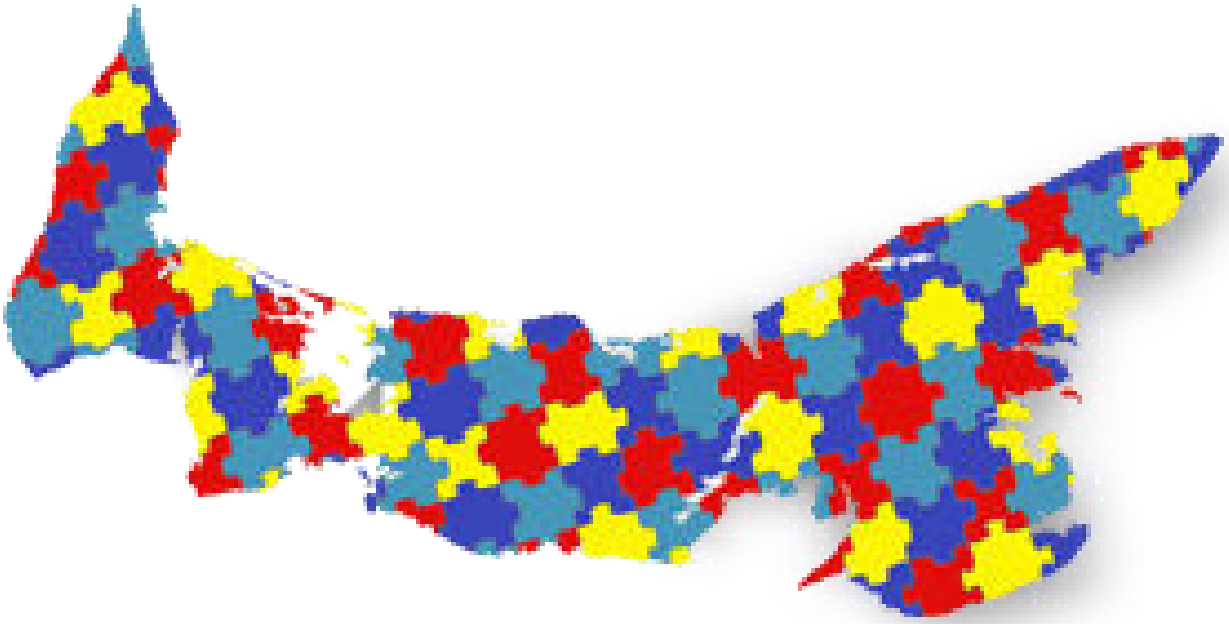


AUTISM SOCIETY
Of Prince Edward Island

School Age 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*

Prince Edward Island
CANADA

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

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

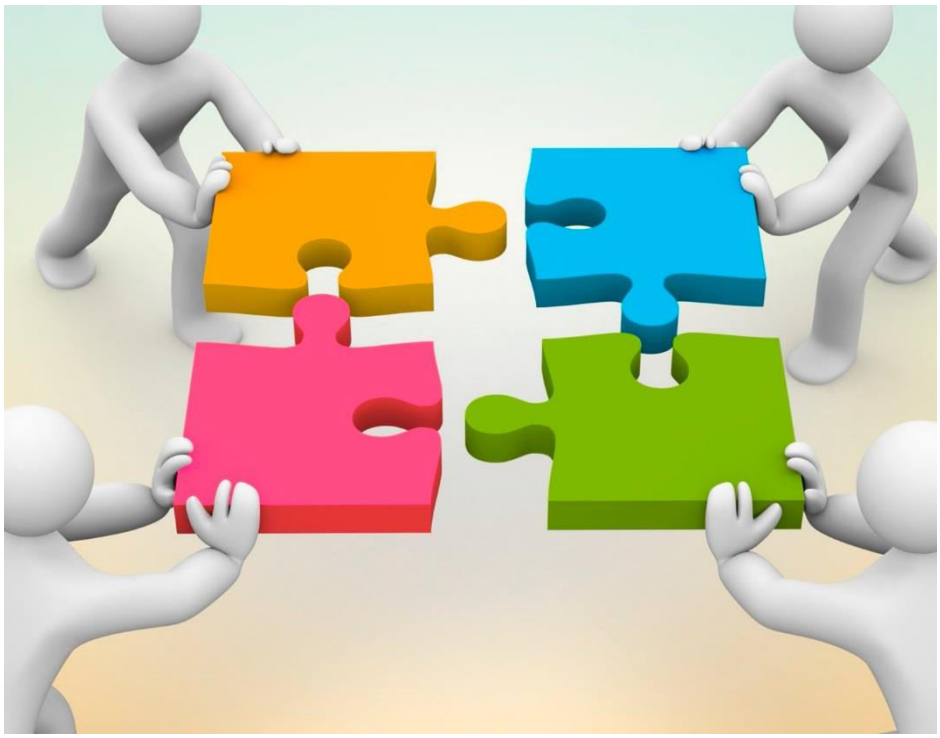
Easy Access
A single point of contact by calling
1-877-569-0546
toll-free makes it easier to access support

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

PrinceEdwardIsland.ca/accessability-supports

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 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; 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 may include: • 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

Revised January 2021

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

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)	Printed Name (For Businesses Only)	Date
Sign Here ▶ X _____		

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
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MAY						
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30	31					

JUNE						
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JULY						
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AUGUST						
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29	30	31				

SEPTEMBER						
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OCTOBER						
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31						

NOVEMBER						
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28	29	30				

DECEMBER						
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JANUARY						
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30	31					

FEBRUARY						
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27	28					

MARCH						
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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:_____

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.

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

Diagnosing Autism Spectrum Disorder in PEI

Autism Spectrum Disorder (ASD) presents itself in a variety of ways and ranges from mild to severe. In PEI, a child may be identified with signs of autism at a very young age through a Public Health Nursing screening program. Public Health Nursing offers pre-school health clinics throughout the province and can assess your child's development in areas such as vision and hearing, growth and nutrition, speech and communication, and personal/social development. Find more information at Pre-School Health.

Because Autism Spectrum is a social-communication disorder, a child needing professional help developing speech and language abilities may be identified with signs of ASD through Speech Language Pathology.

If you suspect your child may have ASD, you should mention this to the public health nurse during your child's screening clinic or to the speech language pathologist, if your child is receiving SLP services. This is also a concern you should discuss with a family doctor or nurse practitioner. Any of these experienced health professionals will be able to help you decide if your child should begin the process for diagnostic assessment.

What if my child is identified with signs of Autism Spectrum Disorder?

1. If your child is identified with signs of ASD, the process for diagnostic assessment begins. It's common for families to have to wait for a diagnostic assessment.
2. A family doctor or nurse practitioner must issue a referral for your child to access pediatrician services. Find more information at Pediatrician Outpatient Services.
3. The pediatric office will contact you with an appointment and have you complete paperwork about your child to help the pediatrician better prepare for the appointment.
4. The pediatrician may refer your child for a diagnostic assessment from Pediatric Psychology Services.
5. Pediatric Psychology Services provides free diagnostic assessments for children up to age 5. A referral from a pediatrician is required to access these services.

What if my child receives an autism diagnosis?

After receiving your child's autism diagnosis, an assessment may indicate that your child needs support with skill development. You can:

- Build a support team tailored to your child's needs – it might include health professionals, therapists, care providers, educators and support workers;
- Apply for autism funding and grants to help cover the costs of support that will help them reach their development goals;

- Reach out for community support through the PEI Autism Society(link is external) and the PEI Association for Community Living(link is external); and
- Connect to community services and programs through 211PEI online at: https://pe.211.ca/(link is external) or by phone: 211

Published date:
May 4, 2021

Who We Are

Speech-Language Pathologists and Audiologists are involved in preventing, identifying and treating speech, language and hearing disorders. We work with families as well as child care and health care providers. Social, emotional, behavioral and/or learning problems may occur if speech and/or hearing problems are not found early. Difficulties with communication affect not only the child, but the whole family.

When To Get Help

Communication develops over time and every child develops at his/her own rate. This brochure outlines the ages at which most children will reach speech, language and hearing milestones. If you think there is a problem, it is important to get help early.

Things To Consider

- parental concern
- low birth weight
- pre-maturity (less than 37 weeks)
- lack of oxygen at birth
- family history of speech, language and/or learning problems
- family history of hearing loss
- drug/alcohol use during pregnancy
- a history of ear infections
- the child speaks loudly or often asks people to repeat

How We Can Help

Health PEI's Speech-Language Pathology Program offers services to children from birth to the time they begin kindergarten. Assessment and a range of treatment services are provided to children and their families in many different communities across the province.

Health PEI's Audiology Program offers services to those who have concerns about their hearing.

How To Reach Us

You may call one of the numbers listed below to be seen by a Speech-Language Pathologist :

Souris	687-7016
Montague	838-0762
Charlottetown	368-4440
Summerside	888-8162
Wellington	854-7259
O'Leary	859-8720

For your child to be seen by the Provincial Audiologist, please call 368-5807.

Health PEI

CASLPA-ACOA

Brochure adapted from information compiled by CASPLA (see CASPLA.ca)

11HPE06-32463

Health PEI

My Steps In Development

- *Speech*
- *Language*
- *Hearing*

"Help Me Grow"

web version

At Birth to 3 months I will...

- make cooing sounds
- have different cries for different needs
- smile at you
- startle to loud sounds
- soothe/calm to a familiar voice

At 4 to 6 months I will...

- babble and make different sounds
- make sounds back when you talk
- enjoy games like peek-a-boo
- turn my eyes toward a sound source
- respond to music or toys that make noise

At 7 to 12 months I will...

- wave hi/bye
- respond to my name
- let you know what I want using sounds and actions like pointing
- begin to follow simple directions (e.g., Where is your nose?)
- turn my head toward a sound
- pay attention when spoken to

At 12 to 18 months I will...

- use common words and start to put words together
- enjoy listening to storybooks
- point to body parts or pictures in a book when asked
- look at your face when talking to you

At 18 to 24 months I will...

- understand more words than I can say
- say two words together (e.g. More juice?)
- ask simple questions (e.g. What's that?)
- take turns in a conversation

At 2 to 3 years I will...

- use sentences of three or more words most of the time
- understand different concepts (e.g. in-on; up/down)
- follow two-part directions (e.g. Take the book and put it on the table.)
- answer simple questions (e.g. Where is the car?)
- take part in short conversations

At 3 to 4 years I will...

- tell a short story or talk about daily activities
- talk in sentences with adult-like grammar
- generally speak clearly so people understand me
- hear you when you call from another room
- listen to TV at the same volume as others
- answer a variety of questions

At 4 to 5 years I will...

- say most speech sounds correctly
- take part in and understand conversations even with background noise
- recognize common signs (e.g. stop sign)
- make up rhymes
- hear and understand most of what is said at home and school
- listen to and retell a story and ask and answer questions about a story

autism speaks®

Parent's Guide to Autism

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 email 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.

Table of Contents

Introduction

If your child has recently been diagnosed with an autism spectrum disorder, you have come to the right place. ***A Parent's Guide to Autism*** was developed as part of Autism Speaks' series of *Family Support Tool Kits* to support you and promote a positive future for your child and family during an often challenging time. You are not alone in this journey and this guide is a step toward finding the help you need to travel the road to optimal outcomes for you, your child and your family.

The Autism Speaks 100 Day Kit for Newly Diagnosed Families (versions for both children under 5 and school age children) was designed to provide you with the information and tools you need to make the best possible use of the days following the diagnosis. It is a comprehensive tool filled with facts and resources such as information about symptoms, treatment, legal rights and advocacy. The *100 Day Kit* can be found at AutismSpeaks.org.

A Parent's Guide to Autism will help you:

- *Learn about how autism may impact your family.*
- *Find strategies and resources for raising a child with autism.*
- *Find support so you don't feel alone or isolated.*
- *Reduce the negative impact of the diagnosis on your family.*
- *Promote a positive future for your child and family.*

For additional guidance and support, the ***Autism Speaks Autism Response Team*** is here to help. The team is specially trained to connect you and your family to resources and information specific to your child's strengths and challenges.

Contact the team at
FamilyServices@AutismSpeaks.org
(888) 288-4762
(en Español 888-772-9050)

Response to the Diagnosis

Learning that your child has been diagnosed with autism is a powerful moment in your life. Suddenly your life may feel very different from what you expected it to be. You worry first about your child and what it will mean for his or her life experiences. You worry about how you and your family will adjust to this in the years ahead. You worry about the day-to-day challenges of caring for your child with autism.

This is an important turning point in your life as well as the lives of your child and other family members. Getting emotional support and factual information to help you cope and promote a positive future for your child and family will be critical during this period.

**For the purposes of this tool kit, the term "autism" will be used to describe children with all types of autism spectrum disorders, including Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)*

Common Reactions to the Diagnosis

Each family's reaction to the diagnosis will be different depending on many factors. When a child is diagnosed with autism, parents and other family members frequently experience a range of uncomfortable emotions. Whether or not you have suspected something for awhile or the diagnosis seems to have been out of the blue, many parents experience shock when they hear the words, "your child has autism."

You may go through periods of denial or refusing to believe this is happening to your child. During this time, you may not be able to hear the facts as they relate to your child. Denial is a way of coping. It may be what gets you through a particularly difficult period. It is important to be aware that you may be experiencing denial, so that it doesn't interfere with making good decisions about your child's treatment.

Some parents mourn some of the hopes and dreams they held for their child before they are able to move on. There will probably be times when you feel sad. Allowing yourself to feel sadness can help you grow. You have every right to feel sad and to express it in ways that are comfortable. Anger is also a natural part of the process and you may find that it's directed at those closest to you. Anger is a healthy and expected reaction to the feelings of stress that come with your child's diagnosis. Expressing your anger is natural and at times healthy.

There are times you might feel isolated and lonely. These feelings come from a variety of sources when you experience a diagnosis or other significant life change. Loneliness may also come from the fact that you simply don't feel you have the time to contact friends or family for company. You may also feel that if you did reach out to others, they wouldn't understand or be supportive.

It's easy to become overwhelmed with your emotions and concerns about what the future may hold. Painful emotions are natural. If you accept your reactions and acknowledge your feelings, you will be able to move forward and begin advocating for your child. Emotions are powerful. If you deny your feelings or ignore them, they will often surface in unpleasant ways.

Ultimately, you will likely feel a sense of acceptance. Your life may not look like what you had planned and you may have to alter your expectations, but your goal remains the same: to help your child live a happy and fulfilling life. Once you accept the diagnosis, you will be ready to advocate for your child and start working toward a brighter future.

Common Areas of Concern

Like any stressful event in your life, learning your child has autism will affect everyone in your family and network of friends. It's probably not a surprise that your role as parent will change and you will go through many positive and negative experiences in your new role. Below are examples of new feelings you may encounter:

- *May feel burden with everyday responsibility of caring child with autism.*
- *May feel pressure to become an autism expert and learn everything overnight.*
- *May worry about child and family's future.*
- *May have difficulty finding balance and time to manage household tasks, other children, daily activities, etc.*
- *May be less inclined to share feelings.*
- *May become stressed about the family's finances and the unknowns of the situation.*
- *May develop other problems such as stress and anxiety that can affect work life.*

It is important to know that most families find a way to work together, grow stronger and learn ways to reduce the negative impact of the diagnosis and promote a positive future for their children and families.

When to Seek Professional Help

If you are experiencing several of the following signs and symptoms over a period of time, you may want to seek professional counseling:

- *You have trouble sleeping and don't feel rested when you do sleep.*
- *You can't control your negative thoughts, no matter how hard you try.*
- *You have lost your appetite or you can't stop eating.*
- *Others point out that you seem irritable, short-tempered or more aggressive than usual.*
- *You are consuming more alcohol than normal or engaging in other reckless behaviors.*
- *You have thoughts that life is not worth living.*

If you have trouble working through your emotions within a reasonable timeframe or you feel unable to function in your usual ways, it may be a good idea to seek professional help. Professional help can prevent serious problems from developing in the future. It can help to empower us to face challenges more effectively.

Your Role as a Parent

Your Child's Advocate

When your child is first diagnosed, you will likely find yourself fulfilling many roles: care coordinator, therapist, parent, teacher, etc. One of the most important roles you will have is serving as your child's advocate. Advocating for your child will be a lifelong journey that will require different skills depending on your child's needs.

In her book, *Everyday Advocate: Standing Up for Your Child with Autism*, Areva Martin describes seven principles that can be applied to serve as an effective advocate for your child:

1. ***Take Responsibility - Be a leader***
2. ***Learn - Be an expert***
3. ***Think Critically - Be discerning***
4. ***Speak with Authority- Be proactive***
5. ***Document - Be prepared***
6. ***Collaborate - Be a team builder***
7. ***Educate - Be a voice for your child***

Martin's book offers examples of each principle as it relates to real world activities that parents can do to advocate for their child with autism.

Supporting Your Other Children

Parents of children with autism can be under tremendous stress. It may seem like there is never enough time to do everything that needs to be done. So much focus and attention is placed on the child with autism, that it is common for parents to have little time or energy left to focus on their other children.

Brothers and sisters of children with autism frequently face their own challenges. Much more may be expected from these siblings. They often need help understanding the emotional reactions they are experiencing as a result of the many changes occurring in their lives. This support is essential to their future well-being.

Some things your other children may be struggling with:

Young children may not understand what is wrong with their brother or sister. *They may be confused and unable to fully comprehend the implications of diagnosis.*

They may have feelings of jealousy and resentment *if they see that their parents are spending less time with them compared to their brother or sister with autism.*

They may feel angry over unequal treatment *if their brother or sister is not disciplined in the same way they are or given similar chores to do.*

They may feel embarrassment *with friends or in community settings where strangers react negatively because of their sibling's unusual and sometimes aggressive behaviors.*

They are often frustrated *by the fact that they are not able to get their brother or sister to respond or interact with them in "normal" ways.*

Quietly, and sometimes secretly, siblings worry *about their brothers and sisters and their parents as everyone in a family is impacted by the disorder in some way.*

Many children are unable to express their feelings *so sometimes revert to "acting out" behaviors. For example, they may misbehave by defying their parents or getting into trouble at school.*

Strategies for supporting your other children:

It is important that your other children understand autism *and what is going on with their brother or sister. Talk with them early and often in age appropriate ways. Many books and other resources are available to help them to understand this diagnosis, some of which are listed on the Books page of the Autism Speaks Resource Library.*

Help your children learn how to play and form relationships *with their sibling with autism. There are a few simple things that you can do that will help with this, including teaching your other children how to get their sibling's attention and give simple instructions. It's also important to praise all your children when they play well together.*

Find sibling support groups *that can help them build friendships and relate to other peers who have a sibling with autism.*

Don't hesitate to consult a professional if you feel your child is internalizing most of his or her feelings or beginning to act out. The earlier you address this, the better. It is not a failure to ask for this type of help. Rather, it is a sign of strength and evidence of good parenting.

Ten Things a Parent Can Do to Help Their Child with Autism

This is a post by Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog about her two children with autism, at ***AutismMommyTherapist.Wordpress.com****. Her book "****Raising Autism****" is available on Amazon.*

Thirteen years ago this fall our beautiful son, Justin, was diagnosed with PDD at seventeen months of age. He would later go on to receive an "official" autism diagnosis, and would remain on the more severe end of the spectrum. I will never forget the day he was diagnosed – it was both comforting to put a name to something I'd suspected he'd had for a long time, and overwhelming because I just didn't know what to do next. I remember leaving the developmental pediatrician's office wishing someone had given me a checklist of things to accomplish which would help both him and our family in those early days post diagnosis.

Here are some things I did (and some things I wish I'd done) – I hope they are helpful to you and your family. Number ten is the most important!

1) No matter how exhausted you are, get your child out in the community. It was a struggle with us with Justin (I have the tiny little bitemarks on my body to prove it) but getting him out so he could have a repertoire of leisure activities was crucial to his happiness and to our family's. It set him up for a lifetime of being able to try different things, which will set him in good stead when I'm no longer here to take him places. Yes, I'm always planning.

2) If you haven't already done so, join a parent group and/or your school district's special education PTA. You will make invaluable connections at both. Try to find parents of kids with your kid's level of autism as you're making friends. These people will be a wealth of information for you and a lifeline.

3) If you can afford it, hire an advocate to check out your child's school program. A fresh set of eyes may see areas that need to improve, or may reassure you that they are doing all they can for your son or daughter. It's always good to know one in case you need an advocate at an IEP meeting. If you've already met, you won't be scrambling to find one.

4) If possible, volunteer at school functions or offer to be a class mom. This is a great way to get to know your child's teacher and your school's administrators better. You may also make friends with other parents too.

5) No matter how difficult your child can be, take any offer of babysitting you can and get out. You need a night off from autism once in a while. Even if it's for a few hours, a break will help.

6) Now that your child's program is set, tackle the big issues one at a time- perhaps it's sleeping, or eating, or potty training. If your child is in a private school there may be a BCBA on staff who can help you. If not and you can afford it, consider hiring a BCBA from an agency. Pick an issue and prioritize.

7) Educate your friends and family as to what's going on in your household. Perhaps you've been too tired up to this point to talk to people not in the "tribe" about what raising an autistic child is really like. It's time to tell them and ask for the support you need, even if it's just an ear to listen. My husband and I kept too much to ourselves, and if I could go back in time I'd be more open with everyone in our lives.

