutual funds and a variety of other investments.

It is important to talk to your financial advisor to ensure that investments are appropriate for RDSPs. Where a non-qualified investment is acquired by an RDSP or where a qualified investment ceases to be qualified, a tax of 50% of the fair market value of the investment would be levied, and income earned on the investment would also be taxable.

Taking money out of your RDSP

RDSP withdrawals are also known as disability assistance payments. There are two types of payments from an RDSP – Lifetime Disability Assistance Payments (LDAPs) and Disability Assistance Payments (DAPs).

Beneficiaries are not required to pay taxes on their RDSP until withdrawals are made or the RDSP is terminated.

Lifetime Disability Assistance Payments

- LDAPs are recurring annual payments that once started, must be paid until the plan is terminated or the beneficiary has died.
- LDAPs may begin at any age, but must commence by the end of the year in which the beneficiary turns 60.
- Payments are generally limited to a maximum tied to the fair market value of the plan and the beneficiary's life expectancy (age 80 in most cases). The maximum amount does not apply where a physician certifies that the RDSP beneficiary is not expected to survive beyond five years.

Disability Assistance Payments

- DAPs are lump sum payments made to the beneficiary or the beneficiary's estate.
- DAPs may only be made if the plan's fair market value after payment will be more than the Assistance Holdback Amount (CDSGs and CDSBs received in the 10-year period prior to a disability assistance payment).

Both LDAPs and DAPs can be used for disability or non-disability-related expenses.

As of 2014, maximum withdrawals are the greater of the LDAP formula or 10% of the value of the plan at the beginning of the year.

Taxation of withdrawals

Disability assistance payments generally consist of original contributions, investment income, CDSGs and CDSBs (subject to repayment obligations). Because original contributions are non-deductible when contributed, they are non-taxable on withdrawal. Investment income, CDSGs and CDSBs are fully taxable to the RDSP beneficiary when received.

RDSP holders cannot encroach on capital alone, as each payment will consist of both taxable and non-taxable amounts. Generally speaking, the proportion of the payment that would be non-taxable is the same as the proportion of total contributions to total plan value.

If an RDSP beneficiary has little or no other income, a portion, if not all of the withdrawal can be received without incurring any tax liability due to the combined effect of the disability tax credit and the basic personal amount on the beneficiary's tax return. Taxable portions of withdrawals will be reported on a T4A-RDSP tax form.

Note: RRSP, RRIF or RPP proceeds transferred from deceased parent or grandparent will be taxable to the RDSP beneficiary. This is also the case with tax-deferred transfers of the taxable amount of RESPs.

Fred just celebrated his 60th birthday, so by the end of the year must begin withdrawals from his RDSP. His financial advisor advises him that $24,500 must be withdrawn from his plan, an amount calculated based on Fred's life expectancy of age 80. Details of his RDSP are as follows:

Plan value: *$587,996*

Total contribution: *$200,000*

CDSGs: *$35,000*

CDSBs: *$0*

Of the $24,500 payable in the year, $8,333 would be non-taxable ($200,000/$587,996 x $24,500). The excess, $16,167 would be taxable to Fred.

However, if Fred has no other income, he can receive the taxable RDSP distribution of $16,167 and not incur any taxes after taking into account his disability tax credit and basic personal amount.

Note: As of 2014, withholding tax will apply to the taxable portions withdrawn from an RDSP. The tax withheld can be claimed by the beneficiary on his or her tax return. The amount withheld should be taken into consideration when determining the withdrawal amount.

Eligible transfers

An RDSP may be transferred to another RDSP for the same beneficiary. To ensure RDSP beneficiaries only have one plan, the transferring plan must be terminated immediately after the transfer. Also, the receiving plan must agree to pay minimum amounts for the year where the transferring plan has not yet done so (generally applicable to beneficiaries age 59 or older).

Tax-deferred transfers from RRSPs, RRIFs or RPPs to an RDSP to the maximum contribution limit are permitted as of July 2011. These transfers must be from an RRSP, RRIF or RPP of a deceased parent or grandparent if the beneficiary of the RDSP was financially dependant on that individual. Tax-deferred transfers of the taxable amount of RESPs are allowed as of 2014.

Impact on Social Assistance Benefits

Payments from an RDSP do not impact other income-tested federal government programs, including:

- Old Age Security (OAS)
- Guaranteed Income Supplement (GIS)
- Canada Pension Plan (CPP)
- The Goods and Services Tax Benefit (GST Benefit)
- Social assistance benefits

As well, generally speaking RDSPs assets and payments should not have a negative impact on eligibility for programs such as subsidized housing and long-term care. However, each province and territory has legislation that provides support to persons with disabilities, so be sure to check with your legal and/or financial advisor for the most up-to-date legislation in your province.

