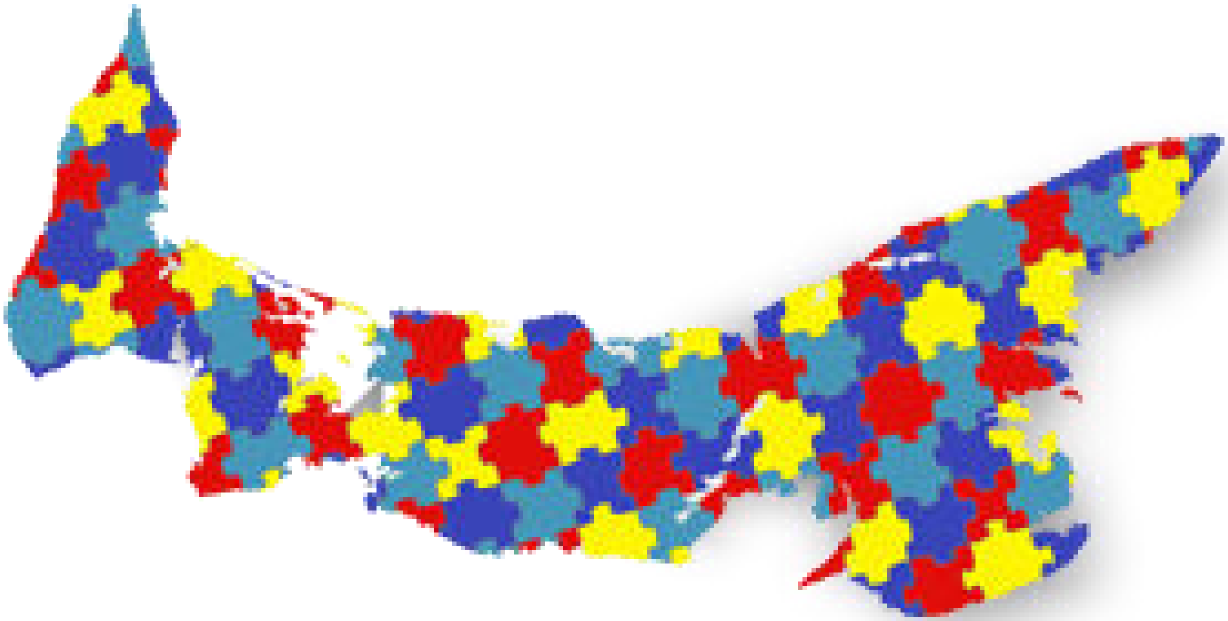


AUTISM SOCIETY

Of Prince Edward Island

Pre-School Diagnosis Kit

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/

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 2021-2022 (Dates April 1st, 2021-March 31st, 2022)

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 $30.00 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 2021-2022 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**

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

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

Pediatric Psychology Services

Share this page:

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

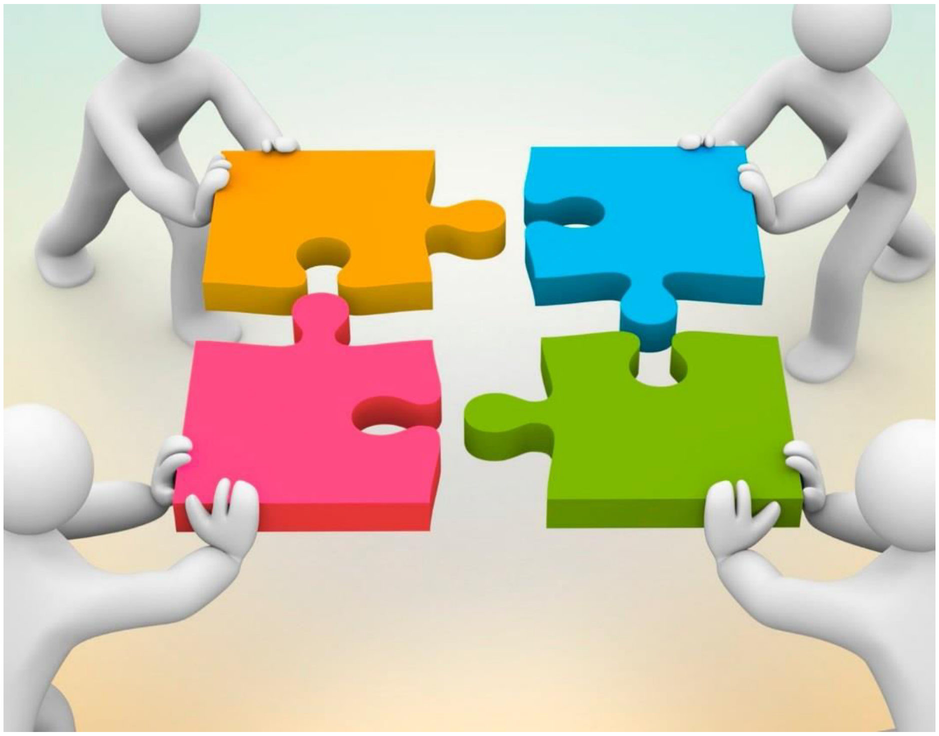
Telephone: (902) 620-3789 (clinic administrative assistant)
Fax: (902) 620-3860

Email: pediatricpsychology@ihis.org(link sends e-mail)

Published date:
August 22, 2017

Department of Social Development and Housing

School Age Autism Funding Guidelines



For more information, please contact:

Toll-free:	1-888-482-5330
Email:	autismfunding@gov.pe.ca

Table of Contents

AccessAbility Supports and School Age Autism Funding

How does AccessAbility Supports connect with School Age Autism Funding?

Autism Spectrum Disorders (ASDs) are diagnosed based on a combination of specific behaviours, communication delays and/or developmental disabilities and varies widely in its severity and symptoms. Early identification, establishing appropriate educational supports, treatments and interventions greatly improve the chances of optimal outcomes for people with ASD.

The School Age Autism Funding is another area of support now offered through AccessAbility Supports. Individuals with ASD are now able to access both AccessAbility Supports and School Age Autism Funding through the same Department while working with one Support Coordinator. The School Age Autism Funding is in addition to all the other AccessAbility Supports described above and does not interfere with the funding that is available through AccessAbility Supports.

AccessAbility Supports – A Brief Overview

AccessAbility Supports offers support and assistance to Islanders living with disabilities. Disabilities may include physical, intellectual, neurological, sensory and mental disabilities. Islanders living with disabilities can access the tools they need to reach their full potential and contribute to society as fully as possible. Supports can be personalized and focus on empowering individuals and their families.

Islanders living with disabilities, or their support person, can call **1-877-569-0546** where they will be asked a few questions about their disability and disability related needs. Once eligibility has been confirmed, an appointment will then be made with an AccessAbility Support Coordinator.

To access supports provided through the AccessAbility Supports Program, an assessment must be completed in order to determine eligibility for AccessAbility Supports as well as identify how disability affects your daily life and how AccessAbility Supports can help meet your needs. This assessment is not required if only accessing School Age Autism Funding.

What type of support is available?

Help is available through the AccessAbility Supports program under five areas of support to help address client's unmet needs.

Personal Supports	Help with personal daily living assistance and <u>may include</u>: • 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	Help with independent living and <u>may include</u>: • financial assistance for a caregiver to provide daily supervision and guidance in a community-based residential setting; and

	- financial help for required home and/or vehicle modifications - $10,000 every 10 years for home modifications & $6,000 every eight years for vehicle modifications.
Community Supports	Help to 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 participation in the community such as day programming, personal aid or specialized transportation.
Caregiver Supports	Help for 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 (over 18 yrs)	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.

School Age Autism Funding

For the purposes of these guidelines, the following **Key Terms** are used:

Parent:	Parent or legal guardian, as applicable.
Employer:	Parent or legal guardian who hires a tutor or aide to provide support to their child or a non-government agency who hires a tutor or aide
Department:	Department of Social Development and Housing

The primary purpose of School Age Autism Funding is to assist students in interacting with peers in the community and/or to further support their learning at school. The funding provided to parents is intended to assist with the cost of employing personnel. In some instances funds may be approved to cover costs for therapeutic activities specific to the student's needs and recommended by a supporting professional. Within these guidelines, the funding is voluntary and flexible and can be used at times or places specific to each child's situation.

Through this funding program, parents of school-age children with a recognized diagnosis of an Autism Spectrum Disorder (ASD) may receive up to $6,600 per fiscal year, including any employer related expenses, towards eligible Autism support services.

If funding is approved for new applicants after the beginning of the fiscal year (April 1st- March 31st) the maximum funding amount is prorated, based on the date of approval.

School Age Autism Funding is specifically intended for PEI based home or community supports outside of school hours or during school vacation periods. To use this funding, the parent employs the tutor or aide directly or may designate a non-governmental agency to be the employer. Supports eligible for funding include:

a) a one-to-one tutor in the home or with an approved agency to supplement the child's school program and minimize loss of skills during school vacation periods and/or

b) a one-to-one aide for the child to access community (PEI-based) activities that support peer relationships and inclusion, specifically when an aide is required to enable participation.

c) costs to support participation in therapeutic activities provided by a recognized non-government agency as recommended by a consulting professional

Eligibility

To be eligible for funding the following criteria must be met:

- The child is younger than 18 years of age and resides within the Province of PEI. Funding eligibility ends at the end of the school year in which the child turns 18.

- The parent has provided the Department with written documentation of an Autism Spectrum Disorder from the diagnosing professional (i.e., registered physician, psychologist or psychiatrist). A provisional diagnosis is not accepted for these funding purposes;

- The child is enrolled in public or private school or registered as being home schooled;

- The parent/child must be an applicant of AccessAbility Supports to access the School Age Autism Funding. Parents may choose to access other disability related supports from AccessAbility Supports, but are not required to.

- School age autism funding is not available for any post-secondary education purposes.

- The parent/child agrees to work with their Support Coordinator to develop a plan that supports the intended use and parameters of the School Age Autism Funding program.

- The child requires the support of an adult to access community PEI-based activities; or tutoring outside of school hours to supplement or help maintain learned skills; or a consulting professional recommends that the student will benefit from a therapeutic activity.

- The parent or designated Agency agrees to follow the payment plan and schedule as per the Department guidelines.

Key Components and Funding Parameters

The parent is responsible for arranging for, selecting and guiding the person or designated Agency who will be providing the tutoring or community aide supports. The Department does not assume responsibility or make recommendations to families regarding individual or Agency service providers.

- The tutor or aide may not be a member of the child’s immediate family (parent, sibling or an individual living in the child’s home) and must be at least 18 years of age. A current criminal and vulnerable person record check is recommended.

- The employer (parent or designated Agency) is reimbursed directly to a maximum total of $6600 per fiscal year for the child for services, based on Time Tracking Log – Invoices submitted (See Appendix A/B). The number of hours for service and rate of pay is at the parent’s discretion, to a maximum total of $6600 per fiscal year.

- Available funding (up to $6600) may not cover all costs incurred by parents in a fiscal year. Parents are responsible for paying any additional costs if the annual amount is exceeded. Families may contact the Department (autismfunding@gov.pe.ca) at any time to confirm the amount of funds remaining in the current fiscal year.

- As for all children who are supplementing school learning at home, the classroom teacher, resource teacher and/or board consultant may recommend activities or materials based on the outcomes being addressed in school.

Funding is provided for:	Funding is not provided for:
Services provided in person within the province	Services provided outside of the province or indirectly (i.e., internet based)
Tutoring outside of school hours or during school vacation periods to help maintain progress	Tutoring during school hours
One-to-one aide wages for after school or summer support or summer camp if required for participation (ie. an aide to attend 1 hr of soccer camp to work one-to-one with the child)	Tuition or fees for services, community events and/ or summer programming. Registration fees for programming costs are not covered.
One-to-one aide to enable access to community based programs, organized sports or service groups (i.e., Scouts, 4H, etc.) if required for participation	Travel time or mileage reimbursement. Registration fees and participant fees are not covered.
The cost of therapeutic activities such as equine or music therapy, or executive function coaching as recommended by a consulting professional that are not otherwise provided through another Government department. These services must be provided by a recognized non-government agency/business.	Professional assessment fees

NOTE: School Age Autism Funding **may not be used for** supports currently provided through other government departments or agencies, including but not limited to:

Disability related supports (i.e., respite, diapers, safety alarms, ID bracelets, etc.)
Assistive technology or augmentative communication devices
Speech, Occupational Therapy or Mental Health services
Medical services
Nutritional or dietary intervention
Psychology
All forms of counseling services

Steps for Applying for School Age Autism Funding

If a new applicant to AccessAbility Supports:

Step 1: The parent calls Social Programs at 1-877-569-0546 to book an appointment with an AccessAbility Supports (AAS) Coordinator. Documentation of the autism diagnosis (and any other disability diagnoses) will be required for the meeting with the Support Coordinator.

If an existing client of AccessAbility Supports:

Step 1: The parent contacts their AAS Coordinator to inform them that they are interested in accessing the School Age Autism Funding.

The remaining steps should be followed for a new applicant or an existing AAS client:

Step 2: Once the Support Coordinator confirms the autism diagnosis, eligibility for School Age Autism Funding can be confirmed. Funding is pro-rated during the first year of the program. After the first year, funding continues uninterrupted from year to year until the child is no longer eligible.

Step 3: The parent works with the Support Coordinator to incorporate use of School Age Autism Funding into the child's AAS Collaborative Support Plan. This portion of the support plan needs to follow the guidelines for School Age Autism Funding (see pages 5 - 7) and include information about the tutor or aide, expectations of the work the tutor/aide will be doing, and the wage rate. The parent identifies an agency, tutor or aide that will work with their child and agrees with the agency/tutor/aide on a wage rate.

This information is captured on Vendor Registration for New Applicant form (Appendix C) and this document must be completed and returned to the Support Coordinator.

Step 4: If the request for School Age Autism Funding includes access to therapeutic activities, the parent must provide a written recommendation from the autism professional working with the child (i.e. Education Autism Consultant). Only recognized non-government agencies will be paid for these supports.

Step5: Once the Support Coordinator receives the completed Vendor Registration for New Applicant form they record the date of receipt and the annual funding amount approved. The pro-rated amount is calculated using the date that eligibility is confirmed (Step 2).

Step 6: Once the Vendor Registration for New Applicant form is finalized and added to the Collaborative Support Plan (date received), the parent can begin to arrange hours of service with the tutor/aide/agency. Hours of service that predate the receipt of the completed Vendor Registration for New Applicant form **are not eligible for reimbursement.**

Step 6: The Support Coordinator signs the completed Vendor Registration for New Applicants form and sends a scanned copy to the Autism Funding Administrator. The original is kept in the client's file so it can be referred to during the year if needed or at the next annual review.

Steps to Submit for Payment or Reimbursement

Step 1: Direct Deposit is the only payment option available. The Payee Registration Form (Appendix D) **MUST** be completed and approved at least 14 days before a payment can be issued. To ensure there are no delays this information should be submitted along with the Vendor Registration for New Applicants form.

Direct payments can be made to non-government agencies provided they complete Part E of the Vendor Registration for New Applicants form and submit a Payee Registration form for Direct Deposit.

Direct payments for private tutors or community aides are issued directly to parents and cannot be set up for direct payments to individual tutors or aides.

Step 2: Hours of service are tracked using the Time Tracking Log – Invoice (Appendix A). When hours of service have been completed by the tutor or aide, the parent or agency submits Time Tracking Log - Invoice to the Autism Funding Administrator to receive payment (See Appendix A/B). Logs must be signed by both the parent and the tutor or aide and specify the actual number of hours, the dates worked and the hourly rate.

Step 3: The Department issues payments to the parent or agency as the employer of the tutor or aide as outlined on the Vendor Registration for New Applicant form (Appendix C).

Step 4: Payments are issued according to a regular Payment Processing Schedule (See Appendix D). Time Tracking Log - Invoices submitted after the scheduled deadline will be processed in the next payment period. Parents/employers are encouraged to submit logs every two weeks as "bulk submissions" of more than four weeks can take longer to process and may result in delays in payments.

Step 5: The Change of Notification form (Appendix E) must be completed any time there is a change affecting payments. This includes adding or removing employee or agency names, updates to mailing or banking information for employer (parent/guardian or designated agency.

PLEASE NOTE:

Effective April 1, 2021 only Department of Social Development and Housing Time Tracking Log – Invoices will be accepted for payment.

Appendices

Appendix A

Department of Social Development and Housing
School Age Autism Funding

Time Tracking Log – Invoice

For the purposes of School Age Autism Funding, the parent, legal guardian or non-governmental agency is the designated employer of the one to one tutor or aide. In all cases, the funding is paid only to the designated employer with required description of service.

Child's Name:			
Employer Identification	☐ Parent or legal guardian	☐ Designated Agency	
Name:			
Address:			
Telephone:			
Employee Identification	☐ Tutor	☐ Community Aide	☐ Therapeutic Activity
Name:			
Address:			
Telephone:			

Dates of Service	**Hours Worked**	**Description of Service**
@ Hourly Rate __________	**Total Hours** _________	**Total Cost** ___________________________

Employer Signature: ____ Date: ________________________

Employee Signature: ____ Date: ________________________

RETURN BY MAIL
Autism Funding Administrator
Social Development and Housing
161 St. Peters Road
Suite 206, PO Box 2000
Charlottetown, PE C1A 7N8

RETURN BY EMAIL
autismfunding@gov.pe.ca

RETURN BY FAX
1-902-368-4720

Appendix B

SAMPLE

Department of Social Development and Housing
School Age Autism Funding

Time Tracking Log – Invoice

For the purposes of School Age Autism Funding, the parent, legal guardian or non-governmental agency is the designated employer of the one to one tutor or aide. In all cases, the funding is paid only to the designated employer with required description of service.

Child's Name: Susie Smith

Employer Identification ✓ Parent or legal guardian ☐ Designated Agency

Name: Mary Jane Smith

Address: 135 Water Road, Summerside, PE C1N 0H0

Telephone: 902-555-5555

Employee Identification ✓ Tutor ☐ Community Aide ☐ Therapeutic Activity

Name: Joe Frank

Address: 204 Wave Street, Summerside, PE C1N 1Q1

Telephone: 902-555-5555

Dates of Service	**Hours Worked**	**Description of Service**
January 4	2 – 5 pm (3 hrs)	One-to-one tutor
January 8	2 – 5 pm (3 hrs)	One-to-one tutor
January 14	2 – 4 pm (2 hrs)	One-to-one tutor
January 15	2 – 4 pm (2 hrs)	One-to-one tutor
January 22	2 – 5 pm (3 hrs)	One-to-one tutor
January 24	2 – 4:30 pm (2.5 hrs)	One-to-one tutor
@ Hourly Rate $13.00	**Total Hours ___15.5_____**	**Total Cost __________$201.50_______________**

Employer Signature: ________________Isabella Smith____________ Date : January 28, 2020

Employee Signature: ____________Joe Frank________________________ Date : January 28, 2020

RETURN BY MAIL
Autism Funding Administrator
Social Development and Housing
161 St. Peters Road
Suite 206, PO Box 2000
Charlottetown, PE C1A 7N8

RETURN BY EMAIL
autismfunding@gov.pe.ca

RETURN BY FAX
1-902-368-4720

Appendix C

Department of Social Development and Housing
School Age Autism Funding

VENDOR REGISTRATION FOR NEW APPLICANTS

PART A – CHILD AND FAMILY INFORMATION

Child's Name:	
Date of Birth (MM/DD/YYYY)	PHN
Name of Parent/Guardian (PLEASE PRINT)	
Address	
Telephone	Email
Signature of Parent /Guardian	Date Signed___________________ (YYYY/MM/DD)

PART B – TYPE OF FUNDING REQUESTED – pick all the apply

- ☐ Funding for **tutor** during non-school hours
- ☐ Funding for community based **one-to-one aide** during non-school hours
- ☐ Funding for therapeutic activity – **copy of recommendation from consulting professional required and must be provided by a designated non-government agency**

PART C – EMPLOYER INFORMATION

- ☐ Parent/Guardian - Complete PART D as soon as this information is available
  - ○ The Payee Registration Form is completed & included for direct deposit – **this is the only payment option available**
- ☐ Designated non-government agency (Complete PART E)
- ☐ Both (Complete PART D and E)

PART D – EMPLOYEE INFORMATION –COMPLETE THIS INFORMATION AS SOON AS IT IS AVAILABLE

Some families choose to have more than one tutor or aide in the same time period. If this is the case, please fill out the Employee Information below for each person employed.

Employee Information #1

Name	
Address	
Telephone	Email
Hourly Wage Rate $_____________per hour	Hours per week__________________________________
Brief Description of the work the tutor/aide will be doing or what the therapeutic activity is including the name of the consulting professional making the recommendation	
☐ Not an immediate family member (parent, sibling or person living in the home with the child) ☐ At least 18 years of age	☐ Vulnerable Persons Check completed (recommended) ☐ Criminal Record Check completed (recommended)

Employee Information #2

Name	
Address	
Telephone	Email
Hourly Wage Rate $_____________per hour	Hours per week ___________________________________
Brief Description of the work the tutor/aide will be doing or what the therapeutic activity is including the name of the consulting professional making the recommendation	
☐ Not an immediate family member (parent, sibling or person living in the home with the child) ☐ At least 18 years of age	☐ Vulnerable Persons Check completed (recommended) ☐ Criminal Record Check completed (recommended)

PART E – DESIGNATED AGENCY INFORMATION –THE DESIGNATED AGENCY MUST COMPLETE THIS SECTION

Agency Name	
Address	
Telephone	Email
Contact Person	
Signature of Agency Representative	
Date	
Hourly Rate payable to the Agency $_____________per hour	Hours per week_________________________________
Name of Tutor to be Employed	
Brief Description of the work the tutor/aide will be doing or what the therapeutic activity is including the name of the consulting professional making the recommendation	
☐ Yes, we would like direct deposit as the employer (Payee Registration Form completed and included) ☐ Agency is already set up as a vendor for School Age Autism Funding	

Please return this completed form to your <u>AAS Support Coordinator</u>
as soon as it has been completed.

Internal Use

Date of receipt:____

Annual Funding Amount Approved: ____

AAS Coordinator Signature:____

Autism Funding Administrator Signature:____

Date processed:____

Personal information on this form is collected under Section 31(c) of *the Freedom of Information and Protection of Privacy Act* and the *Provincial Health Number Act* and will be used for administering the *Social Assistance Act* and the *Rehabilitation of Disabled Persons Act*. If you have any questions about this collection of personal information, you may contact the Manager of Administration, Social Programs, Department of Social Development & Housing, (902) 368–5230.

Appendix D

Prince Edward Island
CANADA

Payee Registration Form

(see reverse for instructions)

PAYEE #	

Freedom of Information and Protection of Privacy

The personal information requested on this form is collected under the authority of section 31(c) of the *Freedom of Information and Protection of Privacy Act* R.S.P.E.I. 1988, Cap. F-15.01, and will be used for the purpose of administering payments to the individuals or suppliers that are identified on this form. This use includes the sharing of this information within the Government of Prince Edward Island and its agencies to update and ensure the accuracy of information for administering payments. Questions on the collection and use of this information can be directed to Payment Processing at (902) 368-4010.

☐ **New Payee** ☐ **Update to Payee Information (i.e. address or updated banking)**

Section A: Personal or Business Information

Fill out this section as an individual OR for your business. All fields are required.

For Individuals Only

First Name	**Full Middle Name(s)**	**Last Name**	**Previous Last Name(s)**
Date of Birth ________ (DD/MM/YYYY)	**If you are a Provincial Government Employee:** **Employee Number**	**Department**	

For Businesses Only

Business Name (Legal name and operating name if different)	**HST/GST No.**	**Contact Person & Position**

For Individuals and Businesses

Current Mailing Address	**City**	**Province or State**	**Postal Code or Zip Code**
Phone Number (including area code)	**Email Address (for payment remittance details)**	**Email Address (for purchase orders if different)**	

Previous Mailing Addresses. Please provide as many previous mailing addresses as possible. We use this information to update our records and to prevent the duplication of your account.

Section B: Payment Information

To receive payments from the Government of Prince Edward Island you **MUST** provide your banking information. Failure to provide banking information will result in unprocessed and delayed payments. Please attach one of the following:

☐ Void cheque

or ☐ Correspondence from Financial Institution (bank)

Section C: Certification

I, as the person named in this form in my own right, or as the representative of the company or business named in this form entitled to receive payments from the Government of Prince Edward Island, hereby authorize the Government of Prince Edward Island or its agencies to share the information collected on this form with each other for the purposes of making a payment that is due. By providing banking information for electronic payment I, as the person named in this form in my own right, or as the representative of the company or business named in this form entitled to receive payments from the Government of Prince Edward Island, hereby authorize the Government of Prince Edward Island or its agencies to electronically deposit those payments into the noted bank account until further notice. If I am the representative of the company or business named in this form, I have the authority to bind the company or business.

Authorized Signature (Forms returned without a signature will not be processed) **Sign Here** ▶ X ____________	**Printed Name (For Businesses Only)**	**Date**

Section D: Additional Information

Section E: For Office Use Only

BUSINESS UNIT: ☐ **FIS** ☐ **MEPS** ☐ **LMDA** ☐ **ISM** ☐ **PSB** ☐ **FLSB**

See Instruction page for form submission details

Appendix E

Department of Social Development and Housing
School Age Autism Funding

PAYMENT PROCESSING

APRIL 1, 2021 – MARCH 31, 2022

APRIL						
S	M	T	W	T	F	S
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

MAY						
S	M	T	W	T	F	S
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

JUNE						
S	M	T	W	T	F	S
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

JULY						
S	M	T	W	T	F	S
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

AUGUST						
S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

SEPTEMBER						
S	M	T	W	T	F	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

OCTOBER						
S	M	T	W	T	F	S
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

NOVEMBER						
S	M	T	W	T	F	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

DECEMBER						
S	M	T	W	T	F	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

JANUARY						
S	M	T	W	T	F	S
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

FEBRUARY						
S	M	T	W	T	F	S
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28					

MARCH						
S	M	T	W	T	F	S
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	27
28	29	30	31			

LEGEND

PAYMENTS ISSUED – April 9, 23, May 7, 21, June 4, 18, July 2, 16, 30, Aug 13, 27, Sept 10, 24, Oct 8, 22, Nov 5, 19, Dec 3, 17, 31, Jan 14, 28, Feb 11, 25, March 11, 25

DEADLINE TO SUBMIT FOR NEXT PAYMENT DATE – April 12, 26, May 10, 25, June 7, 21, July5, 19, Aug 2, 16, 30, Sept 13, 27, Oct 12, 25, Nov 8, 22, Dec 6, 20, Jan 4, 17, 31, Feb 14, 28, March 14, 29

HOLIDAY &/or OFFICE CLOSED – April 2, 5, May 24, July 1, Aug 10, Sept 6, Oct 11, Nov 11, Dec 27, 28, Jan 3, Feb 15

Appendix F

Department of Social Development and Housing
School Age Autism Funding

CHANGE NOTIFICATION

INSTRUCTIONS: You **MUST** complete this form any time there is a change affecting payment(s). This includes adding or removing employee or agency names, updates to mailing or banking information for employer (parent/guardian or designated agency), payment preference.

PART A – CHILD AND FAMILY INFORMATION

Child's Name	
Date of Birth (MM/DD/YYYY)	Personal Health Number (PHN)
Name of Parent/Guardian (PLEASE PRINT)	
Address	
Telephone	
Signature of Parent /Guardian	Date Signed___________________ (YYYY/MM/DD)

PART A – CHANGE REQUESTED

- ☐ Parent/Guardian assuming some or all of the employer function (Complete PART B)
- ☐ Change to Parent/Guardian employer information. Please indicate change below and complete PART B
  - ○ Change in address
  - ○ Change in banking information
- ☐ Adding a Designated Agency as the employer (Complete PART C)
- ☐ Removing a Designated Agency as the employer (Complete PART D)

PART B – CHANGE IN PARENT/GUARDIAN STATUS OR INFORMATION

Name of Parent/Guardian

Address

Telephone and Email

New or Changed payment option

- ☐ Please change my address or contact information (Payee Registration is completed & included)
- ☐ Please change my banking information (Payee Registration is completed & included ***along with*** a void cheque or correspondence from Financial Institution [bank])

PART C – ADDING DESIGNATED AGENCY – Please have the Designated Agency Complete This Section

Agency Name

Address

Telephone and Email

Contact Person

Signature of Agency Representative

Date Signed__________________ (YYYY/MM/DD)

Hourly Rate payable to the Agency $__________per hour

Hours per week____________________________

Name of Individual to be Employed

Brief Description of the work the tutor/aide will be doing or what the therapeutic activity is including the name of the consulting professional making the recommendation

- ☐ The Payee Registration Form is completed and included ***along with*** a void cheque or a correspondence from the Financial Institution (bank). Direct Deposit is the only payment option available.
- ☐ Agency is already set up as a vendor for School Age Autism Funding

PART D – REMOVING DESIGNATED AGENCY – Please have representative of Designated Agency sign this section

Agency Name

Telephone and Email

Effective Date

Signature of Agency Representative

Date Signed__________________ (YYYY/MM/DD)

Please return this completed form to your <u>AAS Support Coordinator</u> as soon as it has been completed.

Internal Use

Date of receipt:____

Annual Funding Amount Approved: ____

AAS Coordinator Signature:____

Autism Funding Administrator Signature:____

Date processed:____

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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

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Director of Clinical Programs
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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*
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Kevin Murray*
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Stuart Savitz*
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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.

American Legion
Child Welfare Foundation
CWF

The Karma Foundation

Joey Lowenstein Foundation
Breaking the Barriers of Autism

The Foundation
Jewish Community Foundation Los Angeles

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Mattresses • Appliances • Countertops

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Parent – indicates a parent of a child with autism

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.