8) Make those doctor appointments for yourself that you've been putting off. Just do it.

9) Get involved in an autism walk in your community. It is so powerful to meet so many families like (and unlike) yours. It will give you strength.

10) I can't stress this one enough – take care of yourself, not just your kid. Autism is a marathon, not a sprint. You owe it to yourself and your child to be whole, healthy, and happy. Do whatever it takes to get there.

Building a Support Network

In today's world, there are a variety of family models and this can be especially true for parents or guardians of children with autism.

Whatever your family structure, you can expect you will need support and help at many times in your journey as a parent of a child with autism. It's important to remember to maintain relationships with your family, friends and community in order for your support network to be there when you need them the most.

Keeping your Marriage Strong

It is important to stay as connected as possible to your spouse and keep the lines of communication open. In addition to the normal demands of marriage, parents of a child with autism may also experience:

- *Additional stress from navigating the maze of agencies, funding sources and paperwork to help your child.*
- *Loss of income due to one parent not working in order to care for your child and the additional expense of hiring and managing specialized caretakers.*
- *Different points of view regarding your child's challenges and decisions about treatments and interventions.*
- *Loss of friendships or loss of time and energy to maintain outside friendships.*
- *Worries about the long-term future of your family.*
- *Changes in your retirement plans, your ability to take vacations or explore enrichment activities, etc.*

Tips to keep your marriage strong while dealing with the everyday challenges of living with autism:

- *Communicate! The more you can communicate in challenging times, the stronger you will be as a couple. You and your spouse may not react to your child's diagnosis in the same way, but try to explain how you feel and listen carefully as your spouse shares his or her feelings as well.*
- *Talk openly about problems as they occur.*
- *Be kind to yourself and your spouse during this difficult time.*
- *Work together to learn all that you can about autism.*
- *Help each other focus on the present and what you can do to make things better today.*
- *Spend time together. Plan some alone time, even if it is just a few hours a week, to relax and have fun together. Try and enjoy the leisure activities you did before your child was diagnosed with autism.*
- *Share the responsibilities at home when possible. Work together on chores, childcare, homework and other household tasks.*
- *Get help if you need it. A marriage counselor can help you and your spouse sort through your feelings and maintain a healthy marriage.*
- *Sort out what is important and what isn't important to the two of you. Take a close look at the best ways to make a good life for you and your family.*

Support for Single Parents

While stress affects all parents, single parents who have a child with autism may experience even more challenges. Single parents are often forced to take on several roles. They may be responsible for both the overall emotional and financial needs of their families while also caring for a child with special needs.

Come to an agreement that involves both parents. *If possible, start with your child's other parent and try to establish "agreements" that support everyone. The best situation is for your child to have frequent contact with the non-custodial parent so that your child will interact with both parents. This also gives the custodial parent a break or some down time.*

Build a support network of friends and relatives. *If you don't have family in your local community, you may want to consider moving closer to family or friends where you and your child will have a support network to fall back on.*

Take time for yourself. *If you can't depend on family or friends, find respite care in your area, so you can recharge and focus on yourself even for a short time each week.*

Social Networking – Find Support Online!

Many parents turn to the internet to avoid feeling isolated. Today's social networking sites will make it easy to seek out support from likeminded parents on the web. Social networking sites such as Facebook, Twitter and autism blogs will allow you to:

- *Connect with parents in similar situations, who are facing the same challenges.*
- *Ask specific question and get immediate feedback.*
- *Get support from other parents without having to travel or leave home.*
- *Read communications from trusted health organizations.*

Remember, your child with autism is part of a family and community. Family and friends are more likely to play a part in your support network if they understand your needs and the needs of your child. Do your best to keep family and friends informed and updated on your child's progress, as well as anything they might be able to do to help.

Taking Care of Yourself

Caring for a child with autism can be physically exhausting and emotionally draining. Parenting responsibilities can create extraordinary stress. Trying to balance your time and energy with the needs of your other children, the needs of your marriage and your own personal needs is not easy. It takes time to find a good balance and put it into practice.

What You Can Do for Yourself Right Now

Practice self-care.
Even if it is just for 15 minutes a day, take a breather. You need to take care of yourself in order to be able to take care of others. Take time to yourself so you can run errands, relax or enjoy time with your partner or other family members.

Acknowledge what you have accomplished.
It's easy at the end of the day to think about all the things you haven't been able to do that day. But this tends to discourage us from trying later. Instead, think about all that you did accomplish that day. You will be amazed at how long that list is, and you will feel better about getting started the next day.

Focus on the positive.
Nothing in life is perfect. Every situation has positive and negative aspects to it. Focusing on the positive, such as the progress your child is making or the amazing speech therapist you found, will give you the energy you need to move forward.

Continue family rituals.
When possible, continue your family routines or rituals. This will be helpful for your entire family. It may be a Friday night trip to the movies, or Sunday lunch in the park. Tradition and rituals give your family an increased sense of stability and create fun times to enjoy together and to remember.

Give yourself time to adjust.
Be patient with yourself. It will take some time to understand your child's disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry that autism has resulted in a life that is much different than the one you had planned. Remember, you will also experience feelings of hope as your child begins to make progress.

Make time for your friends.
Many parents report that long-lasting friendships have given them the strength and comfort during the most difficult times. If you feel isolated, it's time to take action.

Explore creative interests outside of autism.
Try to exercise or explore some creative interests. Take the time to realize that you are important and are more than just the parent of a child with autism.

Get involved with the autism community!
Sometimes families of individuals with autism find themselves feeling isolated from others. It is important to connect with families that share similar experiences and seek the support of others. We encourage you to reach out and come together with other families at one of the many *Autism Speaks Walks* held around the country. For more info on how to get involved, visit AutismSpeaksWalk.org.

Respite Care
If you don't have a family member or friend to babysit, find respite care in your area so you can recharge and focus on yourself even for a short time each week. Building a relationship with a respite provider gives you a reliable caregiver for your child if there is a family emergency. Respite care allows you to take a break in order to relieve you and prevent stress and fatigue. When you are ready to interview respite care providers, keep in mind that the most important step is to observe how the respite worker interacts with your child with autism and your family. If possible, have the worker spend supervised time with your family member. Below is a checklist of what you will want to discuss with a potential respite worker:

- *Previous work experience with an individual with autism*
- *Background checks*
- *Training sessions*
- *Behavioral concerns*
- *Safety issues*
- *Availability and flexibility*
- *Work references*

To find respite care in your area, please look at our online *Resource Guide* for your state's information: AutismSpeaks.org/Resource-Guide.

How I Let Go of My Expectations and Learned Unconditional Love

Ths is a post from blogger Chrissy Kelly who has two sons on the autism spectrum.
*Read more from Chrissy's blog, **Life with Greyson + Parker**, at **LifewithGreyson.com**.*

With one final, excruciating push he flew into the world. All the pressure was released and for the first time in so long I am able to take in a deep inhale. In that same very instant a brick house of expectation was also born.

He was perfect. Ten fingers and toes and I sighed, and fell in love with every single blessed detail. Soaked him up and felt it - the sweetest, purest love. I didn't know it existed quite so lucidly. My expectations already had his life all planned out for him.

He will smile and sit and crawl and one day even walk. He will say Momma, and love ice cream. He will dress up for Halloween. He will love his birthday. He will say the funniest things. I will read him books at night and scare the monsters away from under his bed. He will ask for extra pancakes and wrap me around his currently teeny tiny finger.

He will go to school. He will be smart. I will help him with science projects and pretend to be annoyed but actually love it. He will play sports, and be a humble winner and the very best loser. He will be fast. He will be brave. He will be kind. He will go to college and get married and have babies.

I had great expectations. And then right before his third birthday, I heard the words, "Your son fits the diagnostic criteria for autism". In an instant, my boy's life vanished right before me.

I didn't realize at the time, but it was really just the death of expectation. You see, I confused the two; my real boy and the son I expected him to be. And mourning expectation is so very hard. Letting go of years worth of day dreams doesn›t happen in a day or a week. And like many before me, I deeply grieved the loss of that expectation. Some of what I expected for me. Some of what I expected for him. I ached for each and every single one of those experiences I might not ever have.

But the more I shed the pain of expectation, the better I got to know my boy.

The real one I got, not the made-up one I expected. He doesn't deserve to be expected to be anyone other than who he is, and who he is - is amazing. It took time and strength and a determination to willingly let my expectations go, without throwing hope out at the same time. To wake up every day still, and decide to let go again and again. And the truth is that my real boy is alive and better than any of my wildest expectations- in ways completely different than I could have even imagined.

And as far as his future - anything is still possible. I just don't need certain things to happen in certain order to be happy and to measure the worth of my parenting experience.

The truth is, for most of us, reality is nothing like we expected. It is only in the letting go of our expectations that we are able to realize that our reality may not be so bad at all. When you are living an unexpected life it is easy to focus what you don't have. But there is also incredible beauty, perspective, love and experiences that come with the unexpected. It's so important that we notice those gifts too.

Sometimes I have moments when I still focus on the death of the expected. But now I remind myself how awful it would feel if someone constantly expected me to be different - and to be someone I'm not.

I've learned the very definition of unconditional love is choosing to love someone exactly for who they are.

A love not based on expectations, but on reality. I've finally knocked down that brick house of expectations. Turns out it was hiding the most incredible view.

Frequently Asked Questions from Parents

Q: My daughter is 2 years old and was recently diagnosed with autism. I have some family members who keep insisting she's just delayed. Can you give me any suggestions for how to respond to them?

Your situation is very common in families of children diagnosed with special needs, most especially autism. There are so many emotional processes that are occurring for the family as a unit and for each family member individually after getting this diagnosis. Of course there is the initial shock that can send you spiraling into a true grieving process, and each of you in the family will work through this in your own time frame. Part of that process includes a stage of denial as particularly seen from family members who aren't living with your child day-to-day. It's probable that it will take them longer to come to terms with the diagnosis. In addition to everything else you are doing, you must also remain patient for this to happen. Family members who love your child will benefit most from learning about autism so they can adapt their interactions and expectations to more appropriate levels.

There are also professionals and effective support groups in your community who have a lot of experience and expertise in understanding this process. They may be able to provide you and your extended family with assistance.

Q: My husband refuses to accept the diagnosis and will not attend appointments with our doctor. What can I do?

This is not uncommon, where one parent accepts the diagnosis and the other is in denial. Denial happens both to fathers and mothers. As difficult as it may be for you at a time like this, you must be patient and supportive. Your spouse will eventually work through his or her denial. Meanwhile, you might try to recommend a book or share an article about autism, but be careful not to pressure. Most people need to do this on their own terms.

Q: Since my son was diagnosed, I've felt overwhelmed and I can't even bring myself to read anything about autism.

Being an advocate for your child with autism will most likely be a lifelong activity. Early on when faced with the diagnosis, parents are easily overwhelmed by the news. They feel confused, fearful and angry. Many tire easily as they try to cope. It is helpful to remember that you are not alone, that others are going through this so there is support available for you. Keep a folder of articles and other information material so that when you are able to read it, you will have it available. Pace yourself and in time you will do what needs to be done and your efforts over time will make a difference.

Q: My family's involvement in church is important to us. How do I get my church to be more accepting of my son?

For many people, including those members of your church, autism is not something they may have experience with or adequate information about, so you must help educate them. A good place to start is with your pastor or minister. See what he or she knows and offer information as needed. Sometimes a leader will incorporate the related issues into a sermon or lesson. He or she can also suggest folks who can be approached as more open to learning about autism. Then, suggest the church invite a professional to do a workshop on special needs children, with emphasis on the challenges associated with autism. Suggest the church develop a plan to accommodate special needs children in their various activities such as the Sunday school classes, the worship service, the choir, etc. At some point, it may be helpful to bring in a behavioral specialist to work with and train the staff. It may mean asking teachers, parents and other trained professionals in the church to volunteer time helping out in Sunday school, modifying the lessons, etc. Get your community involved and they will thank you later!

Once members of your congregation are given accurate information, they will become more open and supportive. You may have to suggest ways they can become involved with your child and with advocacy organizations. There are so many opportunities for the religious community to get involved and to partner with parents. As advocates, parents have a unique opportunity to lead the charge.

Q: How do I know everything possible is being done for my child? Sometimes it seems like not enough progress is being made.

Almost daily, every parent with a child with autism asks this question: is there more that can be done to help my child? We work as hard as we can, yet very often we feel as though we aren't doing enough. It is also easy for us to project this on to others involved in our child's life. In fact, historically, not enough has been done and in many ways, more should be done in today's world. This is what advocacy is all about. We must continue to push for the best treatments and services available.

Meanwhile, we must recognize that there are some limits that we have to accept. Treatments available today have limits. We are learning so much, but we have a long way to go. Government funding clearly has limits, especially in today's economy. Teachers are frequently overworked with too many students. Sometimes it does help to focus on what is being done and to acknowledge our efforts and the efforts of others. At the same time, as suggested above, parents must be their child's biggest advocates.

When you look at what you do each day, you may want to give yourself a compliment for what you have accomplished. Your child is doing the best he or she can given the many challenges he or she faces daily. Be kind to yourself and remember that your child with autism, like all children, is going to grow and develop at his or her own pace. While we may want to see our children go from one sentence to five paragraphs in a semester, we must accept and celebrate what they do accomplish and gently encourage them forward. Consulting with outside professionals, such as educational therapists, can also help you set goals and look at progress realistically. On this journey, we have to redefine success and progress. It has to be based on our own child's gifts, and nothing else!

Q: Is there any financial assistance available to assist in the care and education for our child with autism?

Financial difficulty is one of the biggest stressors that families with special needs children face. There seems to never be enough funding or financial help available and each family often finds that their own resources are stretched by providing for their child with little hope of reimbursement for all that gets spent.

The primary funding source for your child's services is mandated through a United States federal law, the Individuals with Disabilities Education Act (IDEA). IDEA governs how states and public agencies provide early intervention, special education and related services to children with disabilities.

In addition, your family's medical insurance may reimburse you for autism services, such as speech therapy or behavioral health treatment, such as Applied Behavior Analysis. Start by speaking with the human resources department where you or your spouse work, and inquire about insurance reimbursement for autism services. Many states now have government agencies monitoring the health insurance industry so this can be a back-up resource to explore benefits as needed.

Continuing to advocate for increased funding by the government and by the insurance industry is important. For more information about autism insurance reform in your state, visit the Autism Speaks website.

Q: My wife and I worry that over time our other children will develop deep resentments for all the attention and "special treatment" their brother gets and this could negatively impact their lives. Do you have any suggestions for raising our other children so they don't feel resentment?

Sibling rivalry occurs in all families with more than one child and it can be especially complex when it involves a child with special needs. There is no way to avoid giving some extra attention and treatment to a child with autism. For siblings of children with autism, these feelings may develop early because the children may be together all the time.

Constantly checking in with your other children about how they are doing, what they need, etc. is a good start. Finding time to be with each child individually also helps immensely, when possible. Involving grandparents, aunts, uncles, trusted neighbors, etc., may help as well.

Children at various ages have the capacity to understand the special needs of someone else if you take the time to explain in terms they will understand. Explain behaviors they see in their brother or sister and why you respond differently to deal with these situations. While you don't want them to become surrogate parents, they do need to know some basic explanations. Also, creating a safe space for them to talk about their feelings with you or with others can prevent later development of toxic resentments. Helping your other children find successful ways to play or interact with their brother or sister is powerful.

Siblings may sometimes feel guilty because they do feel resentment and anger, or even just because they are "normal" while their brother or sister is not. Guilt and resentment are normal growing up issues, made more complex often because of a special needs sibling. But like any feeling, they can be talked about and processed so that your other children move forward in their own emotional development and life journeys.

Resources

Autism Speaks Autism Response Team

*The **Autism Response Team (ART)** is specially trained to connect people with autism, their families and caregivers to information, tools, and resources. A team member can help you find resources to meet your family's specific needs.*

888-288-4762 (en Espanol 888-772-9050)

FamilyServices@AutismSpeaks.org

Autism Speaks 100 Day Kit for Newly Diagnosed Families

*The **100 Day Kit** was created to help families make the best possible use of the 100 days following an autism diagnosis. Important topics include understanding symptoms, accessing services, finding the right treatments and knowing your child's rights.*

AutismSpeaks.org/Family-Services/Tool-Kits/100-Day-Kit

Versions for both young children (under 5) and school age children (5-13)

Autism Speaks Tool Kits

Autism Speaks has developed nearly 50 tool kits for parents and caregivers of children and adults with autism on topics ranging from toilet training and challenging behaviors to housing and employment for adults. All tool kits are available free of charge.

AutismSpeaks.org/Family-Services/Tool-Kits

Find a Local Resource: Autism Speaks Resource Guide

*The **Resource Guide** contains tens of thousands of local resources including pediatricians, behavioral therapists, after school programs and more.*

AutismSpeaks.org/Resource-Guide

Autism Speaks Walk

*The **Autism Speaks Walk** is a great way to connect with families and services in your area. Autism Speaks Walk is the world's largest autism fundraising event dedicated to improving the lives of people with autism. Powered by the love of parents, grandparents, siblings, friends, relatives, and supporters, the funds raised help ensure people of all abilities have access to the tools needed to lead "their best lives".*

AutismSpeaksWalk.org

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

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

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG
AUTISMSPEAKS.ORG/ART

AUTISM SPEAKS®

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

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

autism speaks

Successful Dental Visits for Children with Autism

Getting Started at Home

Oral health is a very important component of healthy daily living. But for some children with autism, oral health habits can be challenging. Our hope is that this guide will provide information for families to help begin a lifetime of good oral care.

To get started, you and your child should pick out the right toothbrush. There are many colors, styles, and types available. It is important that the brush is the right size for your child's mouth and that it has soft bristles.

For some children with autism, brushing teeth can be difficult. The sensation can be uncomfortable at first, and the child may need to be desensitized. You may want to start by using the toothbrush to touch your child's lips or just inside the mouth. You may also want to teach your child to "open wide," so that this direction is understood. Showing your child how you brush your own teeth may also be helpful.

Brushing and Flossing

Brushing Your Child's Teeth

- Stand behind your child with their head on your chest.
- Put a pea size amount of toothpaste on the center of the brush.
- Guide the brush as if you were brushing your own teeth.
- There are six steps to brushing:

    1. Brush the outside, inside and tops of the bottom back teeth on one side of the mouth five times.
    2. Move up and brush the inside, outside and chewing surfaces of the top teeth five times.
    3. Brush the bottom front teeth outside and inside five times.
    4. Move to the opposite side and brush the bottom teeth outside and inside five times.
    5. Brush the top front teeth inside, outside, and chewing surfaces five times.
    6. Brush the opposite top back teeth inside, outside, and chewing surfaces five times.

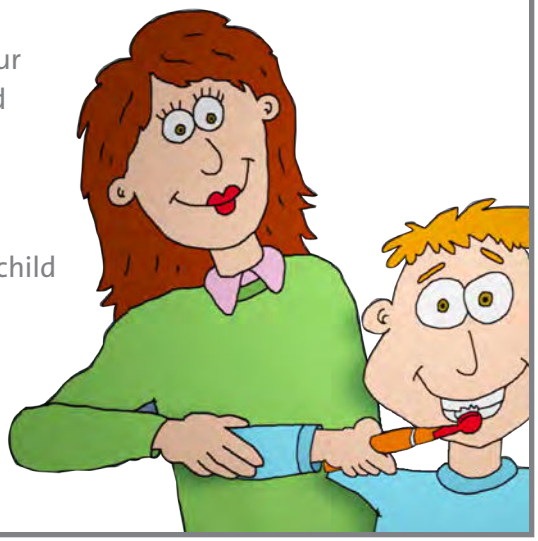
Although most people brush their teeth in the bathroom, in order to accommodate your child and get them accustomed to brushing their teeth, you may want to do this on the couch or in another part of your home where they may feel more comfortable. The ultimate goal is for your child to brush their teeth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

Flossing

Another important oral health skill that should be mastered is flossing. Just like brushing, this should be introduced as soon as possible in small steps, while building upon each success.

- The same technique is used in putting your child's head on your chest and flossing as you would your own teeth.
- Floss one tooth at a time.

Again, the goal is always for your child to achieve independence in this task.



Other Tips

Other Tips That May Be Helpful

- Some families find it useful to use a timer so that the individual with an autism spectrum disorder (ASD) can see when the task will be over.

- Some individuals with autism benefit from visual supports and schedules. A visual schedule can be created by taking photographs of the steps outlined on the previous page.

  - Families can then print the pictures and create visual schedules for their child. Some families may print the page and check off the activities as they occur. The pages can be laminated and a dry erase marker can be used to check off each activity, this way the page can be reused.

  - Others may cut out the photos and laminate them, and place Velcro on the back of each photo. The photos are arranged in chronological order on a board, and as each step is completed, the corresponding picture is removed.

- Another option is to photograph each step of the teeth brushing process, load the pictures on to a digital picture frame and program it so that each photo is displayed for 10 second intervals. This can be used in the bathroom as they are brushing their teeth so that they have a visual prompt when it is time to move on to the next step.*

- Some individuals need to be reinforced with verbal praise or a reward after each step. Others may be able to complete some, many, or all of the steps before verbal praise or a treat is needed. Each child will need to work at their own pace to achieve the skills necessary to brush their teeth.