What if the beneficiary dies or is no longer disabled?

When an RDSP beneficiary dies the RDSP will collapse and full proceeds of the plan will be paid to the beneficiary's estate or the estate beneficiary, respectively (subject to CDSG and CDSB repayment obligations).

Original contributions remain non-taxable, while CDSGs, CDSBs and investment income received will be taxed as ordinary income to the beneficiary or his or her estate.* Recognizing that a beneficiary's estate will receive RDSP proceeds on death of the beneficiary, provision should be made in the beneficiary's will for distribution of the assets so that the beneficiary has greater control over the intended distribution of the assets.

If the beneficiary dies without a will, the proceeds would be distributed according to the laws of intestacy for the province or territory in which the beneficiary resided. These laws generally provide for the spouse and children of the deceased, if any, followed by the next closest relatives.

However, relying on the laws of intestacy could lead to unintended distributions, particularly if the beneficiary has a preference that non-related individuals (e.g., friends, caregivers) inherit. Because the rules differ between jurisdictions, it is important to speak to a lawyer in the jurisdiction of the RDSP beneficiary to determine applicable rules.

If the beneficiary ceases to be eligible for the disability tax credit because their condition has improved, the RDSP must either be collapsed by the end of the year following the cessation of the DTC, or an election, with medical verification can be made to put the RDSP " on hold" (no contributions or withdrawals) for up to four years. If there is a relapse and the beneficiary is again DTC-eligible, then the RDSP can be restarted without requiring an entirely new application.

***Note:** If CDGs or CDSBs were paid into the RDSP within 10 years of the death of the beneficiary, those funds must be repaid to the Government.

Karen recently passed away. At the time of her death, her RDSP was valued at $251,471 of which $100,000 was original contributions. No grants or bonds were received in the 10-year period prior to death. On death, Karen's estate received a payment of $251,471, of which $100,000 was non-taxable. The remaining $151,471, consisting of grants, bonds and investment income was taxable on her final tax return.

Other Planning Issues

Henson Trust

Named after the Henson family, a Henson trust is a formal trust to which assets can be contributed on behalf of a disabled individual. Because the trust is discretionary in nature (i.e., the trustee has full discretion over when, how and if assets are distributed to the disabled beneficiary), the trust can provide a certain level of financial support without having the disabled beneficiary's provincial benefits clawed back. It should be noted that some provinces, Alberta, for example, do not recognize such trusts.

In many provinces, Henson trusts will continue as an effective estate planning strategy alongside RDSPs. Suitability should be discussed with a financial advisor and lawyer. Greater flexibility may be achieved through a Henson trust as maximum and minimum withdrawals do not normally apply. Short-term expenses may also be addressed more easily in the absence of CDSG and CDSB repayment provisions. As an estate planning strategy, a contribution of $200,000 could be put into an RDSP during the contributor's lifetime with any excess being left to a trust in the deceased contributor's will.

As of 2016, a Henson trust may be designated as a "Qualified Disability Trust", which receives preferential tax treatment on income earned in the trust.

For more information on the RDSP or to set up a plan, please contact your financial advisor.

GENERAL INQUIRIES

For all of your general inquiries and account information please call:

ENGLISH	1-800-387-0614
BILINGUAL	1-800-387-0615
ASIAN INVESTOR SERVICES	1-888-465-1668
TTY	1-855-325-7030 416-922-4186
FAX	1-866-766-6623 416-922-5660
E-MAIL	service@mackenzieinvestments.com
WEB	mackenzieinvestments.com

Find fund and account information online through Mackenzie Investments' secure InvestorAccess.
Visit mackenzieinvestments.com for more information.

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This should not be construed to be legal or tax advice, as each client's situation is different. Please consult your own legal and tax advisor. Market conditions, tax laws and investment factors are subject to change. Individuals should consult with their financial advisor, accountant or legal professional before taking any action based upon the information contained in this brochure. The Canada Disability Savings Grant (CDSG) and the Canada Disability Savings Bond (CDSB) are provided by the Government of Canada. Eligibility depends on family income levels. Speak to a tax advisor about RDSP's special rules; any redemptions may require repayment of the CDSG and CDSB.

Commissions, trailing commissions, management fees and expenses all may be associated with mutual fund investments. Please read the prospectus before investing. Mutual funds are not guaranteed, their values change frequently and past performance may not be repeated.