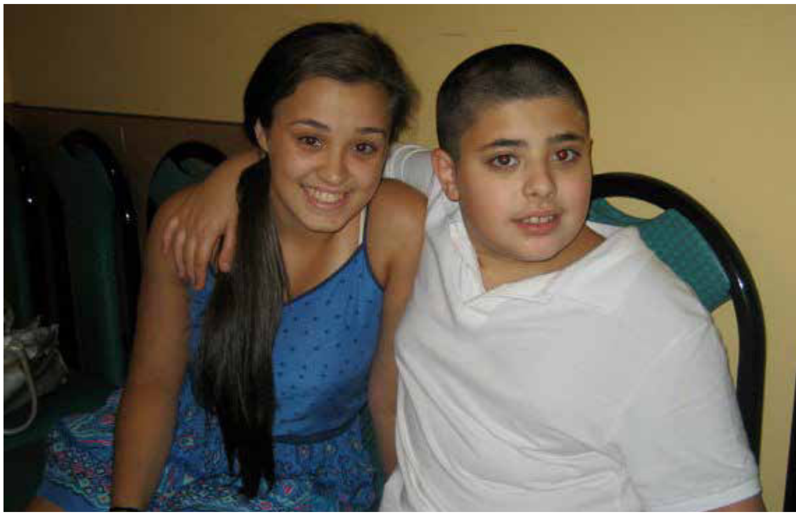
Physical and Medical Issues that May Accompany Autism

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.

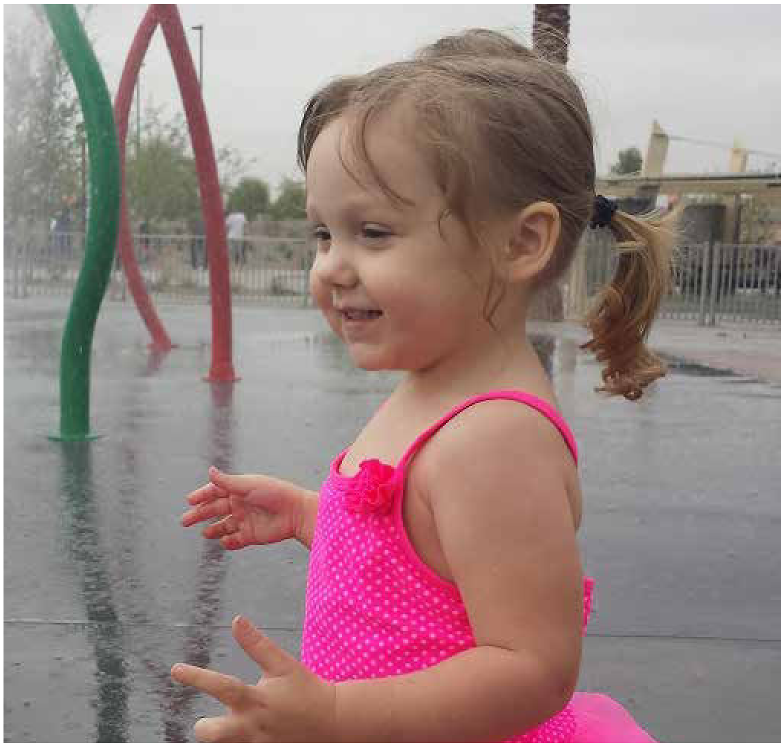
You, Your Family and Autism

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.

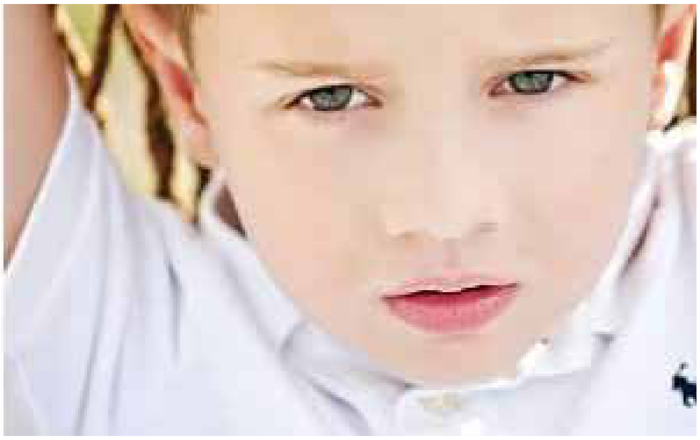
If you are interested in other intervention programs that are not part of these studies, visit the Resource Guide on the Autism Speaks website to help find an early intervention program in your area. autismspeaks.org/resource-guide.

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)*

REFERENCES

Division of Birth Defects, National Center on Birth Defects and Developmental Disabilities and Centers for Disease Control and Prevention (2014). Learn the Signs. Act Early. Milestones Checklist. *Developmental Milestones.* Retrieved April 16, 2014 from **cdc.gov/ncbddd/actearly/milestones/index.html**

Feldman, R. S. (2012). *Child development* (6th ed.). Boston, MA: University of Massachusetts Amherst.

Public Broadcasting Service (n.d.). Social and Emotional Development. *The Whole Child.* Retrieved April 16, 2014 from **pbs.org/wholechild/abc/social.html**

Washington State Department of Social and Health Services (n.d.).The Child Development Guide. *Using the Child Development Guide.* Retrieved April 16, 2014 from **dshs.wa.gov/ca/fosterparents/training/chidev/cd06.htm**

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.

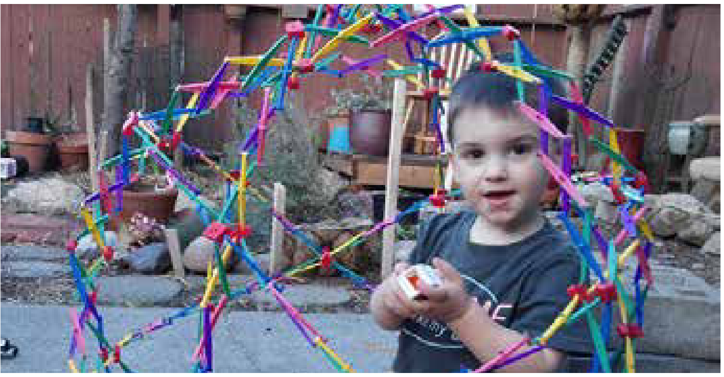
Treatments for associated symptoms address challenges commonly associated with autism, but not specific to the disorder. If your child has biological or medical conditions such as allergies, food intolerances, gastrointestinal issues or sleep disturbances, these will need to be treated too. Treatment 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.

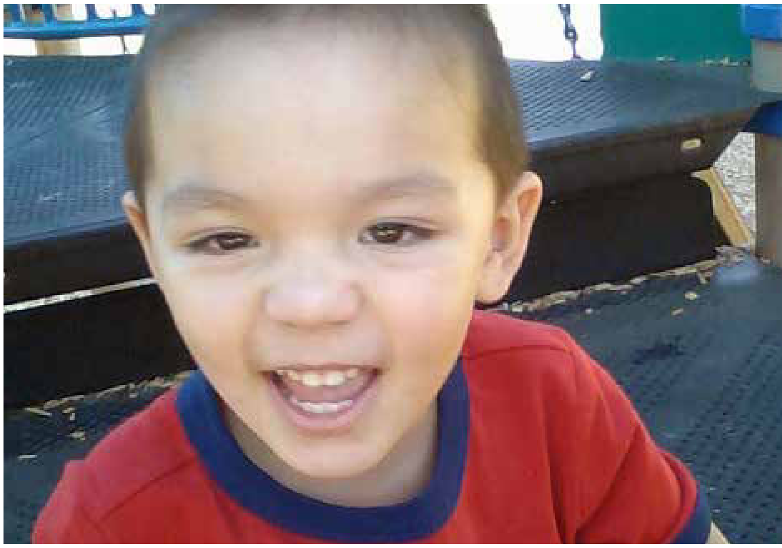
Who provides VB?

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.

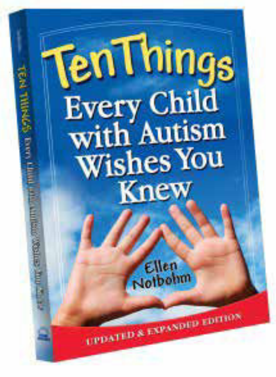
3. Consider an ID Bracelet
Medical ID bracelets will include your name, telephone number and other important information. They may also state that your child has autism and is nonverbal if applicable. If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information.

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	
Phone Number	
Address	
Email Address/ Website	

Specialty	
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Name of Practice	
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Email Address/ Website	

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

CONTACTS: THERAPY

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

Specialty	
Name of Contact	
Name of Practice	
Phone Number	
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CONTACTS: SUPPORT

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CONTACTS: OTHER

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Email Address/ Website	

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: _____________________________________

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: _____________________________________

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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www.AutismSpeaks.org

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.

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

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

An Easter Seals Canada Program

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 TM
Timbres de Pâques MD
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
- ☐ Nurse
- ☐ Social Worker (RSW)
- ☐ Physiotherapist
- ☐ Behaviour Analyst (BCBA)
- ☐ Psychologist
- ☐ Speech Language Pathologist
- ☐ Occupational Therapist
- ☐ Audiologist
- ☐ Psychiatrist
- ☐ Recreational Therapist
- ☐ 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.

Clear Data

Canada Revenue Agency   Agence du revenu du Canada

6729

Protected B when completed

Disability Tax Credit Certificate

Use this form to apply for the disability tax credit (DTC). The Canada Revenue Agency (CRA) will use this information to make a decision on eligibility for the DTC. See the "General information" on page 6 for more information.

Step 1 – Fill out and sign the sections of Part A that apply to you.

Step 2 – Ask a medical practitioner to fill out and certify Part B.

Step 3 – Send the form to the CRA.

Part A – To be filled out by the taxpayer

Section 1 – Information about the person with the disability

First name and initial	Last name	Social insurance number

Mailing address (Apt No. – Street No. Street name, PO Box, RR)

City	Province or territory	Postal code	Date of birth: Year Month Day

Section 2 – Information about the person claiming the disability amount (if different from above)

First name and initial	Last name	Social insurance number

The person with the disability is: ☐ my spouse/common-law partner ☐ my dependant (specify):

Answer the following questions for **all** of the years that you are claiming the disability amount for the person with the disability.

1. Does the person with the disability live with you? Yes ☐ No ☐

   If **yes**, for which year(s)?

2. If you answered **no** to Question 1, does the person with the disability regularly and consistently depend on you for one or more of the basic necessities of life such as food, shelter, or clothing? Yes ☐ No ☐

   If **yes**, for which year(s)?

Give details about the **regular** and **consistent** support you provide for food, shelter or clothing to the person with the disability (if you need more space, attach a separate sheet of paper). We may ask you to provide receipts or other documents to support your request.

Section 3 – Adjust your income tax and benefit return

Once eligibility is approved, the CRA can adjust your returns for all applicable years to include the disability amount for **yourself** or your **dependant under the age of 18**. For more information, see Guide RC4064, Disability-Related Information.

☐ Yes, I want the CRA to adjust my returns, if possible.   ☐ No, I do not want an adjustment.

Section 4 – Authorization

As the **person with the disability** or their **legal representative**, I authorize the following actions:

- Medical practitioner(s) can give information to the CRA from their medical records or discuss the information on this form.
- The CRA can adjust my returns, as applicable, if the "Yes" box has been ticked in Section 3.

Sign here:	Telephone	Year Month Day

Personal information is collected under the Income Tax Act to administer tax, benefits, and related programs. It may also be used for any purpose related to the enforcement of the Act such as audit, compliance and collection activities. It may be shared or verified with other federal, provincial, territorial or foreign government institutions to the extent authorized by law. Failure to provide this information may result in interest payable, penalties or other actions. The social insurance number is collected under section 237 of the Act and is used for identification purposes. Under the Privacy Act, individuals have the right to access, or request 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 at canada.ca/cra-info-source.

Validate and Print **Part A**

(Ce formulaire est disponible en français.)

Canada

Patient's name: ____________________

Part B – Must be filled out by the medical practitioner

Step 1 – Fill out **only** the section(s) on pages 2 to 4 that apply to your patient. Each category states which medical practitioner(s) can certify the information in this part.

Note
Whether filling out this form for a child or an adult, assess your patient compared to someone of similar age with no impairment.

Step 2 – Fill out the "**Effects of impairment**", "**Duration**", and "**Certification**" sections on page 5. If more information is needed, the Canada Revenue Agency (CRA) may contact you.

Eligibility for the DTC is based on the effects of the impairment, not on the medical condition itself. For definitions and examples of impairments that may qualify for the DTC, see Guide RC4064, Disability-Related Information. For more information, go to canada.ca/disability-tax-credit.

Vision – Medical doctor, nurse practitioner, or optometrist

Your patient is considered **blind** if, even with the use of corrective lenses or medication, their vision meets any of the following criteria:

- The visual acuity in **both** eyes is 20/200 (6/60) or less, with the Snellen Chart (or an equivalent).
- The greatest diameter of the field of vision in **both** eyes is 20 degrees or less.

1. Is your patient **blind**, as described above? Yes ☐ No ☐

   If **yes**, when did your patient become blind (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ____

2. What is your patient's visual acuity **after correction**? Right eye ____ Left eye ____

3. What is your patient's visual field **after correction** (in degrees if possible)? Right eye ____ Left eye ____

Speaking – Medical doctor, nurse practitioner, or speech-language pathologist

Your patient is considered **markedly restricted** in speaking if, even with appropriate therapy, medication, and devices, they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to speak so as to be understood by another person familiar with the patient, in a quiet setting.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Is your patient **markedly restricted** in speaking, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in speaking become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ____

Hearing – Medical doctor, nurse practitioner, or audiologist

Your patient is considered **markedly restricted** in hearing if, even with appropriate devices, they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to hear so as to understand another person familiar with the patient, in a quiet setting.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Is your patient **markedly restricted** in hearing, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in hearing become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ____

Walking – Medical doctor, nurse practitioner, occupational therapist, or physiotherapist

Your patient is considered **markedly restricted** in walking if, even with appropriate therapy, medication, and devices, they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to walk.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Is your patient **markedly restricted** in walking, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in walking become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ____

Patient's name: ______________________________

Eliminating (bowel or bladder functions) – Medical doctor or nurse practitioner

Your patient is considered **markedly restricted** in eliminating if, even with appropriate therapy, medication, and devices, they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to personally manage bowel or bladder functions.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Is your patient **markedly restricted** in eliminating, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in eliminating become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ☐☐☐☐

Feeding – Medical doctor, nurse practitioner, or occupational therapist

Your patient is considered **markedly restricted** in feeding if, even with appropriate therapy, medication, and devices, they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to feed themselves.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Feeding yourself **does not** include identifying, finding, shopping for, or obtaining food.

Feeding yourself **does** include preparing food, **except** when the time spent is related to a dietary restriction or regime, even when the restriction or regime is needed due to an illness or medical condition.

Is your patient **markedly restricted** in feeding, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in feeding become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ☐☐☐☐

Dressing – Medical doctor, nurse practitioner, or occupational therapist

Your patient is considered **markedly restricted** in dressing if, even with appropriate therapy, medication, and devices, they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to dress themselves.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Dressing yourself **does not** include identifying, finding, shopping for, or obtaining clothing.

Is your patient **markedly restricted** in dressing, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in dressing become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ☐☐☐☐

Mental functions necessary for everyday life – Medical doctor, nurse practitioner, or psychologist

Your patient is considered **markedly restricted** in performing the mental functions necessary for everyday life (described below) if, even with appropriate therapy, medication, and devices (for example, memory aids and adaptive aids), they meet both of the following criteria:

- They are **unable** or take an **inordinate amount of time** to perform these functions by themselves.
- This is the case **all or substantially all of the time** (at least 90% of the time).

Mental functions necessary for everyday life include:

- adaptive functioning (for example, abilities related to self-care, health and safety, abilities to initiate and respond to social interactions, and common, simple transactions)
- memory (for example, the ability to remember simple instructions, basic personal information such as name and address, or material of importance and interest)
- problem-solving, goal-setting, **and** judgment taken together (for example, the ability to solve problems, set and keep goals, and make the appropriate decisions and judgments)

Note
A restriction in problem-solving, goal-setting, or judgment that markedly restricts adaptive functioning, all or substantially all of the time (at least 90% of the time), would qualify.

Is your patient **markedly restricted** in performing the mental functions necessary for everyday life, as described above? Yes ☐ No ☐

If **yes**, when did your patient's restriction in performing the mental functions necessary for everyday life become a marked restriction (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ☐☐☐☐

Patient's name: ______________________________

Life-sustaining therapy – Medical doctor or nurse practitioner

Life-sustaining therapy for your patient must meet **both** of the following criteria:

- Your patient needs this therapy to support a vital function, even if this therapy has eased the symptoms.
- Your patient needs this therapy at least 3 times per week, for an average of at least 14 hours per week.

The 14-hour per week requirement

Include only the time your patient must dedicate to the therapy – that is, the patient has to take time away from normal, everyday activities to receive it.

If a child cannot do the activities related to the therapy because of their age, **include** the time spent by the child's primary caregivers to do and supervise these activities.

Do not include the time a portable or implanted device takes to deliver the therapy, the time spent on activities related to dietary restrictions or regimes (such as carbohydrate calculation) or exercising (even when these activities are a factor in determining the daily dosage of medication), travel time to receive therapy, medical appointments (other than appointments where the therapy is received), shopping for medication, or recuperation after therapy.

1. Does your patient need this therapy **to support a vital function**? Yes ☐ No ☐
2. Does your patient need this therapy at least **3 times per week**? Yes ☐ No ☐
3. Does this therapy take an average of at least **14 hours per week**? Yes ☐ No ☐

   If **yes**, when did your patient's therapy begin to meet the above criteria (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ☐☐☐☐

It is **mandatory** that you describe how the therapy meets the criteria as stated above. If you need more space, use a separate sheet of paper, sign it and attach it to this form.

Cumulative effect of significant restrictions – Medical doctor, nurse practitioner, or occupational therapist

Note: An occupational therapist can only certify limitations for walking, feeding and dressing.

Answer **all** the following questions to certify the cumulative effect of your patient's significant restrictions.

1. Even with appropriate therapy, medication, and devices, does your patient have a **significant restriction**, that is not quite a **marked restriction**, in **two** or more basic activities of daily living or in **vision** and **one** or more of the basic activities of daily living? Yes ☐ No ☐

   If **yes**, tick at least **two** of the following, as they apply to your patient:

   ☐ vision ☐ speaking ☐ hearing ☐ walking

   ☐ eliminating (bowel or bladder functions) ☐ feeding ☐ dressing ☐ mental functions necessary for everyday life

   Note
   You **cannot** include the time spent on life-sustaining therapy.

2. Do these restrictions exist together, **all or substantially all of the time** (at least 90% of the time)? Yes ☐ No ☐
3. Is the cumulative effect of these significant restrictions equivalent to being **markedly restricted** in **one** basic activity of daily living? Yes ☐ No ☐
4. When did the cumulative effect described above begin (this is not necessarily the year of the diagnosis, as is often the case with progressive diseases)? Year ☐☐☐☐

Clear Data

Protected B when completed

Patient's name: ______________________________

Effects of impairment – Mandatory

The effects of your patient's impairment must be those which, even with therapy and the use of appropriate devices and medication, cause your patient to be restricted **all or substantially all of the time** (at least 90% of the time).

Note
Working, housekeeping, managing a bank account, and social or recreational activities are **not** considered basic activities of daily living. Basic activities of daily living are limited to walking, speaking, hearing, dressing, feeding, eliminating (bowel or bladder functions), and mental functions necessary for everyday life.

It is **mandatory** that you describe the effects of your patient's impairment on his or her ability to do **each** of the basic activities of daily living that you indicated are or were markedly or significantly restricted. If you need more space, use a separate sheet of paper, sign it and attach it to this form. You may include copies of medical reports, diagnostic tests, and any other medical information, if needed.

Duration – Mandatory

Has your patient's impairment lasted, or is it expected to last, for a continuous period of at least 12 months? For deceased patients, was the impairment expected to last for a continuous period of at least 12 months? Yes ☐ No ☐

If **yes**, has the impairment improved, or is it likely to improve, to such an extent that the patient would no longer be blind, markedly restricted, in need of life-sustaining therapy, or have the equivalent of a marked restriction due to the cumulative effect of significant restrictions? Unsure ☐ Yes ☐ No ☐

If **yes**, enter the year that the improvement occurred or may be expected to occur. Year ☐☐☐☐

Certification – Mandatory

1. For which year(s) have you been the attending medical practitioner for your patient? ______________________

2. Do you have medical information on file supporting the restriction(s) for all the year(s) you certified on this form? Yes ☐ No ☐

Tick the box that applies to you:

☐ Medical doctor
☐ Audiologist
☐ Nurse practitioner
☐ Physiotherapist
☐ Optometrist
☐ Psychologist
☐ Occupational therapist
☐ 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.

Sign here: ______________________________

It is a serious offence to make a false statement.

Name (print)

Date: Year ☐☐☐☐ Month ☐☐ Day ☐☐

Telephone

Address

Validate and Print **Part B**

Clear Data

General information

What is the DTC?

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. The disability amount may be claimed once the person with a disability is eligible for the DTC. This amount includes a supplement for persons under 18 years of age at the end of the year. Being eligible for this credit may open the door to other programs.

For more information, go to canada.ca/disability-tax-credit or see Guide RC4064, Disability-Related Information.

Are you eligible?

You are eligible for the DTC only if we approve your application. On this form, a medical practitioner has to indicate and certify that you have a severe and prolonged impairment and must describe its effects.

To find out if you **may be eligible** for the DTC, fill out the self-assessment questionnaire in Guide RC4064, Disability-Related Information. If we have already told you that you are eligible, do not send another form unless the previous period of approval has ended or if we tell you that we need one. **You should tell us if your medical condition improves**.

If you receive Canada Pension Plan or Quebec Pension Plan disability benefits, workers' compensation benefits, or other types of disability or insurance benefits, it **does not** necessarily mean you are eligible for the DTC. These programs have other purposes and different criteria, such as an individual's inability to work.

You can send the form at any time during the year. By sending your form before you file your income tax and benefit return, you may prevent a delay in your assessment. We will review your form before we assess your return. Keep a copy for your records.

Fees – You are responsible for any fees that the medical practitioner charges to fill out this form or to give us more information. However, you may be able to claim these fees as medical expenses on line 330 or line 331 of your income tax and benefit return.

What happens after you send Form T2201?

After we receive Form T2201, we will review your application. We will then send you a notice of determination to inform you of our decision. Our decision is based on the information given by the medical practitioner. If your application is denied, we will explain why on the notice of determination. For more information, see Guide RC4064, Disability-Related Information, or go to **canada.ca/disability-tax-credit**.

Where do you send this form?

Send your form to the Disability Tax Credit Unit of your tax centre. Use the chart below to get the address.

If your tax services office is located in:	Send your correspondence to the following address:
Alberta, British Columbia, Hamilton, Kitchener/Waterloo, London, Manitoba, Northwest Territories, Regina, Saskatoon, Thunder Bay, Windsor, or Yukon	Winnipeg Tax Centre Post Office Box 14000 Station Main Winnipeg MB R3C 3M2
Barrie, Belleville, Kingston, Montréal, New Brunswick, Newfoundland and Labrador, Nova Scotia, Nunavut, Ottawa, Outaouais, Peterborough, St. Catharines, Prince Edward Island, Sherbrooke, Sudbury, or Toronto	Sudbury Tax Centre Post Office Box 20000, Station A Sudbury ON P3A 5C1
Chicoutimi, Laval, Montérégie-Rive-Sud, Québec, Rimouski, Rouyn-Noranda, or Trois-Rivières	Jonquière Tax Centre 2251 René-Lévesque Blvd Jonquière QC G7S 5J2
Deemed residents, non-residents, and new or returning residents of Canada	Sudbury Tax Centre Post Office Box 20000, Station A Sudbury ON P3A 5C1 CANADA or Winnipeg Tax Centre Post Office Box 14000 Station Main Winnipeg MB R3C 3M2 CANADA

What if you 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**.

MACKENZIE
Investments

CONFIDENCE
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.

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.

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.

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.
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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.

MACKENZIE
Investments

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.

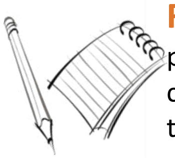
Quick Points to Practice…

- ✓ **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.

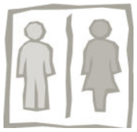
Make sure toilet trips are comfortable. Your child should be comfortable while sitting on the toilet. Use a smaller potty seat and/or provide a footstool. If your child will not sit on the toilet, work on sitting before beginning a toilet training program.

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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AUTISM SPEAKS™ ATN Autism Treatment Network

AIR-P Autism Intervention Research Network on Physical Health

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

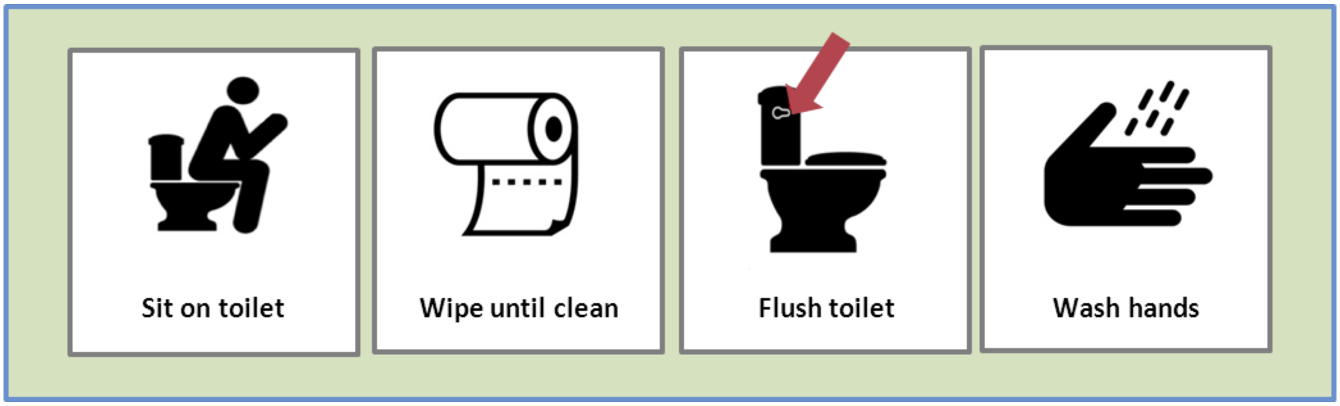
APPENDIX 2: EXAMPLE VISUAL SCHEDULE

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



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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.

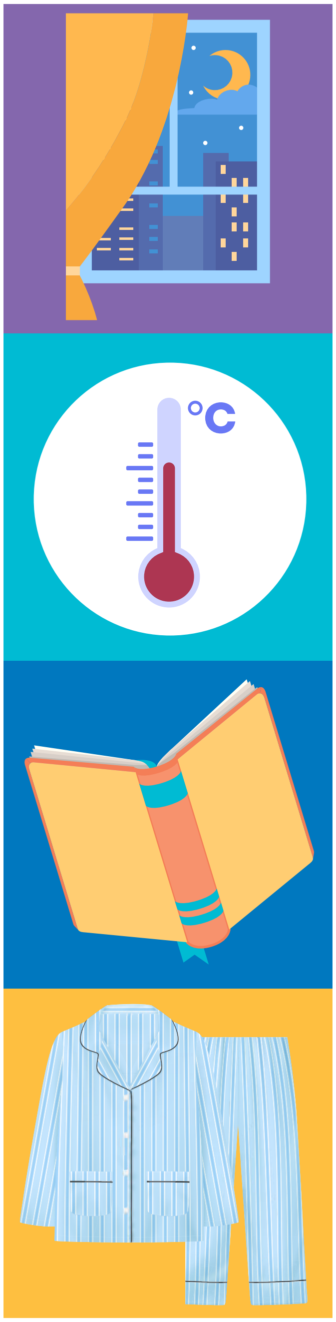
How to select a sleep program for your child:

- **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.*

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.

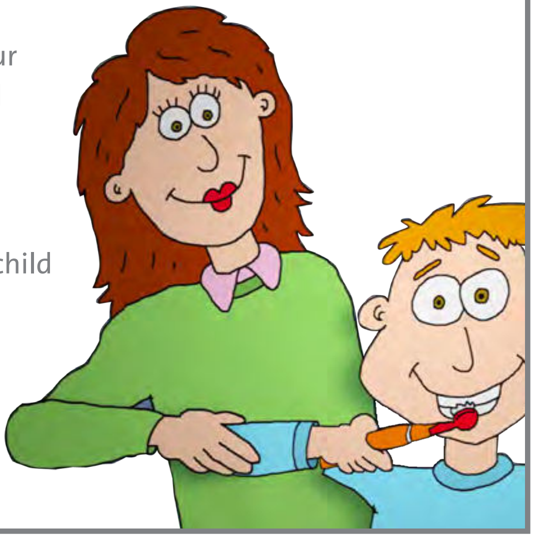
Although most people brush their teeth in the bathroom, in order to accommodate your child and get them accustomed to brushing their teeth, you may want to do this on the couch or in another part of your home where they may feel more comfortable. The ultimate goal is for your child to brush their teeth 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 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.

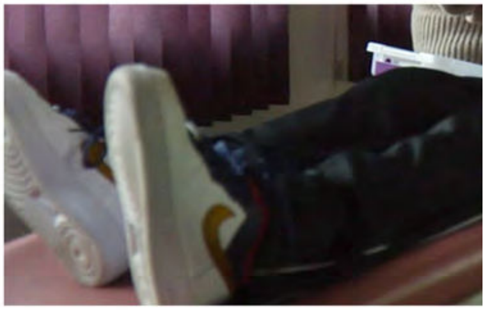
Visual Schedule

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 ☐

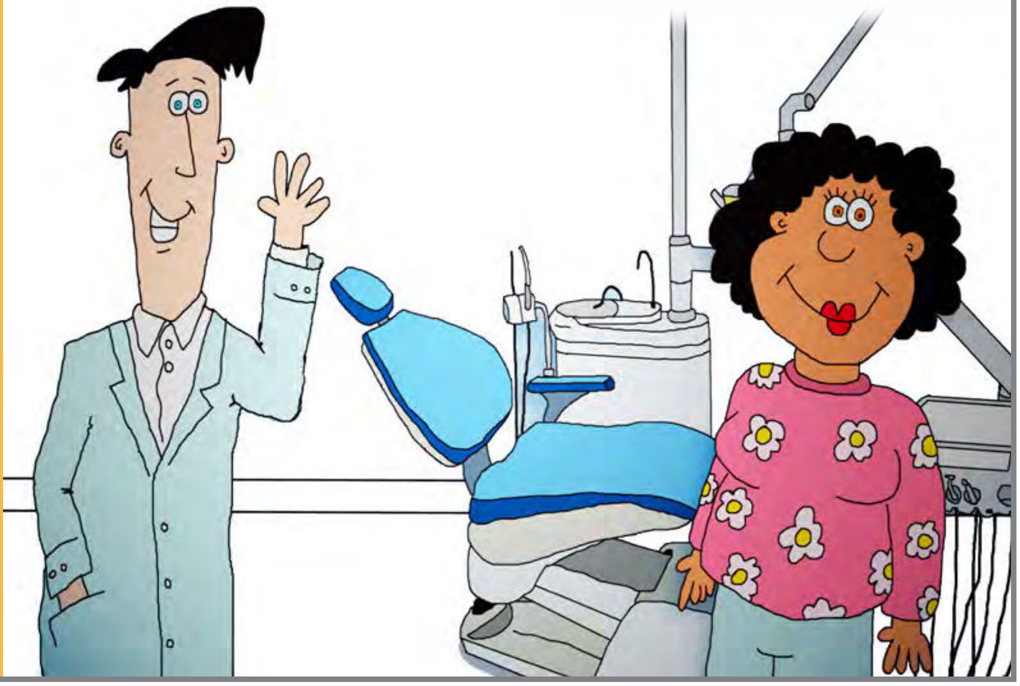

6 Take X-Rays ☐


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

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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:

Autism Speaks®

FAMILY SERVICES

Challenging Behaviors Tool Kit

AUTISM SPEAKS®
It's time to listen.