  Once a manual toothbrush has been mastered, then a power brush can be introduced. The power brush is slightly different in that the brush does the work, so the individual no longer needs to do the "brushing."

  In all cases, the ultimate goal is for the individual with autism to brush their teeth as independently as possible.

*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

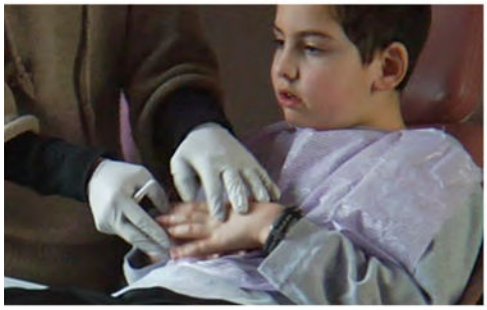
You may also be able to get some dental bite wings from their dentist in advance of the visit, so that your child may practice biting down on the dental bite wings when they need to have X-Rays taken.

Visual Schedule

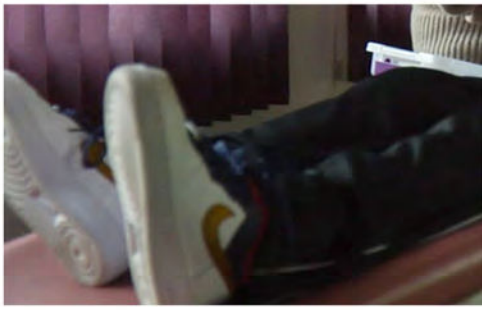
Individuals with autism often benefit from visual supports and schedules. The following visual schedule outlines the steps necessary for a dental visit. Families are welcome to print the pictures and create a visual schedule for their child. Some families may print the page and check off the activities 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



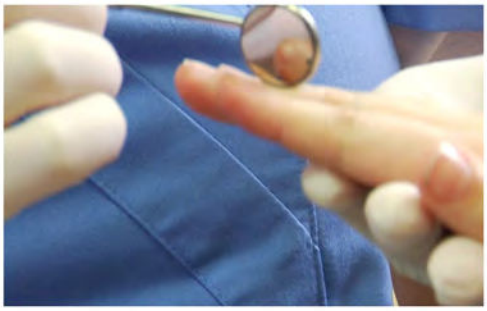
1 Put hands on stomach ☐



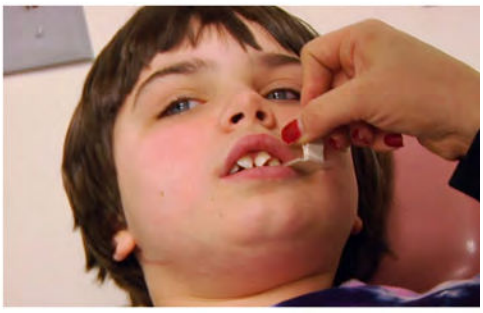
2 Feet out straight ☐

3 Open mouth wide ☐

4 Hold mouth open ☐



5 Count teeth ☐



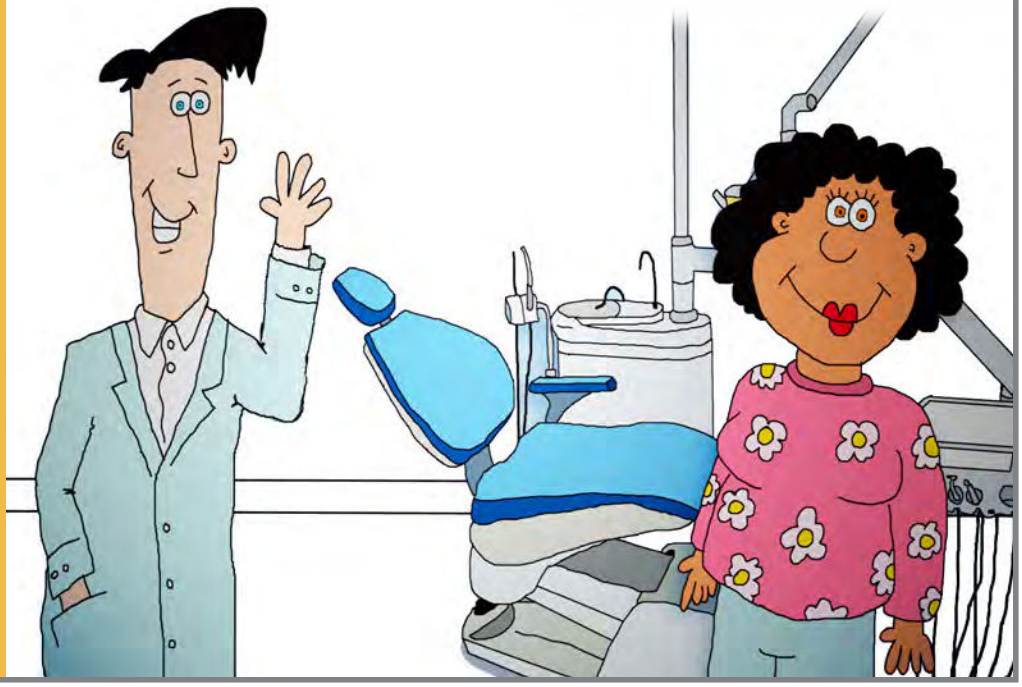
6 Take X-Rays ☐

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.

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.

About Us

About Autism Speaks

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. Through partnerships and collaboration, we are committed to:

- Increasing global understanding and acceptance of people with autism
- Being a catalyst for research breakthroughs
- Increasing early childhood screening and timely interventions
- Improving the transition to adulthood
- Ensuring access to reliable information and services throughout the life span

To find resources, join a fundraising walk or make a donation, go to **www.AutismSpeaks.org**.

CONNECT WITH US

Credits

Illustrations by: Joe Shea

Special Thanks to: Karen A. Raposa, RDH, MBA, Gail B. Stoops, RDH, BSDH, Nicole Weidenbaum, M.S. Ed., SAS, Executive Director NSSA, Kathy Mannion, Associate Director, NSSA, Students, clients and staff at Nassau Suffolk Services for Autism (NSSA), Richard Holstein, D.M.D., Stanton E Young, D.M.D., Dr. Michele Savel, D.D.S., and Kiddsmiles Pediatric Dentistry.

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:

- O Mayer Johnson Symbols
- O Sign Language
- O Picture Exchange Communication System (PECS)
- O 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.

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 toolkit 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.

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?

With gratitude, we thank the members of our Advisory Committees for generously donating their time, experience and resources to this project.

Parent Committee

- *Kameena Ballard*
- *Sallie Bernard*
- *Brandy Krupa*
- *Mia W. McNary*
- *Beverly Moore*
- *Marianne Sullivan*

Self-Advocates

- *Ruth Elaine Hane*
- *Charles Joiner*

Professional Committee

- *Ryan Cramer, LSW*, Center for Autism and Developmental Disorders, Western Psychiatric Institute and Clinic of UPMC
- *Dennis Debbaudt*, Autism Risk & Safety Management
- *Peter Doehring Ph.D*, Director of Autism Services, Foundation of Behavioral Health
- *Richard B. Graff, Ph.D., BCBA-D*, Clinical Director, New England Center for Children
- *Terry Hamlin Ed.D.*, Associate Executive Director, The Center for Discovery
- *Johanna Lantz, Ph.D.*, Assistant Chief of Psychology, Center for Discovery
- *Lucille Esralew, Ph.D.*, NADD-CC, Clinical Administrator SCCAT & S-COPE, Trinitas Regional Medical Center
- *Gary S. Mayerson*, Founding Attorney, Mayerson & Associates
- *Valerie Paradiz, Ph.D*, Director, Valerie Paradiz LLC, Director, Autistic Global Initiative
- *Ricki Robinson M.D., M.P.H*, Co-Director of Descanso Medical Center for Development and Learning Author, Autism Solutions
- *Matthew Siegel, M.D.*, Director, Developmental Disorders Program, Spring Harbor Hospital, Assistant Professor, Tufts University School of Medicine
- *Nicole Weidenbaum, M.S. Ed., SAS*, Executive Director, Nassau Suffolk Services for Autism
- *Joanne Wilken*, Special Education Teacher and Autism Speaks Chicagoland Chapter Board Member
- *J. Helen Yoo, Ph.D., BCBA-D*, Applied Behavior Analysis Laboratory, Department of Psychology, New York State Institute for Basic Research

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.

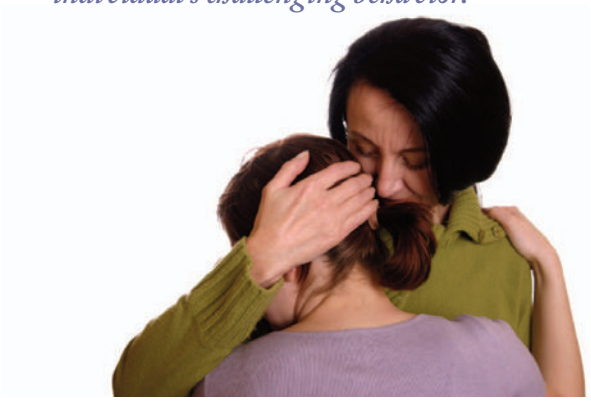
People with autism often report that they find the world confusing and anxiety-producing. Many of the successful supports for increasing appropriate behavior involve creating more predictability and safety, while also building self-regulation, communication and self-determination skills. Meet your child 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."

- *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

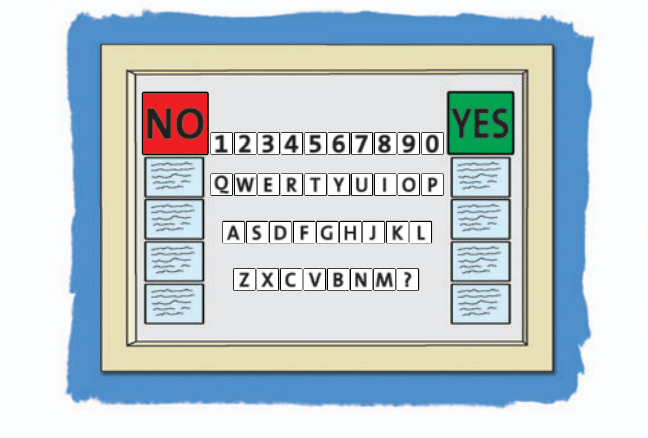
Depression and Anxiety: Exercise Eases Symptoms
Mayo Clinic

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

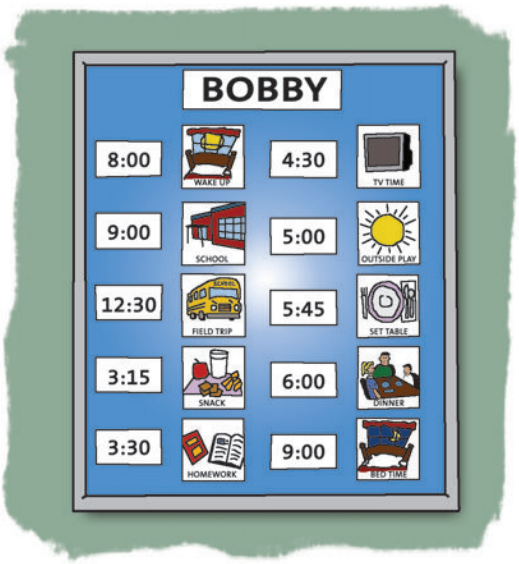
C.O.P.E.S.™

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.



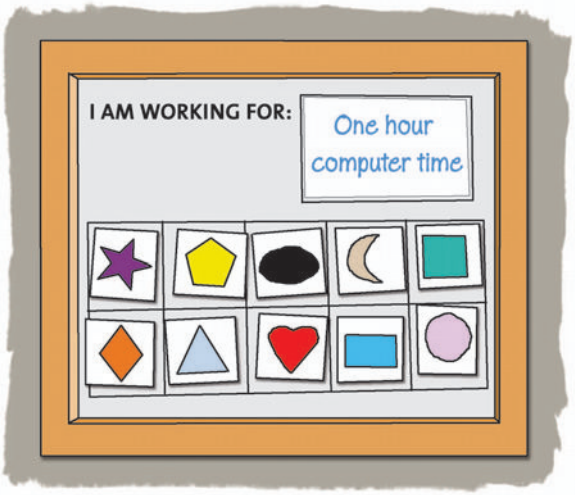
- *Organization:* many of the students showed considerable anxiety and a complex array of escape and avoidance behaviors since they had no systems to help them organize and anticipate events, daily schedules, changes in schedules and or future events. Simple schedules and training on basic contingency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



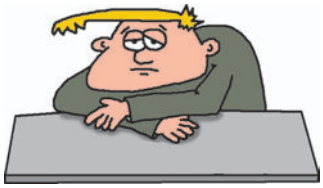
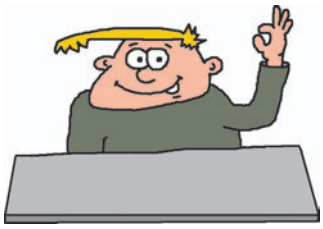
- *Emotional regulation:* Starting on day one of the behavior support plan, each student was systematically taught to understand and identify his own regulatory state and escalation cycle. Proactive programming was essential. Empowerment and self-determination was a significant part of the program and 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

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

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

Private Counselling
See Yellow Pages under 'Marriage, Family & Individual Counsellors'

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

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

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

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

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

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

Anderson House
Women & Children
24hr: 1-800-240-9894
Ch'town 892-0960
Office 368-8658

Red Cross Emergency & Disaster Services
1-800-222-9597

Habitat for Humanity
367-3559

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

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

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

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

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 I.-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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Prince Co Central 436-7721
West Prince 856-0301

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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

Mi'kmaq Confederacy of PEI
Family Pride Prog. (Lennox & Abegweit) & Indian Residential School Supports Toll Free 1-877-884-0808

Alzheimer Society of PEI
628-2257

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

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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

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

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

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PEI Assoc. for Newcomers to Canada . 628-6009

PEI Council of People with Disabilities
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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 I.-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)

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.

Triple P®
Positive Parenting Program

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.*

Triple P®
Positive Parenting Program

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.

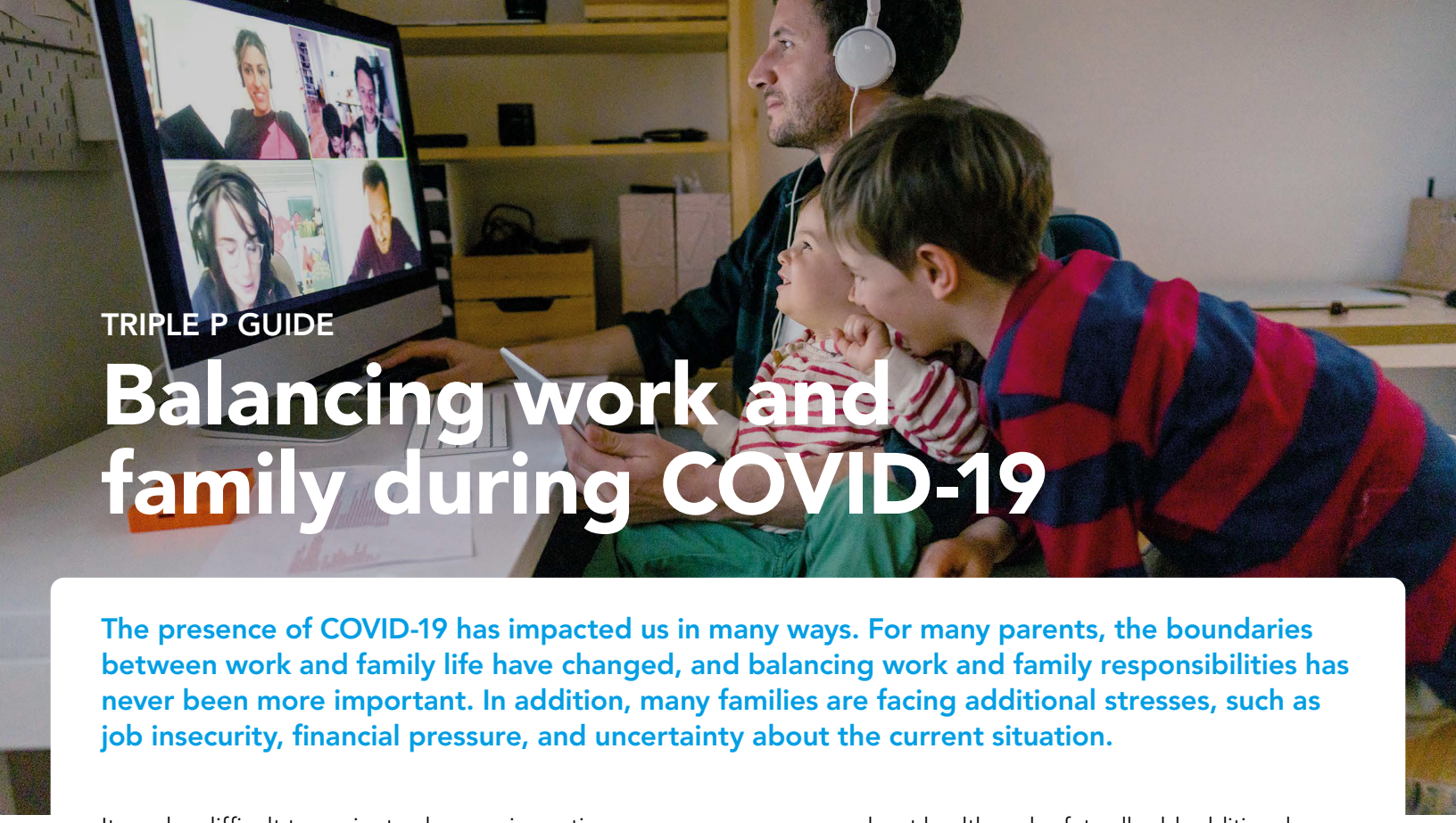
10 Keep up quality family time

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

TT_COVID-19_SL_201020_CAN-EN



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*

Divna Haslam, PhD — is a Clinical Psychologist and author of Workplace Triple P. She has a special interest in supporting working families.

Karen MT Turner, PhD — is a Clinical Psychologist, foundational co-author of Triple P, and an expert in innovative parenting support in diverse communities.

Matthew R Sanders, AO, PhD — is a Clinical Psychologist, Founder of Triple P, and one of the world's leading experts on parenting.

ACCESS 2

An Easter Seals Canada Program

Easter Seals Timbres de Pâques Canada TM MD

Access 2 Card Application Form

Instructions

1. Read this document carefully. If you have any questions, please visit www.access2card.ca

2. If this is your first Access 2 Card, print, complete and submit sections B (Applicant Information), C (Health Care Professional Authorization) and D (Administration Fee Payment) – along with the administrative fee.

3. If you are renewing an expired card or replacing a lost card, submit only sections B and D - along with the administrative fee.

4. Mail, fax, or email completed Sections B and/or C and D to Easter Seals Canada.

5. Include administration fee: by cheque or money order (payable to "Easter Seals Canada") or online payment (credit card, Visa debit, or PayPal - payable at www.access2card.ca*)*. Paying online is highly recommended as you will receive your card faster. See section D for payment details.

6. Keep a copy of the application form for your records.

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

Program Overview

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

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

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

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

Terms and Conditions

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

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

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

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

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

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

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

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

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

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

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

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

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

ACCESS 2

An Easter Seals Canada Program

Easter Seals Timbres de Pâques Canada ™ MD

Access 2 Card Application Form

Section B – Applicant Information

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

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

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

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

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

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

First Name: _____ Last Name: _____

***Date of Birth** (dd/mm/yyyy): _____ / _____ / _____

***Mailing Address**: _____ **Unit #**: _____

***City**: _____ ***Province**: _____ ***Postal Code**: _____

***Phone**: (_____) - _____ - _____

***E-mail**: _____

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

➡ ***Applicant or Guardian's Signature**: _____ **Date**: _____

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

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

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

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

Section C – Health Care Professional Authorization

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

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

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

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

Professional Stamp (if available)

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

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

Name of Health Care Professional OR Executive Director: _____

Professional Registration Number: _____

Practice/Service Address: _____ **Unit** #: _____

City: _____ **Province**: _____ **Postal Code**: _____

Phone: (_____) - _____ - _____ x. _____**E-mail**: _____

Health Care Professional OR Executive Director Signature: _____

Date: _____

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

Section D – Administration Fee Payment

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

- If you are paying by cheque or money order (payable to "Easter Seals Canada"), please mail it along with your application.
- If you are paying online with a credit card, Visa debit card or PayPal account, you must submit your application after payment. Pay online at www.access2card.ca. Paying online results in the fastest turn-around time.