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Plan for Your Future with an RDSP

Registered Disability Savings Plan (RDSP) is a long-term savings tool introduced in 2008 by Employment and Social Development Canada to help people with disabilities no matter their level of income. If you, your spouse, or your child has a disability, you may be eligible for this program.

Obligation:

- **There is no obligation.** A person with a disability can be eligible to receive up to **$10,000** in their RDSP in the form of a Canada Disability Savings Bond without having to contribute any money themselves. An additional **$1000** could be deposited into the plan every year going forward to a maximum of **$20,000**.

Eligibility:

- Be a resident of Canada
- Be 49 years of age or younger
- Have a valid Social Insurance Number (SIN)
- Be eligible or have already been approved for the Disability Tax Credit (DTC)

Benefits:

- An RDSP could help with long-term financial security for the individual with a disability.
- For increased savings, the government could match up to **$3** for every **$1** dollar contributed to the plan by the individual or family member to a maximum of **$70,000** per plan.

Process:

- We are Financial Advisors who are very well versed in this government program. We will fully explain the DTC process and the RDSP process to determine if it is deemed beneficial to the individual with a disability.
- We guide the qualified individual through the DTC eligibility process and then through the RDSP application process.
- We also guide the plan holder through the internal investment process.
- A regular review of the RDSP is also important and we intend to follow-up with the plan holder on a regular basis.

For more information, please contact one of our Advisors.

Justin Richard (902) 394-2748

Anton Mikhailov (902) 218-9367

www.generationsfinancial.ca

Resources

Sports

Swimming

Para Sport – Aqua Abilities – 8-week swimming program.

https://parasportpei.ca/

Additional - https://parasportpei.ca/sports/swimming/

Mr. Bill's Swim School – https://www.facebook.com/groups/2715041871857283/

Special Olympics - https://www.specialolympics.ca/pei

Jumpstart Program - https://www.jstart.org/

Music Therapy

Singing Sands

Shona Pottinger – BMT – MTA – NWT

https://www.singingsandsmt.ca/

Serene View Ranch

https://www.sereneviewranch.com/

Katherine Lowings BMT MC MTA CCC CT. KL Therapy and Wellness

https://www.facebook.com/kl.therapywellness/

Equine Therapy

Grand River Ranch

https://www.facebook.com/GrandRiverPEI/

Serene View Ranch

https://www.sereneviewranch.com/

Hoof Prints Ranch

https://www.hoofprintsranch.net/

Community

Owl's Hollow

https://www.owlshollow.com/

Bricks 4 Kids - https://www.bricks4kidz.com/canada-princeedwardisland-charlottetown/

OFF THE WALLZ

https://www.offthewallz.ca/

Cineplex Sensory Friendly Screenings

https://www.cineplex.com/Theatre/cineplex-cinemas-charlottetown

Social ABC's

https://socialabcs.ca/

Advocacy Representative – Office of the Child and Youth Advocate

Wraychel Horne B.A. M.A

119 Kent Street

902 368-5563

Whorne@ocyapei.ca

Learning

Sylvan Learning- https://locations.sylvanlearning.com/ca/charlottetown-pe

Adult

Stars for Life - https://starsforlife.com/

Emergency Assistance/Services

Project LifeSaver – https://www.projectlifesaverpei.ca/

Angel Sense – https://www.angelsense.com/

Medic Alert - No Child Without

https://www.medicalert.ca/no-child-without

Mental Health and Tele-Health Supports

https://www.princeedwardisland.ca/en/information/health-pei/e-mental-health-and-telehealth-supports

Student Well-being Teams
https://www.princeedwardisland.ca/en/information/education-and-lifelong-learning/student-well-being-teams

Autism Nova Scotia

https://www.autismnovascotia.ca/

PEI Helping Tree

https://savoir-sante.ca/en/content_page/download/79/144/21?method=view

Triple P Parenting

https://www.triplep-parenting.ca/can-en/find-help/triple-p-parenting-in-prince-edward-island/

Strongest Families

https://www.princeedwardisland.ca/en/information/health-pei/strongest-families

PEI 211

https://pe.211.ca/

Dial 811 and 911 Emergency.

If you are experiencing a medical emergency, call 9-1-1 or go to the nearest emergency department.

If you are unsure what to do about a health issue or if you need health information, call 8-1-1.

Looking for additional resources? Check out the Autism Society of PEI resource page @

https://www.autismsociety.pe.ca/resources/