Aggressive and Challenging Behaviors Tool Kit

Johnny runs away and requires constant supervision. Susie screams and covers her ears whenever an airplane is overhead—and she always hears them before anyone else. She screams other times too and it is hard to get her to stop. Tommy refuses to wear shoes and throws them at anyone who tries to get him to put them on. Maria doesn't like riding the bus, and bites her mom each day as it rolls up to the bus stop. Jose will only eat three foods, and they can never touch each other on his plate or everybody is sorry. Sally hits herself in the head whenever someone tells her 'no.'

Sometimes the difficulties of autism can lead to behaviors that are quite challenging for us to understand and address. Most individuals with autism will display *challenging behaviors* of some sort at some point in their lives. These behaviors can often be the result of the underlying conditions associated with autism.

Purpose and Scope of this Tool Kit

Challenging behaviors represent some of the most concerning and stressful features of autism. These behaviors can often cause harm or damage, family and staff stress, isolation, and caregiver burnout. Parents may feel guilty or responsible, but it is important to know that you should not blame yourself for behaviors that you find difficult. Sometimes, the extraordinary steps parents go through for their children with complex needs might not be enough, and additional supports and resources might be necessary. It is important not to think of your child, or these behaviors, as 'bad,' but to learn how to better understand and respond to challenging situations to make them more manageable for everyone. Hopefully this kit will help provide you with strategies and resources, and lead you to professionals within your community.

For the purposes of this tool kit, we classify challenging behaviors as behaviors that:

- are harmful (to the individual or others)
- are destructive
- prevent access to learning and full participation in all aspects of community life
- cause others to label or isolate the individual for being odd or different

Challenging behaviors can occur throughout the lifespan of an individual with autism. The core and associated symptoms of autism can adjust over time and as a result, many individuals with autism experience changes at various stages of life that might result in new behaviors. An individual's behavior can often vary considerably even minute by minute in response to internal (such as stomach pain) or external (people, places, noises, activity levels, etc.) issues. In addition, many individuals with autism experience other associated concerns and co-occurring (*co-morbid*) conditions that can layer on additional concerns, such as those described here and here.

As time passes, families and caregivers adapt to meet the needs and demands of their loved ones. At times their responses and expectations can drift into a place that becomes difficult for everyone. These feelings often increase stress levels and may even limit access to their own friends and community.

Sometimes as children age and become stronger, challenging behaviors can reach crisis levels. Many families who have previously managed the trials presented by autism might experience crisis situations when their child hits older childhood or the teenage years. This may be because the challenges have grown as the child becomes bigger and stronger, or because of new factors that accompany growing up or *puberty*. To address more significant concerns that might create risk to the child or others, later in the kit there is section to help with Managing a Crisis.

> *"When James reached age 18, he was 6'2" and 210 pounds, and strong. He was learning that aggression was an effective way to avoid tasks that he didn't like because it worked – I was afraid of him. Every morning when I asked James to make his bed, he would usually begin doing it correctly but would often make mistakes. When I told him that he had made a mistake, he would start biting himself and hitting me, so I would back away and leave the room. But this allowed James to escape the task of making his bed and taught him (and me) that his aggression worked! With a little help from a behavioral consultant, I decided that whenever James began to get upset while making his bed, I would prompt him to say, "Help me please." It was explained to me that this behavior served the same purpose as his aggression and self-injury. When James asked for help, I'd give him some assistance, which made us both a lot less frustrated."*
>
> *– AG, mother*

The guiding principle used in developing this kit is that each individual with autism and his family should feel safe and supported, and live a healthy life filled with purpose, dignity, choices, and happiness. With this in mind, positive approaches and suggestions are highlighted throughout the kit. The general framework and *intervention* principles included are relevant at any stage of life, and we have included basic background information, with links to further information and resources on a variety of topics.

In this tool kit, the term autism will be used to include all *Autism Spectrum Disorders* that result in the social, communication and behavioral differences characteristic of this population. While we recognize that the autism spectrum encompasses both males and females, for the sake of simplicity, we have used 'he' throughout to represent an individual of either gender.

The kit is broken into different sections. You may want to read the kit in its entirety or work through a section at a time. Please visit the Autism Speaks Resource Guide to find services, contacts or resources in your area, as well as information specific to your state. If you have resources to share, you can add them to the Resource Guide here.

Document Key

- The definitions of the words highlited in the *clay colored italic text* can be found in the Glossary.
- The *blueberry italic text* are quotes from *Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting* by Helen Yoo, Ph.D, New York State Institute for Basic Research *Autism Speaks Family Services Community Grant recipient*
- The blue text are links you can click on for further information.

Table of Contents

As a companion to the information in this kit, we have two video series of frequently asked questions regarding challenging behaviors. One is from a legal perspective and the other from a clinical perspective. You can find them on the homepage of the Challenging Behaviors Tool Kit. The questions addressed in these videos are listed below.

Legal FAQ's

General Crisis Information:

- Can you tell me what a crisis is?
- What's my first objective in a crisis situation?

Crises & Schools:

- What is a school's immediate responsibility if a crisis happens in school?
- What about after the crisis?
- Can my child get kicked out of school for this kind of behavior?
- What should I do if my child does get kicked out of school?
- What is a manifestation hearing?
- What is a school's responsibility if the crisis happens at home?
- If my school isn't helping or can't help with the situation, what should I do?

Adults & Guardianship:

- Is there anybody responsible for helping adults who are having crisis behavior?
- What happens in a crisis situation if the family has no guardianship and the individual is over 18?
- Is there emergency or temporary guardianship for a situation like this?
- If I want to obtain emergency or temporary guardianship, how would I do that?
- What's the advantage of seeking guardianship before a child turns 18?

Hospitals & Residential Placement:

- What are the responsibilities of a hospital and your rights regarding medical interventions?
- Is the hospital required to provide behavioral supports?
- If my child is in the hospital, what happens to their schooling?
- What happens if my child is being repeatedly kicked out of school and sent to hospital settings? Are there any other options?
- If an adult is in residential placement, what is the responsibility of the facility or home in a crisis situation?

Calling 911:

- If I call 911 for an emergency, what should I tell the dispatcher?
- Are there specific terms or phrases that should be used to get help in a crisis situation?
- When the first responders arrive, what information should I give them?

Other Advice:

- What other legal advice do you have for families in crisis?

Clinical FAQ’s:

Understanding Challenging Behaviors:

- What are challenging behaviors?
- What’s the most important thing to know about challenging behaviors?
- What’s important to know about aggressive or self-injurious behaviors?

Addressing Challenging Behaviors:

- Why is it important to address challenging behaviors?
- What should I know before addressing challenging behaviors?
- How important is consistency in addressing challenging behaviors?
- What if I’m having trouble carrying out a behavior plan?

Dealing With A Crisis At Home:

- What should families do in a crisis situation?
- Where can families turn if they feel unsafe in a crisis situation?

Other Advice:

- Can you use Applied Behavior Analysis (ABA) on adolescents and adults with autism?
- What role can medication play in addressing challenging behaviors?
- When should I consider residential placement?
- Where do siblings fit in with all of this?
- Do you have any general advice for families dealing with challenging behaviors?

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The Challenging Behaviors Tool Kit was edited by Liz Bell and designed by Joe Shea.

Why is Autism Associated With Aggressive and Challenging Behaviors?

Autism itself does not cause challenging behaviors. It is likely, however, that some of the underlying biological processes that result in autism might also result in behaviors that are outside of a person's control—similar to how the tremors associated with Parkinson's Disease are brought on by impulses that the person cannot direct. In addition, some behavioral responses are simply reflexes—no more of a choice for your child than when your leg jerks upward when the doctor uses his hammer on your kneecap.

"Some of those behaviors that most professionals and many families would not consider challenging, such as making odd noises, repeating phrases over and over, closing and opening doors in a repetitive fashion, might not be dangerous or destructive. But they sure can be annoying, and raise everyone's stress levels. And when the individual is told to stop again and again but still doesn't, those little things can lead to big things. They can create a tension that makes everyone behave in ways that become problematic. Learning how to think about and deal with these low-level, irritating behaviors certainly changed how we functioned as a family and improved our quality of life."

– NM, mother

In addition, the core features of autism are areas in which difficulties can lead to feelings of frustration, confusion, anxiety or lack of control, resulting in behavioral responses. Since behavior is often a form of communication, many individuals with autism (as well as those without autism) voice their wants, needs or concerns through behaviors, rather than words. This does not mean that they are always knowingly communicating. For example, running away from a barking dog might be the child's biological fight or flight response to scary situations, or even to something that you might not view as frightening. Similarly, shutting down and retreating to a quiet place might be a child's way of saying 'this situation is far too noisy and crowded for me to handle.' This may be an automatic response in the moment, not a choice he is making.

Challenging behaviors are more likely to appear when a person is feeling unhappy or unhealthy. Medical concerns, mental health issues, or sensory responses that we cannot see might bring pain or discomfort to a person with autism that we might not understand, especially when he is unable to say so.

"All of a sudden when Mark was about 8 years old, he needed order. The change came overnight. If we opened a cabinet, he closed it. Loading and unloading the dishwasher was impossible—he could not tolerate the door being open. It was maddening to us, and so clearly compulsive for him. He became anxious and acted out if the order was not maintained. Thankfully, our doctor ran some tests and determined that he had high antibodies to strep, and the compulsiveness was likely due to a sort of obsessive compulsive disorder called PANDAS. The biological factors were not easy to treat and took a long time to resolve, but how we responded to his behavior changed completely when we realized that he wasn't doing this to drive us crazy, and that he was no more in control of what he was doing than we were. We worked a lot on building his tolerance for flexibility, in tiny bits and using positive rewards. Eventually, he returned to his flexible self, but we had to adapt our behavior to help him through this in a way that worked for all of us."

– SP, father

Many behaviors are also responses to previous experiences. A baby who gets a smile when he coos usually learns to coo more often. The same is true for challenging behaviors. If a child has learned that screaming gets him out of a difficult task, he might scream in the future to escape.

How we respond to his actions can have a significant effect on what he does the next time he is in a similar situation.

Because of the learning differences that autism can bring, people with autism might need specialized approaches to learning appropriate behavior. For example, the scolding look that stops your typical two-year-old in his tracks may mean nothing to a 30-year-old with autism who has not learned to recognize emotions and facial expressions.

Without some of the abilities and skills that most of us have developed as children and adults, people with autism are often just using the tools they know how to use. Therefore, it is likely that behavior can be improved by helping them to increase the tools they have available—to communicate, to recognize their own biological and behavioral responses, and to build an increased ability to self calm and self regulate.

Research on Aggression in Autism

A recent study of aggression in autism showed some interesting trends in terms of *risk factors*, which may give some insight into challenging behaviors overall.

- There is a much higher rate of aggression towards caregivers in autism than in the general population and in others with intellectual disabilities.
- Unlike the risk factors in a typical population, aggression was equally common in girls as boys with autism. Several other usual risk factors (lower IQ, lower parental education, less language ability) were not associated with greater risk in autism.
- The research also showed that just like in the typical population, age was a risk factor, with higher levels of aggression occurring at younger ages, which may suggest that learning and growth may help behaviors improve.
- Those children with autism at highest risk of aggression exhibited the following characteristics:
    1. More repetitive behaviors, especially self-injurious or ritualistic behaviors, or extreme resistance to change
    2. More severe autistic social impairment

These results show that core symptoms of autism are associated with the risk of aggression. Perhaps underlying conditions such as a lack of social understanding or the discomfort associated with breaking a routine might promote aggressive behavior.

What is helpful to know about behavior?

Before considering challenging behavior in isolation, it is helpful to think about human behavior in general. Some behavior is biologically driven (we eat when we are hungry) or reflexive (we cover our ears when a noise is too loud). But for the most part, *behavior occurs because it serves a function and/or produces an outcome.* Eating serves the function of satisfying hunger, and covering our ears softens the impact of the loud noise. Behavior also serves as a form of communication. Seeing someone cover his ears, even when we did not find a noise to be offensive, can communicate that he is particularly sensitive to sound.

It is critical to remember that any individual is doing the best he can do in each situation, given his skills, education, physical and emotional state, and past experiences. We classify certain behaviors as challenging because we as individuals or a society find them to be difficult to accept. It will be important for you to become a careful observer, working to understand the purpose of behaviors. Taking a step back and considering why a person might behave in a certain way is the first important step toward understanding and learning how to help. It is also essential to reducing your own frustration. In fact, it is often helpful to think of an individual's actions as a response, rather than a pre-determined or willful behavior.

However, there is a difference between understanding behaviors that we or society might not find appropriate and accepting those behaviors. For example, determining why a child needs to kick, and then developing his skills for communication should be the objective (e.g. ‘ I need a break.’), instead of allowing kicking as a form of speech. Similarly, working to understand and treat biological conditions that might cause challenging behaviors is essential.

"Sam's teacher moved to another city, so he entered his second year of high school with a familiar but less skilled instructor. Soon he was headed to the nurse's office each morning and spending first period on her bed. Clearly the new teacher had anxiety, and the school staff believed that this was being reflected in Sam's behavior and increasing his anxiety as well. Or perhaps it was task avoidance, as there were a lot of language demands in that first period social skills class. Then one morning, he actually gagged and vomited, but once he got home it was clear that Sam was not sick. Soon after, other staff noticed that he would turn his head to the side and his eyes would roll during the period immediately after lunch. We also noticed a tendency to retreat to the couch at home after dinner. That's when we consulted the gastroenterologist, and sure enough, he was diagnosed with reflux. All of these odd behaviors and the trips to the nurse's office subsided once he was treated."

– ED, mother

When thinking about your loved one with challenging behaviors, it is also important to consider his positive features and strengths. Show respect for his thoughts, feelings and the likelihood that he understands far more — or alternately, perhaps far less—than you might consider. Take care not to speak about him in his presence, for it is likely that he understands more than he is able to show. Talk to him and provide him with information, even if you are not sure that he understands what you are saying. It is important to build your child's trust in your support, and shape his motivation and purpose into more acceptable behaviors.

Function of Behavior

Whenever behavior occurs, it is important to consider its purpose, or what is most often called its function. Although some behavior is biologically driven, much behavior is learned over time and through experiences, and shaped by what happens before and after the behavior takes place. Other behaviors may have begun as biologically driven (such as scratching an itch) but may turn into something that serves a different function (perhaps scratching to gain a teacher's attention).

> *"Special educators [and parents] need to look at what a child can do instead of what he/she cannot do. There needs to be more emphasis on building up and expanding the skills a child is good at. Too often people get locked into a label such as dyslexia, ADHD, or autism, and they cannot see beyond the label. Kids that get a label often have uneven skills. They may be talented in one area and have a real deficiency in another. It is important to work on areas where a child is weak, but an emphasis on deficits should not get to the point where building the area of strength gets neglected."*
>
> *– Temple Grandin, Ph.D.*

An example of a productive behavior might be asking for something to eat, then receiving a cookie. The function of making the request is to get the cookie. For a child with limited language skills, the strategies involved in getting a cookie might look very different. But if the end result is the same, whatever the individual needed to do to be fed is the method by which he has learned to 'get a cookie.' Over time, an individual with significant communication challenges is likely to develop some creative and interesting methods for communicating—some of which might be considered challenging.

The Function of Challenging Behaviors

> *Challenging behaviors, such as aggression, disruption, or self-injury are often a chief concern of caregivers of individuals with autism and other developmental disabilities. Many of these challenging behaviors are learned and maintained by what happens immediately before and after the problem behavior. Because they are learned behaviors, problem behaviors can be modified by manipulating or changing situations in the environment, especially the events before and after the problem. In most cases, challenging behavior is seen as a way to request or communicate a preferred outcome (e.g., access to toys, food, social interaction, or cessation of unpleasant activity). Therefore, the goal is to replace the inappropriate "request" with more adaptive (appropriate and effective) communication.*
>
> *-p.13 Targeting the Big Three*

Questions you might ask about why a person is behaving in a certain way include:

- Did this behavior start suddenly? If so, might my child be sick or is there another change that might have caused this?
- Is there some underlying medical concern or condition that is making him reactive? Tired? Stressed?
- What is my child attempting to gain from this behavior? Is he trying to escape something?
- What is he trying to tell me? What can I learn from this?
- Does it happen in certain places, with specific people or in situations where he is hungry or tired? Is there something we might adjust in his surroundings that might improve the situation?

- What happens before the behavior? Is there something that makes it more likely to occur?
- What happens after the behavior occurs? What is helping this behavior persist? What maintains it or makes it work as a tool for this individual?
- What do I typically do to get my child to stop engaging in the behavior? Am I (or is someone else) giving him more attention then, or doing something that might be making the behavior work to get him what he wants?

If you can develop an idea of when or why a behavior is happening, you may realize there are simple solutions that help to improve a situation and make an undesired behavior less likely to occur.

It is also essential to remember that behavior changes, and people adapt. The same behavior that serves a specific function in one situation may serve a different purpose in another setting. In other words, one bite might be out of frustration when a child wants something he is unable to ask for. Another might occur when he is afraid and needs to get away, and yet another might be an automatic response to intense stress. And although biting is the same behavior, the reasons it happens (the function) can be very different.

Behavior generally serves one of several functions:

- Obtaining a desired object or outcome
- Escaping a task or situation
- Getting attention, either positive (praise) or negative (yelling)
- Trying to self-calm, self-regulate or feel good (*sensory input*)
- Blockingor staying away from something painful or bothersome (*sensory avoidance*)
- Responding to pain or discomfortAttempting to gain control over an environment or situation (*self-advocacy*)

Improvements can often be made by changing the situations and environment, or the things that come before and after problem behaviors occur. And since behavior is often a form of communication, teaching more adaptive and appropriate ways of communicating can often reshape problem behaviors into more appropriate requests, protests and responses.

> ***"Before I was able to express myself with my speech, the only way I knew how to escape from situations and people I didn't like was to hit and bite and run. I didn't want to hurt anyone, but I just couldn't stand being there anymore and I couldn't explain my thoughts or feelings in any other way. So many things bothered me, it was like being in intense pain. Now that I've had years of practice – first with signing and then my communication device – I can use my speech and other forms of communication to ask for a break or to move to a quiet space, instead of using aggression. Things are much better for me now."***
>
> ***– DR, a young woman with autism***

Before formal interventions are developed, it is important to consider the wide array of possible contributing factors, including the biological ones. Appropriately determining function is then essential to creating a plan that might effectively address the behavior.

For example, if a child is hitting his mom in order to get out of making his bed, putting the child in 'time out' would actually give the child what he wanted (avoiding the task), and therefore support (*reinforce*) the behavior. In this case, he would be inclined to hit again to escape. Instead, if it is determined that the child hits because the task is too difficult, making the task easier to build success might allow him to stay engaged, and eliminate the need to hit. You may want to start by helping him make the bed, but be sure that he has to finish the job correctly by putting on that last pillow.

In considering behavior, it is important to look at the individual as a whole, and to consider productive as well as challenging or *maladaptive* behaviors. It is also important to recognize that what we might consider negative behavior might have positive elements—the individual might be standing up for his wants or desires. Building appropriate self-advocacy and self-determination skills is essential. Visit the *Positive Strategies for Supporting Behavior Improvement* for more information.

People with autism often report that they find the world confusing and anxiety-producing. Many of the successful supports for increasing appropriate behavior involve creating more predictability and safety, while also building self-regulation, communication and self-determination skills. Meet your child where he is now, celebrate the things he does well, and take small, positive steps to build the skills and the trust that will make him more adapted to your family and the world around him.

Two Vital Things to Remember

By applying the principles of behavior, you will teach the individual a more appropriate way to obtain what she wants (i.e., attention, access to leisure materials, or avoiding doing a task, etc.).

- *Consistency is Vital – While function-based behavior intervention can be very effective, for it to be most successful, it must be implemented consistently at all times by the majority of people who interact with the individual.*
- *Continuation is Vital – More importantly, the behavior intervention should continue even if the challenging behavior begins to decrease, much like the way medication or diet works. Hoping for a lasting effect without continuing the changing agent (i.e., behavior treatment, medication, and diet) will only lead to frustration and failure. With consistency and adherence to the behavioral guidelines, you will see gradual change in the individual's challenging behavior.*

–Page 72 – Targeting the Big Three

Why is it Important to Do Something about Challenging Behaviors?

Easily seeing what the problem is and adjusting the situation may be simple enough to change challenging behaviors. But sometimes this is unsuccessful, in which case continued challenging behaviors may be a sign that an individual needs help. This may be a medical evaluation or a particular treatment if something is affecting his health. Or it may require some changes in the supports, skills or tools that will allow him to feel comfortable, safe, heard and validated.

Challenging behavior might reflect an individual's only way to cope with a certain difficulty at any given time. Without proper intervention, these behaviors tend to continue and may get worse, creating an increasingly challenging cycle for you and your loved one. Promoting and teaching adaptive behavior as early as possible is essential for long term growth.

"Before Lindsay had speech, we could only guess at what was causing her so much pain. It was truly awful to feel so powerless to help your own child. And when she was aggressive or hurting herself, there was no way I was going to sit back and take my time to figure out what was causing it. I had to intervene right away either by moving away from her or restraining her arms. Once we learned to see her behaviors as her form of communication, we could begin to understand the purpose behind them. Then we could really focus on strengthening the few communication skills she had. Eventually, her problem behaviors became less and less frequent as they were replaced by language."

– BK, a father

Your ability to learn the tools to address and reshape challenging behaviors as early as possible is important for the day to day quality of life for your loved one, as well as your family. Many parents make subtle adjustments to adapt to their child's behavior, but over time, they can drift into patterns that become a "new normal." This may mean they no longer take their child shopping because of his aggression in the community. They may no longer bring him to visits with family or friends because he is disruptive, and so they lose their supports and relationships. They may accept that a child is an early riser, but then 6 AM becomes 5 AM, then 4 AM, and everyone is exhausted and no one is functioning well. Over time, these subtle adjustments (sometimes called *behavioral drift*) can become difficult to change, and can accumulate to limit the child's and his family's access to many important things in life.

Challenging behaviors can have a significant impact on the individual in many ways. They can:

- Interrupt academic learning and as a result limit long term growth and development
- Limit experiences and keep a person out of many opportunities for growth over his lifespan, including play dates, mainstream classrooms, recreational options, and eventually his work options, living conditions and ability to be integrated into the community
- Cause physical decline, pain, injury, especially when aggression and self-injury are involved
- Compromise an individual's psychological state, resulting in depression, stress, anxiety, and reduced self-confidence and self-respect
- Impair social relationships, as well as long term interactions with siblings, parents and other family members
- Affect finances as a result of employability, medical and supervision expenses
- Reduce independence and choice

Challenging behaviors can have a significant impact on the family and caregivers in many ways. Effects include:

- Added stress and worry
- Social isolation as a result of the embarrassment or stigma that accompanies the maladaptive behavior
- Anxiety and/or depression for parents and siblings
- Less time and attention for other children, responsibilities or interests
- Physical danger
- Fear of harm to themselves, other family members, others or the individual himself
- Less support from other caregivers, extended family or friends due to added complexities
- Financial concerns that result from the costs of constant care and supports, damage to property, medical bills, or the necessity of a parent to stop working
- Faster staff burnout and increased turnover
- Problem behaviors that might overwhelm the family's ability to cope or intervene

It is important to address challenging behaviors for many reasons, and the sooner the better. A 25 pound toddler with reactive behavior and a fist is a challenge, but that same behavior in a teenager who weighs 175 pounds is a threat. If your child has challenging behaviors that you are not able to change, it is important to seek out professional help.

What are some Challenging Behaviors Commonly Displayed by Individuals with Autism?

Sometimes knowing more about a behavior itself, or learning the language to describe the behaviors you see to a professional, can help others to recognize the seriousness of the problem or find the right team members or approaches to understanding your concerns. The intensity, frequency and severity of behaviors will vary considerably across individuals and settings, and may change over time. For many families, the list below may seem overwhelming and well beyond the concerns you have about your child. Some of these behaviors occur only rarely and many will not describe what you see in your child. However, any of these may require you to learn new skills or perspective and can be addressed with assistance from professionals when they do occur.

Disruption occurs when an individual exhibits inappropriate behaviors that interfere with the function and flow of his surroundings. Examples include interrupting a classroom lesson, the operation of a work environment, or a parent's ability to make a meal. Behaviors might include banging, kicking or throwing objects, knocking things over, tearing things, yelling, crying, or swearing.

Elopement refers to running away and not returning to the place where a person started. In autism, elopement is often used to describe behaviors in which a person leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away.

"There was a young man who was always eloping, He would run and we could not figure out why. Unfortunately this running was both scary and dangerous. We worked to try and figure out why he was running and when we couldn't we decided to try and teach him how to ask to run. Once we opened this door up he would ask before he would run and the parent was able to tell him where he could run and sometimes she would run with him. It wasn't the perfect solution but it worked to keep him safe and that was the best we could do at the time and it worked".

– Behavioral Consultant

Incontinence is the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper. Sometimes there is an underlying physical concern that might need treatment or incomplete toilet training that may need additional teaching. For some individuals, it may be a sign that there is difficulty recognizing body signals before it is too late. Sometimes an individual learns to use 'peeing his pants' or urinating on the floor as a means of gaining attention or escaping an undesirable task or situation.

Non-compliance is used to describe when an individual does not or refuses to follow the directions, rules or wishes of someone else. Non-compliance can be passive, such as not following a direction, or active, such as whining/crying, becoming aggressive or self-injurious. It is helpful to remember that non-compliance can be purposeful, but at times can also result from lack of understanding, lack of motivation, fatigue, or poor organizational or motor planning issues.

Obsessions, compulsions, and rituals are often strong, irresistible urges that can result in difficulty with a person's ability to cooperate, to manage change or to be flexible and adjust. The compulsion involved in obsessions and rituals can often lead to additional challenging behaviors if they are interrupted or forbidden.

- An *obsession* is when a person's thoughts or feelings are dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators.
- A *compulsion* is the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table.
- A *ritual* is used to describe a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle in to sleep.

Physical aggression is an act of force that may cause harm to another person, and might include hitting, biting, grabbing, hair pulling, slapping, kicking, pinching, scratching, pulling, pushing, head butting, or throwing things.

Property destruction includes behavior in which belongings or property are harmed, ruined or destroyed and might include breaking, throwing, scratching, tearing, defacing, etc. belongings (his or those belonging to others).

Self-injury is the attempt or act of causing harm to a person's own body severe enough to cause damage. Self injury can present in a wide range of behaviors including head banging, hand-to-head banging, body slamming, hitting or punching oneself, eyeball pressing, biting oneself, wound picking, and hair pulling. Self mutilation such as cutting one's skin, burning, or bone breaking, is less common in autism unless other psychiatric conditions co-occur.

Sexual inappropriateness can take many forms in autism, and might be described as a lack of sexual inhibition or 'acting out' behavior. Lack of impulse control and poor social understanding might result in acting on sexual impulses that others know to keep private, such as sexual advances (propositions), sexual touching, promiscuity, exposing one's genitals, masturbating in public, sexual talk, obscene phones calls or voyeurism (watching others in private situations). Depending on the severity and the circumstances, sexual inappropriateness may lead to, or be considered, sexual aggression.

Threatening behavior includes physical actions that do not involve injury or actual contact with another person (such as holding up a knife), or stated or written threats to people or property.

Tantrum or meltdown describes an emotional outburst that might involve crying, screaming, yelling and stubborn or defiant behavior. The person might lose control of his physical state, and may have difficulty calming down even if the desired outcome has been achieved.

Verbal aggression generally involves the use of threats, bullying tactics, negative language, ultimatums and other destructive forms of communication.

Less Common Challenging Behaviors

Fecal digging occurs when an individual puts his fingers into his rectum (backside). Fecal smearing and handling of feces (poop) occurs when feces are spread on property or the individual himself. Each of these might be rooted in medical causes such as skin or digestive tract concerns, or may be learned behaviors that serve a purpose such as access to attention or escape from unpleasant situations.

Food refusal occurs when a person refuses to eat anything at all.

Pica is an eating disorder that involves eating things that are not food. Some individuals with autism and other developmental disabilities eat items such as dirt, clay, chalk or paint chips. Pica can also occur when a body craves certain nutrients or minerals that are lacking in the diet/body, as sometimes occurs in women during pregnancy.

Rumination describes the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again or spitting it out. Rumination often seems to be triggered by reflux or other gastrointestinal concerns.

Purposeful or self-induced vomiting is throwing up on purpose. Contributing factors such as reflux, hyper gag reflexes and eating disorders (*bulimia*) should be considered.

It is important to repeat that while these behaviors might all be challenging, they should not be assumed to be purely behavioral, or purposeful. As discussed earlier, they are often learned responses. Sometimes there is a biological root or trigger that might require investigation or treatment in order to help the individual get to a more comfortable place where he might be able to learn adaptive skills. Even if treatment is not immediately effective, sometimes just knowing of a medical or neurological cause of a behavior can change how you think about it and how you respond.