*Select Your Access 2 Card Type:

☐ **3-Year Valid Card ($20)**

☐ **5-Year Valid Card ($30)**

*Select Your Payment Method:

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

*Name of credit card holder:

_____

*Name of Access 2 Card Applicant:

_____

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

ESC - _____

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

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

Please ensure that the cheque/money order is:

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

Application Checklist (For Your Reference)

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

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

Submitting Your Application

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

Mailing Address:

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

Fax:

416-932-9844

E-Mail (Scanned):

access2card@easterseals.ca

If you have any questions, please contact us by:

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

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

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

Clear Data

Protected B when completed

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 ____

Clear Data

Protected B when completed

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

Clear Data

Protected B when completed

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 ☐ Nurse practitioner ☐ Optometrist ☐ Occupational therapist

☐ Audiologist ☐ Physiotherapist ☐ Psychologist ☐ Speech-language pathologist

As a **medical practitioner**, I certify that the information given in Part B of this form is correct and complete. I understand that this information will be used by the CRA to make a decision if my patient is eligible for the DTC.

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.

Fred just celebrated his 60th birthday, so by the end of the year must begin withdrawals from his RDSP. His financial advisor advises him that $24,500 must be withdrawn from his plan, an amount calculated based on Fred's life expectancy of age 80. Details of his RDSP are as follows:

Plan value: *$587,996*

Total contribution: *$200,000*

CDSGs: *$35,000*

CDSBs: *$0*

Of the $24,500 payable in the year, $8,333 would be non-taxable ($200,000/$587,996 x $24,500). The excess, $16,167 would be taxable to Fred.

However, if Fred has no other income, he can receive the taxable RDSP distribution of $16,167 and not incur any taxes after taking into account his disability tax credit and basic personal amount.

Note: As of 2014, withholding tax will apply to the taxable portions withdrawn from an RDSP. The tax withheld can be claimed by the beneficiary on his or her tax return. The amount withheld should be taken into consideration when determining the withdrawal amount.

Eligible transfers

An RDSP may be transferred to another RDSP for the same beneficiary. To ensure RDSP beneficiaries only have one plan, the transferring plan must be terminated immediately after the transfer. Also, the receiving plan must agree to pay minimum amounts for the year where the transferring plan has not yet done so (generally applicable to beneficiaries age 59 or older).

Tax-deferred transfers from RRSPs, RRIFs or RPPs to an RDSP to the maximum contribution limit are permitted as of July 2011. These transfers must be from an RRSP, RRIF or RPP of a deceased parent or grandparent if the beneficiary of the RDSP was financially dependant on that individual. Tax-deferred transfers of the taxable amount of RESPs are allowed as of 2014.

Impact on Social Assistance Benefits

Payments from an RDSP do not impact other income-tested federal government programs, including:

- Old Age Security (OAS)
- Guaranteed Income Supplement (GIS)
- Canada Pension Plan (CPP)
- The Goods and Services Tax Benefit (GST Benefit)
- Social assistance benefits

As well, generally speaking RDSPs assets and payments should not have a negative impact on eligibility for programs such as subsidized housing and long-term care. However, each province and territory has legislation that provides support to persons with disabilities, so be sure to check with your legal and/or financial advisor for the most up-to-date legislation in your province.

What if the beneficiary dies or is no longer disabled?

When an RDSP beneficiary dies the RDSP will collapse and full proceeds of the plan will be paid to the beneficiary's estate or the estate beneficiary, respectively (subject to CDSG and CDSB repayment obligations).

Original contributions remain non-taxable, while CDSGs, CDSBs and investment income received will be taxed as ordinary income to the beneficiary or his or her estate.* Recognizing that a beneficiary's estate will receive RDSP proceeds on death of the beneficiary, provision should be made in the beneficiary's will for distribution of the assets so that the beneficiary has greater control over the intended distribution of the assets.

If the beneficiary dies without a will, the proceeds would be distributed according to the laws of intestacy for the province or territory in which the beneficiary resided. These laws generally provide for the spouse and children of the deceased, if any, followed by the next closest relatives.

However, relying on the laws of intestacy could lead to unintended distributions, particularly if the beneficiary has a preference that non-related individuals (e.g., friends, caregivers) inherit. Because the rules differ between jurisdictions, it is important to speak to a lawyer in the jurisdiction of the RDSP beneficiary to determine applicable rules.

If the beneficiary ceases to be eligible for the disability tax credit because their condition has improved, the RDSP must either be collapsed by the end of the year following the cessation of the DTC, or an election, with medical verification can be made to put the RDSP " on hold" (no contributions or withdrawals) for up to four years. If there is a relapse and the beneficiary is again DTC-eligible, then the RDSP can be restarted without requiring an entirely new application.

***Note:** If CDGs or CDSBs were paid into the RDSP within 10 years of the death of the beneficiary, those funds must be repaid to the Government.

Karen recently passed away. At the time of her death, her RDSP was valued at $251,471 of which $100,000 was original contributions. No grants or bonds were received in the 10-year period prior to death. On death, Karen's estate received a payment of $251,471, of which $100,000 was non-taxable. The remaining $151,471, consisting of grants, bonds and investment income was taxable on her final tax return.

Other Planning Issues

Henson Trust

Named after the Henson family, a Henson trust is a formal trust to which assets can be contributed on behalf of a disabled individual. Because the trust is discretionary in nature (i.e., the trustee has full discretion over when, how and if assets are distributed to the disabled beneficiary), the trust can provide a certain level of financial support without having the disabled beneficiary's provincial benefits clawed back. It should be noted that some provinces, Alberta, for example, do not recognize such trusts.

In many provinces, Henson trusts will continue as an effective estate planning strategy alongside RDSPs. Suitability should be discussed with a financial advisor and lawyer. Greater flexibility may be achieved through a Henson trust as maximum and minimum withdrawals do not normally apply. Short-term expenses may also be addressed more easily in the absence of CDSG and CDSB repayment provisions. As an estate planning strategy, a contribution of $200,000 could be put into an RDSP during the contributor's lifetime with any excess being left to a trust in the deceased contributor's will.

As of 2016, a Henson trust may be designated as a "Qualified Disability Trust", which receives preferential tax treatment on income earned in the trust.

For more information on the RDSP or to set up a plan, please contact your financial advisor.

GENERAL INQUIRIES

For all of your general inquiries and account information please call:

ENGLISH	1-800-387-0614
BILINGUAL	1-800-387-0615
ASIAN INVESTOR SERVICES	1-888-465-1668
TTY	1-855-325-7030 416-922-4186
FAX	1-866-766-6623 416-922-5660
E-MAIL	service@mackenzieinvestments.com
WEB	mackenzieinvestments.com

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Secondary Transition Planning

A Framework for Successful Transition Planning for Young People with Special Needs

Prince Edward Island
CANADA
Education and Early Childhood Development

Secondary Transition Planning

A framework for successful transition planning for young people with special needs

Department of Education

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Raeanne Adams
Autism Consultant
Western School Board

Marlene Breitenbach
Special Education Autism Coordinator
Department of Education

Bridget Cairns
Executive Director
PEI Association for Community Living

Pat Coady
Family Liaison Officer
PEI Association for Community Living

Rachel Fitzpatrick
Autism Consultant
Eastern School District

Jackie Hicken
Elementary Language Arts Specialist
Department of Education

Linda Inman Hyson
Teacher
West Royalty Elementary School

Terri MacAdam
Special Education Consultant
Eastern School District

Nancy MacIntosh
Principal
Tracadie Cross Consolidated School

Angela Seaman
Autism Consultant
Eastern School District

Contact Information
Special Education Autism Coordinator
Student Services Division
Department of Education
PO Box 2000, Charlottetown, PE C1A 7N8
Tel (902)569-7792
Fax: (902)368-4622

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Table of Contents

Individual Transition Planning

Individual Transition Planning

Overview

Resource Components

What Is Transition Planning?

Individual Transition Planning

Overview

The transition from school to work, further education and community living can be particularly challenging for students with special needs especially those with an autism spectrum disorder. Thoughtful planning and coordination are required in order for these students to be well prepared for their post high school living, learning, working and leisure environments. **Collaboration** including the student, family, school and community agencies is needed to identify desired post-school outcomes that can guide the student's educational programming during the final school years.

The transition **planning** process should begin **early** by age 14. The Transition Action Plan is a dynamic document which is cumulative over the last several years in school. Each year the team reviews and adds to or revises the plan as needed and insures that planning is **continuous**. Careful documentation of this information enables the Transition Team to provide continuity based on the desired long term goals. Goals are initially broad and become increasingly more focused and specific as the student nears graduation.

To ensure a smooth transition, it is essential that the last years of school focus on **teaching skills** that will be required in the new environment**.** These may include daily living skills including personal care, work and social skills and/or functional academic skills. Current skill **assessment** in the targeted areas is important in determining appropriate objectives.

Over the course of the transition planning process, the student and family are also introduced to the adult service system for individuals with special needs and helped to establish **connections** that will be important in this transition. Community service providers learn about the individual needs of the young adult and can begin to identify **supports** that will be needed for the student to live, work and recreate in the community as an adult.

Resource Components

The purpose of *Secondary Transition Planning* is to assist schools and families as they begin this essential process of preparing students with special needs for post school environments. Not all sections of this resource will be relevant or necessary for every student. Following the suggested process, choose the most important components for each individual based on your knowledge of the student and input from the student and family.

Secondary Transition Planning includes:

- a student centered process describing the steps and time line for transition planning
- suggestions for establishing the transition team and an organizational structure outlining roles and responsibilities of team members
- suggested formal and informal assessment information to be gathered from parents, the school and the student. Structured interviews are included to facilitate this.
- examples of informal assessments and checklists which can assist the team in identifying interests, strengths and weaknesses for and with the student
- suggestions for creating a Student Transition Portfolio, including adapted checklists for more challenged students
- considerations for developing the Transition Action Plan
- forms to facilitate monitoring and recording of the plan and completed steps in the process

- *Community Resource Guide.* PEI Association for Community Living (2006). Charlottetown, PE.

  This is a listing of PEI community agencies and educational programs which may provide services or support for the student in the post school environment. Description of available services as well as contact information is included.

- *PEI Transitions From School to Community. Post-secondary Scholarship and Bursary Guide for Students with Disabilities.* PEI Association for Community Living (2006). Charlottetown, PE.

  This comprehensive listing includes funding, scholarship and financial aid information for individuals with disabilities

- *Secondary Transition Planning* CD

  Reproducible forms contained in this resource have been included on a CD to make the tool user friendly and adaptable. This allows the forms to be filled out using a computer if desired.

Additional Resources provided:

- *Transition Planning Inventory (TPI).* Clark, G. & Patton, J. (1997). Austin, TX: Pro-Ed

  This is an informal assessment instrument for identifying and planning for the transitional needs of students. It is designed to provide a systematic way to address critical transition planning areas and take into account the individual student's needs, preferences, and interests

- *Informal Assessment for Transition Planning.* Clark, G., Patton, J. & Mouton, L. (2000). Austin, TX: Pro-Ed.

  This resource can be used to determine transition needs and to develop appropriate transition plans. It includes a comprehensive listing of competencies that have been identified as important to adult functioning. In addition, it contains a number of informal instruments that assist with the generation of transition-related information. This resource can be used as stand-alone material or to extend information derived from the *Transition Planning Inventory (TPI)* on which this resource is based.

What is transition planning?
Transition planning is an **outcome oriented process** which is designed to promote success in the post school environment. Planning is **student centered** and based on the individual student's needs, preferences and interests. The planning process provides a systematic framework through which information is gathered to guide the development of the school program. Information gathered throughout the process is **carefully documented** to ensure that the plan is **continuous** and evolves from year to year. A written record of the Transition Action Plan is included in the Individual Education Plan and is developed collaboratively by the student, family and school.

Who may need specific transition planning?
- students with identified special needs who have required significant resource support in their educational programs
- students who have required individualization in their educational programming as documented in Individual Education Plans
- students who have required significant modifications to their educational program
- students who need adapted assessment strategies in order to help them participate in the transition planning process

What long-term outcome areas will be considered in planning?
The intent of the process is to assist the student in determining how he or she will live, work, learn and recreate in the community after leaving high school. Thus, the main areas of focus are Living, Employment, Community-Leisure and Learning-Education. In all areas, the focus is on selecting actions and objectives that will lead to the greatest degree of independence and choice in the future environment.

Living Outcomes
This area explores the student's wishes for living arrangements as well as personal management, social interaction and self care skills needed in that living environment. Families and students are encouraged to consider living options that may change over time as students increase their independence or family needs change.

Employment Outcomes
This key area is directly linked to the student's interests, preferences and current skills and requires thoughtful assessment and collaboration. Work, volunteer, school jobs and coop experiences during the final school years will help in

determining the student's motivation and interest in particular work environments and tasks. For some students, on-the-job training may be an option. The Team is encouraged to think "outside the box" about the types of job possibilities that may be satisfying for the student and help the student develop the social and work behaviours that are needed in that future environment. Community agencies who may be able to assist in supports, funding, or transportation are essential to developing this plan.

Community-Leisure Outcomes

Quality of life is often closely related to our engagement with others who enjoy similar interests and activities. It is important to ensure that the student develops an awareness of actions and activities that would promote friendships and good health. The last years of school can often be used to expose the student to more opportunities in this area through school sports, special interest groups, or social skills groups. Accessible transportation and mobility within the community is often a key element and should be planned for, including safety skills and independent use of local transportation when possible.

Do all students with special needs require *comprehensive* assessment and transition planning?

The main outcome areas should be reviewed each year for each student, however, some students may require less detailed plans or perhaps, actions in only one area. The plan is individualized and depends on the nature and extent of the disability. The process outlined here provides suggested steps to assist the transition team in identifying which outcome areas will need more detailed plans.

The transition planning process should...

- begin by age 14 or earlier
- involve the student as much as possible in setting personal goals and setting a plan of action
- reflect the strengths, skills, interests and needs of the student
- identify realistic outcomes for work, further education or community living that are attainable given appropriate supports
- provide critical information for developing appropriate IEP goals and objectives, including current assessment
- define actions needed to help the student achieve the goals

Steps to Transition Planning

Creating the Transition Team

Gathering Information

Initial Planning

Assessment

Transition Action Plan (TAP)

Creating a Student Transition Portfolio

Follow-up and Review

Steps to Transition Planning

Step 1 – Creating the Transition Team
- Team Roles and Responsibilities

Step 2 – Gathering Information
- Parent Interview
- Student Interview
- Teacher Observation Checklist
- Community Social Skills Rating Checklist
- Student Information Summary

Step 3 – Initial Planning
- Post Secondary Outcomes (Sample)
- Post Secondary Outcomes Checklist
- Questions to Guide the Planning Process

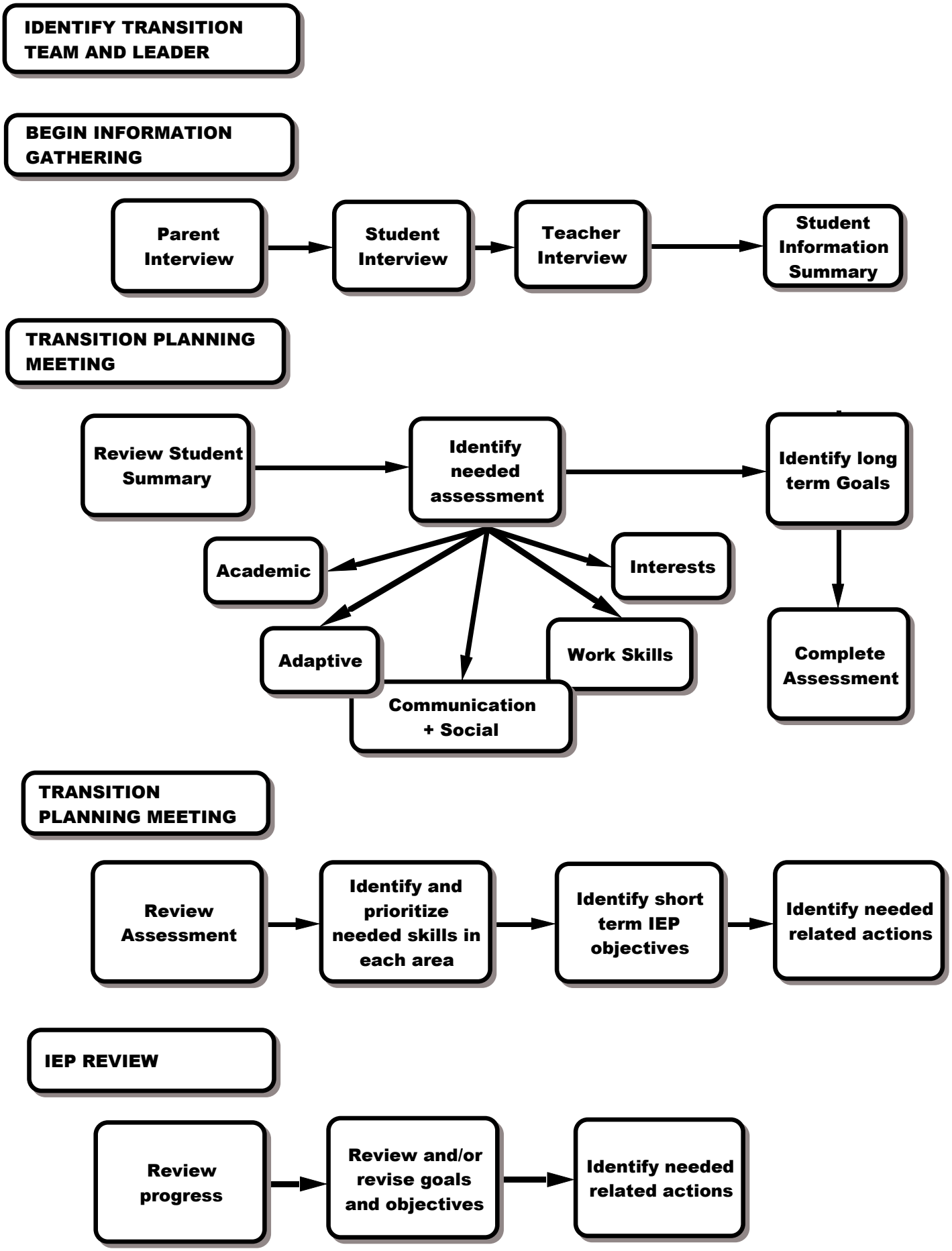
Step 4 – Assessment
- Formal Measures
- Informal Measures

Step 5 – Transition Action Plan (TAP)
- Creating the Transition Action Plan

Step 6 – Creating a Student Transition Portfolio
- Student Portfolio Fact Sheet

Step 7 – Follow-up and Review

TRANSITION PLANNING



Step 1 - Creating the Transition Team

Effective planning requires the cooperation and effort of a team where the input of all members is valued. In the Spring of Grade 8 or the Fall of Grade 9, the Principal designates a staff member to coordinate the student's Transition Planning Team. The designated Transition Team Leader is often a Resource Teacher or Special Educator who oversees the Individual Education Plan. The Team Leader identifies the Transition Team members for the student including the following:

Core Team: These members have a commitment to working for the student's benefit in this planning process and will generally meet two-three times a year during the student's last school years. Although some team members may of necessity change, continuity in the planning process is essential. The transition team leader, as the plan facilitator, will ensure that new team members are informed of the process and the steps that have been taken thus far.

- Student
- Parents or Guardians
- Team Leader
- Teacher(s) and School Counselor

Extended Team: Additional members are invited as appropriate or applicable and *may be permanent or temporary team members*. Board or Department Consultants with specific areas of expertise may assist with the transition planning process. When the student has specific physical or medical needs (I.e communication, vision, or hearing impairment or mobility issues), the team should request participation or input from these professionals. Community agencies or services who will be providing support after high school should be represented on the team especially during the last two years of school. Depending on student and family goals and needs, the input of a Disability Support Worker and/or community agency representative is very helpful in this transition process, in particular in facilitating connections with community resources and governmental supports.

- Special Education or Autism Consultant
- Disability Supports Worker
- Health or Social Work professionals
- Disability Specific Professionals (APSEA, HEAR, etc.)
- Members from community disability (or other involved) organizations

Team Roles and Responsibilities:

School:

- Identify Transition Team Leader and Team members
- Schedule and facilitate transition planning meetings
- Involve appropriate Board Consultants as needed
- Coordinate the development, implementation and monitoring of the Transition Action Plan
- Conduct and/or arrange for assessment
- Document the transition planning process through the IEP
- Maintain a record of team members and completed assessments
- Provide opportunities for the student to foster work and independent living skills in addition to academic programming during their high school years.

Parents:

- Assist their child to identify realistic goals in keeping with their family and cultural values
- Share their knowledge of their child's interests, strengths and needs with the team
- Participate in the selection of appropriate goals and objectives for the IEP and Transition Action Plan
- Become familiar with resources available for adults with special needs

Student:

- Participate in the planning process as much as possible
- Share information on interests, skills and hopes for the future
- Participate in assessment designed to further identify current skills and needs
- Help develop a personal Transition Portfolio as appropriate

Community Agencies:

- Become familiar with the individual needs of the youth
- Share perspective on skills needed in community work and leisure settings
- Assist in identifying supports that will be available to the youth after graduation

A ***Transition Team Member List*** is included on the Transition Action Plan form to record team members and changes to the team membership over time.

Step 2 - Gathering Information

Parent, Teacher and Student Interviews

Once the Transition Team has been identified, the Transition Team Leader or designee meets with the parents or guardians and the student to explain the planning process and their essential involvement. In addition, the Team Leader interviews the parents and student using the structured interviews as a guide. The *Family and Student Interviews* are used to focus the discussion on desired post school goals. It is most helpful to complete these interviews in person. In this way, the family can begin the planning process in a small group and ask questions as needed. Since this occurs as a first step, the student and family have the opportunity to discuss their preferences together before the first planning meeting and perhaps identify priority areas.

See *Family Interview* and *Student Interview* forms in Information Gathering section, page 27

In addition to the student and parent interviews, the Team Leader collects initial general information from one or more of the student's teachers. The ***Teacher Observation*** and /or the ***School and Community Social Skills Rating Checklist*** can be filled out by one or more subject area teachers and provides a general starting point for discussion of the student's strengths and needs in the school setting. If the Team Leader (or Consultant) is less familiar with the student, they may want to do a direct observation.

See *Teacher Observation* and *School and Community Social Skills Checklist* forms in Information Gathering section, page 35

After completing the interviews, the Team Leader summarizes the information from the parents, student and teachers using the ***Student Information Summary*.** The form is then copied and shared with the team members at the initial transition planning meeting. Collecting initial information in this way helps focus the planning meeting and gives a "head start" to the family especially those who may be looking closely at this issue for the first time.

See *Student Information Summary* forms in Information Gathering section, page 41

Step 3 - Initial Transition Planning

The Transition Team Leader schedules and facilitates an initial meeting which includes all Transition Team members. The purpose of the initial meeting is to begin the transition planning process. Discussion points include:

1. Identifying the anticipated number of school years remaining
2. Reviewing the *Student Information Summary*
3. Identifying the global post secondary outcomes for the student based on the student/family's vision in the following areas. The outcomes are "big picture" statements that describe the student's life after high school. The statements can be worded in straightforward language and entered in the Transition Action Plan form in each domain.
   - Living
   - Employment
   - Community Participation and Mobility
   - Recreation
   - Education and Training Opportunities

See *Post Secondary Goals Checklist* and *Sample Post-secondary Outcomes* in Transition Action Plan section, page 82

4. Discussing the student's strengths and needs as they relate to the identified outcomes.
5. Identify assessments or additional information which would be helpful in planning and assign responsibility for completing the assessment or gathering the information. This may involve the family, the student, school or Board/District staff.
6. Decide if input from other professionals or community agencies is needed at this point in the planning process
7. Decide if additional information is needed about post school options.
8. Schedule a follow-up meeting within six to eight weeks to allow time for needed assessment

See *Questions to Guide the Transition Planning Process* in Transition Action Plan section, page 79

Step 4 - Assessment

Some students with special needs may be able to participate in general education career guidance activities. For those who are more challenged, individualized assessment is needed in order to effectively plan for success after school. The assessment process provides information that will assist in selecting transition goals and objectives for the IEP. The responsibility for completing assessment may be shared, but should be designated at the team meeting. Both formal and informal assessment may be helpful. Completed assessment can be tracked on the Transition Action Plan form.

Formal Measures:

Assessment may include standardized measures of academic, social, communication, cognitive or adaptive living skills. Each assessment tool generally has specific administration requirements which will determine who may complete the assessment. Cognitive assessment may be required for some post-secondary education or bursary options (i.e. ACE program at UPEI). The need for this should be identified as soon as possible in order to meet submission deadlines.

Informal Measures:

- **Record Review** - A review of the student's records can provide information about learning rate, as well as academic strengths and weaknesses. The review should include the current IEP and report cards as well as any documentation relating to current skills and interests. Medical concerns or environmental accommodations needed should also be noted.

- **Communication Checklist** - If communication skills are a concern, updated assessment in this area may be warranted. Informal parent and teacher checklists may provide an overall picture of functional communication skills and are included in this resource. Referral to appropriate professionals can be made if this does not provide adequate information.

See *Communications Summary* in the Assessment Tools section, page 48

- **Direct observation** of particular skill areas or behavioural challenges can provide valuable insight into specific need areas. Observation of the student in different activities or subject areas can highlight tasks that are preferred or non-preferred and suggest employment avenues.

- A **Personal Transition Portfolio** documenting independent work samples or skills is very helpful in capturing important information about the student's interests and long term plans.

- **Supervisor evaluations** of work or volunteer placements or written feedback from teachers.

- **Checklist of Daily Living Skills** - Knowledge about the student's independence in this area is essential in identifying needed skills in the post school living setting. The *Adolescent Autonomy Checklist* is included in this resource and can be filled out by the student or the family. If additional information is needed, the *Transition Planning Inventory (PTI)* is recommended.

See *Adolescent Autonomy Checklist* in the Assessment Tools section, page 50

- **Interest inventories** can be completed with the student to help identify employment possibilities. These can be adapted using pictures or picture symbols. Once completed, these can become a permanent part of the Personal Transition Portfolio.

See *Adapted Checklists* in the Student Transition Portfolio section, page 103

Step 5 - Transition Action Plan (TAP) and Individual Education Plan (IEP)

An IEP for an elementary student usually includes skill areas such as Fine or Gross Motor, Self-Care, Social Skills, or subject content areas such as Math, Reading and Social Studies. The emphasis is on skill development based on modified grade level curriculum outcomes.

Goals and objectives written in the Transition Action Plan are more long range outcome oriented and target specific skills the student needs in order to be successful in the community as an adult. The desired outcomes in Living, Employment, Community Participation, Recreation and Education domains guide the selection of instructional objectives. Progress made on these objectives needs to be measurable.

Actions are also included in the transition plan. These are single steps or activities that represent "linkages" between the school and the post school environments. Actions are community or inter-agency connections that cannot be addressed within the IEP objectives but are complementary to them. These actions or activities may be critical to the achievement of the student's goals, but they are not intended to be measurable objectives. Rather they specify a needed activity, who will complete the activity and a suggested time frame. The following example illustrates outcome oriented actions and objectives for a high-needs student in one domain.

Employment (Where do you want to work as an adult?)
would like part time paid work outdoors with support; would like to use some earnings to buy music

Related Strengths	Related Needs	Actions Needed and Person Responsible	Completion Date
enjoys working outdoors, especially in garden or with plants	uses mostly gestures to communicate	Parents and student will visit local plant nursery and landscape company	May, 2007
follows directions	not yet independent in the community	Teacher will investigate option for related school job or coop placement	September, 2006
can follow through after demonstration	needs assistance with transportation	[Community Agency] will provide information on funding for job coach	November, 2006
identifies and counts coin values by 1, 5 and 10	needs help to count amounts and pay for items purchased	Teacher will identify opportunities for community trips to practice safety and mobility	2006-2007 School Year
		Resource Teacher to complete Adolescent Autonomy Checklist to identify related need areas	December, 2006

Related IEP Objectives:

1. [Student] will request help by signing when job or learning materials are needed during structured tasks, 4/5 opportunities

2. [Student] will give personal information by handing an ID card when requested 4/5 opportunities

3. [Student] will identify 20 common plants and flowers in pictures

4. [Student] will use a calculator to add two prices and pay for items using dollar coins and "add one" strategy with 90% accuracy

5. [Student] will identify community signs and correct response with 100% accuracy (men's room, traffic signal, danger)

This example illustrates outcome oriented actions and objectives in one domain for a student who has milder disabilities.

Employment (Where do you want to work as an adult?) Love movies and want to work in a video store or at empire theatres			
Related Strengths	**Related Needs**	**Actions Needed and Person Responsible**	**Completion Date**
enjoys busy environments good "people skills" like to converse about favourite topic responsible and detail oriented reads at grade 3 level	sometimes becomes distracted and forgets next steps in task needs help to identify appropriate conversational topics needs help with personal hygiene	Student and parent to interview video store owner to identify job skills Resource Teacher to assist in connecting student with Peer Helper Student will be enrolled in Life Skills course Parents and student will complete personal hygiene checklist and prioritize objectives in this area.	May, 2007 September, 2006 September-December, 2006 November, 2006

Related IEP Objectives:

1. [Student] will complete a school job or learning activity by following a written "to do list" in Home Ec and Shop class 4/5 days

2. [Student] will initiate appropriate conversational topics during lunch, with peer helper coaching 4/5 days

3. [Student] will place items in alphabetical order by first and second letter with 90% accuracy.

4. [Student] will describe steps in personal hygiene using a sequenced script and complete a self-monitoring checklist daily.

At the Transition Action Plan meeting, the team reviews the assessment information and uses this to generate and prioritize appropriate objectives relating to long term outcomes. Objectives or actions selected are those that the family, school and student feel are most directly related to the post-school goals. In general, the Transition Action Plan will be completed as part of the student's IEP process, reviewed mid-year and updated annually. Copies of the Transition Action Plan are shared with the Transition Team, as appropriate.

Step 6 - Creating a Student Transition Portfolio

What is a student transition portfolio?

This is an optional but very helpful component of the transition planning process for a student with special needs. A Student Transition Portfolio is a visual display or collection that represents personal characteristics or skills the student feels are important to planning the future.

Who develops the portfolio?

Some students may be able create this independently, but often the student will need the support of a mentor, teacher or family member.

What is included in the portfolio?

The portfolio should include an introduction to the student from a first person perspective. Pictures and descriptions of activities can be used to illustrate the student's independent skill level as well as areas where support is needed. It may include a collection of student academic work that exhibits the student's efforts, progress and achievements in one or more areas. This need not be limited to written work, and could include labeled photographs showing the student completing school jobs, participating in activities with friends, engaged in favorite activities or demonstrating independent skills in different areas. Checklists or interest inventories which help the student identify living or working options might also be stored in the portfolio. Some examples of items that may be useful in the portfolio are recognition or participation awards, photographs of team activities or clubs, an exercise or job schedule, attendance record, report cards, examples of writing skills, photograph of a completed project, letters from employers or volunteer supervisor, photograph of adaptive equipment or environmental accommodations needed.

If the student or mentor is interested and has computer skills, consider creating an "electronic portfolio". This opens many other media options, including audio and video files, graphics and other online resources. Creating a short video that illustrates some of the student's skills can be a very effective tool when giving student information to prospective employers or training agencies. For more information about this option, Dr. Helen C. Barrett's website is an excellent starting point. (http://electronicportfolios.com/) This site is devoted to developing electronic portfolios and provides numerous articles, links and resources on the topic of alternative assessment and electronic portfolios.

What are the benefits of creating a Student Transition Portfolio?

Portfolios help students value themselves as learners as they proceed through the process of developing a portfolio and they are able to see their accomplishments. This development process emphasizes what students can do, not what they cannot do. Since the student is involved in selecting items to include, it is an opportunity to reflect on his/her own vision of the future and explore ideas for the post school environment. This can lead to increased student participation in selection of learning goals. In addition, a portfolio allows for documentation of skills the student may not be able to accurately describe in more traditional means.

How much time will it take to develop the portfolio?

The portfolio is developed over a 3 to 4 year period while the student is in the last years of school, so the portfolio can evolve slowly and be added to at any point. The decision to create a Transition Portfolio should be discussed during the Transition meeting, so that appropriate expectations and support can be designated. The creation of the portfolio may also be included as an objective in the student's Transition Action Plan and viewed as a personal career planning project.

What components of a Transition Portfolio are included in this section?

A portfolio is a very individualized project and the samples included in the related resource section are intended as suggestions only. Sample forms and checklists in both their original and adapted formats have been included to demonstrate how these might be modified for more challenged students.

Step 7 - Followup and Review

In the Spring of the Grade 9 year, the Transition Team meets again to review progress, revise and update the Transition Action Plan for the Grade 10 year. Each time the Transition Team meets, the desired long term outcomes should be reviewed, to insure that they continue to be realistic and that appropriate followup is planned. The Transition Action Plan should be viewed as a dynamic document which will be revised and updated yearly throughout the remaining school years following the procedure outlined.

Information Gathering

Student Information Handout

Parent Information Handout

Family Interview for Transition Planning

Student Interview

Teacher Observation

School and Community Skills Checklist

Student Information Summary

What ***Students*** Need to Know

Now that you are 14, you can't wait to be an adult and make your own decisions. Many students feel that way at your age. Moving from junior high to high school and from high school into the community can seem scary, but it doesn't have to be. These changes are called transitions and for all students, preparation is the key to success. When we face change, careful preparation can help ease the worry we might feel.

When you become an adult, you will be making many decisions including where to live and work, how to get around, where to get help and how to enjoy your free time. Being an adult is a responsibility and now is the time to start thinking about your future. As young adults, we look forward to being more independent. Independence is being able to take care of yourself, make choices and be responsible for your own actions. Sometimes it's fun and sometimes it's hard work. Independence means telling others what you want and helping yourself to the best of your ability. The key to independence is responsibility. When you take care of yourself you are being responsible and independent. Each person may be independent in some skills and need help in others.

Getting Started - Making a Plan

A group of people who care about you will help you along the way. This is called your Transition Team. It will include you and your parents, as well as teachers and sometimes people from the community. Together the Team will help you learn more about what you want your life to be like after high school. You will choose new skills to learn while you are still in school that will help you achieve those goals. This is called the Transition Action Plan. You can help by taking an active role in making your wishes and interests known. Only you know what you want your future to be!

Here are a few things you can start thinking about and discussing with your family.

- What are your hopes and dreams?
- When you finish high school, where do you want to live?
- What kind of work interests you?
- Do you want to continue learning new skills and where? (on the job, in a special course or college setting?)
- In the community, what kinds of activities do you like to do in your free time?
- What are you worried about?
- What are you looking forward to?
- What do you need more information about to help you decide on possible jobs or careers?
- Think about your interests. What are your favourite classes, clubs, sports, subject areas?
- Do you know what help you might need and can you ask for it?

Working Toward Your Goals

Each year in high school, you will meet with your Transition Team and think about what other information is needed and perhaps add new ideas to your plan. You may invite other people from the community to join the Team who will be able to help you after high school. You may visit different places in the community to see what skills some jobs require or learn more about how to take part in community recreation. It is important to begin early to learn about jobs that match your interests. Some students may be able to volunteer or do school or summer jobs or "co-op" placements. These experiences will help you decide what jobs will work for you later.

Remember that you are the most important person on your Transition Team. Make sure you take the opportunity to tell your story. You can write it on paper or draw it. You can talk about it with your parents or with one of your Transition Team members. You can create a portfolio that shows things you are proud of or enjoy and what you want others to know about you. There are checklists you can fill out that will help you figure out your strengths and weaknesses.

Remember, get involved, share information and ask questions! If you want more information about this, please see _____.

What ***Families*** Need to Know

Families often become concerned when their teenage son or daughter with special needs moves through intermediate school to high school. The transition from high school into the community looms in the not so distant future, and parents may be worried about the path their child will take. While the future holds many unknowns and can seem scary, it doesn't have to be. For all students and their families, preparation is the key to transition success. Whenever we face change, thoughtful preparation can help ease the anxiety we might feel.

Getting Started –Making a Plan

Transition Planning is the process of preparing the youth for life after high school and looks different for each person. Each youth has unique wants, needs, strengths and weaknesses so the plan must be individualized. It is important to begin this process by age 14 to insure that the last years of high school are focussed on teaching skills that will be needed in the post high school environment.

Transition Planning is most successful when the student, family, school and community work together. A *Transition Team* is created which includes the youth and their parents, as well as teachers and sometimes people from the community. When the student and family actively participate in this process, a successful and thoughtful plan can be made that is based on family wishes, cultural values and hopes for their youth.

- A *Transition Team Leader* from the school will provide information about the process and begin collecting information through interviews with the parents, the student and teachers.
- Next, a meeting of the Team will be held to summarize the information collected thus far and begin to create statements or long term goals which are agreed upon. The goals will focus on *Living, Working, Community*

Recreation/Leisure areas as well as further *Learning* opportunities. Sometimes more detailed information or assessment will be needed about the youth's current skills in academic or other areas.

- Once long-term goals have been selected, shorter term objectives will be chosen which will be addressed at school or home during that school year and *relate directly to the post-secondary goals.*
- Other actions which complement the plan may include parents, teacher or student follow-up activities, such as visiting a potential job site, collecting information about community supports, connecting the student to a Peer Helper or school job, etc
- The long-term goals, objectives and actions are recorded in the *Transition Action Plan* and are reviewed yearly. Transition planning is a process which builds on itself each year with goals evolving and changing as the youth grows and interests and options become more clear.

Working Toward Long-term Goals

How can you can help create and support an effective transition plan?

- Take an active role! You and your youth are an essential part of his or her transition team. Take the opportunity to share your perspective and insight into your son or daughter's skills, and interests
- Find out all you can about what your youth wants to do when he or she leaves high school and what resources are available
- Encourage your youth to choose realistic goals that are a good fit with your family values
- Learn about the different jobs available in your community. Begin early to help your young adult learn about jobs that match his or her interests.
- Learn about community agencies that provide supports related to employment (i.e job coach, on the job training, supervised day programs)
- Give your son or daughter many opportunities to make choices and practice decision making.
- Work toward increasing independence in personal and self care skills.
- Create opportunities for your teen to be socially active in the community,(i.e shop, use community facilities, participate in church activities, sports, clubs)
- Help your son or daughter learn about their disability so they will be better able to advocate for themselves.

For more information about the transition process, please contact _____.

Encouraging Teens to Think About Transition

(adapted from Lasting Gifts, 2000)

Teens need to think about the things that they would like to do in the future; teens with exceptionalities are no different. The following are some ideas for parents that will assist them in helping their child think about and plan for the future:

- Begin thinking about your teen's future in a broad way that includes much more than just a work placement.
- Help your teen to think about adult life, that is, interests, what matters, with whom friendships or other relationships might be, or how time would be spent.
- Think of planning for the future as a process. Focus on accomplishing small steps towards a goal. Remember that once a decision is made, it doesn't mean that it can't be changed if things don't work out or if your child changes his or her mind.
- Look at the "messages" about your teen's future that your child is receiving from all sources. Consider and develop the positive messages that you want understood.
- Encourage your teen to volunteer and gain work experience.
- Encourage yourself to think beyond what you think is realistic for your teen's future life, so you won't leave out any options. You may be surprised.
- Be very conscious of the skills your teen is demonstrating, for example, self-awareness skills, life skills, job skills. Help develop these skills even more. They can be a great source of support in future life
- Treat barriers as challenges that may cause you to try something new.
- Allow your child the opportunity to make mistakes. We all learn from our mistakes and become better people because of them. In learning to deal with mistakes in a positive way, your teen will be learning a very important skill necessary for his or her future ability to be independent.
- Be a good role model and talk with your teen about the activities you are engaged in and find interesting and fun.
- Listen to what your teen is telling you about his or her dreams for the future. Teens with exceptionalities are like other teens in that they need your help and guidance to think about the possibilities for the future and to develop as much as possible towards independence.
- Watch your teen to see what he or she loves to do and encourage your teen to develop this as a natural strength. Emphasize these strengths when you begin to consider employment options.

Source: Resource for the Transition of Students with Exceptionalities. From School to Work or Post Secondary Education and Adult Life. NB Dept of Education, May 2001. Reprinted with permission.

Family Interview for Transition Planning

Parent's Name: _____ **School:** _____
Student's Name: _____ **Date:** _____

1. Have you begun planning for your child's transition from high school to the adult world?

   _____
   _____
   _____

2. Following school, which of the following best describes your young adult's living arrangements?

   - living at home or with relatives
   - living in a group home or supported residence
   - living independently
   - other _____

3. What do you want for your young adult after high school? Where do you hope he/she will learn, work, spend leisure time?

   _____
   _____
   _____

4. In which of the following independent living areas does your young adult need instruction? (Please check all that apply)

   ☐ clothing care
   ☐ meal preparation/nutrition
   ☐ hygiene/grooming
   ☐ travel training
   ☐ community awareness
   ☐ time management
   ☐ getting along with others
   ☐ self advocacy
   ☐ self advocacy
   ☐ sex education
   ☐ health/first aid
   ☐ household management
   ☐ interpersonal skills
   ☐ safety
   ☐ problem solving
   ☐ communication/language

5. Do you expect your young adult to be financially independent?

_____
_____
_____

6. How much support beyond the family, do you imagine your young adult will need to be successful in the adult world?

_____
_____
_____

7. What type of career (job/occupation) does your young adult seem interested in at this time?

_____
_____
_____

8. Has your young adult ever done work for which he/she has been paid? Please describe.

_____
_____
_____

9. Was he/she successful in a work or volunteer situation?

_____
_____
_____

10. Does your young adult show responsibility at home? (I.e complete home jobs, follow home and community rules, show awareness of danger)

☐ usually ☐ sometimes ☐ rarely

11. What kind of occupation/job do you expect your young adult to have when he/she finishes school?

- ☐ working full time independently
- ☐ working part time independently
- ☐ working full time with support or job coach
- ☐ working part time independently with support or job coach
- ☐ working in day treatment or supported environment
- ☐ other _____

12. Are there particular skills you want your young adult to learn to prepare for adulthood?

_____
_____
_____

13. Will your young adult be able to travel to and from a job or learning environment alone?

☐ YES ☐ NO

14. How does your young adult currently spend his/her leisure time?

_____
_____
_____

15. How do you spend time as a family?

_____
_____
_____

16. Describe some of the qualities, strengths or abilities you appreciate in your young adult.

_____
_____
_____

17. What are your young adult's challenges or needs?

_____
_____
_____

18. Are you aware of any behaviours that might interfere with your child's getting an holding a job?

_____
_____
_____

19. Are there particular education courses you want your child to take to prepare for later employment?

_____
_____
_____

20. How would you like the team to assist you in planning for your young adult's goals?

_____
_____
_____

Student Interview Questionnaire

Student's Name: _____ Date: _____

1. What are your favorite classes at school? Why?

_____

_____

_____

2. What classes at school do you like the least? Why?

_____

_____

_____

3. What type of teachers do you get along with best? Why?

_____

_____

_____

4. What do you think are your best academic areas? Are you better in math, reading, or writing?

_____

_____

_____

5. What vocational, trades or work skills classes have you taken and which were the most interesting for you? Why?

_____

_____

_____

6. Which academic areas are the most difficult for you? What is the hardest for you to do at school?

_____

_____

_____

7. What ca teachers do to make those difficult areas easier for you?

_____

_____

_____

8. What jobs have you had? List all jobs, both at school and at home, for pay or without pay. What tasks did you do on these jobs?