Resources:

- *Asperger's Syndrome: Meltdowns;* IAN Community,
  http://www.iancommunity.org/cs/about_asds/aspergers_syndrome_meltdowns
- *Autism Solutions, How To Create a Healthy And Meaningful Life For Your Child*,
  Ricki Robinson, MD, MPH
  http://www.drrickirobinson.com/
- *Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting*
  by Helen Yoo, Ph.D, New York State Institute for Basic Research
  Autism Speaks Family Services Community Grant recipient
  http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf
- *The Autism Revolution*, Martha Herbert
  http://www.marthaherbert.org/

Who Can Help?
What is this Idea of a Team?

Individuals with autism are often quite complex, so it is helpful to take a broad approach when evaluating concerns, and deciding how to provide appropriate support. In order to meet their various needs, many individuals with autism, especially those with challenging behaviors, need a team to develop specialized and individualized care.

Team Members to Consider

Depending on the placement, circumstances, services, supports and concerns surrounding your loved one with challenging behaviors, the team might include the individuals and professionals from the disciplines outlined below. The actual mix of professionals and titles will vary across situations, but for most people it will be important to have someone in each of the roles described, either as an ongoing advisor, or as a consultant at some point.

- *Individual with Autism:* To maintain a person-centered approach and treat your loved one with dignity and respect, it is essential to include his voice at the table. Keep his wellbeing in the forefront of your mind as you plan and program as a team. Seek his perspective on the behaviors that are concerning, and why they take place. With some kids, it might help to ask, *'Why do you need to do this? How can we help?'* Wherever possible, involve him in the decision-making. Some individuals will have strong preferences that can greatly affect outcomes.

  Even if it seems that your child is not able to understand what you are saying, let alone make decisions about his care, talking to him directly might deliver more information and generate more understanding than you might expect. In addition, a person who does not respond verbally can deliver a great deal of information about his comfort, preferences and dislikes through his behavior. Involving him in the treatment process can help to build his social skills, self-advocacy skills, and independence. Remember to be sensitive to talking about him in his presence, as it is possible that he understands more than he can show.

Below is an excerpt from A Full Life with Autism, from the perspective of Jeremy, a young man with autism who learned to type to communicate:

"I have often times been the victim of ignorance. I think you have to be brave to get over the horrible times people hurt you by talking like you don't understand the comments they are making about you within earshot. I don't think people realize the kind of effect they have on nonverbal people. You know that intentional abuse is unforgiveable, but in some cases ignorance is just as painful. I remember when I was in junior high the occupational therapist told the teacher I would never learn and she did not understand why I was in mainstream classes ….. I was so upset because even though I could not talk or type, I could listen and learn. I wanted to die."

From A Full Life with Autism by Chantal Sicile-Kira and Jeremy Sicile-Kira. Copyright © 2012 by the authors and reprinted by permission of Palgrave Macmillan, a division of Macmillan Publishers Ltd.

- *Parent(s):* You are the key informant and advocate and an absolutely essential member of the treatment team. Outcomes are better with family involvement. No one knows your loved one, his history or the dynamics of your beliefs and your household the way you do. You might need to tell a story or give an example to fully describe the situations you find difficult or the needs you might see in your child.

  Be prepared to ask questions, raise your concerns and preferences, and ask for help. Effective communication across the team is essential, and in many cases you may be the one facilitating the sharing of information. Take notes, but also request information, suggestions and treatment plans in writing, since afterwards it may be hard to recall what was said. Ask for referrals to additional resources and share concerns about time and financial abilities. Ask for training and where else you might find help.

  If you are asked to do something you cannot do because it is too expensive, too difficult, or you don't understand the objective, speak up and ask for other ideas.

  You are likely to fall into a role as the team leader or coordinator, but if this is too much for you to take on, there might be help. Look into finding a case manager (see below), *special needs parent advocate*, family member or friend. Ask for suggestions from a primary care provider. Ask someone to accompany you to medical or specialist appointments to take notes and help you understand the choices and information being presented. You do not need to do this alone, but you may need to seek out and advocate for the level of supports that your family needs.

"When my daughter was moving from 1st grade to a new school, I created a 3-ring binder notebook with plastic inserts and dividers. In each plastic insert, I placed sheets of her school work both good and bad to show her growth. I included artwork, certificates and added a picture to the front. Almost just as important, I included information from her Medical Home and all of the other care providers on her team. This gave each team member and everyone who saw it, the full scope of who my daughter was. That notebook gave me the tools I needed to be the best Team Leader for my daughter. Not to mention, it helped me effectively communicate with our entire team. I still update and use this notebook method for everything from IEPs to Summer Camps...it works!!" - KD, parent

- *Case Manager:* Depending on the age or placement of your loved one, this might be a school case manager, or a representative from a service agency, such as a regional center (in California) or your state's Division of Developmental Disabilities or Department of Child and Family Services. Ideally, this person should be your direct contact, and should be helping to gather resources, team members and ideas. The effectiveness, skill set and time availability of a case manager will vary considerably due to many factors, and in some circumstances, you may not have one. You may have to advocate strongly in order for the case manager to understand the level of your concerns. If you do not have a case manager, sometimes a friend or family member can help you to research, track and organize the body of information that comes with the challenges of your loved one.

- *Medical Professional:* If you do not yet have one, try to build a 'medical home'—a relationship with a doctor who knows your child, and who you know and trust. Involve your primary doctor in evaluations, as he should be able to help when considering medical triggers for behavioral concerns. If your provider does not have a lot of experience in autism, it might help to share the list of Things to Consider in the next section and work through the possibilities together. Your doctor might refer you to specialists in areas of concern, and may be helpful in finding some of the other team members or therapists in the roles described below.

- Among others, referrals to specialists might include:
- hearing assessments (*audiologist*)
- vision evaluation (*ophthalmologist or optometrist*)
- stomach or digestive tract concerns (*gastroenterologist*)
- diet or nutrition issues (*nutritionist*)
- allergies (*allergist*)
- immune concerns (*immunologist*)

Just because an individual has autism, it does not mean that he is exempt from any of the other health concerns that affect any of us.

Sometimes doctors try to consider symptoms and signs, relate them back to what they know about autism and write off anything difficult to interpret as behavior. This is especially difficult if your loved one has limited language and cannot describe pain or perception issues. You might have to advocate in order to keep the focus on the individual and your concerns. Just because a broken leg is not associated with autism in the research literature, doesn't mean your child who just fell out of a tree does not have one!

In some states, you might have access to an Autism Treatment Network site, where the medical concerns associated with autism are being researched and treated according to collaboratively developed protocols with teams who specialize in autism treatment.

Is your loved one an adult or approaching adulthood?

It is important to note that while pediatricians are becoming increasingly aware of some of the issues related to autism, individuals on the spectrum are still relatively rare and novel in the world of adult medicine. Sometimes individuals with developmental disabilities stay in pediatric care far beyond childhood. If a switch to an adult provider is necessary, try to facilitate a transition of medical records as well as conversations with the pediatric caregiver. You may want to pass along this introduction for internists: 'Gently does it,' caring for adults with autism, from the American College of Physicians.

If you find your loved one in the care of an adult doctor new to autism, you may need to share the information and resources provided in this tool kit, or additional general background information such as Your Next Patient Has Autism….

- *Behavioral Health Provider* or *Behavior Analyst:* A team member who is trained in behaviorally based evaluations and interventions is often instrumental in understanding your child's challenging behaviors and developing supports and strategies. This might be a school *psychologist*, general psychologist, *Board Certified Behavior Analyst* (BCBA) or other behaviorally trained provider. These providers will use the elements of *Applied Behavior Analysis* (ABA) in supporting your loved one.

  ABA techniques involve controlling factors in the environment and monitoring interactions prior to a behavior (antecedents) and responses after a behavior (consequences). These techniques, including using positive reinforcement, are powerful in shaping behavior in individuals with autism. For more information, see the ATN Applied Behavior Analysis: A Parent's Guide and tips on Partnering with your Child's ABA Instructor.

"I honestly do not know where my son, Tyson, would be today without ABA. I am a true believer, although it was definitely not easy in the beginning. I hadn't realized how much work it was going to be for me and my wife, not to mention for our BCBA, but it was well worth it in the end. We basically started breaking down every task in Tyson's life into very small, manageable steps, and we rewarded him for even his 'smallest' successes. Then the BCBA would have us systematically raise the bar as he did more and more independently. I can say that Tyson is in an inclusive middle school today (with lots of accommodations) because ABA therapy helped him learn how to do almost everything from looking, listening, and sitting in his chair."

– HK, a father

- *Educator/Job Coach/Habilitator:* If your child is under the age of 21, it is likely that he is in a school based program with a teacher. Once he reaches adulthood, instruction is more likely to come through a habilitator or staff member at a day program, or a job coach. In both instances, finding a lead educator with autism experience and background in behavioral interventions will likely be helpful. Schools will require credentials on a state-by-state basis, but there is very little licensing or required training for adult service providers in most states.

- *Mental Health Provider:* Consideration of emotional and mental health concerns, as well as training and supports for the individual and the family, can come from a psychologist, school psychologist, psychiatrist, social worker, or community mental health worker.

- *Speech Pathologist or Speech Language Pathologist (SLP):* A trained speech specialist can evaluate an individual's ability to understand language as well as produce speech. These specialists are trained to see subtle concerns that might reflect communication deficits that an individual might find frustrating., A speech professional can also be invaluable in developing *functional communication* skills.

  Sometimes schools or agencies will resist providing speech services for a person who is non-verbal. But it is the development of communication systems (e.g. use of gestures and visuals, *picture exchange systems (PECS)*, sign language, *voice output technology*), not the pronunciation of sounds, that is the target for many speech therapy interventions in autism. Be persistent!

- *Occupational Therapist (OT):* An occupational therapist can help to evaluate concerns with fine motor issues, as well as the sensory and stimulation differences. Many OTs have also been trained in interventions and coping strategies to help make individuals feel more comfortable in their surroundings.

Physical therapists (PT), who generally work on large motor tasks and functions, may also be trained in related techniques. Both OTs and PTs can be instrumental in developing effective exercise programming.

Each of these team members might bring a different view of the same person to the table, providing perspective and expertise in understanding and creating systems of support. It is up to the parent, hopefully with the support of another key team member such as the case manager or doctor, to weigh and prioritize the input from these team members. A combined approach from the team should help to address physical, mental and learning concerns, and create a positive support plan for addressing challenging behaviors and helping you help your loved one with autism to grow and adapt.

Things to Look For in Your Child's Team (and Questions You Might Ask)

It might be helpful if you first go through the list of questions included below so that you have a sense of your own expectations and perspectives and can find a good match. Also keep it mind that certain personalities and styles will fit you or your child better than others.

- *Person-centered approach:* Professionals who think of your child as a person first—not the disability or the behaviors—will be the most helpful in discovering his strengths and his challenges. A person-centered approach will allow your team to find the tools and strategies that will be most helpful to him as an individual and to you as a family. A family-centered approach is also important, so it is essential to consider the values, priorities and specific needs of your family.
    - *What do you see about my child that you think is meaningful? Helpful? Different?*
    - *What are his strengths? What can you see of his preferences and fears?*
    - *This concern is as much about the questions the provider asks you, as it is about how he answers your questions. Does he try to understand your loved one, family dynamics, priorities, strengths, confounding factors, etc?*
- *Collaborative:* The challenging behaviors that might develop from a variety of factors will require many points of view. There may be a need for multiple providers or even multiple agencies, and the team will need to work together on the person's behalf. Collaboration also requires good communication between the members of the team. Some parents carry a notebook, an informational sheet and even makeshift brochures regarding their child to share with other team members.
    - *How do we communicate as a team?*
    - *What information can you give me to share with other team members?*
    - *How have you worked collaboratively in the past?*

"I have to say, we were lucky enough from the beginning to have assembled a group of fine people who had the very best intentions of helping my son Eli. But a few months into his preschool year, after Eli's progress seemed to have stalled, the school psychologist realized that we were not communicating well enough with each other. We were a patchwork team in which one hand hardly knew what the other one was doing. Once we started holding monthly

team meetings at the school where we could coordinate what each person found helpful, Eli really started to make a lot of progress. Keeping a daily communication book in his backpack (and now an email chain) was terrific because it kept us all in the loop and it was a way to document everyone's ideas." – SW, a mother

- *Broad thinking approach:* Given the complexities and variability associated with autism, it is critical that team members think about all of the possible driving and complicating factors that might influence an individual's behavior. (See Things to Consider) Especially when a challenging behavior is new or has dramatically increased, medical issues should be considered early in the evaluation process.
  - *What do you know about other interventions?*
  - *Do you have any suggestions for other team members with ____ expertise who might be helpful?*
  - *Do you think _____ might reflect something physical or emotional? Is there something else we should be considering?*
- *Experience with Autism:* Especially when it comes to challenging behaviors, it is important to try to connect with providers who are experienced with autism. For example, a doctor who understands that a minimally verbal child cannot report pain may have developed other ways of gathering information about possible concerns. A psychologist who understands that sensory issues may cause a child to be more anxious in certain situations may utilize a different approach to evaluation. You can learn about the provider's experience by asking at his office, or by connecting with school or agency staff, other parents, or local support groups for suggestions and recommendations.
  - *What is your experience in working with individuals with autism? This age group? This type of challenging behavior? This intervention plan?*
- *Commitment to evidence-based interventions:* Team members should focus on medications, interventions and programming that research has shown to be effective. However, it is important to remember that each individual should be treated as such. An intervention that has been validated in a diagnosed co-occurring condition, such as depression, should not be tossed aside just because it has not been established as a treatment in autism.

  The team should treat the person and the presenting symptoms, not the 'autism.'

  In addition, the field of autism is evolving, and for many interventions the research has not been done. A lack of research may not mean a lack of effect or relevance to your child's situation. Consult other team members to help you assess suggestions, but also know that you might not all agree. You should work within your team to weigh risks and benefits. For more on autism best practices, see the National Autism Center's A Parent's Guide to Evidence-Based Practice and Autism and the National Professional Development Center on Autism Spectrum Disorders.
  - *What does the research say about the use of this intervention for ____? What other information is available?*

- *Professional judgment:* While research studies show the general effects of an intervention across a population, an evaluation of effectiveness should take place for interventions used with any specific person. Assessing effects requires set targets, goals and protocols, as well as a plan for collecting and analyzing data. Data analysis is important so that you know what is working, and when and if alternate treatment choices should be considered.
  - *What is the target behavior of this intervention?*
  - *How will we know if it is working? What are we tracking?*
  - *What are the side effects?*
  - *What is our role in the intervention?*
- *Responsiveness:* Providers should give you as much information as you need to understand the intervention and your role in it. They should listen to your concerns and priorities—cultural, familial, financial, etc.—and be able to adjust interventions to make them work for your family, the team, and the individual's needs. Voice your concerns and challenges so the providers can best support you and your loved one.
  - *What is my role in this plan or intervention?*
  - *How can we adjust _____ to take into consideration our family's needs? My travel schedule? Our insurance plan?*
  - *This is too hard. Data reflects that it is not working. This medication is making him worse. What do we do now?*
- *Licensing, board certification or other credentials:* It might be helpful to request references and talk to others who have used a provider you are considering. A list of certification and credentials required for the team members above is listed below:
  - *Occupation Therapist/Physical/Speech Therapists:*
    OT/PT/SLT State Certification Required (available online)
    National Board for Certifying Occupational Therapy (voluntary certification)
    American Speech-Language-Hearing Association (voluntary certification)
  - *Mental Health Provider:*
    Psychologist License: State Licensing Board (available online)
    Psychologist Certification: American Board of Professional Psychology or
    National Association of School Psychologists
    Clinical Social Worker: State license or certification (available online)
  - *Behavioral Health Provider:*
    Certification, required for BCBA designation, but not required to use ABA:
    Behavior Analyst Certification Board
  - *Medical Professional:*
    License: United States Medical Licensing Examination
    Certification required: American Board of Medical Specialties or American Osteopathic Association

How and Where to Find a Team

For school age children, many of these providers will be available through your school (ask your child's teacher or *Individualized Education Plan (IEP)* team case manager), or by referral from your school team or your doctor. Schools are required under the *Individuals with Disabilities Employment Act (IDEA)* to use *Functional Behavior Assessment (FBA)*, and then to support the learning of a child in school using a *Behavior Improvement Plan (BIP)* when necessary. Further information is available here and here.

Additional case management and referral ideas might come through your state disability agency, county offices, or social services agencies. Often there are printed resource directories or you might search online for your state's agency for developmental disabilities. Check phone books and county websites for government offices that might lead to the right agency. You may need to call several numbers to find out how to get to the right place for what you need. This may be quite frustrating, but be persistent! Public health departments, offices of children and family services, disability services or developmental disabilities may be helpful; sometimes their work is subcontracted to other organizations such as Easter Seals or United Cerebral Palsy, or groups that only exist in your state or city. The Autism Speaks Resource Guide also contains state information by age.

"Each time we saw a new doctor or therapist, or my daughter joined a new group or activity, I became increasingly overwhelmed. I oftentimes found myself just staring at papers and numbers and not knowing where to start. A friend of mine, whose child is also on the spectrum, suggested I reach out to a case manager to help me sort through everything. I wanted to think I could do this all on my own but decided to call. After an hour-long meeting with a case manager at a local organization I felt much better. There's still so much to do but I feel like I have a clear path to get there now."
– MM, a parent

Some states have *wraparound* programs, designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities. In autism, wraparound services can sometimes fund behavioral programming. You can find a Board Certified Behavior Analyst (BCBA) here.

For adults, referrals might come through an existing service provider, medical home or *Medicaid* case manager. Contacting the county or state agencies will be similar to what is described above, but different agencies may be involved in care for adults.

It is important to note that your primary or initial contacts may not have the necessary time or specific skills necessary to fulfill the needs of your child, his evaluation, or ongoing supports and interventions. You may need to ask for additional referrals and supports. Keep asking.

Contacting other parents, often through your child's school, program or local autism support groups, might reveal additional suggestions and resources, especially for providers who are already working in the field of autism. Attend conferences, lectures, or fundraising events such as Walk Now for Autism Speaks. Even if you don't have time for the lectures or the event itself, take a pass through the vendor tables that are often set up just outside to meet area providers who might be able to help.

To access supports or resources specific to your state, please consult the Autism Speaks Resource Guide. If you have found providers that have been helpful, please submit them to the database here.

Funding Sources

Even if you have an experienced professional team assembled, paying for the additional services and supports can be yet another hurdle. Services provided by the school under the stipulations of IDEA are required to be free and appropriate. That means you do not need to pay, and if the school does not have the necessary skills or staff to meet your child's needs, it is their responsibility to pay for the services required to do so. It may require significant advocacy to get them to do what the law requires. More information on your rights under IDEA can be found here.

Ask your Human Resources officer about benefits, or check with your insurance company. Contact the public health department to learn about community plans such as those for mental health or those targeted to children. Funding for medical needs is often covered through health insurance and/or Medicaid. Speech and occupational therapists, as well as medical specialists, are often covered under medical plans. Historically, some of these benefits were specifically denied for autism and developmental disabilities, but as autism has become more common and research and advocacy efforts have increased, coverage for these items is improving.

Some states have mental health parity laws, which indicate that mental health care has to be covered to the same degree as physical health issues. Some insurance plans also have stipulations for behavioral health supports and interventions, and Medicaid programs provide *wrap around* services for behavioral interventions. It may take some significant investigation through your Human Resources department, your insurance company or the Medicaid office to find out the details of the mental or behavioral health coverage available. You may find assistance through your primary care provider or a case manager.

Military families are covered by *TRICARE*, the military healthcare program, which provides for limited ABA coverage for certain beneficiaries under the TRICARE Extended Care Health Option (commonly referred to as the ECHO program). Learn more about TRICARE eligibility criteria here.

Autism insurance legislation is in the process of being enacted state by state, with various terms regarding implementation and coverage. More than 30 states have passed autism insurance laws; they are listed on the National Conference of State Legislatures website. It is advisable to investigate and understand your coverage so that you know what to expect before beginning services. To find out the status of specific laws for insurance coverage for autism services in your state, visit the Autism Speaks Autism Votes website and select your state.

Certain state agencies can also provide funding for *respite*, which is helpful in giving you a chance to catch your breath. These agencies, such as Departments or Divisions of Developmental Disabilities or Children and Family Services may have programs, supports or suggestions of resources.

Sources/Resources:

Behavior Analyst Certification Board, Inc. (BACB)
http://www.bacb.com/

'Gently does it,' caring for adults with autism
http://www.acpinternist.org/archives/2008/11/autism.htm#sb3

National Autism Center's *A Parent's Guide to Evidence-Based Practice and Autism*
http://www.nationalautismcenter.org/learning/parent_manual.php

National Conference of State Legislatures (autism insurance information)
http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx

National Professional Development Center on Autism Spectrum Disorders
http://autismpdc.fpg.unc.edu/

Special Needs Parent Advocate
www.specialneedsadvocate.com

Wrightslaw (special education and disabilities legal information)
www.Wrightslaw.com

US Bureau of Labor Statistics *Occupational Outlook Handbook*
(Information on practitioner training and qualifications)
www.bls.gov/OCO/

Your Next Patient Has Autism…
http://www.northshorelij.com/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1247088820137&ssbinary=true

What are the Things to Consider?

When trying to understand what might be contributing to challenging behaviors in any person at a certain point in time, the team needs to utilize a broad approach. Thoughtful consideration must be given to the various issues that might be resulting in the individual's actions. You may want to have your providers explore possible medical and mental health factors (also referred to as applying the principles of *differential diagnosis*). In this way, they can better evaluate what might set up, trigger, or maintain the behavior.

Some of these concerns might be quite obvious. For example, you would expect pain if a child has a visibly broken arm. However, other issues might require the skills of an expert who knows what subtle signs to look for, such as staring spells that might suggest seizure activity, certain behaviors that might suggest belly discomfort, or patterns that suggest an additional mental health concern.

"Until age 9, generally I lived in my own world relating to things, shiny coins, marbles and sparkly objects that I collected and hid in a secret place. I focused intently on these objects, lining them up over and over in patterns only I understood. If anyone disturbed them I had a tantrum, a meltdown, banging my head against the floor or wall for fifteen minutes. Nothing seemed to assuage my rage, it seemed to run a predictable course. I pulled my hair, picked at my skin and bit my arms. When it was over I was very thirsty and tired. Often, I returned to my activity to repair the interruption. My world was a house of cards, any breeze could collapse it.

I was an escape artist. I ran wildly, arms flailing until I became too winded to continue. Then I fell down, rolled onto my back and stared at the sky. I usually fell asleep. I believe that I had seizures.

I played with others if I could lead, and control the activities. If not, I left without a word. I seldom fought with other kids, except my bossy older sister who felt responsible for me. I didn't have a connection to people until I was in grade school.

High School and College I succeeded academically and socially pursuing artistic interests. I had many casual friends, none were close."

– Ruth Elaine Hane,*
a married woman with High Functioning Autism

**To read more about Mrs. Hane, please refer to Appendix 1 at the end of this section.*

It might be helpful to know that in general, people with developmental disabilities (including autism) are more likely to receive inadequate or inappropriate medical treatment. They receive fewer routine physical examinations, less preventative dental care and less mental health care than other Americans. People with communication issues are at greater risk of poor nutrition, overmedication, injury, neglect and abuse. There are likely multiple factors involved in these statistics, but certainly it is harder to care for someone who does not reliably say 'This hurts,' or 'Hey mom, why can't I see the blackboard at school?' Often, it is the parent's ability to be a watchful observer and careful reporter, combined with the skilled listening and evaluation of an experienced provider, that brings the necessary factors of a person with autism's health and other factors into consideration.

The following chart lists areas of potential consideration for the professionals on your team, and the types of questions you might ask in each area. This list is not complete, but hopefully it will support you and your team in considering topics that might be relevant with respect to your loved one and his concerns. If this list suggests an area that a provider is not investigating, be sure to bring it up. Know that you may have to be persistent or consult with other team members for each of your concerns to get the attention your loved one deserves.

Things to Consider

Possible Cause	Potential Areas of Focus	Questions to ask
Medical	Pain e.g. ear infection? Toothache?	Could this person be in pain?
	Seizure	Could this be seizure related?
	Sedation / Poly pharmacy (multiple medications)	Is this individual sedated? Is he on too many medications? Is he on the wrong medications or dose?
	Insomnia/Inadequate sleep	Does the person get enough sleep?
	Allergies	Are there seasonal, food or environmental allergies involved?
	GI Issues/Nutrition	Is behavior related to meal times or food? Has there been a change or concern about bowel habits?
	Dental concerns	When was the last dental exam? Is there tooth pain?
	Vision/Hearing	Is there a change in or problem with perception?
Genetic	Fragile X, Down Syndrome, etc.	Could this behavior be related to an undiagnosed genetic syndrome?
Mental health	Co-occurring mental illness	Could he be experiencing anxiety, depression, ADHD? OCD?
Cognitive	Intellectual ability/ Processing abilities	Are the demands on the individual too high or low for his cognitive level?
Communication	Adequacy of communication system	Does this person have a functional communication system? Does he use it spontaneously (without prompt)?
Sensory Dys-regulation	Unmet or overwhelming sensory factors	Is the behavior supplying sensory input/ attempting to meet sensory needs?
	Sensory defensiveness	Is the behavior in response to sensory overload? Are there big responses to things in the environment? (Loud noises, etc.)
Environmental factors	Location, time of day, setting, activity	Is he too exhausted at the end of the day to handle this demand? Why is he okay at other doctors' offices, but not here? Is this task beyond his motor ability?
Environmental reinforcement of behavior	Family/ Staff / Educator / Caregiver responses to behavior	Is the behavior responded to with attention? Removal of a request? Other?
Family / Staff dynamics	Changes in family environment	Have we had losses/changes in our family?
	Changes in staffing	Has a favored staff member left? Are new staff members adequately trained? Is there a shift in schedules/patterns?

Adapted from: *"Psychopharmacology of Autism Spectrum Disorders: Evidence and Practice,"* in press, Child and Adolescent Psychiatry Clinics of North America, 2012, Matthew Siegel, M.D.

Physical Concerns

As the previous chart outlines, there are many potential physical causes of and medical contributors to behavior. Gathering information about pain and symptoms can be especially difficult in individuals with autism due to communication difficulties, variable responses to sensory input and pain and even in those with good verbal ability, a lack of self-awareness.

It is also important for the team to know about medical concerns that often accompany autism, or more specifically, challenging behaviors. Addressing these less obvious concerns can often change behaviors. The most recognized of these include the following:

- *Seizure disorder* or epilepsy occurs in as many as a quarter of individuals with autism. Spotting seizures is sometimes tricky, since some seizures might occur at night but leave daytime effects, and others can appear in milder forms such as *staring spells* or times of 'spacing out.' Sometimes the after effects of a seizure can leave the person lethargic or reactive. You can find resources related to epilepsy here.
- *Gastrointestinal complaints or digestive disorders* such as reflux, stomachache, constipation, bowel pain, and diarrhea are often reported in autism. Investigation can be difficult in light of language challenges, but treatment has been shown to improve comfort and increase access to learning environments. See Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.
- *Sleep disorders or disturbances* such as difficulty falling asleep, insomnia, *sleep apnea* (disrupted breathing), and night waking are often reported in autism. Sleep is always an important consideration, both for the individual and the caregiver. Sleep is essential for physical as well as psychological restoration. It is hard to remain calm and keep perspective when you are exhausted, so evaluating and treating sleep concerns is essential. See the ATN Sleep Strategies Guide.
- *Sensory issues* are important to consider, since many individuals with autism respond to sensory input in an altered way. Sounds are louder, lights are brighter, words and visuals cannot be taken in at the same time, and the world is hurtful or confusing. It is also important to remember to assess sensory input. Have your child's eye sight and hearing checked? Make sure the doctor uses the right tests, since these concerns can be a challenge to evaluate in people with autism. In addition, these issues can change over time. Any of these factors might change a person's reactivity and promote a behavioral response.
- *Allergies, immune dysfunction, or autoimmune conditions* may show behavioral features that vary with exposure. Seasonal or *food allergies* or *intolerances* only occur at certain times of year, or when a particular food is eaten. Some food intolerances cause discomfort but not obvious rashes or breathing concerns, and may be difficult to identify. Immune activation such as eczema, joint pain or other conditions can cause a chronic discomfort that goes unnoticed.
- *Headaches or migraines* can result in a person with autism walking around with pain that you or I might readily fix with an over the counter pain killer. The inability to report pain—or even in more verbal individuals to identify pain in a certain place—can lead to discomfort that results in challenging behavior.
- *Genetic disorders* are associated with autism, and some can be accompanied by additional challenges that are worthy of medical consideration. Sometimes knowing about genetic differences can help you be more aware of other associated conditions, such as seizures.

Reflections on my childhood:

"I had terrible belly pain, and I did not know what to do about it. So I would run. I ran for miles just to try to get away from the pain. Of course, it was a small town and everyone knew me, so eventually I would end up back at home."

- RT, adult with autism

Other medical conditions have been noted in individuals with autism that may cause significant changes in behavior. These concerns may not immediately come to mind for your medical provider. But there is growing awareness of and investigation into the role they may play in autism, and sometimes in the appearance of challenging behaviors.

- *Whole body condition* is important to consider as autism is being increasingly recognized as a condition of the body, not just the brain. Many of the associations discussed above highlight the idea that there is likely more going on physically than was once thought. Insights into nutrition and various body processes might be worth considering.
- *Missed infections*, such as Lyme's Disease, PANDAS, an ear infection, an ongoing upper respiratory infection that harbors strep, or other low grade infections might cause immune activation but perhaps not obvious signs like a fever. Sometimes, there are effects on the nervous system as well as physical results of these infections. A doctor might check blood samples to look for titers (evidence of infection in the immune system) if behavior changes, such as extreme lethargy, tics, or a sudden onset of obsessions take place.
- *Catatonia* might be worth investigation if there is behavioral regression and significant changes in *motor* function (the ability to move, or to control one's movements). With catatonia, an individual may appear to hesitate, develop strange body postures, limit eating, and develop odd movements and tremors. Behaviors can appear such as self injury and aggression as a result of the individual's lack of motor control. Though it is not well recognized in the U.S., catatonia has been shown to develop in a significant number of teenagers and young adults with autism in studies in the UK as discussed in *Catatonia in autism* and may be worthy of consideration if these symptoms sound familiar.
- *Changing hormones* and the onset of *puberty* can make a typical child seem like a stranger, and these same effects can occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. It is important to consider whether some of the behavioral features you are seeing are a natural, developmentally appropriate strive towards greater independence. If so, you should consider allowing additional choices and other proactive strategies (described in the next section) that will address this need. In addition, statistics show that individuals with developmental disabilities are at greater risk of abuse, including sexual abuse. The team should give consideration to this as a potential factor in sudden challenging behaviors. You can learn more by visiting the Autism Speaks Safety Project website.