Job: _____ Tasks: _____

Job: _____ Tasks: _____

Job: _____ Tasks: _____

9. Which jobs did you like the best? Why?

_____

_____

_____

10. Which jobs did you like the least? Why?

_____

_____

_____

11. What would be your dream job? The most important part of this question is WHY? Be as specific as possible.

_____

_____

_____

12. What are your favorite things to do on weekends or after school?

_____

_____

_____

13. After high school, would you most like to:

- ☐ Go to university or college.
- ☐ Go to a vocational training or apprenticeship program.
- ☐ Go to work and learn on the job.

14. What plans have you made or activities have you done to get ready for your life after high school?

_____

_____

_____

15. Which of the following most describes you at this time in your life:

- ☐ I haven't really thought about life after high school and am not worried about it.
- ☐ I have a few ideas of what I might like to do and what I am good at.
- ☐ I am sure of what I want to do after I leave high school and have started making plans for it.
- ☐ I am very worried about what I will do after high school and wish someone could help me figure this out.

16. I would like some help from the school getting ready for life after high school. I would like help with the following areas:

_____

_____

_____

Adapted from Center for Change in Transition Services, Seattle University, Seattle, Washington

Teacher Observation

Student Name: _____ Course/Subject: _____

Teacher Name: _____ Date: _____

In what setting is the student most successful at school? Which classes specifically and which activities?

_____

_____

_____

Is the student involved in extracurricular activities? How does the student function in social settings with other students?

_____

_____

_____

Is the student involved in any peer or cross age tutoring?

_____

_____

_____

Has the student participated in any school based work experiences? (Office, kitchen, library?)

_____

_____

_____

How well does the student follow directions? Do they need specific directions or does s/he respond to general directions?

_____

_____

Can the student remember directions or scheduled activities or do they need notes or lists?

_____

_____

_____

How well does the student use "down time"?

_____

_____

_____

Does the student need ongoing reinforcement or do they work well without feedback?

_____

_____

_____

Additional Comments:

_____

_____

_____

School and Community Skills Checklist

Student's Name: _____ Date: _____

School: _____ Date of Birth: _____

Rater:_____ Current Grade: _____

Directions: Check each item that describes the student.

Classroom Related Behaviors

The student adequately and appropriately:

☐ 1. attends to teacher during instruction

☐ 2. maintains correct sitting posture

☐ 3. gains the teacher's attention.

☐ 4. answers questions asked by th teachers.

☐ 5. asks teachers for assistance or information.

☐ 6. shares materials with classmates.

☐ 7. keeps own desk in order.

☐ 8. enters class without disruption.

☐ 9. follows classroom rules.

☐ 10. cooperates with work partners.

☐ 11. ignores distractions.

☐ 12. stays on task during seatwork.

☐ 13. completes work on time.

☐ 14. participates politely in classroom discussion.

☐ 15. makes relevant remarks during classroom discussion.

☐ 16. follows verbal directions.

☐ 17. follows written directions.

☐ 18. speaks politely about schoolwork.

☐ 19. participates in classroom introductions.

☐ 20. completes homework on time.

☐ 21. uses free time in class productively.

School Building Related Behaviors

The student adequately and appropriately:

☐ 22. follows procedures for boarding school bus.

☐ 23. follows bus riding rules.

☐ 24. walks through hallways and passes to class.

☐ 25. waits in lines.

☐ 26. uses rest room facilities.

☐ 27. uses drinking fountain.

☐ 28. follows lunchroom rules.

☐ 29. uses table manners.

☐ 30. responds to school authorities.

☐ 31. deals with accusations at school.

Personal Skills

The student adequately and appropriately:

☐ 32. says “please” and “thank you.”

☐ 33. speaks in tone of voice for the situation.

☐ 34. take turns in games and activities.

☐ 35. tells the truth.

☐ 36. accepts consequences for wrong doing.

☐ 37. maintains grooming.

☐ 38. avoids inappropriate physical contact

☐ 39. exhibits hygienic behavior

☐ 40. expresses enthusiasm.

☐ 41. makes positive statements about self.

☐ 42. expresses anger in nonaggressive ways

☐ 43. accepts praise.

☐ 44. stays out of fights.

☐ 45. deals with embarrassment.

☐ 46. chooses clothing for social events.

☐ 47. deals with failure.

☐ 48. deals with being left out.

Interaction Initiative Skills

The student adequately and appropriately:

☐ 49. greets peers.
☐ 50. borrows from peers.
☐ 51 asks other children to play.
☐ 52. expresses sympathy.
☐ 53. asks peers for help.
☐ 54. makes invitations.
☐ 55. introduces self.
☐ 56. makes introductions.
☐ 57. initiates conversations.
☐ 58. joins activities with peers.
☐ 59. congratulates peers and adults.
☐ 60. makes apologies.
☐ 61. excuses self from groups and conversations.
☐ 62. expresses feelings.
☐ 63. expresses affections
☐ 64. stands up for a friend.
☐ 65. asks for dates.
☐ 66. gives compliments.
☐ 67. makes complaints.

Interaction Response Skills

The student adequately and appropriately:

☐ 68. smiles when encountering acquaintances.
☐ 69. listens when another child speaks.
☐ 70. participates in group activities.
☐ 71. helps peers when asked.
☐ 72. accepts ideas different from own.
☐ 73. meets with adults.
☐ 74. maintains conversations.
☐ 75. responds to teasing and name calling.
☐ 76. responds to constructive criticism.
☐ 77. recognizes feelings of others.
☐ 78. respects the space of others.

☐ 79. responds to peer pressure.

☐ 80. deals with an angry person.

☐ 81. makes refusals.

☐ 82. answers complaints.

Community Related Skills

The student adequately and appropriately:

☐ 83. asks for directions in public.

☐ 84. gives directions.

☐ 85. exhibits sportsmanship as a game participant.

☐ 86. exhibits polite behavior and sportsmanship as a spectator.

☐ 87. disposes of wastepaper and debris in public.

☐ 88. respects the rights of others in public.

☐ 89. respects private property

☐ 90. exhibits good audience behaviors.

☐ 91. responds to public authority.

☐ 92. asserts self to gain service.

☐ 93. deals with public officials over the phone

Work Related Social Skills

The student adequately and appropriately:

☐ 94. sets goals for work.

☐ 95. negotiates on the job.

☐ 96. responds to unwarranted criticism.

☐ 97. asks for feedback on the job.

☐ 98. minds own business on the job.

☐ 99. chooses a time for small talk.

☐ 100.refrains from excessive complaining.

Source: Social Skills for School and Community (pp.269-273), by L.R. Sargetn, 1991, Reston, VA: Division of Mental Retardation, Council for Exceptional Children. Copyright 1991 by the Council for Exceptional Children. Reprinted with permission.

Student Information Summary

Name:	**Parents/Guardians:**
Date of Birth:	**Address:**
Diagnosis:	**Medical Alert/Allergies:**

Current Level of Support	**Frequency**
Resource	
Educational Assistant	
Mentor	
Guidance	
Youth Worker	
Tutor	
Peer Helper	
Does the student have a current IEP? In which skill or content areas?	
Does the student need curriculum adaptations?	
Does the student need a modified curriculum?	
Does the student need adaptive equipment? (Vision, hearing, mobility?)	

Student Information Summary

Student Name:_____ Date: _____

Transition Team Leader: _____

Interests	Strengths	Challenges	Work/volunteer Experience

Student Information Summary – Example 1

Student Name : _____ **Date: _____**

Transition Team Leader: _____

INTERESTS	STRENGTHS	CHALLENGES	WORK/VOLUNTEER EXPERIENCE
Expressed (by family and student) • sports • helping Mom at home • music-dancing • visiting grandmother in nursing home **Observed:** • stock car races • fairs • Special Olympics	friendly, smiles and laughs easily can follow 2-3 step directions 20 functional sight words can use phone with number written out (no phone book) can input up to 6 digits in adding machine or computer	lack of control when frustrated or confused no fear of strangers - safety issues easily confused - has outbursts when excited transportation - may need to learn to ride bus to job	school office errands - with supervision office tasks - made copies for teachers nursing home - helped give snack to residents

Adapted from Center for Change in Transition Services, Seattle University, Seattle , Washington

Student Information Summary – Example 2

Student Name : _____ **Date: _____**

Transition Team Leader: _____

INTERESTS	STRENGTHS	CHALLENGES	WORK/VOLUNTEER EXPERIENCE
mechanics - enjoys working with hands, putting things together motorcycle racing computer games music, plays drums in band skateboarding with friends	above average non-verbal problem solving reads at Grade 5-6 level when familiar with content good persistence when working on tasks he finds enjoyable good memory and ability to follow verbal directions has interview experience, good resumé	written language at Grade 2 level difficulty sounding out words poor spelling skills not aware of disability and needs help with self advocacy difficulty completing tasks especially written tasks	Burger King - cook, 2 summers, didn't like the work summer job with friend at bike store worked in lube shop likes shop environment helped make repairs to fishing boat (volunteer)

Adapted from Center for Change in Transition Services, Seattle University, Seattle , Washington

Assessment Tools and Forms

Assessment Tools Information

Assessment is an individualized process. The information that is needed for one student may not be important to include for another. In this section, information and sample pages from selected assessment tools provide the Transition Team with user friendly and readily available options. Each tool provides information that can help guide the selection of appropriate Transition IEP goals and objectives in one or more skill areas. When one or more of these are used in conjunction with interview information from the parent, teacher (s) and student, a more comprehensive picture of strengths and needs will emerge.

Communication Summary

This checklist would primarily be used to give a global picture of communication strategies used by a student who has limited or no verbal language. By interviewing those who know the student well, use the listed options to describe how the student typically communicates (expressive) or understands communication (receptive).

Adolescent Autonomy Checklist

This checklist is divided into sections that include skills commonly needed at home and in the community. It can be filled out by the parents or the student and used to select appropriate objectives related to desired post school outcomes. This checklist can also be useful as an ongoing measurement of independent skills as the student progresses.

Transition Planning Inventory (TPI)

The *Transition Planning Inventory* is an instrument for identifying and planning for the comprehensive transitional needs of students. It is designed to provide school personnel a systematic way to address critical transition planning areas and take into account the individual student's needs, preferences, and interests. Information on transition needs is gathered from the student, parents or guardians, and school personnel through the use of three separate forms designed specifically for each of the target groups. The accompanying software allows for a quick summary of the information collected.

Informal Assessments in Transition Planning

This book includes a comprehensive listing of competencies that have been identified as important to adult functioning as well as a number of informal instruments that assist with the generation of transition-related information. It can be used as stand-alone material or as a way to provide further assessment alternatives extending information derived from the *Transition Planning Inventory* (TPI) on which this resource is based. Also included are reproducible examples of informal checklists which can be used for further assessment and may be appropriate to include in the Student Transition Portfolio. The selected instruments vary in format (survey, interview, checklist, questionnaire) and in respondent (student, family member, school professional). Transition planning teams may photocopy and use any instrument included in the collection.

Brigance Life Skills Inventory

The *Brigance Life Skills Inventory* assesses listening, speaking, reading, writing, comprehending, and computing skills within the context of everyday situations. Assessments range in difficulty from grade levels 2–8. The assessments are easy to administer and no special training or additional materials are necessary. A sample is included here for reference.

Ansell-Casey Life Skills Assessment (ACLSA)

The *Ansell-Casey Life Skills Assessment* (ACLSA) is an online resource that evaluates independent living skills. It consists of statements about life skills that the youth and his/her caregivers complete and would be appropriate for a student with mild to moderate impairment. All assessments can be completed by the student independently or with the assistance of an adult and are free of charge. There are ACLSA versions for four suggested age ranges from age 8-18. The ACLSA was designed to be as free as possible from gender, ethnic, and cultural biases. It is appropriate for all youths regardless of living circumstances, whether with one parent, in foster care, in group homes or in other places. The ACLSA does not collect personal identification information and the results are kept anonymous. Areas assessed can be individually selected, including Career Planning, Communication, Daily Living, Home Life, Housing and Money Management, Self Care, Social Relationships, Work Life, and Work and Study Skills. A sample is included here for reference.

www.caseylifeskills.org/pages/assess/assess_aclsa.htm

Communication Summary Form

Directions:

Complete this form by reviewing the student's records and interviewing the student's parents, peers, teachers, and speech-language pathologist.

Student: _____ Date _____

Unaided Systems	Respond to receptively		Uses expressively		If yes, describe special instructions/procedures
Nonsymbolic behaviors*					
Vocalizations	Y	N	Y	N	_____
Affect	Y	N	Y	N	_____
Body movement	Y	N	Y	N	_____
Gestural	Y	N	Y	N	_____
Physiological	Y	N	Y	N	_____
Visual	Y	N	Y	N	_____
Symbolic behaviors*					
Gestures	Y	N	Y	N	_____
Sign language	Y	N	Y	N	_____
Speech	Y	N	Y	N	_____
Pictures	Y	N	Y	N	_____
Printed word	Y	N	Y	N	_____
Braille	Y	N	Y	N	_____

Aided Systems	Respond to receptively		Uses expressively		If yes, describe special instructions/procedures
Nonelectronic devices*					
Single-sheet	Y	N	Y	N	_____
Multiple-sheets	Y	N	Y	N	_____
Electronic devices*	Y	N	Y	N	_____
Tape recorder	Y	N	Y	N	_____
Personal computer	Y	N	Y	N	_____
Dedicated aids (eg. Touch Talker, Wolf, or SpeechPac)	Y	N	Y	N	_____
Vocabulary displays*					
Objects	Y	N	Y	N	_____
Photographs	Y	N	Y	N	_____
Line drawings	Y	N	Y	N	_____
Symbols	Y	N	Y	N	_____
Printed words	Y	N	Y	N	_____
Brailled	Y	N	Y	N	_____
Methods of using the devices					
Direct selection	Y	N	Y	N	_____
Scanning	Y	N	Y	N	_____

*attach vocabulary lists or sample overlays from communication devices

Source: Student Portfolio: A System for Documenting the Strengths, Needs and Abilities fo Students Who are Deaf-Blind, by Kansas State Board of Education, 1996, Topeka, KS: Author.

Adolescent Autonomy Checklist

Skills at home	Can Do Already	Needs Practice	Plan to Start	Accomplished
Kitchen: Operate appliances (cook top, oven, microwave, toaster, dishwasher)				
Use common kitchen tools (can opener, bottle opener, knife, measuring cups and spoons, grater, timer, egg beater, ice cream scoop)				
Help plan and prepare meals				
Follow a recipe				
Put away the leftovers				
Set the table				
Do the dishes				
Familiarity with contents of packaged foods				
Laundry				
Put dirty clothes in hamper				
Sort clothes				
Use washer and dryer				
Iron				
Hand wash				
Fold clothes				
Put clothes away				
With the Family				
Watch TV news and discuss together				
Help take care of siblings				
Participate in family decisions				
Plan family outing				
Take care of pets				
Housekeeping				
Clean room				

Developed by the Youth in Transition Project (1984-1987) University of Washington Division of Adolescent Medicine and based on a Model developed by the Children's Rehabilitation Center at the University of Virginia.

Adolescent Autonomy Checklist, Cont'd.

Skills at Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
Housekeeping, Cont'd.				
Make the bed/change the bed				
Choose decorations for room				
Minor repairs (change light bulbs, repair or assemble toys)				
Take out the trash				
Basic sewing/mending skills				
Gardening				
Plant a garden				
Mow/water the lawn				
Weed the garden				
Learn appropriate use of garden tools				
Emergency				
Plan fire exits and emergency procedures				
Know where candles and flashlights are				
Use a fire extinguisher				
Know how to turn water off				
Know community emergency telephone numbers				
Know where extra house key is located				
Unclog the sink or toilet				
Personal Skills				
Use the phone				
Have a house key				
Budget allowance				
Go shopping				
Have privacy in the bathroom				
Manage personal grooming (shampoo, bath, shower)				

Developed by the Youth in Transition Project (1984-1987) University of Washington Division of Adolescent Medicine and based on a Model developed by the Children's Rehabilitation Center at the University of Virginia.

Adolescent Autonomy Checklist, Cont'd.

Skills at Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
Personal Skills, Cont'd.				
Get a haircut				
Choose appropriate clothes to wear				
Health Care Skills				
Understand health status				
Be aware of existence of medical records, diagnosis information, etc.				
Prepare questions for doctors, nurses, therapists				
Respond to questions from doctors, nurses, therapists				
Know medications and what they're for				
Get a prescription refilled				
Keep a calendar of doctor, dentist appointments				
Know height, weight, birthdate				
Learn how to read a thermometer				
Know health emergency telephone numbers				
Know medical coverage numbers				
Obtain sex education materials/birth control if indicated				
Discuss role in health maintenance				
Have genetic counseling if appropriate				
Discuss drugs and alcohol with family				
Make contact with appropriate community advocacy organization				
Take care of own menstrual needs and keep a record of monthly periods				
Community Skills				
Get around the city (pedestrian skills, asking directions)				

Developed by the Youth in Transition Project (1984-1987) University of Washington Division of Adolescent Medicine and based on a Model developed by the Children's Rehabilitation Center at the University of Virginia.

Adolescent Autonomy Checklist, Cont'd.

Skills At Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
Community Skills, Cont'd.				
Get around the city (pedestrian skills, asking directions)				
Use public transportation (taxi, bus, etc.)				
Locate bathroom in unfamiliar building (i.e. know how to ask)				
Know about neighborhood stores and services				
Use a pay phone				
Use a phone book				
Open a bank account				
Get a library card				
Get a picture ID				
Get a Social Security Card				
Use Post Office				
Volunteer for community services				
Leisure Time Skills				
Help plan a party				
Invite a friend over				
Subscribe to a magazine				
Read a book				
Plan a TV viewing schedule				
Go for a walk				
Join the Scouts, YMCA/YWCA, 4-H Club				
Go to a recreation center				
Go to camp				
Attend school functions (plays, dances, concerts, sports)				
Go to Church				
Keep a calendar of events				
Participate in a sport				

Developed by the Youth in Transition Project (1984-1987) University of Washington Division of Adolescent Medicine and based on a Model developed by the Children's Rehabilitation Center at the University of Virginia.

Adolescent Autonomy Checklist, Cont'd.

Skills At Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
Skills For The Future-Education				
Meet with school Guidance Counselor				
Check future educational options				
Vocational/Technical Options				
Contact school Guidance or DVR Counselor				
Check on local workshops/job opportunities				
Find out about apprentice programs				
Get information from community colleges				
Learn how to apply for a job				
Vocational/Technical Options, Cont'd.				
Check on local workshops/job opportunities				
Find out about apprentice programs				
Get information from community colleges				
Learn how to apply for a job				
Living Arrangements				
Be aware of federal housing regulations for the disabled				
Explore group homes and tenant support apartment living programs				
Find out about financial assistance programs				
Learn how to manage money and budget household expenses				
Understand leases				
Know the responsibilities of a tenant & landlord				
Know how to fill out an application				
Check for wheelchair accessibility if needed				
Look into transportation				
Know about services: electricity, phone, water				

Developed by the Youth in Transition Project (1984-1987) University of Washington Division of Adolescent Medicine and based on a Model developed by the Children's Rehabilitation Center at the University of Virginia.

Transition Action Plan

Transition Checklist

Questions to Guide the Planning Process

Post-secondary Outcomes Checklist

Sample Post-secondary Outcomes

Transition Action Plan Form

Transition Checklist

The following is a general checklist of transition activities to consider when preparing Transition Action Plans with the Team. It is not all inclusive and the time frames may need to be individualized. The student's skills, interests and desired long term outcomes will determine which items on the checklist are relevant and timely. Use this checklist to ask yourself whether or not these transition issues should be addressed at transition meetings. Some items may begin four years before leaving school and continue until that date. Other actions may be completed in one school year. Responsibility for carrying out the specific transition activities should be determined at the transition planning meetings.

Four to Five Years Before Leaving School (Approx. Grade 8 -9)

☐ Identify year of planned school exit.

☐ Identify personal learning styles and the necessary accommodations to be a successful learner and worker.

☐ Identify initial long term outcomes in living, employment, community participation and recreation/leisure areas

☐ Begin career exploration. Identify career interests and skills, complete interest and career inventories, and identify desired education or training outcomes

☐ Identify interests and options for future living arrangements, including supports.

☐ Learn to effectively communicate interests, preferences, and needs.

☐ Begin a student portfolio and update it as needed.

☐ Be able to explain your disability and the accommodations you need.

☐ Investigate money management and identify necessary skills.

- ☐ Acquire identification card and/or the ability to communicate personal information in community settings

- ☐ Identify and increase independence in skills necessary for planned living environment

- ☐ Learn and practice personal health care.

Two - Three years Before Leaving School (Approx. Grade 10 - 11)

- ☐ Adjust course of study to match planned outcomes

- ☐ Identify community support services and programs that will provide post school supports or community connections. Invite adult service providers to the Transition Planning Meeting.

- ☐ Broaden experiences with community activities and expand friendships.

- ☐ Explore options for post-secondary education and admission criteria. Gather information on funding and/or support services offered

- ☐ Investigate assistive technology tools that can increase community involvement and employment opportunities.

- ☐ Pursue and learn to use local transportation options outside of family.

- ☐ Match career interests and skills with course work, school or volunteer jobs and community work experiences.

- ☐ Identify health care providers and become informed about healthy sexuality and family planning issues.

- ☐ Participate in career awareness information sessions with parents
- ☐ Inquire about applicable financial support programs.
- ☐ Provide opportunities for job sampling through coop or volunteer placements
- ☐ Learn and practice appropriate communication and social skills for different settings (employment, school, recreation, with peers, etc.).
- ☐ Practice independent living skills, e.g., budgeting, shopping, cooking, and housekeeping.

One Year Before Leaving the School District (Grade 12+)

- ☐ Practice effective communication by developing interview skills, asking for help, and identifying necessary accommodations at post-secondary and work environments.
- ☐ Specify desired job and obtain paid or volunteer employment with supports as needed.
- ☐ Take responsibility for arriving on time to work, appointments, and social activities.
- ☐ Practice transportation and shopping skills in community settings
- ☐ Assume responsibility for health care needs (making appointments, filling and taking prescriptions, etc.)
- ☐ Visit potential employment or recreation locations

Adapted from the National Network, Parent Brief - Winter, 1996.
http://ici2.coled.umn.edu/ntn/pub/briefs/tplanning.html

Questions to Guide the Transition Planning Process

The questions suggested here are a starting point to assist the team in planning. The list is not meant to be all-inclusive as the information to be collected is highly student and outcome specific.

Living

1. Does the student already have the independent skills needed to live in the identified living situation? [self care, time organization, budgeting, cooking, communication skills, first aid, safety skills, etc]

2. How can we find out? [Academic or adaptive assessment, Adolescent Autonomy Checklist, Vineland Adaptive Behavior Scales, Transition Planning Inventory, Brigance® Diagnostic Life Skills Inventory.etc.]

3. What skills do we need to teach in this area to make this possible?. [Base this answer on the results from #2.]

4. What other information do we need from those who will provide the living situation? Who will gather this information?

Employment

5. Does the student already have the independent skills needed to work in the identified working situation? [time organization, communication skills, job specific skills, math and reading skills, etc.]

6. How can we find out? Academic assessment, related school job, coop experience, etc.

7. What skills do we need to teach in this area to make this possible? [Base this answer on the results from #6.]

8. What other information do we need from those who will provide the working situation? [job description, tour of typical job sites, social interaction, communication skills required?] Who will gather this information?

9. If the student does not have a specific job in mind, what information or experience can we provide to provide guidance in this area? [Job fair, career exploration activities, job shadowing, school jobs and coop experiences, etc.]

Community Participation and Mobility

10. Does the student already have the independent skills needed to participate actively in the community? [transportation, connections with community groups, etc.]

11. How can we find out? [Student and Parent Interview*;* Investigate transportation options - family, friends, agency, local resources]

12. What skills do we need to teach in this area to make this possible?

    [Base this answer on the results from #11.]

13. What other information do we need from community resources, services or transportation options? Who will gather this information?

Recreation

14. Does the student already have the independent skills needed to participate actively in individual and group recreation, sport and leisure activities? Has the student been exposed to a variety of options for involvement both at home and in school?

15. How can we find out? [Student and Parent Interview*;* Investigate recreation, sport and leisure options in school and home community]

16. What skills do we need to teach in this area to make this possible?. [Base this answer on the results from #15.]

17. What other information do we need from community resources or recreational clubs, etc.? Who will gather this information?

Education and Training Opportunities

18. Does the student already have the independent skills needed to pursue the identified post-secondary education or training? [time organization, study skills, communication and social interaction skills, pre-requisite courses, etc]

19. How can we find out? [Transition Planning Inventory, academic assessment, review of college /university requirements, etc]

20. What skills do we need to teach in this area to make this possible?

    [Base this answer on the results from #19.]

21. What other information do we need from those who will provide the post-secondary education or training? [What supports or accommodations are available for students with special needs, Funding information; etc.] Who will gather this information?

Post -secondary Goals Checklist

Living

The student wants to:

- ☐ Live independently without support
- ☐ Live in a supervised living arrangement
- ☐ Live with family
- ☐ Live with a friend
- ☐ Live in a dorm room while attending post-secondary education
- ☐ Live in a group home
- ☐ Other.....

Employment

The student wants:

- ☐ to be independently employed and knows the field he wants to pursue
- ☐ to be independently employed but not sure what field
- ☐ a job and the Transition Team anticipates the need for time limited supports (job coach)
- ☐ a job and the Transition Team anticipates supported employment (e.g long term support)
- ☐ part time employment through an adult service provider
- ☐ day habilitation services through an adult service provider
- ☐ Other.....

Community Participation

The student wants:

- ☐ to be independently mobile in the community and access services of choice
- ☐ to be independent in the community with support for transportation to access services
- ☐ community access with the support of family and friends
- ☐ community access with a provider
- ☐ Other.....

Leisure and Recreation

The student has:

- ☐ identified specific recreation and leisure activities of choice and can participate independently (specify activities)
- ☐ identified specific community facilities to join for recreation and leisure services (specify)
- ☐ identified activities of choice to do with families and friends
- ☐ identified activities of choice to do with a provider
- ☐ Other.....

Post-secondary Education or Training

The student wants to attend:

- ☐ a four-year college or university to gain a degree in a specific field
- ☐ a four-year college or university but unsure what field he will pursue
- ☐ a community college prior to continuing in a four year program
- ☐ a community college for non-academic courses (specify)
- ☐ a vocational or trades training program in a specified field
- ☐ non-academic courses offered in the community(e.g. public library, community school, non-profit organizations, adult education)
- ☐ on the job training
- ☐ Other.....

Adapted from:

Transition Services: helping Educators, Parents and Other Stakeholders Understand: Ed O'Leary, Mountain Plains regional Resource center, and Wendy Collison, Arizona Department of Education, February 2002. Used with permission.

Post-secondary Outcomes

Example 1:

Living

I will be capable of living with a friend or roommate but will need assistance with budgeting, buying food, and paperwork related to paying monthly bills.

Employment

I would like to work full-time after graduation. I would like to work around people and animals.

Community Participation and Mobility

I like sports and participating in the Special Olympic Program. I attend a singles group at church and sing in the choir. I will need help with transportation.

Recreation

I will continue to be active in Special Olympic and church activities. I am looking into participating in a bowling league. I like to fish and go camping with friends.

Education and Training Opportunities

Any training will be on the job.

Example 2:

Living

I will live with my parents. Eventually, I may live in a group home. I want to learn to help with shopping and cooking.

Employment

I like to put things in order. I might like to stock shelves or work in a library

Community Participation and Mobility

I like to help with strawberry and apple picking for my uncle. I like to go to church suppers.

Recreation

I like to go to hockey games. I enjoy spending time outdoors with my friends and running on the trails

Education and Training Opportunities

I would like to attend the ACE program at UPEI.

Transition Action Plan

_____ School Year

Student Name:	**School Name:**
D. O. B.	**Address:**
Age:	**Phone:**
Current Grade:	**Principal:**
Parents/Guardians:	
Address:	**Date Transition Plan Developed:**
Home Phone: **Work Phone:**	**Anticipated Date of School Completion:**

Transition Team Members:

	Transition Team Leader

Record of Transition Planning and Review Meetings

Date	Outcome

Record of Assessment for Transition Planning

Assessment	Date	Location of Record

Student's Post-secondary Goals and Action Plan

Living (Where do you want to live as an adult?)			
Related Strengths	**Related Needs**	**Actions Needed and Person Responsible**	**Completion Date**
Related IEP Objectives			

Career – Employment (As an adult, what kind of work do you want to do?)			
Related Strengths	**Related Needs**	**Actions Needed and Person Responsible**	**Completion Date**
Related IEP Objectives			

Community Participation **(As an adult, what kind of hobbies and recreational activities do you want to have?**)

Related Strengths	Related Needs	Actions Needed and Person Responsible	Completion Date

Related IEP Objectives

Education – Training **(After high school what additional education or training do you want?**)

Related Strengths	Related Needs	Actions Needed and Person Responsible	Completion Date

Related IEP Objectives

Signatures

_____	_____
Parent/Guardian	**Date**
_____	_____
Student	**Date**
_____	_____
Transition Team Leader	Date

Student Transition Portfolio

Ideas for your Portfolio

Learning Style Preference Inventory

Self-determination/Self-advocacy Checklist

Describe Yourself Interest Inventory

Adapted Picture Symbol Checklists
Living, Employment, Community

Ideas for your Portfolio

A ***transition portfolio*** is a collection of items ***you choose*** that tell about your ***interests*** and ***skills*** now as well as your ***hopes*** for the future. You can add to this over your last years in school and share it with people who are interested in helping you achieve those goals. Here are some samples to help you think about what you might want to include.

- ★ Photograph of yourself and family
- ★ Report card
- ★ Letter introducing yourself to readers
- ★ Photos and descriptions showing you completing home or school jobs
- ★ Letter of recommendation from teacher, counselor or supervisor
- ★ Awards recognizing achievement or participation
- ★ Interest inventories
- ★ Supervisor's letter from co-op or volunteer placement
- ★ Personal career plan
- ★ Pictures of jobs or recreational activities you are interested in
- ★ Picture or description of club or team you participate in
- ★ Picture, CD or video of a completed project
- ★ Video/cd documenting particular skills or favorite activities
- ★ Membership card for community organizations or school clubs
- ★ Training certificate
- ★ Writing sample

Learning Style Preference Inventory

Name: _____ Date: _____ Grade: _____

This inventory will help determine your dominant learning style. By knowing this you can understand how you learn best

Often ---- 3	**Sometimes ---- 2**	**Seldom ----1**

1.	I can remember the words to a song after hearing the song a few times .	3	2	1
2.	I would rather read the directions myself instead of someone telling me the directions.	3	2	1
3.	I can remember people's faces easier than I can remember their names.	3	2	1
4.	I like to write things down to remember them.	3	2	1
5.	I remember things better when I say them out loud a few times.	3	2	1
6.	I need to take a lot of stretch breaks when I am reading or studying.	3	2	1
7.	I remember what I see better than what I hear.	3	2	1
8.	I would rather someone tell me the directions instead of me reading them.	3	2	1
9.	I work well with my hands doing things like needlework, puzzles or using tools.	3	2	1

10.	I can concentrate easily on visual tasks even with visual distractions around me.	3	2	1
11.	I talk to myself when I am thinking.	3	2	1
12.	I would rather work on a project than just think about it.	3	2	1
13.	I can concentrate on something even with noises around me.	3	2	1
14.	I can remember things better if I picture them in my head.	3	2	1
15.	I like to hold things in my hands like pens and paper clips when I am studying.	3	2	1
16.	I picture words in my mind to help spell them.	3	2	1
17.	I am very good at sports.	3	2	1
18.	I would rather listen to a story than tell a story.	3	2	1
19.	I use my fingers when I am counting in my head.	3	2	1
20.	I like to have music or background noise on while I am working on something.	3	2	1
21.	I do well reading maps, charts or graphs.	3	2	1

***Learning Style Preference Inventory**, Adapted from Fontana Unified School District*

Learning Style Preference Inventory
Scoring

Place the point value on the line next to its corresponding question number. Add the values of your scores under each heading.

VISUAL	AUDITORY	KINESTHETIC
2. _____	1. _____	4. _____
3. _____	5. _____	6. _____
7. _____	8. _____	9. _____
10. _____	11. _____	12. _____
14. _____	13. _____	15. _____
16. _____	18. _____	17. _____
21. _____	20. _____	19. _____
Total Visual	Total Auditory	Total Kinesthetic
_____	_____	_____

Your highest score reflects your dominant learning style. No learning style is preferable to another. We all use all three daily. Understanding our strengths is the key to understanding how we learn best.

***Learning Style Preference Inventory**, Adapted from Fontana Unified School District*

Name: _____ Date: _____

Self-Determination/Self-Advocacy Checklist

How well do you know yourself? How well do you know what you like or prefer? How well do you know what you value as important in your life and how those values affect your decisions? How well can you tell others about yourself, your strengths and weaknesses? How well can you tell others how they can be supportive when you need help? How well can you look at your life and make changes when you see things you want to change?

The checklist below can help you know yourself better in these areas. Answer as honestly as you can. If you don't know, check DK.

Descriptions of me	**School**		**Home/Community**		
	Yes	No	Yes	No	DK
1. I can describe my strengths.	☐	☐	☐	☐	☐
2. I can describe my weaknesses.	☐	☐	☐	☐	☐
3. I can explain my disability.	☐	☐	☐	☐	☐
4. I can explain how I learn best.	☐	☐	☐	☐	☐
5. I know my interests.	☐	☐	☐	☐	☐
6. I can ask for help without getting	☐	☐	☐	☐	☐
7. I can state what I want to learn.	☐	☐	☐	☐	☐
8. I can state what I want to learn or do when I graduate.	☐	☐	☐	☐	☐
9. I can tell teachers or supervisors what I need to be able to do my work.	☐	☐	☐	☐	☐
10. I know how to look for help or support.	☐	☐	☐	☐	☐
11. I know how to set goals for myself.	☐	☐	☐	☐	☐

Descriptions of me	**School**		**Home/Community**		
	Yes	No	Yes	No	DK
12. I know how to get information to make decisions	☐	☐	☐	☐	☐
13. I can begin my work on time.	☐	☐	☐	☐	☐
14. I can work independently.	☐	☐	☐	☐	☐
15. I can stay on tasks until they are done.	☐	☐	☐	☐	☐
16. I can tell if my plan is working or not.	☐	☐	☐	☐	☐
17. I can change goals or my plan of action.	☐	☐	☐	☐	☐

Describe Yourself!

Think about your interests. What are your interests in these areas?

- The things you like to do.
- The environment around you.

You use this information about yourself to help make decisions about your life. To choose a life for yourself you need to know these:

- Your interests for activities and environments
- Your skills and abilities
- Your strengths and weaknesses

When you compare activities with your interests and your skills and abilities, you can begin to make decisions about your life. You can begin to choose a life for yourself!

Part I – Describe Yourself in the Environment

Think about being outside

Do you like to be outside?	Yes___ No___
Do you like to be outside when it is hot?	Yes___ No___
Would you like to work outside most of the day?	Yes___ No___
Do you like to be outside when it's cold?	Yes___ No___

Think about being around people

Do you like to do a job by yourself?	Yes___ No___
Do you like to cooperate with someone to get a job done?	Yes___ No___
Can you work in a crowded place?	Yes___ No___
Is it ok if someone bumps into you by accident?	Yes___ No___
Do you like being in a public place?	Yes___ No___
Are you comfortable being around and talking to people you do not know?	Yes___ No___
Can you be polite if someone is rude to you?	Yes___ No___

Think about noise!

Can you work around noisy equipment for long periods of time? Yes___ No___
Do you need a quiet workplace? Yes___ No___
Can you alternate between a noisy environment and a quiet environment? Yes___ No___

Think about smell.

Do most smells bother you? Yes___ No___
Can you work around smells for much of the day? Yes___ No___
Do chemical smells bother you? Yes___ No ___
Do animal smells bother you? Yes___ No___

Think about work materials

Do you like to work with tools? Yes___ No___
Can you wear gloves, if needed? Yes___ No___
Can you handle cleaning supplies? Yes___ No___
Does it bother you if you get dirty? Yes___ No___
Does it bother you if you get wet? Yes___ No___

Type of physical activity

Do you like to work seated for most of the day? Yes___ No___
Do you prefer to move around during most of the day or be physically active? Yes___ No___
Do you want to alternate between being seated or standing <u>and</u> moving around? Yes___ No___

Variety in what you do

For something you like, can you do the same thing all day? Yes___ No___
Do you like to do different things throughout the day? Yes___ No___
Can you switch easily from one thing to another? Yes___ No___

Your work hours

Do you want to work the same hours everyday?	Yes___ No___
Do you want to work during the day, from Monday - Friday?	Yes___ No___
Can you work evenings?	Yes___ No___
Can you work weekends?	Yes___ No___

Helping and taking care of others

I like to help and take care of people.	Yes___ No___
I like to work with and help animals.	Yes___ No___

Enjoying and taking care of the environment

I enjoy nature.	Yes___ No___
I like flowers, trees, and plants.	Yes___ No___
I like to work with plants.	Yes___ No___
I like to take care of the environment.	Yes___ No___

Building or fixing things

I like to work with tools and build things.	Yes___ No___
I like to work with tools and fix things.	Yes___ No___
I like construction.	Yes___ No___

Art activities and expressing yourself

I like to draw and make things.	Yes___ No___
I like to express myself through art.	Yes___ No___
I like to use a camcorder and make videos.	Yes___ No___
I like music and dance.	Yes___ No___

Food service

I like to work in a kitchen, use kitchen tools, and cook.	Yes___ No___
I like to clean in the kitchen - and I like to operate a dishwasher.	Yes___ No___
I like to work in a dining room.	Yes___ No___

Cleaning and fixing things

I like to clean.	Yes___ No___
I like to take care of a building.	Yes___ No___
I like to work with equipment.	Yes___ No___
I like to work with cars.	Yes___ No___

Working in a store or warehouse

I like working in a store that sells something I like.	Yes___ No___
I like working in a warehouse with supplies and equipment I like.	Yes___ No___
I like handling and counting money.	Yes___ No___
I like working with numbers.	Yes___ No___

Working in an office.

I like working in an office.	Yes___ No___
I like using a computer.	Yes___ No___
I like working with numbers and words.	Yes___ No___
I feel comfortable taking telephone messages.	Yes___ No___

Problem solving

I like to figure things out.	Yes___ No___
I like to make decisions.	Yes___ No___
Pictures and drawings help me figure things out.	Yes___ No___
Written directions help me figure things out.	Yes___ No___

Part II – What are you Good at Doing?

Everyone is different! Name three things that you do well.

1. _____

2. _____

3. _____

Something I do well is _____

What do I like about it? _____

What skills and abilities do I use to do it? _____

These skills and abilities may be strengths for me.

A second thing I do well is _____

What do I like about it?_____

What skills and abilities do I use to do it?_____

These skills and abilities may be strengths for me.

A third thing I do well is_____

What do I like about it?_____

What skills and abilities do I use to do it? _____

These skills and abilities may be strengths for me.

Part III - What is Hard for Me?

Something that is hard for me is _____.

What is hard about it? _____

What skills and abilities do I need to do it? _____

If I do not have these skills, this may be a weakness for me.

Something else that is hard for me is _____

What is hard about it? _____

What skills and abilities do I need to do it? _____

If I do not have these skills, this may be a weakness for me.

Choose a Life for Yourself

When I Know These...

- My interests for activities and environments
- My skills and abilities
- My strengths and weaknesses

I can use this information about myself to help make decisions about my life!

Everyone is different! What is most important to me?

Name three things that are most important to me

1. _____

2. _____

3. _____

Name: _____ Date:_____

Resources

Prince Edward Island Community Resource Guide: Transitions from School to Community

PEI Transitions from School to Community. Post Secondary Scholarship and Bursary Guide for Students with Disabilities

References

Canada Study Grants for Students with Permanent Disabilities

If you have a permanent disability, you may be eligible for a Canada Study Grant of up to $8,000 per loan year to help cover exceptional education-related costs associated with your disability, such as a tutor, interpreter (oral, sign), note taker, reader, technical aids, alternate formats, attendant care for studies, specialized transportation (to and from school), or 75 per cent of the cost of a learning disability assessment up to a maximum of $1,200. Eligible equipment includes computers, software, scanners, braillers, etc.

In order to qualify for this grant, you must:

- have a permanent disability (supported by appropriate medical documentation) and
- have a need for exceptional education-related services or equipment required to participate in post-secondary studies.
- first apply and qualify for full-time or part-time Canada Student Loan assistance

Contact Information:

PEI Department of Education
Student Aid Division
PO Box 2000
Charlottetown C1A 7N8
(902) 368-4000

Resources

Adolescent Autonomy Checklist

Source: Youth In Transition Project (1984-1987) at the University of Washington Division of Adolescent Medicine. Available online at http://depts.washington.edu/healthtr/Checklists/intro.htm

Ansell-Casey Life Skills Assessment

available online at
http://www.caseylifeskills.org/pages/assess/assess_aclsa.htm

Brigance Diagnostic Life Skills Inventory

Curriculum Associates, Inc.
153 Rangeway Road
North Billerica, MA 01862

Communication Summary

Source: Student Portfolio: A System for Documenting the Strengths, Needs and Abilities for Students Who are Deaf-Blind, by Kansas State Board of Education, 1996, Topeka, KS: Author.