Although it is not specific to autism, the chart of *"Common" behavior problems and speculations about their causes* might trigger some thoughts of additional considerations in your child (please see Appendices 2 & 3).

For some children, evaluations may have been skipped or avoided because of difficulty or fear of the procedures themselves. If anxiety about procedures affects the ability of your medical or dental team to evaluate your child, these tool kits, which were created by the *Autism Treatment Network (ATN)* might be helpful to you or your providers:

- Blood Draw Tool Kit
- Dental Tool Kit for Families
- Dental Tool Kit for Professionals

Mental Health Considerations

Studies of individuals on the autism spectrum show frequent overlap with symptoms that meet diagnostic criteria for other mental health conditions. This is a difficult area and interpretation often varies by provider, since many of the features of autism also occur in other named disorders and there is no distinct line. For instance, various providers might use different criteria in distinguishing between the repetitive behaviors of autism and a diagnosis of obsessive-compulsive disorder.

Sometimes the features of *depression*, *anxiety*, *ADHD*, *obsessive compulsive disorder*, *Tourette's Syndrome*, *bipolar disorder* or *schizophrenia* are significant enough that they stand on their own as worthy of specific diagnosis and treatment. When a person has two or more diagnosed conditions, this is called a *co-morbid condition* or *dual diagnosis*. Challenging behaviors are common in individuals with dual diagnoses, and it may be that another mental health concern has not yet been diagnosed or considered.

Statistics for dual diagnosis in individuals on the 'higher functioning' end of the spectrum or with Asperger's Syndrome are high. This might be because they are better able to report concerns. It may be that the combination of the social aspects of autism and the effects of the co-morbid condition combine to cause challenges that drive them to evaluation, services and hopefully, treatment. More information is available through the National Association of Dual Diagnosis (NADD).

The role of the mental health provider might include differential diagnosis, medications, therapy and/or *cognitive behavior* interventions, as well as partnership with other team members. It might be important for a mental health provider to educate the team about the features of a dual diagnosis, so that, for example, the uncontrollable tics of *Tourette's* might be considered and treated as something different from *behavioral stereotypy*. A mental health provider might ask questions about the behavior, as well as changes in behavior that might reveal new circumstances or areas of concern such as depression, anxiety, *post-traumatic stress*, or *psychosis*.

It is important to note that mental health disorders and symptoms should not be considered purely psychological. There are biological factors that can drive anxiety, anger, tics and other behaviors. Just as it may be impossible to know when a seizure is coming, the biological triggers for some of these symptoms in some individuals, and the resulting behaviors, can be unpredictable. If this is the case, your mental health provider should help you understand this situation better and may be able to help. Together with your behavioral/educational team, you may be able to determine subtle signs that your child is headed towards a surge and then develop approaches that will minimize its effects.

Recent research has shown preliminary evidence of *biomarkers* of depression in teenagers. A biomarker is a sign of an objective, measurable biological state. For many, the presence of a biomarker makes something 'real', like high cholesterol or an infection with a specific virus. In contrast, autism and most mental health concerns are diagnosed based on observed behaviors, and therefore more subjective and likely to be thought of as psychological in nature. Identification of biomarkers in autism is an objective of the research field, but even if only potential co-morbid conditions can be assessed this way, it could be helpful in defining concerns, and tailoring treatments for many individuals.

Another potential factor is the role of adolescence in changing behaviors. Puberty is often a time when conditions such as depression and anxiety appear. The physiological changes, as well as the developmentally programmed need for greater independence and breaking away from parental control, are just as real in an individual with autism as they are in a typical teen. For those who have academic and functional skills closer to their peers, such as young people with Asperger's Syndrome, teenage years can be a sensitive time when a growing awareness of their differences or difficulties making friends and fitting in becomes increasingly frustrating. A mental health provider might be able to help your child, and also aid in your understanding of these changes and how you might adapt to grow with your child as he strives for more autonomy and self-advocacy.

Post-traumatic stress (PTSD is another condition worthy of consideration, especially for someone who cannot describe what he has experienced. Some individuals may have been in situations that have caused significant stress, such as medical concerns/pain/procedures, changes in surroundings/staff/family, neglect, or abuse. *It is important to be aware that research also shows a higher likelihood of sexual abuse in the developmentally disabled population.* The possibility of abuse or trauma should be considered when challenging behaviors develop suddenly.

Other individuals may feel additional stress in response to interventions that have targeted challenging behaviors using approaches such as *seclusion* (putting a person in a place alone), *restraints* (tying, wrapping or otherwise restricting a person's ability to move), *over correction*, *'aversives'* (interventions that are painful or disliked), or other punishments. In these instances, caregiver/staff responses to challenging behavior may be instrumental in creating a disturbing cycle that raises stress and increases the likelihood of more difficult behaviors. In other words, how the people around your child are responding to his behavior might be making his situation even more stressful and challenging. More discussion of the effects of intervention is included in the behavioral section that comes later in this tool kit.

Medication

If your loved one takes medicine, it might also be worthwhile to talk to your doctor about the possible effects on behavior. Many of the medications we use affect more than just the intended outcome. These side effects can sometimes be quite significant and can change an individual's sensitivity or ability to regulate. For example, some medications can be *ototoxic*—which means they might be damaging to the ears, causing sound sensitivities, dizziness or balance issues. Other medications might cause stomach pain in a person who never had digestive issues before. It is not just traditional *psychotropic* (acting on the brain) medications that need to be considered. It is possible that a prescription for acne medication might be having an effect that might trigger new behavior. Carefully review side effect lists and discuss the side effect profiles of each medicine with your doctor, especially in someone who might not be able to report on his symptoms.

In considering medication, note that proper dosage can be very sensitive, particularly in individuals with autism. Sometimes too much medication can be *over-stimulating* or *sedating* (tiring), perhaps even causing the person to find other ways (through new or difficult behaviors) to try to get back to a sense of stability or normality. Some medications can have unexpected or rebound effects. Layering on multiple medications at one time, called *poly pharmacy*, can also have unintended effects. Some doctors have reported success in slowly taking a person off all medications to re-establish 'baseline' in an effort to sort out 'what is the autism?' from 'what is the medication?'

"I recall that when Jack was little our doctor suggested that we try a stimulant. This was meant to calm and focus him. As time went on, Jack didn't sleep for 48 hours sometimes, and we were all a mess as he was bouncing off the walls. We couldn't imagine what he would be like without the benefit of those calming meds. Eventually we tried a weekend drug holiday as they often suggest for stimulants, and he was lethargic the whole weekend. Aha! We realized it was the drugs, not the autism, that was causing the behavior. In hindsight it seems obvious, but in the moment, it was hard to see the relationship."

– SG, parent

As an individual grows and changes, medication may need to do so as well. For example, a larger teen might need more medication to achieve the same effect on attention or anxiety. Medical expertise specific to autism is often quite helpful in carefully determining the right pharmacological interventions for an individual at any point in time.

Families often struggle with decisions about the role of medication in addressing challenging behaviors, and when and what kinds of medication might be useful. This Medication Guide is designed to help in defining your values and goals surrounding medication use. It also provides perspective and talking points to assist in speaking with your doctor and making decisions. It can be used for new medication decisions, or in re-evaluating current medications.

If medication is started, it is important to track side effects and look for other concerns to ensure that the medication is helping where it is supposed to help, and not causing other problems. Sometimes a provider might use a measurement tool that involves asking the family or staff questions prior to starting a medication or other intervention. One often-used tool is the Aberrant Behavior Checklist. The provider might repeat this test after a few weeks or months as a way of measuring the effects of the medication. It is wise to have multiple responders, as well as to compare baseline and follow-up responses from the same person.

The use of simple *tracking scales* for both target behaviors and side effects is another way to assess the effects of a medication. This might be undertaken in cooperation with a behavioral provider or team using their data collection systems, or you could create or modify something like this tracking scale:

Date: ______________________________

Medication Name: ______________________

Medication Dose: ______________________

Behavior/Symptom Occurred	Morning	Midday	Evening
Burping			
Sleepiness			
Uses iPad to make request			
Hitting			
Kicking			
Other			

"We did not like the weight gain associated with the meds that Sammy was on, and we weren't even sure it was helping. So, every few months, I would decrease his dose just as the doctor instructed, and I would start on a Friday so that we would be able to see changes that we wouldn't see while he was off at school. I would not tell my husband, so that at least one of us was getting a 'blinded' view of any changes. By Sunday afternoon, in the midst of some frustrating situation, he would say, 'are you doing that meds withdrawal experiment with Sammy again?' And we knew the meds were still working."

– BW, parent

Sometimes it is helpful to keep some team members or family members *'blinded'* to a new intervention. Often, if we know something is supposed to help in a certain way, we are more likely to see it, even if it is not really there. For example, if you tell the lead teacher about a new medication but not the classroom aides, you might get better information from the team about the true effects of a medication on your child's behavior.

Consideration of changes in the effects of medications should be ongoing. Sometimes adjusting dosage, form (some medications come in time-release forms for more even delivery), time of delivery (before vs. after meals, at bedtime instead of morning, etc.), or other factors can help to increase the benefits and reduce the side effects of a medication.

Being a careful observer and a good reporter to your doctor, and discussing both the benefits and downsides of a medication in advance and as the intervention progresses, can often help to manage a medication so that it is most helpful. Using a chart such as the one above can help you to see if the medication is effective. If medical concerns are a feature of your loved one's profile, it is important to maintain good records and share information among team members.

Behavioral Considerations

When a person behaves in a way we find difficult or offensive, we often reflect on the impact of that person's actions on us—how we feel threatened or embarrassed or hurt. This is absolutely normal, but not always helpful. Instead, it is important to think about the behavior from the individual's perspective.

What is so scary about entering this place that my child is so panicked that he has to bite me? What pain is occurring in his body that he might be trying to over ride it by hitting himself in the head? Is this something biological over which he does not have control? If so, can we help him to learn how to adapt?

Shifting our thinking from how a particular behavior affects us (and the siblings, the classmates, the furniture, etc.) to what might be happening from the individual's perspective is an important step in finding ways to understand behavior. Understanding the behavior will allow you to support the replacement of disturbing or *maladaptive* behaviors with functional skills.

Going back to the basics of behavior, it is important to consider the possible purpose or function. *How does this behavior serve the person? Does he get something out of it? Does he get to escape something boring or difficult? Does he get attention? Does it allow him to assert a little bit of control over his life or surroundings? Does it help to block out pain? What is good about the behavior? Is he trying to tell me something?*

Taking the time to understand the function can often give a window into the motivation behind the behavior. Proper evaluation of function is usually essential to crafting an appropriate response.

For example, suppose a child kicks when it is time to go to gym class and the response to his kicking is to put him in a 'time out.' This is likely to be an ineffective intervention if the whole reason for kicking was to avoid going to gym. He just got what he wanted, and he learned that kicking is an effective way of making his argument. Next time he doesn't want to go to gym class, what is he likely to do? But if kicking keeps him out of the loud, echoing chaos of gym that he finds hurtful or disturbing, he is likely to use the communication he has learned *unless and until* he is taught a better way of coping with gym class (e.g. asking for a different activity) or advocating for avoiding the unpleasant situation.

In the field of Applied Behavior Analysis, the three components that are documented and considered in looking at a specific behavioral episode are called *A-B-C (antecedent-behavior-consequence) analysis*, and include the following components:

- a clear description of the behavior (behavior)
- the situation, events and conditions that occurred before the behavior began (antecedent)
- the situation and events that immediately followed the behavior (consequence)

These behaviors may be tracked using a sheet such as this:

ABC SHEET

Student: ______________________________ **Observer:** ______________________________

Target Behavior: ____

Antecedent: The event that occurs immediately before the behavior

Behavior: The occurence of the target problem behavior (reecord frequency)

Consequence: The event that immediately follows the occurence of the behavior

Date	Time	Antecedent	Behavior	Consequence	Comments

A professional with expertise in behavioral assessment and intervention (e.g. a BCBA) will use a variety of tools to help understand the function of a behavior at any given point in time. It is important to remember that the scales are tools, not answers. A good *functional behavior assessment (FBA)* will use several measures—questionnaires as listed below, observational assessments, active listening, and the professional's experience and background.

An FBA should be broad based and should take into account the observations of behaviors and how and when they occur. They should also seek to be empathetic and to understand why the person might feel the need to behave in a certain way. Make sure your provider is using a broad approach, since this is essential to getting a good handle on the concerns, potential causes of the behavior, and possible interventions and solutions for replacing this behavior with skills.

The following resources will help you learn more about how behavior is often evaluated and considered by professionals:

- Parents' Guide to Functional Assessment
- Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know
- Targeting the Big Three parent training manual

For a school-aged child, the school district is responsible (under the laws of *IDEA*) to perform a FBA and create positive interventions for a child whose behavior inhibits his learning, or the learning of those around him. If they do not have this expertise on staff, they need to secure these services through other agencies or consultants. Some schools will provide additional training and instruction in the home, or through other community providers such as *wraparound* supports. Behavioral interventions through your health insurance provider may also be able to provide this support.

If you do not have access to a behavioral support provider or team, you can begin to become a more advanced observer of the elements of behavior yourself. Tools such as Barbara Doyle's data collection and communication dictionary might be helpful.

After defining and evaluating the behaviors, the behavioral team, teaching staff or other providers should explain the results to you and develop instructional strategies using *Positive Behavior Supports (PBS)* and *Reinforcement Strategies*. Using Positive Behavior Supports is a way to promote functional skill development and motivation and can be used at home, school, work, and in the community. These supports often need to be individualized to the needs of the child, and the functions of his behaviors, to be effective. Classroom based supports are often not sufficient for challenging behaviors, so you may have to advocate for these to be individualized. More on positive behavior supports, training and resources for families, schools and staff, and strategies for building positive behavior are included in the next chapter.

If the function of the behavior is to gain attention, challenging behavior can be reduced if attention and interaction are no longer given when the individual engages in the problem behavior. This means not giving direct eye contact or calling the individual's name, no reprimands, no reasoning and lecturing, or showing that you're upset. Attempts to redirect the behavior by giving attention may inadvertently increase the problem behavior.

Note: Ignoring challenging behavior may initially increase the challenging behavior because that is how he communicated what he wanted and how he got his way until now. Keep the faith. Ignoring will ultimately decrease the likelihood that the individual will engage in challenging behavior to gain attention.

-Page 73 Targeting the Big Three

Other Concerns to Consider

Communication Issues

Teachers, behavioral providers and/or speech pathologists should also evaluate the *functional communication* skills available to an individual, as this can be a critical factor. After all, behavior is often a form of communication—sometimes the only form available to an individual who has not learned other skills.

It will be helpful to consider: *Did he understand what I said? Can he independently use speech or other forms of communication to raise concerns? Report pain? Make requests? Ask to get away? If not verbally, does he have cards or a device that he uses independently for this? Even if he can speak well, does he have the language or the confidence to make his needs and concerns known verbally?* If not, it is likely he is finding other ways to express wants, frustration, fear or other information.

Many individuals with autism have difficulty processing information—hearing all the parts of what someone said, matching what they see to what they hear, or being able to decide what information is important and relevant in light of all the possible sights, sounds, smells, etc. Many people with autism are visual learners, or otherwise benefit from information presented in pictures, words or video. Verbal information (speech) disappears as soon as it is said, but visuals have staying power—they can be available and accessed as long or as often as the individual needs.

It is essential that the functional communication system is something that your child can initiate and use independently. Often a speech pathologist can perform an evaluation and design appropriate interventions. Many skilled autism intervention teams have also developed expertise in communication supports and development. If supports and training in functional communication are needed, there are a variety of systems that the team should explore, such as PECS and voice output devices, to find a fit for the individual and his specific needs and preferences.

"I remember how he would throw himself to the floor when he was thirsty. The speech pathologist taught me how to take his little hand and shape his fingers into a point, then lead his hand to touch the cup. We did this hundreds of times, moving from the cup to toys and movies he wanted to watch. When he pointed, he got what he wanted. He started pointing. He was learning to ask!"

- TO, parent

Sometimes even highly functional individuals with autism can have difficulty communicating certain concerns. For example, many individuals with Asperger's Syndrome lack self-awareness. So as a result, isolating pain, describing emotions or identifying what is causing a negative feeling can be very difficult. Expectations that a 'straight A student' should be able to navigate social situations or other challenging experiences can often leave an individual unsupported, and as a result, increasingly anxious and reactive. Specific instruction in social and self-awareness can be hugely beneficial for someone who might have an incredible vocabulary but difficulty communicating about socially relevant concerns.

Sensory Concerns

Individuals with autism often report on their different ways of experiencing the world, and it is helpful to keep these issues in mind when considering a person's specific behaviors. A child may scream or run out of the singing of the Happy Birthday song not to be difficult, but because the singing and/or the cheering that follows is truly painful for him. Often these responses are more like reflexes than behavioral choices. When a person stays away from certain experiences—sounds, touch, smells, food tastes/textures, certain types of movement, etc., it is often called *sensory avoidance* or *sensory defensiveness*. Even in these same individuals, there is often a contrasting need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state. This is called *sensory-seeking behavior*.

It is important to consider whether the individual has some sensory need that is otherwise not being met. Is he jumping up and down because it feels good? Alternatively, is there sensory defensiveness? Is there something about this tag in his shirt, this lighting, this sound, this crowd, these odors that he finds painful or overwhelming?

> ***"He had a fascination with birthday parties and blowing out candles, and at one point we would have to re-light, re-sing, and re-blow – 20 times or more each birthday. We developed a program to teach Joey how to end Birthday Parties. Of course all of this was after at age 5, because until then he couldn't tolerate listening to the song 'Happy Birthday' at all."***
>
> ***– BH, Parent***

To investigate whether sensory factors might be a consideration with your loved one, an Occupational Therapist or other provider might use an age-appropriate form of the Sensory Profile or the Sensory Processing Measure (SPM). A sensory checklist and additional information are available at the Sensory Processing Disorder Foundation website. More information can be found here.

Support Systems and Environment—Family, Staff, Supports Dynamics

Change is difficult for any of us, but it may be more so for those who do not understand what changes are taking place and why. Consider potential contributing factors that might be leaving your loved one with autism feeling confused or anxious.

If challenging behaviors come on suddenly or intensify, it is important to ask what changes have occurred in his life. *Have there been changes in schedules? School, work or residential placement? Changes in the family environment? A sibling heading off to college? Loss of a family member? Have there been changes in staff? Loss of a preferred staff member? If there is a behavior plan, is it being followed consistently? Perhaps new staff who need additional training or who employ methods that are stressful? Is there any concerning behavior in caregivers? What is their stress level?*

Resources:

General:

Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum
Autism Solutions; How to Create a Healthy and Meaningful Life for Your Child,
Ricki G. Robinson, MD, MPH
National Autism Center's A Parent's Guide to Evidence-Based Practice and Autism
http://www.nationalautismcenter.org/learning/parent_manual.php

Behavior Function and Evaluation:
Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know
http://www.wrightslaw.com/info/discipl.fba.jordan.pdf
How to Think Like a Behavior Analyst, Jon Bailey and Mary Burch
Parents' Guide to Functional Assessment
http://pages.uoregon.edu/ttobin/Tobin-par-3.pdf.

To Walk in Troubling Shoes: Another Way to Think About the Challenging Behavior of Children and Adolescents,
Bernie Fabry PhD, 2000
http://www.parecovery.org/documents/Troubling_Shoes_2000.pdf

Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting
IBR Autism Speaks Family Services Grant Challenging Behaviors Curriculum
http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf

Skill Evaluation/Development:
The ABLLS-R; The Assessment of Basic Language and Learning Skills,
James Partington and the AFLS too!

Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners),
V. Mark Durand

Sensory Profile
http://www.pearsonassessments.com/HAIWEB/Cultures/en-us/Productdetail.htm?Pid=076-1638-008

Sensory Processing Measure (SPM)
http://portal.wpspublish.com/portal/page?_pageid=53,122938&_dad=portal&_schema=PORTAL

Medical/Medication:

Buie T, Campbell DB, Fuchs GJ, et al.,
Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.
[Consensus Development Conference, Journal Article, Research Support, Non-U.S. Gov't]
Pediatrics 2010 Jan.:S1-18.
http://pediatrics.aappublications.org/content/125/Supplement_1/S1.long

Buie, et al.
Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.
http://pediatrics.aappublications.org/content/125/Supplement_1/S19.long

Herbert, Martha,
The Autism Revolution
www.marthaherbert.org

Loschen, EL and Doyle, B,
Considerations in the Use of Medication to Change the Behavior of People with Autism Spectrum Disorders
http://www.asdatoz.com/Documents/WebsiteCONSIDERATIONS%20IN%20THE%20USE%20OF%20MEDs%20ltrd.pdf

Siegel M & Beaulier A, Journal of Autism and Developmental Disorders, November, 2011
Psychotropic Medications in Children with Autism Spectrum Disorders: A Systematic Review and Synthesis for Evidence-Based Practice.
http://www.ncbi.nlm.nih.gov/pubmed/22068820

Siegel, M,
Psychopharmacology of Autism Spectrum Disorder: Evidence and Practice,
Child and Adolescent Psychiatry Clinics of North America, 2012, in press,
http://www.ncbi.nlm.nih.gov/pubmed/22068820

Appendix 1

Ruth Elaine Hane, who was diagnosed with High Functioning Autism in 1995, lives in Minneapolis, with her husband and their two cats. Contributing author to *Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum* and *Sharing Our Stories* and numerous other publications, Ruth Elaine mesmerizes audiences with her vivid memories of growing up in a large family without knowing the characteristics of autism. Born as a Rubella measles baby; unable to swallow or tolerate touch, Ruth Elaine did not talk until nearly five years old, when she began using full sentences with reciprocal language. Her strength lies in her unique view of how things are, and an insatiable desire to improve her life by learning to read faces and understanding complex nonverbal messages. Ruth Elaine mentors and coaches others, effectively teaching the skills she has learned, and serves on boards and task forces for many autism organizations. Presently she is focusing on developing her Face Window idea to work to overcome face blindness , by assisting in Child Psychology research at the Fraser Family Services and the University of Minnesota. Ruth Elaine is a gifted healer, utilizing Reiki Energy to balance the whole body system, believing that an underlying deficit in autism is an unbalanced whole- body system.

Appendix 2

Common "problem" behaviors and speculations about their causes

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

"High pain tolerance"

- A lot of experience with pain.
- Fear of expressing opinion.
- Delerium
- Neuropathy (disease of the nerves)/many causes

Fist jammed in mouth/down throat

- Gastroesophageal reflux
- Eruption of teeth
- Asthma
- Rumination
- Nausea

Biting side of hand/whole mouth

- Sinus problems
- Eustachian tube/ear problems
- Eruption of wisdom teeth
- Dental problems
- Paresthesias/painful sensation (e.g., pins and needles) in the hand

Biting thumb/objects with front teeth

- Sinus problems
- Ears/Eustachian tubes

Biting with back teeth

- Dental
- Otitis (ear)

Uneven seat

- Hip pain
- Genital discomfort
- Rectal discomfort

Odd unpleasurable masturbation

- Prostatitis
- Urinary tract infection
- Candidal vagina
- Pinworms
- Repetition phenomena, PTSD

Waving head side to side

- Declining peripheral vision or reliance on peripheral vision

Walking on toes

- Arthritis in ankles, feet, hips or knees
- Tight heel cords

Intense rocking/preoccupied look

- Visceral pain
- Headache
- Depression

Won't sit

- Akathisia (inner feeling of restlessness)
- Back pain
- Rectal problem
- Anxiety disorder

Whipping head forward

- Atlantoaxial dislocation (dislocation between vertebrae in the neck)
- Dental problems

Left handed or fingertip handshake

- Frightening previous setting
- Pain in hands/arthritis

Sudden sitting down

- Altlantoaxial dislocation (dislocation between vertebrae in the neck)
- Cardiac problems
- Seizures
- Syncope/orthostasis (fainting or light-headedness caused by medication or other physical conditions)
- Vertigo
- Otitis (thrown off balance by problems in the ear)

Waving fingers in front of eyes

- Migraine
- Cataract
- Seizure
- Rubbing caused by blepharitis (inflamation of the eyelid) or corneal abrasion.

Pica

- General: OCD, hypothalamic problems, history of under-stimulating environments
- Cigarette butts: nicotine addiction, generalized anxiety disorder
- Glass: suicidality
- Paint chips: lead intoxication
- Sticks, rocks, other jagged objects: endogenous opiate addiction.
- Dirt: iron or other deficiency state
- Feces: PTSD, psychosis

Common "problem" behaviors and speculations about their causes continued

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

General scratching

- Eczema
- Drug effects
- Liver/renal disorders
- Scabies

Self-restraint/binding

- Pain
- Tic or other movement disorder
- Seizures
- Severe sensory integration deficits
- PTSD
- Parasthesias

Scratching stomach

- Gastritis
- Ulcer
- Pancreatitis (also pulling at back)
- Porphyria (bile pigment that causes, among other things, skin disorders)
- Gall bladder disease

Scratching/hugging chest

- Asthma
- Pneumonia
- Gastroesophageal reflux
- Costochondritis/“slipped rib syndrome”
- Angina

Head banging

- Pain
- Depression
- Migraine
- Dental
- Seizure
- Otitis (ear ache)
- Mastoiditis (inflammation of bone behind the ear)
- Sinus problems
- Tinea capitis (fungal infection in the head).

Stretched forward

- Gastroesphageal reflux
- Hip pain
- Back pain

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Ruth Myers, MD

What are the Positive Strategies for Supporting Behavior Improvement?

As highlighted in the previous section, there are many possible contributors to the development of challenging behaviors. It is important to investigate and evaluate these, but also to take action sooner rather than later, since many behaviors can become increasingly intense and harder to change as time goes on.

Often a necessary approach to managing behavior involves a combination of addressing underlying physical or mental health concerns, and using the behavioral and educational supports to teach replacement skills and self-regulation. There is no magic pill, but there are a number of strategies that can often be helpful.

The use of *Positive Behavior Supports* is more than just a politically correct approach to behavior management. Research shows that it is effective. The alternative is usually *punishment*, which decreases the likelihood of a behavior by taking something away (such as removing a favorite toy) or doing something unpleasant (yelling, spanking.) While punishment might work immediately, it has been shown to be ineffective in the long run and can increase aggressive behavior, provide a model for additional undesirable behaviors, and strain the relationship with the caregiver (you). It is worth noting that to continue to be effective and maintain improvements, positive supports and feedback need to be ongoing as well.

"Withholding reinforcement for problem behavior (i.e., extinction) is technically an example of punishment. Proponents of Positive Behavior Support (PBS) acknowledge that controlling access to reinforcement is necessary when trying to change behavior. What PBS does not condone is the use of aversive (e.g., demeaning, painful) procedures to suppress behavior. Such approaches have been demonstrated to be ineffective in producing durable changes in people's behavior and do not improve to quality of their lives." –Association for Positive Behavior Support

If you have made changes to improve your child's health or happiness, and these have not helped to improve his behavior in a reasonable time frame (a couple of weeks), or you are concerned about safety, help may be needed. Positive strategies and an intervention plan can be developed by a behavioral or educational team, usually in response to what is learned in a *functional behavior assessment* (FBA) as described in the previous section.

When several challenging behaviors exist, it is important to establish priorities. You may want to first target behaviors that are particularly dangerous, or skills that would help to improve situations across several behavioral scenarios. Remember to set goals that are realistic and meaningful. Start with small steps that can build over time. A non-verbal child is not likely to speak in full sentences overnight, but if learning to hold up a 'take a break' card when he needs to leave the table allows him to exit, and keeps him from throwing his plate, that is a huge success.

A plan for you and your team should meet four essential elements:

- *Clarity:* Information about the plan, expectations and procedures are clear to the individual, family, staff and any other team members.
- *Consistency:* Team and family members are on the same page with interventions and approaches, and strive to apply the same expectations and rewards.

- *Simplicity:* Supports are simple, practical and accessible so that everyone on the team, including the family, can be successful in making it happen. If you don't understand or cannot manage a complicated proposed behavior intervention plan, speak up!
- *Continuation:* Even as behavior improves, it is important to keep the teaching and the positive supports in place to continue to help your loved one develop good habits and more adaptive skills.

Please recognize that many skills take time to develop, and that changes in behavior require ongoing supports to be successful. In some cases, especially when you are ignoring a behavior that used to 'work' for your child, behavior may get more intense or more frequent before it gets better. Your team should keep good records and track progress and responses to intervention to know if the plan is effective.

There are increasing numbers of tools and apps for behavioral intervention tracking that are portable and simple to use.
Links can be found here.

Being realistic at the outset is crucial. It can help parents and caregivers appreciate that they are making small yet meaningful changes in their lives and the lives of the individual they care for. Making goals realistic means they are achievable. Being realistic keeps the picture positive. It focuses attention on progress towards a goal, rather than perfection.

Setting Realistic Behavioral Goals:

Setting goals allows us to objectively measure progress toward an identified desired outcome. It also allows caregivers and parents to ask themselves, "What behavioral changes would really make the greatest improvements in our lives together?" It allows them to identify what really matters. For instance, it may be more important to address a behavior such as throwing things during a classroom activity than to address that person's tendency to stand up during meals.

p.23 – Targeting the Big Three

For example, it is possible that you or your team may have misinterpreted the function of a behavior, or that the function has changed over time. A-B-C data often indicates that screaming has the function of attention, because attention from others is a common (and usually natural) consequence. But it may be that screaming is triggered by painful reflux and attention is not the true function. Tracking and interpreting the data is important since it may help to show that more investigation is needed, and the plan may need to be adjusted to be effective.

Information on supports for teaching behavior management can be found in the Autism Treatment Network's An Introduction to *Behavioral Health Treatments* and *Applied Behavior Analysis;* A Parent's Guide.

In the end, you are trying to teach your child that life is better, and that he can get what he needs, without having to resort to challenging behaviors. The suggestions below are strategies to help make individuals with autism feel more comfortable and more empowered.

Adapt the Environment

As you learn to think like a detective about your child's behavior, your observations (or the FBA) are likely to show that behavior occurs at specific times, with certain people or in particular environments. You and your team will need to tune in, learning to recognize the signs of increasing tension, anxiety or frustration that eventually lead to challenging behaviors. Often there is a ramping up, or escalation period, and learning to recognize that early and using many of the approaches here can help to calm a situation and prevent behavioral outbursts. Sometimes these signs may be very subtle—red ears, a tapping foot, heavier breathing, higher pitched speech—but it is essential that everyone on the team responds to the importance of tuning in and working towards *de-escalation*.

Changing the environment can often reduce behavioral episodes. Expand situations, relationships, places and opportunities that are successful. If possible, try to adjust or avoid situations that are triggers for challenging behavior. Incorporate ways to reduce frustration and anxiety and increase understanding. Below are some things to consider when working to create a more successful environment:

- *Organize and provide structure:* Provide clear and consistent visual schedules, calendars, consistent routines, etc. so that the person knows what is coming next.
- *Inform transitions and changes:* Recognize that changes can be extremely unsettling, especially when they are unexpected. Refer to a schedule, use countdown timers, give warnings about upcoming changes, etc.
- *Use Visual Supports:* Pictures, text, video modeling and other visuals are best for visual learners, but they are also critical because they provide information that stays. The ATN Visual Supports Tool Kit provides a step-by-step, easy-to-understand introduction to visual supports.
- *Provide a safe place and teach when to use it:* A calming room or corner, and/or objects or activities that help to calm (e.g. bean bag) provide opportunities to regroup and can be helpful in teaching self-control.
- *Remove or dampen distracting or disturbing stimuli:* Replace flickering fluorescent lights, use headphones to help block noise, avoid high traffic times, etc.
- *Pair companions or staff appropriately for challenging activities or times:* Some people are more calming than others in certain situations. If going to the store with dad works better than with mom, focus on that and celebrate successes.
- *Consider structural changes to your home or yard:* These changes might address some of the specifics of your situation to increase independence or reduce the risks when outbursts occur. Making Homes that Work includes a range of potential changes that can be made to reduce property damage, improve safety, and increase choice and independence.

"One of the barriers that we often find for children with autism in toilet training has to do with the condition of the bathroom itself. Often times we find that people with ASD can be very tactfully defensive so the space itself needs to be as neutral as possible. There needs to be enough room around the toilet so people don't feel too confined. It is really helpful if the space is warm and you address other types of sensations around the toileting experience. For example, is it cold, is there a fan running, is the light too bright, or not bright enough? You can sometimes help encourage people to use the toilet if the bathroom is a friendly place for them to be

– George Braddock, President,
Creative Housing Solutions LLC

What else can I do to promote a Safe Environment?

Even the best-laid plans don't always work in every situation or at the necessary speed. Despite proactive strategies, particularly challenging times and stressful situations can get beyond our control. Aggression or self-injury can get to a point where the situation is dangerous. It is good to be prepared if you think this might happen.

Communicate to Others

Many families have found it helpful to communicate to those around them about their child's special needs and some of the behavioral situations that might arise. Sometimes it is helpful to let others know what is going on so that they can also be observers and help provide helpful input about your child. Some families have found it helpful to talk to their neighbors, or to communicate with others in the community using stickers, cards, or other visuals.

I carry a note card stating:

> *"Thank you for your concern. My child has autism. He finds many situations difficult, including this one. Right now, we are doing a treatment plan recommended by our therapist, Dr. BCBA. This includes not giving attention to my child when he is acting out in order to discourage it. If you have any questions, you can contact Dr. BCBA at 123-456-7890."*

I post these cards in the windows of my car, on the front door of my house and at any other environment, like family members houses. My child has Autism printable card
http://card.ufl.edu/handouts/Autism-Card-w-border.pdf

Preparing for an Autism Emergency

Because autism often presents with special considerations, tools have been developed to help families prepare ahead of time for some situations that might arise. The following resources have suggestions for families, as well as information that can be shared with local law enforcement and first responders:.

- Autism Speaks Autism Safety Project
- First Responders Tool Kit
- Community and Professional Training Videos for First Responders
- National Autism Association's Big Red Safety Boxes
- Autism Wandering Awareness Alerts Response and Education Collaboration (AWAARE)
- Making Homes that Work

Use Positive Behavior Supports

Your team should develop strategies for you to use to increase the behaviors you want to see in your child. These will need to be individualized to his particular needs and challenges. They can often be helpful in building a sense of pride in accomplishments and personal responsibility, and a sense of what is expected. This will reduce the anxiety and reactivity that results in aggression or other behaviors. Some helpful strategies:

- *Celebrate and build strengths and successes:* Tell him what he does well and what you like. A sense of competence often fosters interest and motivation. Strive to give positive feedback much more frequently than any correction or negative feedback. 'Great job putting your dishes in the sink!'
- *Respect and listen to him:* You may have to look for the things he is telling you, verbally or through his choices or actions. 'You keep sitting on that side of the table. Is the sun in your eyes over here?'
- *Validate his concerns and emotions:* Do not brush aside his fears or tell him not to worry. His emotions are very real. Help to give language to what he is feeling. 'I know you do not like spiders. I can see that you are very afraid right now.' 'I can see that you are angry that our plans have changed.'

- *Provide clear expectations of behavior:* Show or tell your child what you expect of him using visual aids, photographs or video models. A great way to teach new skills is Tell-Show-Do.
- *Set him up for success:* Provide accommodations. Accept a one word answer instead of demanding a whole sentence. Use a larger plate and offer a spoon to allow him to be neater at the dinner table. Use Velcro shoes or self-tying laces if tying is too frustrating.
- *Ignore the challenging behavior:* Do your best to keep the challenging behavior from serving as his way of communicating or winning. This is hard to do, but in the long run it is effective. Do not allow his screams to get him out of brushing his teeth, or his biting to get him the lollipop that he wants. Behaviors may get worse before you start to see them get better. Stay the course! And make sure all family and team members are consistent in this approach and that you pair this with other positive strategies.
- *Alternate tasks:* Do something that is fun, motivating or that your child is good at. Then try something hard. He will be less inclined to give up or get agitated if he is already in a positive framework.
- *Teach and interact at your child's or loved one's learning level:* Take care to set him up for growth and accomplishment, rather than the anxiety produced by constant failure or boredom.
- *Give choices, but within parameters:* Everyone needs to be in control of something, even if it is as simple as which activity comes first. You can still maintain some control in the choices that you offer. 'Do you want to eat first, or paint first?'
- *Provide access to breaks:* Teach the individual to request a break when he needs to regroup (e.g. use a *PECS* card that represents "break"). Be sure to provide the break when he asks so he learns to trust this option and does not have to resort to challenging behaviors.
- *Promote the use of a safe, calm-down place:* Teach him to recognize when he needs to go there. This is a positive strategy, not a punishment.
- *Set up reinforcement systems:* Use simple, predictable processes that reward your child for desired behavior. Catch him being good and reward that, verbally and with favored activities, objects or 'payment.' *'I love that you stayed with me during our shopping trip. You earned a ride on the airplane toy!'*
- *Allow times and places for him to do what he wants:* Even if it is a 'stim', it is important to provide these options when it is not an intrusion or annoyance to others.
- *Reward flexibility and self control: 'I know you wanted to go to the pool today and we were surprised when it was closed. For staying cool and being so flexible about that change in plans, let's go get some ice cream instead!'*
- *Pick your battles:* Strive for balance. Focus on the behaviors and skills that are most essential. Be sure to include positive feedback and intersperse opportunities for success and enjoyment for you, your family, and your loved one with autism. Be resilient. Celebrate the fun and the good things!
- *Use positive/proactive language:* Use language that describes what you want the individual to do (e.g. *'I love how you used a tissue!'*), and try to avoid saying 'NO', or 'don't' (e.g. *'stop picking your nose.'*).

Teach Skills and Replacement Behaviors

Since behavior often represents communication, it is essential to replace behavior by building more adaptive skills. It is important that you and your team not assume that a child has the skills needed to do something 'the right way' and that you are prepared to use systematic instruction and motivation to build new abilities.

Focus on communication and functional skills to promote greater independence, social skills to promote greater understanding and reduce apprehension, and self-regulation skills. The team should specifically work on skills that will address the behavior's function, and thereby help to replace, the target behavior. Skill building can take some time, so be persistent and celebrate the small steps along the way.

> *"Communication-based intervention refers to an approach that reduces or eliminates problem behavior by teaching an individual specific forms of communication. Because the communication forms that are taught are more effective ways of influencing others than the problem behavior, they eventually replace the problem behavior itself… By communication training, we mean that individuals are taught specific language forms including, for example, speech, signing, and gestures that can be used to influence other people in order to achieve important goals."*
>
> *– Ted Carr, Ph.D.,*
> *State University of New York at Stony Brook*

When you adjust to give different feedback or to help your child develop a new skill, celebrate yourself as much as you celebrate your child's growth! Reward a sibling for being extra patient or modeling a skill you are teaching. Use the pride in your successes to help you stay focused and dedicated, and to help you reflect on the good things in your child and your family.

It is essential to teach skills in the context of a positive learning situation, which is NOT while a behavior is occurring. These skills need to be part of a comprehensive educational plan. Just like math facts, they may need to be practiced many times during the day when the child or adult is calm and attentive. Label 'calm' and 'ready to learn' states and teach your child what they feel like.

- *Develop and expand functional communication:* Find a way to build effective communication that is appropriate for the person across his daily activities. Use language instruction, *PECS*, sign language, communication devices or other tools. For example, teach an over-stimulated child to ask for quiet time (using his words, PECS, pointing to a picture, or an iPad app), instead of running away. Functional communication should be rewarded with immediate access to the requested item to build the connection. This allows you to use request = item rather than behavior = item. A trained autism specialist or speech therapist will be very helpful in choosing and supporting effective interventions for functional language development. More information and possible resources:
  - The National Professional Development Center's Functional Communication Training
  - Functional Communication Training
    http://www.autismspeaks.org/sites/default/files/challenging_behaviors_caregiver_manual.pdf
  - Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners), by V. Mark Durand

    - Picture Exchange Communication System (PECS) and Associated Apps
    - Other Autism Apps, such as Proloquo

Developing a voice can be life changing, and finding the right supports can help to increase functional communication in a variety of ways. For one dramatic example, watch Carly's story.

- *Teach Social Skills*: Use social stories to explain expectations and build skills and awareness. Recognize that some skills might require a team approach. For example, messy eating or toileting can be the result of a combination of sensory concerns, motor planning and social awareness, so working with an occupational therapist and using social stories as well as behavioral interventions might be needed
- *Create Activity Schedules:* Teach the use of schedules using pictures, written words or videos to help organize a chunk of time (e.g. a day, a class period, etc.) and break tasks into small, manageable steps. These schedules often reduce anxiety, provide skill development, and promote independence. Examples and resources:
    - Picture Activity Schedules, from Do2Learn
    - Activity Schedules for Children With Autism, Second Edition: Teaching Independent Behavior, by Lynn E. McClannahan and Patricia Krantz
    - Other Autism Apps, such as ReDo
- *Teach Self-Regulation and De-escalation Strategies:* Learning to self regulate is essential to a person's ability to remain calm in the face of the assaults that the world will undoubtedly bring his way. Your child is most likely to show problem behaviors when he is in an emotional state of anxiety or agitation. Strategies and programs for building self-regulation relate to both arousal and emotions. Many of us have had to learn these ourselves—counting to ten, taking a deep breath—and the same principles apply to the learning needs of an individual with autism.

> ***"My behavior began to improve when I started to learn about emotions-- how to recognize them not only in others, but in me. This was an essential step to learning self-regulation, and it was then that I started to take more control of my actions."***
>
> ***– RH, adult with autism***

    - Use The Incredible 5-Point Scale to teach social awareness and emotions
    - Teach recognition of arousal levels: The Alert Program: How does your engine run?
    - Employ Behavioral Relaxation Training (BRT) which uses motor exercises (posture, breathing, etc) to find a relaxed state, and has been shown to be helpful in individuals who are less able to talk through issues or concerns.
    - Teach self control and behavioral targets using Social Stories or Cognitive Picture Rehearsal.
    - Teach the individual to recognize the triggers for his behavior, and ways to avoid or cope with these when they occur.
    - Find ways to arouse and ways to calm your child, which can vary from person to person, and teach him to do these when he needs to.
    - Review additional tips and hundreds of sample behavior charts and targets, including feeling charts.

- *Find providers who use Cognitive Behavior Therapy* or teach cause and effect, self-reflection, and social understanding through tools such as the Social Autopsy. While these techniques lend themselves to more verbal individuals, they can be used with individuals of all verbal abilities with appropriate accommodations such as use of visuals and role-play.

- *Teach Self-Management Skills:* Self-management focuses on becoming aware of one's actions and learning responsibility for behavior and tasks without the support of caregivers. This is especially important in the adolescent years, as young adults with autism often feel the need for greater autonomy and independence just like their peers. Teaching self-management provides your child with a sense of personal responsibility, pride and accomplishment. Some books include:

    1. How to teach self-management to people with severe disabilities: A training manual, by Lynn Koegel
    2. Self-Management for Children With High-Functioning Autism Spectrum Disorders, by Lee A. Wilkinson

- *Promote Exercise:* Exercise can be a powerful factor in overall quality of life, for reasons beyond just physical fitness and weight issues. Research shows that aerobic exercise can influence behavior, decreasing self-stimulatory behaviors such as rocking and spinning, as well as discouraging aggressive and self-injurious behavior. Sometimes the challenges of autism (e.g. sensory input, motor planning, social aspects of team sports, etc.) can require a little extra creativity in terms of designing an approach to physical activity that is beneficial and motivating for a specific person. However, if implemented appropriately, the addition of physical activity to an autism intervention program can address some of these specific challenges, increase self-confidence and social interactions, and improve overall quality of life. The same interventions that are used to teach other skills (ABA, structured teaching, etc.) can be used to build exercise skills and routines.

    - The Benefits of Sports and Exercise in Autism
    - Top 8 Exercises for Autism Fitness *from AutismFitness.com*
    - Autism Fitness Exercise Videos *from AutismFitness.com*

- *Address Hormones and Sexuality Considerations:* The hormone and brain changes of puberty can make a typical child seem like a stranger, and these same effects occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. Tell your child, even if you think he may have difficulty understanding, about what is happening to his body. Specific teaching to the skills of appropriate social considerations (personal space, privacy, feelings vs. actions, etc.) can help to keep an individual with autism out of situations that others might find disturbing or inappropriate. Responding to Inappropriate Sexual Behaviors Displayed by Adolescents With Autism Spectrum Disorders by Jenny Tuzikow, Psy.D., BCBA-D has helpful insights.

Editor's Note: This story reflects the need for the team to take into consideration the culture and comfort of those being asked to take part in an intervention. Your family's perspective and concerns need to be considered as you program, as a team, for your child.

"Just like any other teenage boy, my 13 year old son with autism starting having occasional, unexpected erections that seemed outside of his control. He found them funny, but obviously others did not. We explained to him what was taking place, but that it was something that he should keep private. Even if he understood what we were saying, we recognized this would be difficult to do when you don't have the language to let others know you just 'need a few minutes at the desk.' His behavioral team thought the way to address this was to give it an outlet, suggesting some

Victoria's Secret catalogs and some modeling from Dad. I was so relieved that I could not be asked for this duty! But we were also concerned about what else we were teaching him. What if Victoria's Secret became his 'trigger' and we went to the mall??? We reasoned with the team, and instead taught our son to ask for Private Time-- in his room, at home, with a Private Time sign on his door. Eventually he outgrew this phase and it has not been an issue. We can even go to the mall and pass Victoria's Secret without concern!"

– ES, a mother

An Intervention Example: C.O.P.E.S. ™

One school intervention team has had success using strategies for 12 teenage students with long histories of failed interventions and high incidence of aggressive and self-injurious behaviors. C.O.P.E.S. ™ involves consistent implementation of a collection of individualized approaches. This program incorporated several interventions to greatly reduce behaviors and build positive skills and happier students. For a description and accompanying visual examples, please see the Appendix at the end of this section.

Punishment vs. Rewards: What does science tell us?

Punishment is often used in shaping behavior. It works because it reduces the chances that the behavior will happen again. Punishment often takes two forms— *doing something* such as spanking or giving extra chores, or *taking something away* such as TV time or the car keys. We often use punishment in its more subtle forms without even realizing it—raising our voices, removing a favorite toy or withdrawing attention.

The short term consequences of punishment bring focus to a problem and may stop the behavior in the moment. But studies show that punishment is largely ineffective in the long run, especially when it is not used together with positive and preventive approaches. It can promote emotional responses such as crying and fearfulness, and aggressive behavior by providing a model (e.g. hitting). It can also promote a desire for escape and avoidance of the person or the situation that caused the punishment. It often needs to be repeated and often becomes more intense, because punishment may teach what *not to do*, but does not build skills for what *to do*. The negative feelings associated with punishment are often paired with the person delivering the punishment, causing the relationship with the parent or caregiver to be affected as time goes on.

Of course, every child exhibits behavior that needs to be corrected, or shaped, so what else can I do?

Rewards, or using *reinforcement*, are one of the most consistent ways to change behavior and build desired responses. For people with jobs, the reward is a paycheck at the end of the month. Children, especially those with autism, often need their rewards much more immediately, and in connection with the desired behavior. So, as soon as he buckles his seatbelt, he gets a 'high five'.

Sometimes reinforcement is viewed as simple, such as giving an M&M after a correct response, but reinforcement can be much more than that. When a tangible reward (M&M) is paired with a social reward (*'Great job saying Good Morning to your brother!'*), the positive feeling of success gets paired with both the verbal praise, and the person giving the reward. This helps to build the desired behavior, and also often improves the relationship with the parent or teacher using the reward.

Reinforcers can vary considerably from person to person. It is important to observe your child to learn what he finds rewarding so that you can give him what he wants after he has responded in the way that you desire. Watch what he does in his free time, or when he has choices—some children love to be tickled, others do not. Consider edibles (such as a cookie or other favorite food) but also other *tangibles* (a toy, bubbles, etc.) or experiences (listening to music, taking a walk, curling up on the bean bag). Be creative and mix it up. Know that the more opportunities a person has to encounter a reinforcer, the less rewarding it might become—so the 'power' of a reward is often increased if it is saved for certain times when you want to celebrate your child's behavior.

Research shows that positive, reinforcement-based strategies are most effective in creating long-term behavioral change. However, it is also important to have an immediate response to a behavior in order to maintain safety or minimize disruptions. Planning in advance for the type of situation is important, so that caregivers across settings (home, school, etc.) are consistent in their responses and delivery of consequences. Most reactive strategies fall into three areas as listed below.

- *Ignoring the behavior* (*extinction*) is often used when the behavior is used for attention, and is mild or not threatening.
- *Redirection*, often supported with visuals, may involve redirection to an appropriate behavior or response and is often paired with positive strategies.
- *Removal from a situation or reinforcement* through a time out is often used for calming down opportunities.

Ignoring challenging behavior means not giving in to the behavior that you are trying to eliminate, to the best of your ability. If he kicks to get a cookie, ignore the kicking and do not give him a cookie. But, use other strategies here to teach him to request a cookie, and be sure to give the cookie when he asks, so as to build his trust in you. Note that when you first start to ignore a behavior (called *extinction*) it may increase the behavior. This is called an *extinction burst* and is very normal. Stay the course.

- Certain behaviors (those that are dangerous or injurious) are more difficult to ignore and sometimes need to be redirected or blocked (e.g. putting a pillow by his head so that his self-hitting does not do damage), even as you strive to not allow the behavior to 'win.' link to Yoo section on ignoring?

"When Joey was little, every time he spilled his glass of water, he banged his head on the edge of the table. I learned to wipe-up his spilled water quickly, in order to avoid this self-injurious behavior. If I was really fast, he'd attack me on my way to cleaning it up – grabbing my hair and pulling. I also noticed that his aggression didn't stop once I had cleaned up the obvious puddles, but continued as I wiped what I thought was a dry surface.

This behavior continued because, try as we might, we could not completely avoid spilling water. By the time Joey was age 9, the entire family was very alert to the importance of not spilling water and the need to respond quickly trying to reduce the duration of Joey's aggression. Only after we started a home ABA program was it pointed out that my rushing to clean up spilled water followed Joey's becoming self-injurious and aggressive. By wiping up the water, we were reinforcing Joey's inappropriate behaviors. I realized that Joey did not know how to clean up the water himself. He also did not have another way to ask us to clean up the spilled water or to tell us that it bothered him, other than banging his head or pulling our hair.

With the help of our behavior consultant, we learned to clean-up the spilled water only before Joey becomes aggressive or self-injurious. We also learned to prompt appropriate language "clean up" as we cleaned up. If Joey aggressed, we ignored the spilled water and followed our behavior protocol. After practice, Joey learned to say "clean up" instead of banging his head and pulling hair. Eventually, we taught Joey how to ask for a towel or to get a towel and clean up the water himself."

– BH, parent

Redirection can be a very powerful tool, giving you the opportunity to steer your child into a situation that is more positive, or more manageable. It also helps to avoid or calm an escalating situation. The use of a time out can vary considerably, and to be most effective, it is important that it is done correctly. A time out is not just a change in location—it means your child loses access to something he finds rewarding or cool. For more complete discussion on how best to use time out, see the ATN ABA guide or this parent training information.

Other strategies your behavioral team might employ include teaching accountability (if he spilled the milk, he is the one to clean it up), or using positive practice, sometimes known as do-overs. For example, if he let the door slam in someone’s face, he might practice in the doorway how to enter the house and hold the door five or ten times. *‘Oops, let’s practice doing that that the right way.’* In doing this, try to limit the sense of punishment, keeping positive strategies employed (reinforcement, praise) to build the desired behaviors over time. *‘I love that you noticed I am right behind you and you held the door open!’*

- When behavior does occur, be careful not to:
- Feed into the behavior, give in or provide what your child wanted to get from the behavior
- Show disappointment or anger
- Lecture or threaten
- Physically intervene (unless necessary for safety, such as keeping a child from running into the street)

A new look at time-out

Contrary to popular belief, time-out is not sitting in a chair for a few minutes. Time out is losing access to cool, fun things as a result of exhibiting problem behavior, usually by removing the individual from the setting that has those cool, fun things. Time-outs can only occur when the individual is in time-in. That is, if nothing enjoyable was happening before time-out, you are simply removing the individual from one non-stimulating, non-engaging room to another.

For example, if the individual is watching her favorite TV show, but hits and screams at her sibling for getting in the way, taking her to a chair located in the same room will not serve as a time-out since she can still see and listen to the TV. Removing her from accessing the TV completely, however, is an example of a time-out. In this case, time-in (watching a favorite show) was in place, allowing for time-out to be effective upon the occurrence of the problem behavior. Once the individual is in time-out, let her know that she must be calm for at least 10 seconds (or a duration of your choosing, usually shortly after he is calm) before she can return to time-in. Do not talk to the individual or explain to her what she did wrong while she is in time-out. You may use a timer to indicate to the individual when the time-out will be over. When the timer goes off, he should be allowed to return to what he was doing, i.e. time-in.

How to use time-out correctly

- *A fun, enjoyable activity should be in place before using time-out (e.g. playing video game, visiting friends).*
- *Time-out should not lead to the individual avoiding or delaying an unpleasant task or work activity*
- *Time-out should take place in a boring and neutral setting.*
- *No attention should be given during time-out. Simply tell the individual, “You hit your brother, no TV. Go to time-out until you are calm”.*
- *Time-out should be discontinued shortly after the individual is calm and quiet (approximately 10 seconds of calm behavior).*

– page 74, Targeting the Big Three

Resources:

Behavioral Relaxation Training and Assessment
by Roger Poppen

Behavioral Relaxation Training (BRT): Facilitating acquisition in individuals with developmental disabilities
by Theodosia R. Paclawskyj, Ph.D., BCBA, and J. Helen Yoo, Ph.D.,

The Cycle of Tantrums, Rage, and Meltdowns in Children and Youth with Asperger Syndrome, High-Functioning Autism, and Related Disabilities
by Brenda Smith Myles and Anastasia Hubbard

How to teach self-management to people with severe disabilities: A training manual
by Lynn Koegel

Self-Management for Children With High-Functioning Autism Spectrum Disorders
by Lee A. Wilkinson

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism
by Mary Wrobel

Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting
by Helen Yoo, Ph.D, New York State Institute for Basic Research
Autism Speaks Family Services Community Grant recipient

Autism Fitness.com : Leading Authority in Autism Fitness
Eric Chessen

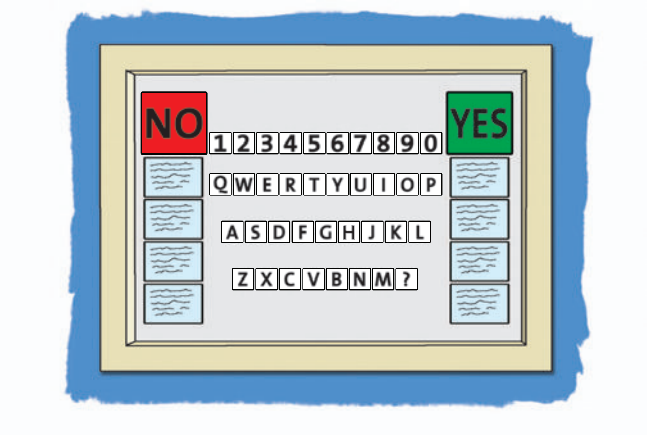
Depression and Anxiety: Exercise Eases Symptoms
Mayo Clinic

Exercise for Mental Health
Primary Companion to the Journal of Clinical Psychiatry

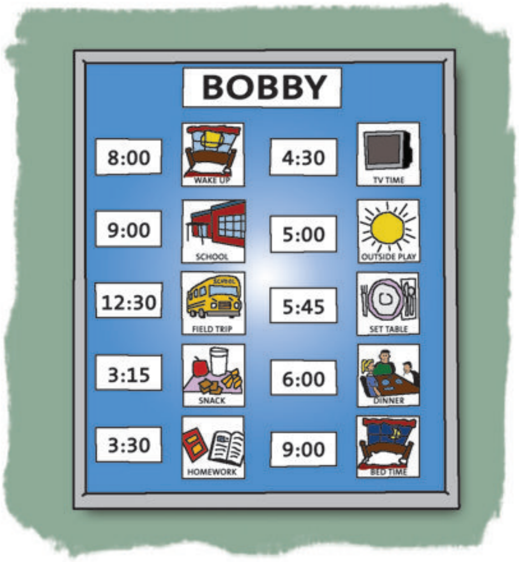
C.O.P.E.S.™

The COPES program uses individualized programs for each of their students that incorporates the following elements:

- *Communication:* students were given immediate access to communication for emotional issues. Multi access approaches were tailored to the student's needs using YES - NO boards, icons, and iPads with augmentative apps. Teach communication at his level and start with what is most essential.



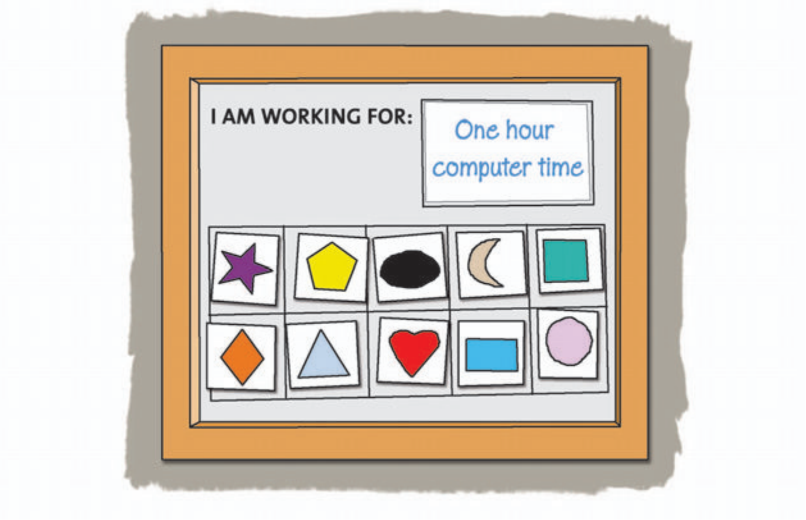
- *Organization:* many of the students showed considerable anxiety and a complex array of escape and avoidance behaviors since they had no systems to help them organize and anticipate events, daily schedules, changes in schedules and or future events. Simple schedules and training on basic contingency management and use of visual supports showed rapid changes in behavior and reduced anxiety.



Tommy's Schedule Monday	All Done
Put Backback in Cubby	
Independent Work	
Morning Meeting	
Reading Time	
Music Class	
Lunch	
Recess	
Special Reading Group	
Pack Up Backback	
Go Home	

- *Postive behavior supports:* Even though all of the students had prior FBAs and complex contingency management systems, the interventions often failed since they were too little, too late. By being reactive instead of addressing why the behavior occurred in the first place, the previous interventions were sending the message that the student's behavior was frustrating, but missing the opportunity to prevent its occurance in the future. Prevention had to be addressed as a primary objective and replacement skills needed to be built using positive behavior supports. Simple token charts were introduced and each student was reinforced for success, as simple as walking into a room nicely to sitting for a minute in a chair. The students responded immediately to being honored and acknowledged for the things they did right, though they were in shock at first since they were accustomed to primarily negative feedback. You could almost see the questions in their faces—What do you mean I'm being given constant feedback? And it's positive!

  Example of reinforcement steps to earning computer time:



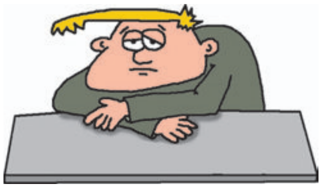
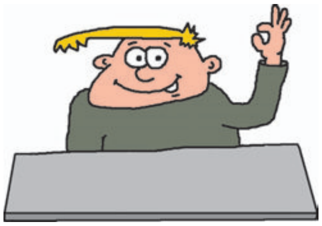
- *Emotional regulation:* Starting on day one of the behavior support plan, each student was systematically taught to understand and identify his own regulatory state and escalation cycle. Proactive programming was essential. Empowerment and self-determination was a significant part of the program and the students responded immediately to their involvement in their plans. The plans were based on knowing that the student who understands that stress, anxiety and specific activities or situations often result in tension, frustration, and behaviors, is a student who has a chance of self-regulating.

  The program has been taught successfully to numerous students with limited to no verbal skills. Individuals with limited verbal skills are often assumed to be without a full range of emotions, with limited ability to comprehend what others are saying. As a result they live frustrating lives. These students are often misunderstood and their emotions, feelings and responses are not fully considered. People talk about them as if they are not there and they make judgments and statements that do not take into account for the full depth of their feelings, thoughts and opinions.

  - Teaching the student his escalation cycle does two main things:
  - it allows him to have some say or opinion in his program
  - it teaches him to be aware of the things that cause him anxiety or frustration that often leads to disruptive behaviors, and teaches him corresponding strategies for self-regulation

An example of the visuals used to teach a student to identify his regulatory state and what to do to 'get to green':

My Self -Management Plan

	The behaviors I exhibit when I feel this way	What I need to do-
 I AM HIGH	🟥 I grab others 🟥 I hit and bite 🟥 I yell loud 🟥 I cry loudly	🟥 Sit and breath- deep breaths 🟥 I need to be in a safe place 🟥 go to the beanbag and stay there! 🟥 Get to yellow
 I AM LOW	🟨 I look tense, my shoulders and body are tense 🟨 I bite my tongue 🟨 I click my neck and fingers 🟨 I look red and sad 🟨 I need everything to be in its place	🟨 Take a sensory break 🟨 Ask for help 🟨 I need someone to write and explain what's going on! 🟨 I need to take DEEP breaths
 I AM CALM	🟩 I can sit and focus 🟩 I can follow my schedule 🟩 I can answer with my voice 🟩 I do respond to others and I look relaxed!	🟩 I can earn my points and get preferred breaks

- *Sensory and social:* Each student has a systematic exposure to community and or social outings that includes the golden rule--no community and/ or social access when the student is in any other state but green. This decreases the chances for the student to be in dangerous situations where staff have to try to manage behavior and risk inadvertently reinforcing behaviors because the safety risk is too high.

  Social skills are focused on as reciprocal interaction, not necessarily frustrating, overwhelming exposure to typical students. The social success is based on the student being motivated and able to access the social situation. Start small and be successful. Building confidence in the student has to come first and regulation is key to that confidence.

What might I need to know about Managing a Crisis Situation?

Generally, when a child is engaged in the active, disruptive stage of a behavior, such as a tantrum or aggression, the essential focus has to be on the safety of the individual, those around them, and the protection of property. It is important to keep in mind that when he is in full meltdown mode, he is not capable of reasoning, being redirected, or learning replacement skills. However, this level of agitation does not usually come out of thin air. You can learn skills to help anticipate and turn around an *escalating* situation that seems to be headed in this direction.

In case of emergency, call 9-1-1. Always take suicide threats seriously!

"Both my husband and I have thought of calling 911 before but we were too scared of the unknown. Finally one afternoon we were in a difficult situation with our son and we knew it was time to make the call. It was one of the hardest decisions we have ever had to make, but it was the right one – for our son's safety and ours as well."
–CH, Mother

Have a Plan

Preparation and strategies for coping and staying safe in these situations is essential and it is important for the team, including the family, to develop a *crisis plan* together. A well-designed plan will include:

- Defined setting events, triggers or signs that a crisis situation might develop
- Tools and strategies for keeping the individual and those around him safe in any setting (school, home, community)
- Intervention steps and procedures promoting de-escalation that are paired at each level with increasing levels of agitation
- Lists of things to do and NOT to do specific to the history, fears and needs of the individual
- Hands on training and practice for caregivers and staff
- Data collection and monitoring for continued re-evaluation of the effectiveness of the plan
- Knowledge of the best prepared facility if hospitalization or an Emergency Room visit might be necessary
- Secured guardianship if your child is above age 18 and you need to continue to make decisions for him (See the Autism Speaks Transition Tool Kit for more information)

Providers and families who have experienced crisis highlight the need to maintain safety first and foremost. This is not the time to teach, make demands, or to shape behavior.

Know Ways to Calm an Escalating Situation

- Be on alert for triggers and warning signs.
- Try to reduce stressors by removing distracting elements, going to a less stressful place or providing a calming activity or object.
- Remain calm, as his behavior is likely to trigger emotions in you.

- Be gentle and patient.
- Give him space.
- Provide clear directions and use simple language.
- Focus on returning to a calm, ready state by allowing time in a quiet, relaxation-promoting activity.
- Praise attempts to self-regulate and the use of strategies such as deep breathing.
- Discuss the situation or teach alternate and more appropriate responses once calm has been achieved.
- Debrief with the individual, as well as the team, to prepare for increased awareness of triggers and strategies for self-regulation in future experiences.

In the midst of a Crisis Situation

- Remain as calm as possible
- Assess the severity of the situation
- Follow the Crisis Plan and focus on safety
- Determine whom to contact:
  - Dial 211 for free, confidential crisis counseling
  - Dial 911 for an emergency: fire, life-threatening situation, crime in process, serious medical problem that requires mental health and basic life support ambulance services
  - Call local police for non-emergencies

Disclosure to a Police Officer:

> *"The decision to disclose your (or your child's) diagnosis to a police officer will always be yours to make. If you have learned through experience that disclosure would be helpful in the particular situation, you may decide to disclose to a police officer. Law enforcement officers report that they make their best decisions when they have their best information. A good, strong autism or Asperger Syndrome diagnosis disclosure that includes the use of an information card, contact information for an objective professional, and proof of diagnosis should be considered."*
>
> – *Dennis Debbaudt, a parent and leading voice*
> *on autism training for law enforcement and*
> *emergency responders*

When severe and dangerous behaviors pose a risk of physical harm to the individual or to others in the vicinity, physical restraints or seclusion as a brief intervention are sometimes necessary to maintain safety.

Physical restraints are physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely.

Seclusion (putting the individual briefly in a room by himself to 'calm down') is often employed in schools and other group environments. Seclusion can provide a quick halt to an immediate threat, but in the long run, seclusion is not a solution to the behavior itself, especially if the function of the behavior is to escape or avoid something. School programs should be focused on developing functionally based, positive behavior intervention plans to eliminate the need for seclusion practices all together.

It is important to note that while restraints and seclusion can serve to maintain safety, it is an intervention of last resort and should only be used when less restrictive and alternative interventions are not effective, feasible, or safe. Improper use of these techniques can have serious consequences physically and emotionally. Parents and caregivers should seek out and receive professional guidance and training on positive behavior interventions and supports, crisis prevention, and the safe implementation of restraints and seclusion techniques when necessary.

Managing a Crisis at Home

Having a Crisis Plan is an important step, and it might be helpful to create this with your team or behavioral provider. Some families have emergency information cards with vital information and signs posted to alert first responders. Strategies for keeping the individual with autism and other family members safe during episodes of aggression or self-injury are most important. Being prepared for an individual who is inclined to outbursts and times of aggression or property damage can help everyone feel safer. The strategies outline in Making Homes that Work might be helpful.

Managing a Crisis at School

For school age children, there are protections under the *Individuals with Disabilities Education Improvement Act (IDEIA)* that pertain to behavioral considerations, functional behavior assessments, and positive supports. The school will need to have a behavior intervention plan (BIP), and your child's educational team should provide you with materials to explain your rights and your child's rights under educational law. You need to approve the plan, and the defined behavioral targets, expectations and interventions should be clear to you, your loved one and his entire team. If you need information or training, ask! Be persistent.

In the case of a significant aggressive or other concerning behavior at school, the staff or the family can call an emergency IEP meeting to discuss placement, BIP and other considerations. Special Needs, Special Gifts offers some insights into challenging behaviors in the school environment and the responsibilities and warning signs.

Your school team may suggest the use of seclusion and/or restraints, but these controversial interventions should not be undertaken lightly. It may also be helpful to know the regulations as they pertain to challenging behaviors and the use of suspensions and expulsions. There are certain protections afforded students with special needs under a provision in IDEA. The Wrightslaw page Behavior Problems & Discipline: What Parents and Teachers Need to Know contains great information on this topic.

Managing a Crisis in the Community

"My daughter has had quite a few tantrums in our community that have escalated. This encouraged my family and I to take steps to let my local neighborhood know about my daughter's behavior— by posting autism cards, in my car window, on our front door, etc.

The other thing that really helps my family is that we travel in pairs. This means that someone is always around to help whomever my daughter is with. As a parent, I always worry about my child's safety, so I try to find a "safe place" while I'm out to take her to when there's a problem, Places like family bathrooms or even dressing rooms in clothing stores work when she needs to calm down or re-focus. I also spoke to our state's DMV about getting a handicap placard for my car that I only use when my daughter is with us--so I can make that bee-line to the car even faster!

The other thing that helps a lot is placing a Family Emergency Kit in the trunk of each car we travel in. Much like the ones used during pregnancy and in Disaster Emergency Preparedness Kits, I add a comfortable change of shoes/clothes, personal items, an extra insurance card, her medic alert necklace info, even my CPI card-to show that I'm trained. I complete each kit with a few extra sensory items she might like and extra water and snacks, in case she might be cranky because she's hungry and cannot say so. Also, in each kit, I started packing a few care items for myself, just in case we had to go to the hospital so that I would be more at ease, during our wait. The last thing I do very *frequently, is make sure I bring any medication for my child and for myself so that neither one of us get off our meds. One time my daughter's meds had changed recently, and my daughter had to go to the ER. As it turned out ,I was the only one with the meds she needed, right there in my kit!"*

– KV, a parent

Emergency Personnel Response and Interacting with Law Enforcement

Training in autism awareness is increasing, but has certainly not been universal across the United States. It is important that you understand that EMS personnel might not know that 'he has autism' means that he might have difficulty understanding directions, or respond poorly to flashing lights, a blood pressure cuff or other actions. It can be helpful to have information (on a card) ready to pass along or to find ways for your local responders to get to know your child. You might advocate for training in your local emergency departments. Visit the Autism Safety Project page for tools and more information for emergency personnel.

Police and Law Enforcement Response, Judicial System

It is important to remember that police and law enforcement officers, such as security guards and TSA agents, often have little training in autism awareness and response. Sometimes a person with autism will appear to be dangerous or on drugs to a law enforcement officer. The unpredictable behaviors and communication challenges of autism, coupled with variable social understanding of authority have been known to have dire consequences. It is important to keep these factors in mind when interacting with law enforcement.

You may encounter law enforcement when you are out in the community. If your loved one has especially troubling behaviors, you may have occasion to call them into your own home. It is important to get to know your local police department and have them get to know your child. Advocate for training and sensitivity concerns. Find resources and training information to pass along to law enforcement officers and other professionals on the Autism Safety Project page.

If police are involved and your loved one is charged with a crime, there are special considerations within the legal system. Information for Advocates, Attorneys, and Judges supplies additional background information and statistics on autism for legal representatives.

"Persons with autism who are able to navigate the community without assistance should strongly consider developing personal handouts, along with the skills and resiliency to risk necessary to appropriately disclose their need for accommodations. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome. What's the best tool to use when you decide to disclose your autism or Asperger Syndrome to a police officer? A handout card:

- *Develop a handout card that can be easily copied and laminated.*
- *Remember that the handout card is replaceable. You can give it away to the officer on the scene.*
- *Carry several at all times.*
- *The handout card can be generic or specific to you.*
- *Work with an autism support organization to develop a generic handout.*
- *Work with persons whose opinions you trust and value to develop a person-specific handout."*

– Dennis Debbaudt, a parent and leading voice
on autism training for law enforcement and
emergency responders

How do I know it is time to get more help?

Many families work diligently at home to help their children with autism negotiate the many challenges the world presents for them. However, it is important and necessary to seek professional help when:

- Aggression or self-injury become recurrent risks to the individual, family or staff
- Unsafe behaviors, such as elopement and wandering, cannot be contained
- A threat of suicide is made
- An individual presents with persistent change in mood or behavior, such as frequent irritability or anxiety
- A child shows regression in skills
- The family can no longer care for the individual at home

Sometimes this journey starts with a trip to the Emergency Room, when a person is in crisis and the caregiver or family needs immediate help. Sometimes it occurs in a more planned way, at the advice or urging of a doctor, mental health provider or other member of a team.

What can I expect at the Emergency Room?

Whether it is for behavioral concerns or just necessary medical care, the emergency room can be a difficult place for people with autism. Treating autism patients in emergencies presents challenges describes some of the challenges and makes suggestions for medical staff regarding how they might be more accommodating. It might be helpful to pack this in your emergency prep kit and pass it along to ER staff upon your arrival. Be prepared to advocate yourself.

If you are requesting a *psychiatric evaluation*, it is important to bring documentation of the behaviors that are causing concern, information about psychiatric history, any previous psychiatric evaluations, recent FBA and/or BIP, a list of current and past medications and other relevant information. Names and contact information for doctors, your behavioral provider or other important team members will be helpful. Having all of this information in writing, in one place, will help you be prepared in the event of a crisis.

Alternately, a call to the police might trigger their concern for the person or those around him, and the officer might issue orders to have the individual transferred to the ER, even if that is not your wish. In either case, the police officer or the hospital staff can place the person on a *Mental Health Hold*. When a person is placed on a mental health hold, they can usually be held for up to 72 hours for a psychiatric evaluation. This does not necessarily mean that the person will be held for the entire 72 hours. The evaluation often takes place within 24 hours.

Before a psychiatric evaluation can occur, the ER staff must evaluate and medically clear the individual. In many cases, they are likely to do a drug screen and toxicology report. The process to get medical clearance may take several hours, and maybe longer based on the staffing and volume at the ER and the complexity of the medical situation. Then a psychiatric evaluation will be performed, and will include interviews, a record review and an examination. For more information, see Psychiatric Evaluations in the Emergency Room.

Many trips to the emergency room will involve calming the individual, often with medication, and then releasing him and sending him home. Arriving at an ER does not necessarily translate into an admission to the hospital. Sometimes, the ER visit will turn into a longer stay of 1-2 weeks, with the length of stay sometimes a reflection of insurance issues.

If the hospital staff decides that the individual is at particular risk of harm to himself or others, they may recommend commitment to a mental hospital or psychiatric ward. It is important to know that if you or the adult patient does not approve, the law provides for a process known as *Involuntary Commitment* or *Civil Commitment*. This allows for court-ordered commitment of a person to a hospital or outpatient program against his will or protests.

Psychiatric Inpatient Hospitalization: How do you choose a facility?

Often individuals are brought to the nearest hospital or the closest one that has an open bed. While this may be the fastest response in a crisis, it is best to be at a facility that can best respond to the needs of your child. If possible, discuss with your providers ahead of time if there is a preferred treatment setting for individuals with autism in the event of crisis. Some hospitals have a psychiatric emergency room.

In a few states, there are specialized hospital programs specifically designed for individuals with autism and other developmental disorders. These Crisis Intervention Centers can often provide more targeted treatment options and assessment expertise. Pre-planned stays in *bio-behavioral units* may be hard to arrange since so few of these facilities exist, but the length of stay is generally a 3 to 6 month period.

What happens when you check into a hospital?

Just as you might do when planning a trip, it is important to remember to bring your loved one's necessary supports, including communication devices, visual supports, preferred toys and sensory items, as well as a familiar blanket or pillow. Entering a hospital can be quite stressful, so anything you can do to reduce anxiety and increase predictability should be considered.

If your child or loved one is placed in a psychiatric facility or ward, it will be important for you to help the staff understand his particular skills and challenges. You should be prepared for the fact that unlike many medical situations you may have experienced, a psychiatric ward is likely to have locked doors and may have stricter limits on visitation. You may not be able to be present during your child's entire stay or there to be his 'interpreter' of behaviors, food aversions, fears and anxieties as you might otherwise do. These facilities are not obliged to provide behaviorally-based treatments and interventions, though some do.

You may need to advocate for a role in helping the hospital to understand your child. In particular, it might be important to advocate against the use of restraints for your loved one, as this may increase anxiety and the intensity of negative behavioral responses. There are established policies on the use of restraints and seclusion in healthcare that you can read here. You can also request that a medical provider who knows your child be involved with the hospital staff.

> *"When Kevin ended up in the psych unit at our state hospital, it was incredibly valuable to have out autism doctor involved in his care. The hospital staff did not get it when it came to autism and Kevin, and our doctor was very helpful at running interference."*
>
> *– SB, parent*

Most hospitals are family-friendly and have extended visiting hours for children. Separating from your child can be difficult and leave you with feelings of guilt, but it is essential to remember that this is in the child's best interest. He needs specific help, and you need an opportunity to recover from a challenging situation.

Patient Rights

Patients receiving services in a hospital have the same human, civil and legal rights accorded all minor citizens (those under the age of 18) or adults. Patients have the right to a humane psychological and physical environment. They are entitled to respect for their individuality and to recognition that their personalities, abilities, needs and aspirations are not determined on the basis of a psychiatric label. Patients are entitled to receive individualized treatment and to have access to activities necessary to achieve their individualized treatment goals.

Commitment-Involuntary vs. Voluntary: As mentioned above, a psychiatric evaluation will be performed to determine if the individual is a danger to himself or others. If he is considered a danger, he can be committed against his (or your) will with a court order.

Parent Rights

Parents (or guardians) retain their legal rights for decision-making regarding the health and welfare of their child under the age of 18. Parents have the right to informed consent to treatment, including notification of the possible risks and benefits of any treatment that is proposed. Parents have the right to be involved in the treatment that is provided to their child, which includes visiting their child during the course of their treatment, ongoing communication from the providers about the child's progress, and copies of medical, behavioral and educational records.

If you feel your child would be better served in a different setting, you should engage the attending physician and other members of the hospital clinical team in a discussion of the risks and benefits of changing treatment programs. While you know your child best, it is important to evaluate the implications for safety and treatment in any setting being considered.

Age of Majority and Guardianship: For many years, you have been making decisions on behalf of your loved one with autism. But at the age of 18, the law says he gets to decide for himself and can give the required *'informed consent.'* He can refuse treatment or be declared unfit to decide. Either way, unless you apply for and are granted *guardianship*, the decisions are now out of your hands. If you think your loved one will need your assistance in making medical, safety and/or financial decisions, it will be important for you to learn about and consider your state's laws and procedures for obtaining guardianship status. This may take some time and the process involves a series of procedures, so it is important to consider this in advance of his 18th birthday, if possible. Sometimes there are allowances for temporary guardianship status while guardianship proceedings are in process. Guardianship is different from conservatorship, which allows for financial responsibility of another person. You can learn more in the Transition Tool Kit section on Legal Matters to Consider.

What happens when the Hospital Stay is over? What is a Discharge Plan?

When the hospital stay is complete, your child or loved one should leave with a Discharge Plan created by the hospital, ideally with the input of other team members. It is not necessary for you to agree to the terms or components of the plan, but the hospital is required to counsel you, your loved one and other relevant team members about the components of the plan. The hospital is also supposed to begin implementation of the plan and assist in the coordination and connection to local social services organizations, making referrals or transfers and forwarding information and records. Such a plan is not likely to occur after a brief ER stay, but should be developed for your child over the course of an extended inpatient hospitalization. A discharge plan should include:

- A statement of your child's need, if any, for:
  - Supervision
  - Medication (what, when, how much)
  - Aftercare services and supports
  - Assistance in finding employment
- Recommendation of the type of residence in which your child is to live and a listing of the services available to your child in such residence
- Lists of the organizations, facilities, and individuals who are available to provide services in accordance with each of your child's identified needs
- Notice to the appropriate school district, if relevant, regarding the proposed discharge or release of your child
- An evaluation of your child's need and potential eligibility for public benefits following discharge, including public assistance, Medicaid, and *Supplemental Security Income*
- Follow-up evaluation plans

For anyone who has been hospitalized for any reason, recovery is best when there is a solid support network. This network can be family, friends or team members, often working together. Involving others in the discharge process will help your loved one and support you in moving forward. To learn more, visit **Discharge Planning in Mental Health**.

Contributions to this section were made by Matthew Siegel, M.D.

Long Term Solutions: What if we just can't do this anymore?

Sometimes, a team gels beautifully and medical supports and positive interventions are effective in bringing an individual with autism the sense of security and the skills he needs to thrive in his home or community environment. However, sometimes factors such as limited resources, dual diagnoses, biological triggers or learning history can mean that a family needs more support than can be provided at home, and alternate solutions need to be considered.

This is not an easy decision to make, and often comes with considerable stress for everyone involved. It is important to remember that this decision is NOT giving up on your child. In many ways, it is recognizing that your child needs more than you can provide, and taking the steps necessary to allow him to grow and thrive in a place that is able to provide what he needs. This might mean a place with a 24-hour staff who can provide something that is not possible for a single individual, or a residential facility that supports his physical concerns as much as his behavioral needs. It is hard to be consistent and upbeat and follow a behavior plan when you are exhausted and deflated. It is difficult to be a family and support each person's needs, wants and growth, when everyone is afraid. Many families who have experienced a family member with significant challenging behaviors have reported on a much-improved relationship with their child once he was placed in a residential program that met his needs.

"If I could give any advice to parents going through this, I would tell them that it's not always an easy road, and a lot of times it can be scary. But you aren't alone, it can get better. I would tell them to reach out for help, because you can't walk this road alone. Each day is a new adventure, new challenges and new successes."

– DM, a mother

Residential placement is a personal decision that should be made when a family is no longer able to care for the needs of their child at home. For individuals with challenging behaviors such as aggression or self-injury, this may occur earlier in life than the usual transitions that occur in adulthood. It is also important to note that a residential placement is not necessarily permanent. If your team is able to build supports and skills and address underlying concerns, it may be possible for your child to return home.

A case manager or service coordinator from your school or social services agency can help to search for an appropriate setting for your child. Often, parents want to find something close to home so that they can maintain a relationship and contact with the child and his providers.

For help, visit these resources:

- Autism Speaks Housing & Residential Supports Tool Kit
- Autism Speaks Catalog of Residential Services
- National Disability Rights Network
- Disability.gov Housing Resources
- Global & Regional Asperger Syndrome Partnership (GRASP) – list and map of GRASP support groups

Where can we learn more?

Family and Caregiver Training

This tool kit is a lot of information in writing, and that is not always the best way to learn. Families who need additional information and supports will benefit from specific training and supports.

- *Hands on Training:* Ideally, this is from a behavior analyst or other behavioral provider who is part of your child's team at school or home who can individualize training to your child's needs. It is individually designed to the needs of your child, your family, and responsive to the findings of the functional behavior assessment. It would occur in your home or in the settings where you need the assistance and training. Insurance laws are increasingly providing coverage for autism services, including ABA and behavior supports. Ask your doctor or case manager for suggestions.
- *State or local ABA or autism conferences:* Many conferences, presentations and workshops will focus on autism and case studies related to the treatment of challenging behaviors, or skills that might help to replace those behaviors. Visit ABA International to learn more.
- *Training Classes in Behavioral Approaches:* Parenting classes are often held at autism support groups, local hospitals, YMCAs, social services agencies, and the National Alliance on Mental Illness. Only some will be autism specific. These classes may provide you with tips and skills, as well as access to people and resources you might not already know about who can provide or suggest more specific services. Mental Health First Aid USA may also be a helpful resource.
- *Watch SuperNanny episodes on TV or YouTube:* She employs good behavioral strategies with respect to setting boundaries and expectations, staying calm, rewarding desired behavior and incorporating fun. These principles apply in autism just as they do with typical children.
- *Take care of yourself:* Parenting is hard enough, let alone when the demands of a child with special needs and challenging behaviors are added into the mix. Find strategies to improve your sleep, your *resilience* and your ability to remain calm and nourished. Classes in yoga, mindfulness and other stress reducers might be helpful. Talk to your friends and family, and find some time for fun. Seek out local supports for *respite* from community agencies, your place of worship or friends and family. Spend time with your other children and your spouse. Ask for help. Breathe. Visit the Autism Speaks Resource Guide to find respite care and support groups in your area.

"My friends were always reaching out to me to get lunch or a cup of coffee. Most of the time I felt too busy to step away from taking care of my son. Any time away from his needs felt like I wasn't being a good parent. One day my friend happened to call just as I was running out to the grocery store – she convinced me to meet her for a cup of coffee beforehand. Once I met her and sat down to chat and relax for a few minutes, I realized how much I needed it. I now make time every week to see my friends, or have a little 'me' time. Ultimately I think I'm a better parent and person because of it."

– AC, a mother

Resources:

211 Database Service
Available in much of the US, this service connects people with important community services, sponsored by United Way Worldwide (UWW) and the Alliance for Information and Referral Systems (AIRS).

ABA Training & Treatment - Behavior Frontiers

Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns
by Brenda Smith Myles and Jack Southwick

Managing Threatening Confrontations DVD
from the Attainment Company

No More Meltdowns: Positive Strategies for Managing and Preventing Out-Of-Control Behavior
by Jed Baker Ph.D.

The Way to A: Empowering Children with Autism Spectrum and Other Neurological Disorders to Monitor and Replace Aggression and Tantrum Behavior
by Hunter Manasco

Provider Training

Many schools and service providers will have trained staff accustomed to handling challenging behaviors. Others will not. Service providers who need additional information on positive supports and crisis prevention and management can utilize the following resources for information and training:

- Positive Behavior Supports
- Kansas Institute for Positive Behavior Support
- The New England Center for Children "CALM" Curriculum
- Safe and Civil Schools
- Crisis Prevention Institute
- Quality Behavioral Solutions to Complex Behavior Problems
- Mental Health First Aid USA

Conclusion

Autism can bring a family many challenges, especially when a loved one with autism exhibits behaviors that are challenging, disruptive, or dangerous. These are often experiences that our siblings, parents and best friends do not quite understand, since they have not necessarily faced the same concerns. As a result, many families with loved ones with autism experience significantly high levels of stress, which can be disruptive and unsettling. However, many families have also shown resilience and an ability to bounce back from the challenges that autism presents with humor, grace and increasing strength.

It is important to get help. Cry when you need to. Lean on your friends, extended family, and other social supports. Connect with other parents who are experiencing similar challenges and swap stories and vent together—find them at support groups or places like www.meetup.com. Investigate counseling supports through your insurance plan, place of worship or community services agency.

Use the information in this tool kit to seek out information and team members who will support you, and help your loved one to grow to become all he can be. Take small steps, and celebrate the growth and accomplishments along the way. Be the detective that helps you better understand—and hopefully better accept—your child and the difficulties he faces as he goes through life. Use the strategies and resources in this kit and from your team to help you build a place in which everyone feels safer and more successful. Advocate for help when you need it. Find resources or create a plan for respite care so that you get a break too, and use it!

Recognize the resilience your loved one with autism shows each and every day. Celebrate the things he says or does that make you laugh: his dimples, his artwork, his smile. Sure, you may cry or swear sometimes. But also rest. Breathe. And celebrate the successes one at a time, whenever and wherever they come.

"A multidimensional, comprehensive approach to ASD that emphasizes the development of positive, constructive behavior, builds family cohesiveness and mutual support, focuses on successful home and community living, and addresses systemic barriers to progress will not "cure" autism, but it will make it possible to live happily with autism. These goals are realistic and can be achieved now."

– Ted Carr, Ph.D.,
State University of New York at Stony Brook

Challenging Behaviors Glossary

- *A-B-C Analysis:* an approach to understanding behavior by examining the Antecedent (the cause), the Behavior, and the Consequence (the result)
- *ADHD (Attention Deficit Hyperactivity Disorder):* a problem with inattentiveness, over-activity, impulsivity, or a combination, that is out of the normal range for a child's age and development
- *Age of majority:* the age established under state law when an individual is no longer a minor and has the right to make certain legal decisions without consent
- *Allergies:* adverse immune responses or reactions to substances that are usually not harmful (i.e. pollen, peanuts, gluten)
- *Anxiety disorder:* a pattern of constant worry or tension under many different circumstances
- *Applied Behavior Analysis (ABA):* the systematic approach to the assessment and evaluation of behavior, and the application of interventions that change behavior
- *Audiologist:* a professional who diagnoses and treats a patient's hearing and balance problems using advanced technology and procedures
- *Autism Spectrum Disorders:* a group of complex disorders of brain development characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors
- *Aversive:* an unwanted stimulus designed to change an individual's behavior through punishment
- *Behavior Improvement Plan (BIP):* a plan to improve a student's behavior in school created based on the results of a Functional Behavior Assessment
- *Behavioral disorder:* a condition in which behavior significantly deviates from acceptable norms
- *Behavioral drift:* changes in behavioral patterns resulting from gradual and subtle adjustments over time
- *Behavioral stereotypy:* repetitive or ritualistic movements such as body rocking or crossing and uncrossing of legs
- *Biobehavioral unit:* a psychological and psychiatric clinic within a hospital or research center that treats behavioral, anxiety and mood disorders
- *Biomarker:* an indicator of a certain biological state
- *Bipolar disorder:* a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks; also known as manic-depressive illness
- *Blinded:* unaware of a new or different intervention, which prevents bias during evaluation
- *Board Certified Behavior Analyst (BCBA):* a professional certified to provide ABA therapy by the Behavior Analyst Certification Board (BACB)
- *Bulimia:* an illness in which a person binges on food or has regular episodes of overeating and feels a loss of control, then uses different methods – such as vomiting or abusing laxatives – to prevent weight gain

- *Case manager:* a professional from a school or service agency such as the Department of Developmental Disabilities who serves as a direct contact for families and helps gather resources, team members and ideas
- *Catatonia:* a state in which a person does not move and does not respond to others
- *Challenging behaviors:* behaviors that are destructive and harmful to the individual or others, that prevent learning and cause others to label or isolate the individual for being odd or different
- *Civil Commitment:* a legal process in which an individual experiencing a mental health crisis is ordered into treatment against his or her will, including to a hospital
- *Comorbid:* pertaining to a disease or disorder that occurs simultaneously with another
- *Cognitive behavioral therapy:* a type of therapy designed to help improve an individual's inappropriate or challenging behaviors by replacing the negative thoughts that cause these behaviors with positive thoughts
- *Compulsion:* the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table
- *Conservatorship:* the legal right given to a person to be responsible for the assets and finances of a person deemed fully or partially incapable of providing these necessities for himself or herself
- *Crisis plan:* a document that outlines in specific detail the necessary strategies and steps that must be taken when a crisis occurs
- *Data analysis:* the process of thoroughly inspecting information related to challenging behaviors in order to draw out useful information and conclusions that may result in strategies to improve behavior
- *De-escalation:* the process of stopping a challenging behavior or crisis from intensifying, and calming the situation
- *Depression:* a mood disorder in which feelings of sadness, anger, or frustration interfere with everyday life for an extended period of time
- *Differential diagnosis:* distinguishing between two or more diseases with similar symptoms to identify which is causing distress or challenging behavior
- *Disruption:* an event that causes an unplanned deviation from a situation
- *Dual diagnosis:* the identification of an additional mental health disorder individuals with developmental disabilities
- *Elopement:* a situation in which an individual leaves a safe place, a caretaker, or supervised situation, either by 'bolting,' wandering or sneaking away
- *Epilepsy:* a brain disorder in which a person has repeated seizures (episodes of disturbed brain activity or convulsions) over time
- *Escalating:* increasing or worsening rapidly
- *Extinction:* a response used to eliminate a behavior that involves ignoring a mild behavior when it is used for attention

- *Extinction burst:* the short term response to extinction in which there is a sudden and temporary increase in the response's frequency, followed by an eventual decline
- *Face blindness:* an impairment in the recognition of faces
- *Fecal digging:* the process in which an individual puts his fingers into his rectum
- *Fecal smearing:* the process in which feces are spread on property or the individual himself
- *Food allergies:* an adverse immune response to a food protein (i.e. dairy products) that may cause rashes, gastrointestinal or respiratory distress
- *Function:* the purpose or desired result
- *Function of behavior:* the purpose or reason behind a specific behavior for an individual
- *Functional Behavior Assessment (FBA):* the process by which a school thoroughly examines a student's problem behavior using strategies such as close observation, questionnaires, active listening, previous experiences, etc.
- *Functional communication:* effective and appropriate communication that an individual uses across his daily activities to meet his or her needs
- *Gastroenterologist:* a professional specializing in disorders of the digestive system
- *Guardianship:* the legal right given to a person to be responsible for the food, health care, housing, and other necessities of a person deemed fully or partially incapable of providing these necessities for himself or herself
- *Hormones:* chemical messengers that travel in an individual's bloodstream to tissues or organs slowly, over time, and affect many different processes, including brain activity and behavior
- *Immunologist:* a physician specially trained to diagnose, treat and manage allergies, asthma, and other immunologic disorders
- *Incontinence:* the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper
- *Individualized Education Program (IEP):* a written statement for each child with a disability that is developed, reviewed, and revised in meetings within the school so an individual's education best meets his or her needs
- *Individuals with Disabilities Education Improvement Act (IDEIA):* the 2004 reauthorization of the Individuals with Disabilities Act that states that in exchange for federal funding, states must provide a free appropriate public education (FAPE) to individuals with disabilities in the least restrictive environment (LRE)
- *Individuals with Disabilities Education Act (IDEA):* a law ensuring services to children with disabilities throughout the nation that governs how states and public agencies provide early intervention, special education and related services to more infants, toddlers and children with disabilities
- *Informed consent:* a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention
- *Intervention:* a strategy or process put in place in order to improve or modify an individual's behavior (i.e. medication, Applied Behavior Analysis)

- *Intolerance:* the inability, unwillingness or refusal to endure something (i.e. specific foods)
- *Involuntary Commitment:* a legal process in which an individual experiencing a mental health crisis is ordered into treatment against his or her will, including to a hospital
- *Lyme Disease:* a bacterial infection spread through the bite of the blacklegged tick
- *Maladaptive behavior:* a type of behavior that is often used to reduce anxiety, but the result does not provide adequate or appropriate adjustment to the environment or situation
- *Medicaid:* a government program that provides healthcare coverage for low-income families and individuals with disabilities in the United States
- *Medical home:* a team based healthcare delivery model led by a physician that provides comprehensive and continuous medical care to patients
- *Mental Health Hold:* involuntary hospitalization due to a mental health crisis
- *Motor function:* the ability to move that results from messages sent from the brain to the muscular system
- *Nutritionist:* a professional specializing in diet and nutrition issues
- *Obsession:* a repetitive thought or feeling dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators
- *Obsessive Compulsive Disorder (OCD):* an anxiety disorder in which people have unwanted and repeated thoughts, feelings, ideas, or sensations (obsessions) that make them feel driven to do something (compulsions)
- *Ophthalmologist/optometrist:* a professional specializing in vision issues and eye care
- *Ototoxic:* damaging to the ears, causing sound sensitivities, dizziness or balance issues
- *Over correction:* a punishment mechanism for a challenging behavior that involves requiring an individual to engage in repetitive behavior to an excessive extent in an attempt to prevent the behavior from reoccurring
- *Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS):* a subset of children and adolescents who have Obsessive Compulsive Disorder (OCD) and/or tic disorders, and in whom symptoms worsen following infections such as "Strep throat" and Scarlet Fever
- *Pica:* an eating disorder that involves eating things that are not food (i.e. dirt, plastic)
- *Picture Exchange Communication System (PECS):* a unique augmentative/alternative communication intervention package that involves teaching an individual to give a picture of a desired item to a “communicative partner,” and goes on to teach discrimination of pictures and how to put them together in sentences
- *Polypharmacy:* the use of multiple medications by a patient
- *Positive Behavior Supports (PBS):* an approach to helping people improve their difficult behavior by understanding what is causing it, and then developing strategies to increase positive behaviors
- *Post-Traumatic Stress Disorder (PTSD):* an anxiety disorder that can occur after witnessing or experiencing a traumatic event

- *Psychiatric evaluation:* a mental health examination by a psychiatrist or other mental health professional
- *Psychologist:* a professional with the training and clinical skills to help people learn to cope more effectively with life issues and mental health problems
- *Psychosis:* a loss of contact with reality that usually includes delusions and hallucination)
- *Psychotropic:* a medication or intervention that affects brain activity, behavior or perception
- *Puberty:* the process of physical changes that occur when a child's body matures into an adult
- *Regional center:* agencies throughout the state of California that serve individuals with developmental disabilities and their families
- *Reinforce:* to strengthen with additional material or support
- *Reinforcement strategies:* methods used to promote or increase positive behavior by providing motivating reinforcers (i.e. praise, a favorite toy, a cookie)
- *Resilience:* an ability to recover from or adjust easily to change or a difficult situation
- *Respite care:* a service that provides short-term breaks that can relieve stress, restore energy, and promote balance for caregivers
- *Restraints:* physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely
- *Reward:* a prize, token, or preferred activity given to an individual for good behavior, designed to promote the same behavior in the future
- *Risk factors:* conditions that increase the likelihood of aggression
- *Ritual:* a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle in to sleep
- *Rumination:* the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again or spitting it out.Rumination often seems to be triggered by reflux or other gastrointestinal concerns
- *Schizophrenia:* a chronic, severe, and disabling brain disorder that makes it hard for individuals to think clearly and tell the difference between what is real and not real
- *Seclusion:* a situation in which an individual is put briefly in a room alone to 'calm down'
- *Sedating:* calming, sleep-inducing, numbing an individual experiencing challenging behaviors or struggling during difficult situations
- *Self-advocacy:* the ability of an individual to communicate his or her wants and concerns, and make his or her own decisions
- *Sensory avoidance:* blocking or staying away from something that is painful or bothersome

- *Sensory defensiveness:* a tendency to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating
- *Sensory input:* any source that creates sensation and activates one or more of the senses -vision, smell, sound, taste, and touch
- *Sensory-seeking behavior:* behaviors caused by a need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state
- *Sleep apnea:* a usually chronic, common disorder in which an individual has one or more pauses in breathing or shallow breaths up to 30 or more times per hour during sleep, and results in daytime sleepiness
- *Special needs parent advocate:* an advocate for parents of children with special needs who helps ensures that the child's rights and needs are met in school and in the community
- *Staring spells:* occasions when an individual is in a trance staring into space, which can often signal seizure activity
- *Stimulation:* excitement or activity triggered by a stimulus either internally or externally
- *Supplemental Security Income (SSI):* a Federal income supplement program designed to help aged, blind, and disabled people who have little or no income, and provides cash to meet basic needs for food, clothing, and shelter
- *Tangibles:* items or rewards that can be touched, such as a toy or piece of candy
- *Tourette's Syndrome:* a neurological disorder characterized by tics, or repetitive, stereotyped, involuntary movements and vocalizations
- *Tracking scales:* a document or other tool used to track information such as changes in an individual's behaviors, side effects of medications, school performance, etc.
- *TRICARE:* the health care program for Uniformed Service members, retirees and their families worldwide
- *Voice output technology:* a technological device that helps people who are unable to use speech to express their needs and exchange information with other people
- *Wraparound:* an integrated, multi-agency, community-based planning process designed to build teams of providers, family members and natural supports to help keep complex youth in their homes and communities

AUTISM SPEAKS®
It's time to listen.

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

Our Mission

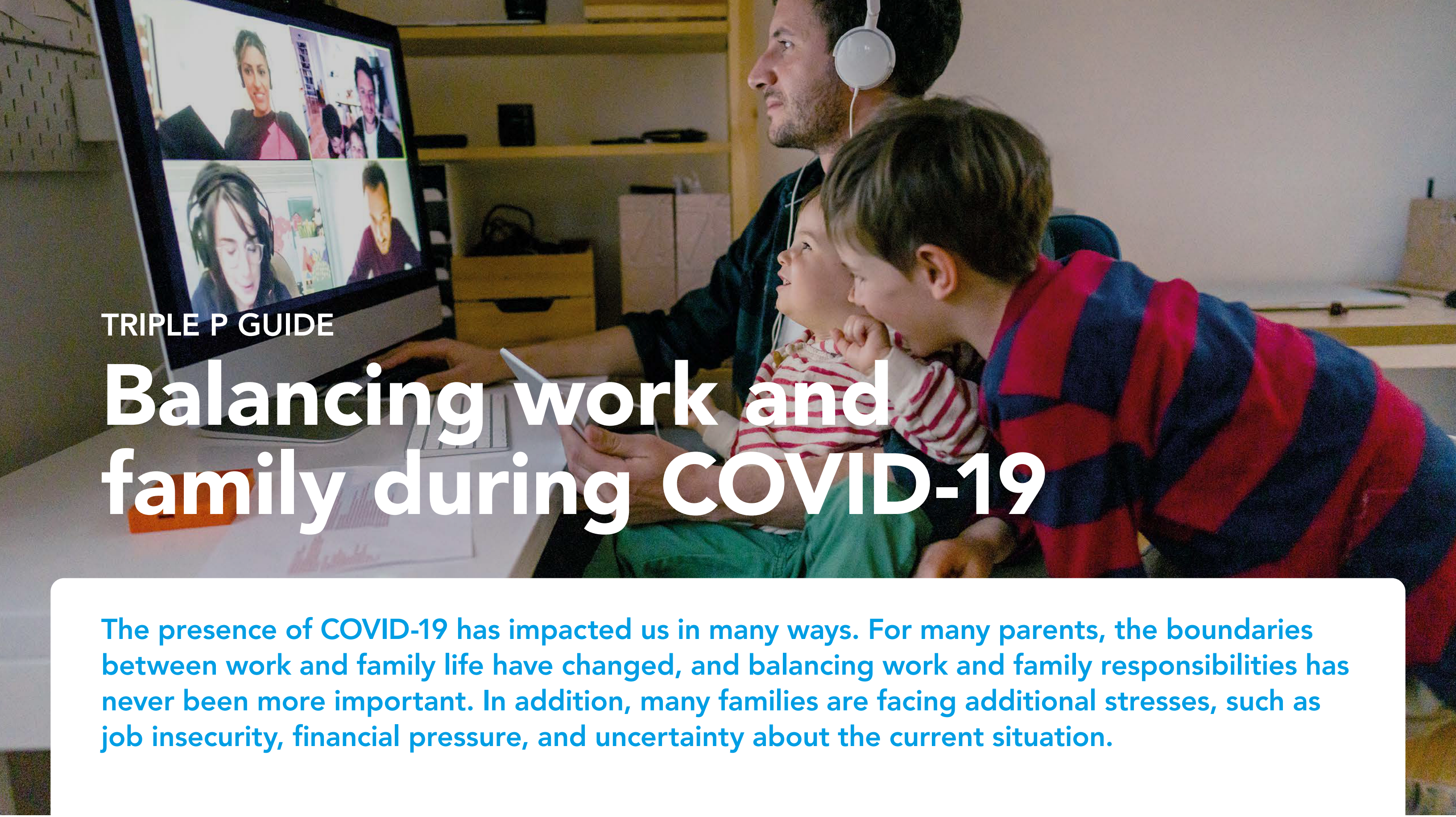
At Autism Speaks, our goal is to change the future for all who struggle with autism spectrum disorders.

We are dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

AUTISM SPEAKS®
It's time to listen.

www.AutismSpeaks.org



TRIPLE P GUIDE

Balancing work and family during COVID-19

The presence of COVID-19 has impacted us in many ways. For many parents, the boundaries between work and family life have changed, and balancing work and family responsibilities has never been more important. In addition, many families are facing additional stresses, such as job insecurity, financial pressure, and uncertainty about the current situation.

It can be difficult to navigate changes in routine such as working from home while meeting family responsibilities, as well as periods of lockdown and social isolation. There's no perfect way to get the balance right and what works best may be different for different families and vary as things change. The key is for parents to take care of themselves and work towards a balance between work and family, and have a sense of being calm and in control. It's a challenging time for everyone, especially families. This guide offers suggestions to help you find solutions for your family. There will still be some tough days but choosing some strategies to use when you can will help make things a little easier.

Recognise that balancing work and family is challenging

Balancing work and family responsibilities can be tricky at the best of times. During the constantly changing landscape of COVID-19 it is especially hard. Many children are home and require care, help with schooling, or more supervision. Many families are also caring for or worried about elderly family members. Periods of isolation, job instability and economic uncertainty, and concerns about health and safety all add additional stress. Parents working from home may miss the social interaction that work usually provides. Parents working outside the home face different challenges. Working in 'front line' positions (e.g. health care, child care, working in essential stores, cleaning) and commuting to work can lead to worries about potential virus exposure. For these parents, supporting children and teens in their various forms of learning can be extra difficult.

Children and teenagers who are doing 'virtual' schooling may become bored with staying at home, spend extra time using technology, and feel isolated from their peers, and they may not understand the restrictions on their life. Increases in challenging behaviour in children are also common and place extra pressure on parents.

All of these things inevitably impact on parents' own wellbeing. Feeling worried, irritable, guilty, frustrated, angry and exhausted makes it even harder to manage daily demands. All parents need to consider how to help their children through this time while also finding time to take a break and look after themselves. Calm, relaxed parents are more able to provide the safety and stability children need in uncertain times.

Take care of yourself as best you can

Taking care of yourself is a responsibility not a luxury. The most important thing you can do for your family or work is take care of yourself. Find some time to focus on your own needs. For example, take advantage of time you would normally spend commuting and schedule some self-care. This might be something like talking to a partner or friend about how you are feeling, a video meet up with friends, getting some fresh air and sunshine, or viewing or sharing something uplifting on social media. Try to manage any unhelpful emotions such as worry, guilt or anger. Stress management skills such as mindfulness, meditation, relaxation and/or deep breathing can also help reduce stress. Combat negative thoughts with more realistic, helpful coping statements like — *This is hard but I'm handling it or It's natural to feel a little overwhelmed I need to focus on one thing at a time.* If you focus on your own wellbeing (e.g. exercise, eat well, try to get enough sleep, avoid using alcohol or drugs to handle stress), you are more likely to stay healthy and be available for your work and your family.

Have realistic expectations

Be realistic about what you can accomplish each day. This might be different to what you can usually manage, and that's OK. Give yourself permission to do what is achievable and avoid setting unrealistically high expectations that lead to unhelpful feelings of guilt and frustration. Everyone wants to be a good parent but aiming for perfection (both at home and work) is unachievable and sets you up for unnecessary stress. Give yourself permission to do things 'well-enough.' Consider how you spend non-work time to ensure your most important priorities are met. Avoid spending all your free time doing unnecessary chores. Consider if anything can be delayed and encourage children to be independent and contribute to household chores. Let go of unrealistically high standards and focus on what is most important.

Set times to focus on family

When work and family boundaries are blurred, it's easy to let work take over and feel guilty about not spending enough time with your family. Setting specific times to engage with your family and have quality time together will help you know your family's needs have been met and allow you to concentrate on work when working. This is especially important if you find yourself working in what would normally be family times such as the evening or weekend. Make sure you have time to talk, play and do activities together, like going for walks, working on projects or cooking as a family. You may need to be extra creative when normal opportunities for social activities are limited.

Talk with your employer and colleagues

Aim to work with your employer to find solutions that work for both you and your employer. If possible, negotiate work hours that fit with your family and childcare needs. This may include requesting certain shifts or avoiding scheduling meetings at times when your child is most likely to need you. Talk to your employer about whether flexible work hours are possible. Avoid taking on extra work and reduce unnecessary commitments. If saying 'No' to work is not possible or risky, ask for extra time to complete tasks if you need it. Let your employer know about any family commitments you have, such as supporting virtual schooling. Many employers will be dealing with similar issues themselves. They may also be able to make some accommodations to make life easier. Use your discretion about which of these suggestions may work for your current employment situation.

Share your experiences with colleagues as well. Co-workers can be a great source of support and they may be more understanding when work changes are required if they know what you are juggling. If you are working remotely, and opportunities for informal chats are low, consider setting up a video call or chat group where people can share their experiences.

Be clear about work time and space

Let your family know when you are working and under what limited conditions you should be interrupted. Create work boundaries and set some clear ground rules about being quiet and respectful when others are working, and how to politely interrupt and ask for help if needed. Try to work at set times if you can, to avoid work taking over your entire week. Where possible, it's also best to work in the same space, so you are not associating work with everywhere in your home.

Ensure children have adequate child care or supervision

Knowing your child is safe and cared for allows you to concentrate on work. If working from home, see if it's possible to work at times when young children require less supervision, or 'tag team' parenting responsibilities with your partner or another support person. Teens require less supervision but it is still important to monitor their activities.

Encourage behaviour you like

Use praise to encourage behaviour you'd like to see more often. For example, if your child plays quietly while you are on a work call, use descriptive praise — *Thank you for being so quiet when I was on that call. That was really helpful.* Act early to prevent and manage any challenging behaviour. Set your child up with things to do when you know you need to concentrate on something, and encourage them to play or study independently. You can even set up some small incentives or treats for blocks of time when your child follows the rules. If rules are broken, give a clear instruction of what you want to your child to stop doing and what to do instead. Praise them for doing the right thing. You may need to back up your instruction with a brief consequence (e.g. loss of a privilege like screen time for a short time) if problems continue. Afterwards, catch your child following the rules and praise them. It's best to praise as soon as you can, especially with younger children, but if find yourself forgetting to praise you can always praise later.

With older children, try to stick with the same, or similar, ground rules, rewards and consequences as pre-pandemic. Maintain similar routines and bedtimes to provide a sense of structure and keeps things as normal as possible. Monitor excessive social media or technology use by implementing family screen-free time and providing other engaging activities. Praise teens for behaving well and acting responsibly. Privileges can be withdrawn for a short time if rules are broken. If teens are emotional, validate their experiences. Make time to listen to them and check you understand what is going on for them. Help them name what they are feeling and ask if there's anything you can do to help.

Focus on work when you are working

You can work more efficiently by focussing only on work during work times. Avoid distractions like checking the news or social media. Task lists and setting yourself specific goals to achieve can help you focus your attention and work more efficiently. If you are interrupted, try to get straight back into the task you were working on as soon as possible. Working efficiently will allow you to get more done in less time, which will reduce workload-related stress and give you more free time.

Schedule breaks

Scheduling regular breaks helps with concentration. Many people find that 20-30 minutes of focussed work followed by a 5-minute break works well. If children are home, this is a good time to spend a few minutes of quality time with your child or check in on what teens are doing. This will help your child know you are there for them and care about what they are doing even if you are busy with work. Build in time to plan out the day and debrief with a co-parent or other support person.

Develop clear transition routines

Whether you are working in or out of the home, developing a clear transition-to-work routine will help you focus on work. Do the same things in the same order daily. Having predictable routines also helps children know what to expect and what you expect of them. If you are working at home with children, having mini transitions during breaks will also help. Something as simple as giving your child a warning you are going to work in five minutes then saying goodbye will help.

End your work day well. It can be hard to switch off from work when it is right there in your home. Be clear about the end of the work day and try not to think about work after this. Aim to have a clear finishing-work transition at the end of the day. This might involve making a list of what to do the next work day (so you don't have to remember and worry about it) or taking a shower or a walk. If you use technology for work, put practices into place so that it doesn't intrude on family time (e.g. turn off push notifications, close email programs). Unless you need to be on call 24/7, consider putting away computers and phones for a period of time so you have a complete break from work. If you find yourself thinking about work during family time, simply acknowledge the thought then let it go so that you can focus on the moment and enjoy family life.

Get more tips and strategies online to help during this crisis: triplep-parenting.ca

You may like to look at the parenting tips in these Triple P – Positive Parenting Program resources:

- *Triple P Guide: Parenting During COVID-19*
- *Top Parenting Tips for Parents and Carers During COVID-19*
- *Triple P Guide: Supporting Healthy Relationships and Managing Disagreements During COVID-19*
- *Top Parenting Tips for School Life During COVID-19*
- *Teen Triple P Guide: Parenting Teens During COVID-19*
- *Stepping Stones Triple P Guide: Parenting Children with a Disability During COVID-19*
- *Top Parenting Tips During COVID-19 for Parents and Carers of Children with a Disability*
- *Triple P Online*

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TOP PARENTING TIPS
FOR SCHOOL LIFE DURING COVID-19

With schools opening and closing in line with COVID-19 restrictions and local lockdowns, some children may be finding school difficult. They may feel anxious or reluctant about going to school in person, mixed with other feelings such as excitement if they have had time away. Others may have concerns about 'virtual' learning from home, such as falling behind in their work, or losing touch with their friends. Parents may also have a range of feelings about children's schooling, such as concern or relief if they are attending school, and the stress of juggling responsibilities if they are schooling at home.

1 Help your child make good choices

If your child is concerned about the safety of being at school, help them prepare to maintain their own safety. They may need reminders about washing their hands, wearing a mask or maintaining physical distancing. Explain that if everyone does it, even if it's uncomfortable, it keeps everyone safe. They may also need help to decide how best to respond to peer pressure not to do these things, even practice about what they could say. The important thing is for children to be aware of what they can do to protect themselves and others from the spread of the virus, and what to do if they have any symptoms. If they are schooling at home, help them set up a study space and manage their daily routine with periods of study and regular breaks.

2 Take care of yourself the best you can

Deal with any concerns you may have about your child's schooling by taking actions that give you a better sense of personal control. Stay in contact with your child's school so you feel connected and know what is going on. Stress management skills such as mindfulness and/or deep breathing can also help reduce stress. If you focus on your own wellbeing (e.g. exercise daily, eat well, get enough sleep, avoid using alcohol or drugs to lessen stress), you can stay healthy and be available for your child.

3 Make sure your child knows you are ready to talk

Children need to be able to talk to their parents about their concerns and have their questions answered. This is especially true if your child is worried about being at school or doing their schoolwork. Let them know you are always there for them and try to make yourself available when they want to talk. If it's not possible right then (e.g. if you are working), make a time to talk as soon as you can.

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TOP PARENTING TIPS FOR SCHOOL LIFE DURING COVID-19

4

Show you are listening

When your child wants to talk, stop what you are doing and listen carefully. Avoid telling your child how they should feel, such as *That's silly. You shouldn't be scared about that.* Let them know it is OK to be worried. Talking or drawing can help children get in touch with their feelings. Ask them about how they are feeling to help them figure out what they are anxious about.

5

Be truthful in answering children's questions

Find out what your child knows about the issue before answering their questions. Keep answers simple and honest. Get information from trusted sources like your child's school or official health websites rather than social media.

6

Maintain everyday school routines

In an uncertain situation, maintaining routines is helpful in providing a sense of predictability. Involve your child in working out their school routine — even if this involves returning to an old, pre-lockdown routine. For example, your child might write out a daily timetable that includes the time they need to wake up to get ready for school, and a time for homework. Or they might write a list of the things they need to do in the morning to get ready for school.

7

Take notice of behaviour you like

Be on the lookout for any behaviour that reflects optimism or preparations for going back to school or managing schooling from home. Use plenty of praise and positive attention to encourage the behaviours you like and want to see repeated. Let them know you are pleased by telling them what they have just done — *I know you're a bit nervous about going to school and I really admire the way you're focusing on the good things like seeing your friends. That's a great attitude!* or *I really like the way you're managing your study space at home. You're keeping everything really well organised.*

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TOP PARENTING TIPS FOR SCHOOL LIFE DURING COVID-19

8

Help children learn to tolerate uncertainty

The COVID-19 crisis has created uncertainty for everyone. Parents need to find a way to accept uncertainty and show this through their actions and words. It's OK to say, *I don't know. Let's find out what we can.* Swapping between learning from home and returning to school in person represents more uncertainty. You can encourage your child to check in with their teachers about managing their workload and preparing for exams if they are worried about falling behind. When schools are open, no one can know whether they may perhaps need to close again for a short or longer time. Big changes and uncertainty in children's lives can be hard, but they are also an opportunity for developing emotional resilience. This will be useful in the future as children navigate the inevitable ups and downs of life.

9

Reach out and stay connected

Children will feel happier and more confident if they feel supported in their relationships. Make sure you keep up your use of phones, online communication (e.g. video conferencing), and social media to keep in touch with family, friends, and neighbours. It is particularly important that children feel like they are connected to their friends and peers.

10

Keep up quality family time

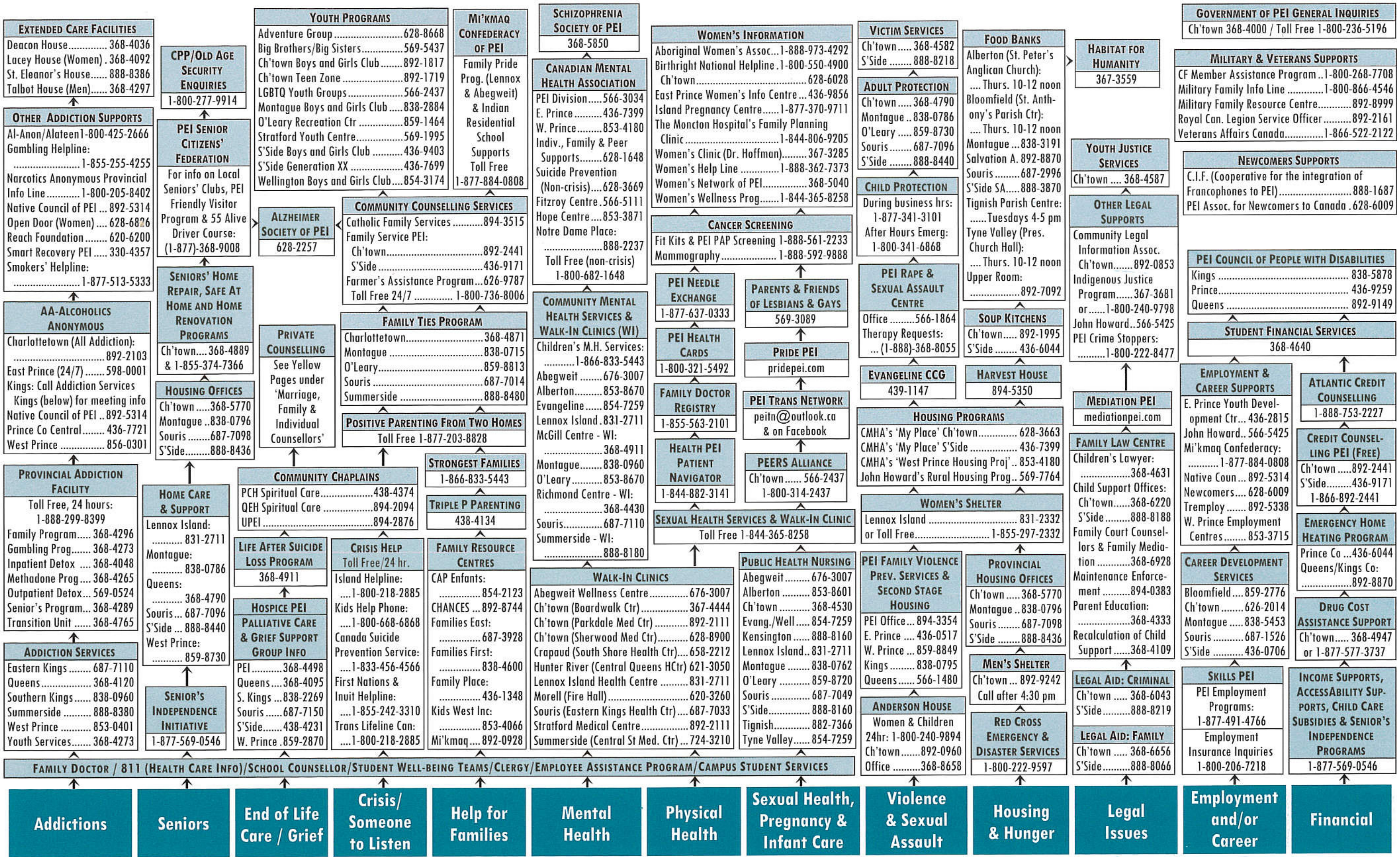
Your child may have enjoyed having so much time with their family during lockdown and may be worried this will stop with the busy return to school commitments. Try to carry on the positive things that happened during lockdown, like making sure you have time to talk play and do activities together, like going for walks, working on projects and cooking as a family. We can all take some positives out of this uncertain and challenging time.

Written by Matthew R. Sanders, Vanessa E. Cobham and Karen M. T. Turner

Triple P® Positive Parenting Program

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

PEI HEALTH CARDS

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

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)

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& 1-855-374-7366

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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

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Stratford Youth Centre	569-1995
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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

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O'Leary	859-8813
Souris	687-7014
Summerside	888-8480

POSITIVE PARENTING FROM TWO HOMES

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STRONGEST FAMILIES

1-866-833-5443

TRIPLE P PARENTING

438-4134

CRISIS HELP

Toll Free/24 hr.

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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

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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
Indiv., Family & Peer Supports	628-1648
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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

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

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Souris (Eastern Kings Health Ctr)	687-7033
Stratford Medical Centre	892-2111
Summerside (Central St Med. Ctr)	724-3210

WOMEN'S INFORMATION

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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
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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

PEI HEALTH CARDS

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

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

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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

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)

Canadian Mental Health Association
Prince Edward Island

Réseau Santé
en français Î.-P.-É.

The Island Helpline
1-800-218-2885
24/7
Ligne d'écoute de l'Î.-P.-É.