FISH: Functional Independence Skills Handbook
Transition Planning Inventory (TPI)

PRO-ED, Inc.
8700 Shoal Creek Boulevard
Austin, TX 78757-6897
www.proedinc.com

Mayer-Johnson LLC

P.O. Box 1579
Solana Beach, CA 92075
U.S.A.
(858) 550-0084
www.mayer-johnson.com

Prince Edward Island Community Resource Guide: Transitions from School to Community

PEI Transitions from School to Community. Post Secondary Scholarship and Bursary Guide for Students with Disabilities

PEI Association for Community Living
158 Belvedere Avenue Suite 1
Charlottetown, PE C1A 2Z1
(902) 566-4844

Resource for the Transition of Students with Exceptionalities From School to Work or Post Secondary Education and Adult Life

New Brunswick Department of Education
Educational Programs and Services Branch
Student Services Unit
PO Box 6000 Fredericton, NB E3B 5H1

Private Practice Directory
Psychological Association of Prince Edward Island
Updated February 8, 2021

Kathren Allison, Psychologist
PEIPRB Registration #: 064
Telephone: (902) 314-1113
Email: kathy.allison@rogers.com
Office address: 1 Rochford St., Charlottetown, PE C1A 9L2
Currently accepting referrals: Yes
Typical referral wait time: 6 months
Language in which service provided: English
Formal assessment services provided: Psycho-educational assessments for children and adults; ADHD; Adult ADHD; cognitive/intelligence; learning disability; learning assessments
Relevant areas of practice: Learning disabilities; ADHD/attention problems;
Services provided to: individuals
Age groups served: children; adults
I am a registered psychologist who has been working full time in my own comprehensive private practice (assessment and treatment of anxiety, depression, PTSD, learning disabilities, ADHD, etc.) for over 10 years. I am now focusing exclusively on assessments for learning disabilities and attention problems/ADHD, for both children and adults.
This entry last updated: 30 April, 2018

Dr. Christine Beck, Psychologist
PEIPRB Registration #: 042
Telephone: (902) 367-4446
Email: drchristinebeck@gmail.com
Office Address: 51 University Avenue, Suite 204, Charlottetown, PE C1A 4K8
Currently accepting referrals: Yes
Typical referral wait time: 6 months
Language in which service provided: English
Formal assessment services provided: behavioural / emotional; cognitive / intelligence; learning disability; neuropsychological
Relevant areas of practice: psychotherapy
Services provided to: individuals; groups
Age groups served: adolescents; adults; older adults

Thank you for your interest in my private practice. I am a doctoral level Psychologist with training in adult and geriatric neuropsychology, adolescent and adult community mental health, educational assessment, health and rehabilitation psychology and psychotherapy with a variety of referral concerns.

Please call my office to see if my services are appropriate for your needs.

Sincerely,
Dr Christine Beck
This entry last updated: 23 April, 2016

Dr. Freda Burdett, Psychologist
PEIPRB Registration #: 081
Telephone: (506) 461-9959
Email: drfredaburdett@gmail.com
Office address: 224 Queen Street, Charlottetown, PE, C1A4B6
Currently accepting referrals: Yes
Typical referral wait time: New practice
Languages in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: Abuse; Addictions; Anxiety; Attachment issues (adult); Assertiveness; Depression; Grief / loss / bereavement; Habit change; Health issues; Loneliness; Obsessive-Compulsive Disorder; Personal growth / wellness; Personality Disorders; Phobias / fears / panic; Post Traumatic Stress Disorder (PTSD) / trauma; Psychotherapy; Relationship issues; Self-esteem; Separation / Divorce; Sexual issues; Social skills; Stress management; Workplace issues
Services provided to: individuals
Age-groups served: Adolescents and Adults
Dr. Burdett has a PhD in Clinical Psychology. Her primary area of focus has been on trauma assessment and treatment. She works with first responders, military members, and the general public; treating a wide range of clinical disorders, such as PTSD, anxiety, and depression (including post-partum depression). She has been trained in CBT, DBT, ACT, CPT, EMDR, and Prolonged Exposure. She welcomes you to contact her with any questions about her practice and availability.
This entry last updated: 02 August 2019

Sarah Carr, Psychologist
PEIPRB Registration #: 068
Telephone: (902) 367-4722
Email: carrpsychological@gmail.com
Office address: 49 Kensington Rd., Charlottetown, PE C1A 5H6
Currently accepting referrals: No
Typical referral wait time: 8 – 10 weeks
Provides services through telehealth: Yes
Language in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: abuse; ADHD/attentional problems; anger management; anxiety; assertiveness; behavioural problems; blended/step family issues; conflict resolution; depression; family therapy; grief/loss/bereavement; obsessive-compulsive disorder; parenting; personal growth/wellness; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; relationship issues; self-esteem; separation/divorce; stress management; workplace issues
Services provided to: individuals; couples; families; groups
Age groups served: pre-school children; school-aged children; adolescents; adults; older adults
This entry last updated: 27 March, 2020

Rebecca Deacon, Psychologist
PEIPRB Registration #: 051
Telephone: (902) 940-6157
Email: rjhooley@hotmail.com
Office Address: Suite 2C, 126 Richmond St, Charlottetown, PE C1A 1H9
Currently accepting assessment referrals: Yes
Currently accepting therapy referrals: No
Typical referral wait time: 3 - 6 months
Provides services through telehealth: Yes
Language(s) in which service provided: English
Formal assessment services provided: ADHD, behavioural/emotional; cognitive/intelligence; learning disability
Relevant areas of practice: ADHD/attentional problems; anger management; anxiety; behavioural problems; conflict resolution; depression; disabilities; family therapy; gifted/talented children; obsessive-compulsive disorder; parenting; phobias/fears/panic; psychotherapy; self-esteem; separation/divorce; social skills
Services provided to: individuals; families
Age groups served: pre-school children; school-aged children; adolescents

Rebecca Deacon's primary area of practice is in School Psychology and she has extensive experience in Psycho-Educational Assessment of School Aged Children, including the diagnosis and treatment of learning, behavioral, and social-emotional problems. Having worked within the school system for many years, Ms. Deacon is knowledgeable regarding evidence-based intervention, academic and behavioral program planning, and collaborating with families, schools, and other professionals. In addition to extensive assessment experience, Ms. Deacon has also treated a wide range of Anxiety Disorders in children and youth using a primarily Cognitive-Behavioral Approach, while also integrating other evidence-based strategies. Ms. Deacon also works with individuals and families to support the development of emotional and behavioral regulation, particularly as it relates to behavioral disorders such as ADHD.
This entry last updated: 27 March, 2020

Dr. Jason Doiron, Psychologist
PEIPRB Registration #: 038
Telephone: (902) 394-1249
Email: psychologist@pei.sympatico.ca
Office Address: 160 Belvedere Ave., Charlottetown, PE
Website: https://peipsychologist.wordpress.com/
Currently accepting referrals: Yes
Typical referral wait time: 2 months
Language(s) in which service provided: English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/intelligence; learning disability
Relevant areas of practice: addictions; ADHD / attentional problems; anger management; anxiety; assertiveness; behavioural problems; conflict resolution; couple therapy; depression;

grief/loss/bereavement; habit change; loneliness; obsessive-compulsive disorder; parenting; personal growth / wellness; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; relationship issues; self-esteem; separation/divorce; sports psychology
Services provided to: individuals; couples; groups
Age-groups served: school-aged children; adolescents; adults
Following my undergraduate years at the University of Prince Edward Island I was trained as a clinical psychologist at the University of New Brunswick, where I obtained my PhD in 2005. My part-time private practice (I am a full time professor at UPEI) is best be described as relatively general in nature. Much of my clinical work presently involves the assessment of cognitive ability and academic skills, along with the diagnosis of learning disabilities and other conditions related to learning (e.g., ADHD) in children and adults. I also have a smaller caseload of individuals who work with me in a psychotherapy / counselling context. My therapeutic work with clients is usually shorter-term with the goal of achieving some improvement or growth within approximately 8-12 sessions of work together. I tend to view clinical issues (such as anxiety or depression) through the lens of cognitive behavioural theory while integrating ideas from other evidence-based approaches as well.
This entry last updated: 14 December, 2015

Dr. Lee-Anne Greer, Psychologist
PEIPRB Registration #: 33
Telephone: (902) 620-9144
Office Address: 126 Richmond Street, Suite 2C, Charlottetown
Currently accepting referrals: No
Typical referral wait time:
Language in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: psychotherapy
Services provided to: individuals
Age-groups served: adults; older adults
This entry last updated: 17 November, 2020

Chris Hartley, Psychologist
PEIPRB Registration #: 045
Telephone: (902) 396-8465
Email: hartleypsychology@hotmail.com
Office address: Suite 2C – 126 Richmond St., Charlottetown, PE C1A 1H9
Currently accepting referrals: No
Typical referral wait time:
Language in which service provided: English
Formal assessment services provided: Pain assessment
Relevant areas of practice: Pain management; rehabilitation; sleep disorders; stress management; workplace issues
Services provided to: individuals

Age-groups served: adults
I am a registered psychologist working full time in private practise offering psychological services to adults facing a variety of chronic pain related issues including self management skills and adjustment, pain education, psychological difficulties and sleep problems.
This entry last updated: 08 February, 2021

Barbara Jones, Psychologist
PEIPRB Registration #: 061
Telephone: (902) 393-3829
Email: windhorseps@gmail.com
Office address: 174 Pickles Lane, Alexandra, PE
Box 24076, Stratford, PE C2B 2V5
Currently accepting referrals: Yes
Typical referral wait time: 5 – 6 months
Language in which service provided: English
Formal assessment services provided: behavioural / emotional
Relevant areas of practice: anger management; anxiety; attachment issues; assertiveness; depression; grief/loss/bereavement; habit change; health issues; loneliness; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; personality disorders; rehabilitation; relationship issues; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; stress management; workplace issues; mindfulness interventions
Services provided to: individuals; groups
Age-groups served: adults
Trained as a contemplative psychotherapist, mindfulness practices are embedded in all my work. My primary focus is PTSD I've worked extensively with first responders including veterans, police and fire fighters. I am working full-time at Serene View Ranch Psychological Services (www.sereneviewranch.com) where I offer individual therapy using mindfulness and CBT, psycho-educational and support groups as well as providing assessment services related to PTSD capacity and return-to-work.
This entry last updated: 15 December, 2018

Ruth Lacey, Psychologist
PEIPRB Registration #: 007
Telephone: (902) 675-4282
Email: rlacey688@gmail.com
Office mailing address: P.O. Box 512, Charlottetown, PE C1A 7L1
Currently accepting referrals: Yes
Typical referral wait time: 1 - 4 weeks
Languages in which service provided: English, Italian, Spanish
Formal assessment services provided: n/a
Relevant areas of practice: abuse; addictions; adoption issues; ADHD / attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; depression; family therapy; family violence; gifted/talented children; grief/loss/bereavement; health issues; loneliness; obsessive-compulsive disorder; pain

management; parenting; Post Traumatic Stress Disorder (PTSD)/trauma; relationship issues; self-esteem; stress management; troubled children and youth; workplace issues
Services provided to: individuals; couples; families; groups
Age-groups served: pre-school children; school-aged children; adolescents; adults; older adults

I believe that education is important: people do the best they can and when they know better, they do better. I believe that people are inherently good. I believe that people need to be accountable, recognizing that they have choices and that they make their own decisions. I believe that every person who works on doing better benefits society. I have faith that with my experience and the client's desire to change, between us, solutions and better ways of doing things will emerge.

This entry last updated: 2 January, 2016

Caroline LeBlanc, Psychologist
PEIPRB Registration #: 020
Telephone: (902) 393-3829
Email: caroline11leblanc@gmail.com
Office address: 174 Pickles Lane, Alexandra, PE
Currently accepting referrals: No
Typical referral wait time: Not accepting referrals
Language in which service provided: French and English
Formal assessment services provided: Work disability assessments
Relevant areas of practice: abuse; anxiety; depression; health issues; loneliness; obsessive-compulsive disorder; personal growth / wellness; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD) / trauma; psychotherapy; rehabilitation; relationship issues; CISD; equine assisted psychotherapy
Services provided to: individuals; groups
Age-groups served: adults; older adults

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

This entry last updated: 27 December, 2019

Dr. George Mallia, Psychologist
PEIPRB Registration #: 040
Telephone: (902) 367-4446
Email: drgeorgemallia@gmail.com
Office Address: 51 University Avenue, Suite 204, Charlottetown, PE C1A 4K8

Currently accepting referrals: Yes
Typical referral wait time: 1 year
Language(s) in which service provided: English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/ intelligence; custody / access; learning disability; neuropsychological; parental capacity
Relevant areas of practice: abuse; addictions; adoption issues; ADHD / attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; body image; conflict resolution; depression; disabilities; eating disorders; family therapy; gifted/talented children; grief/loss/bereavement; health issues; loneliness; obesity; obsessive-compulsive disorder; pain management; parenting; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; rehabilitation; relationship issues; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; sports psychology; stress management; workplace issues
Services provided to: individuals; families
Age-groups served: school-aged children; adolescents; adults
This entry last updated: 3 December, 2014

Dr. Rhonda Matters, Psychologist
PEIPRB Registration #: 027
Telephone: (902) 388-8846
Office address: 126 Richmond St. Suite 2C, Charlottetown, PE C1A 1H9
Currently accepting referrals: No
Typical referral wait time:
Language in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: abuse; ADHD/attentional problems; anxiety; depression; family therapy; family violence; grief/loss/bereavement; obsessive-compulsive disorder; phobias/fears/panic; post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; relationship issues; separation/divorce; stress management
Services provided to: individuals; couples; families
Age-groups served: children; adolescents; adults

Dr. Matters has a PhD in Clinical Psychology from the University of Windsor in Ontario. She has been practicing for more than 20 years, with her primary focus being the treatment of behavioural disorders in children, depression, and anxiety disorders in both children and adults.

She uses primarily a Cognitive-Behavioural Approach but has also been trained in Eye Movement Desensitization and Reprogramming (EMDR), Interpersonal Therapy, Solution Focused Therapy, and Narrative Therapy

This entry last updated: 8 February, 2021

Dr. Brent Macdonald, Psychologist
PEIPRB Registration #: 072
Telephone: (403) 229-3455
Email: brent@complexlearners.com
Office Address: 320, 1167 Kensington Cres. NW (Calgary); local office on PEI upon request

Currently accepting referrals: Yes
Typical referral wait time: Varies; assessment clinics run in 2-week cycles through the year
Provides services through telehealth: Yes
Language(s) in which service provided: English
Formal assessment service provided:
ADHD; Adult ADHD; Behavioural / Emotional; Career / Vocational; Cognitive / intelligence; Learning disability
Relevant areas of practice: ADHD / attentional problems; Anxiety; Autism spectrum disorder; Behavioural problems; Depression; Disabilities; Gifted / talented children; Parenting
Services provided to: Individuals and Families
Age-groups served: School-aged children, Adolescents, and Adults

While currently a resident of Calgary, Dr. Macdonald is a native Islander who maintains active registration and practice as a psychologist in his home province of PEI. Dr. Macdonald provides psychoeducational assessments through ongoing 2-week clinics on PEI, offered as needed. Once initiated, comprehensive psychoeducational assessments can be completed in a timely manner, allowing for fast and effective planning for students of a wide range of ages. Assessments focus on attention, learning, and social/emotional & behavioral issues, with a focus on providing practical and effective recommendations and strategies.

Since clinics run through the year, there is also the opportunity to follow-up and review the effectiveness of interventions, allowing Dr. Macdonald to maintain ongoing contact and support for his clients. Collaboration with schools, where possible, is also a service that can be incorporated into the assessment process.

Learn more at complexlearners.com or contact Dr. Macdonald directly at brent@complexlearners.com.
This entry last updated: 27 March, 2020

Dr. Wm. Neil McLure, Psychologist
PEIPRB Registration #: 009
Telephone: (902) 432-3910
Fax: (902) 432-3007
Email: mclure@pei.sympatico.ca
Office address: 292 Water St., Summerside
Currently accepting referrals: Yes
Typical referral wait time: 3 - 4 weeks
Language in which service provided: English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/ intelligence; insurance; learning disability; legal; neuropsychological; pain assessment
Relevant areas of practice: abuse; acquired brain injury; addictions; adoption issues; ADHD / attentional problems; anger management; anxiety; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; couple therapy; depression; disabilities; family therapy; gifted/talented children; grief/loss/bereavement; health issues; loneliness; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma;

psychotherapy; rehabilitation; relationship issues; self-esteem; separation/divorce; social skills; sports psychology; stress management; traumatic brain injury; workplace issues
Services provided to: individuals; couples; families
Age-groups served: pre-school children; school-aged children; adolescents; adults; older adults
This entry last updated: 1 March, 2013

Dr. Terry Mitchell, Psychologist
PEIPRB Registration #: 023
Telephone: (902) 394-0034
Email: mitchellcounselling.consulting@gmail.com
Office address: 75 Villa Ave., Charlottetown, PEI, C0A 2B2
Currently accepting referrals: Yes
Typical referral wait time: 1 week
Provides services through telehealth: Yes
Languages in which service provided: English
Formal assessment services provided: n/a
Relevant areas of practice: anxiety; body image; colonial trauma, depression; eating disorders; grief/loss/bereavement; obsessive-compulsive disorder; pain management; parenting; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; relationship issues; sleep disorders; and stress management.
Services provided to: individuals
During this time of self-isolation and social distancing I am providing counselling services by telephone and video conferencing with pro-bono services for registered health professionals and front line workers. I am a psychology professor with many years of experience working with survivors of child sexual abuse and other forms of trauma. My counselling practice is based on a client-centred, feminist, psychodynamic approach using Mindfulness Practices, Cognitive Behaviour Therapy (CBT) and Dialectical Behavioural Therapy (DBT).
This entry last updated: April 23, 2020

Parise Nadeau, Psychologist
PEIPRB Registration #: 35
Telephone: (902) 438-1109
Email: parisenadeau@gmail.com
Office address: Summerside
Currently accepting referrals: Yes
Typical referral wait time: 3 - 6 weeks
Languages in which service provided: French; English
Formal assessment services provided: ADHD; Adult ADHD; behavioural/emotional; cognitive/intelligence; learning disability
Relevant areas of practice: ADHD/attentional problems; anger management; anxiety; assertiveness; autism spectrum disorder; behavioural problems; body image; depression; gifted/talented children; grief/loss/bereavement; habit change; loneliness; obesity; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; phobias/fears/panic; psychotherapy; self-esteem; social skills; stress management

Services provided to: individuals; families
Age-groups served: pre-school children; school-aged children; adolescents; adults

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

This entry last updated: 1 March, 2013

Ken Pierce, Psychologist
PEIPRB Registration #: 006
Telephone: 1-877-569-3710
Email: contact@kenpiercepsychologist.com
Website: www.kenpiercepsychologist.com
Office address: 549 North River Rd., Vision Care Building, 2nd floor, Charlottetown, PE C1E 1J6
Currently accepting referrals: Yes
Typical referral wait time: 5 - 7 days
Provides services through telehealth: Yes
Language in which service provided: English
Formal assessment services provided: behavioural/emotional; career/vocational; custody/access; pain assessment; parental capacity
Relevant areas of practice: abuse; addictions; adoption issues; ADHD/attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; body image; conflict resolution; couple therapy; depression; disabilities; eating disorders; family therapy; family violence; financial loss; gifted/talented children; grief/loss/bereavement; habit change; health issues; infatuations; loneliness; obesity; obsessive-compulsive disorder; pain management; parenting; personal growth/wellness; personality disorders; phobias/fears/panic; Post Traumatic Stress Disorder (PTSD)/trauma; psychotherapy; rehabilitation; relationship issues; resentments; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; spiritual; sports psychology; stress management; workplace issues
Services provided to: individuals; couples; families; groups
Age-groups served: pre-school children; school-aged children; adolescents; adults; older adults

I am a registered psychologist with over 30 years experience in a variety of roles including drug crisis, early childhood education, post secondary education, corporate training, community development and private practice.

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

I have the privilege of working with clients aged 2 to 82 years. I have assisted individuals and groups to move on from: assault, abuse, addictions, ADHD, allergies, auto collisions, auto immune diseases, bullying, bankruptcy, bipolar disorder, cancer, Crohn's, death, depression,

divorce, harassment, incest, injuries, job loss, learning disabilities, PTSD, workplace strikes and other traumatic events. I have a special interest in working with couples and those struggling with bulling, depression and self esteem.
This entry last updated: 27 March, 2020

Peter Joseph Pierre, Psychologist
PEIPRB Registration #: 044
Telephone: (902) 436-6799
Email: pjpierre@live.com
Office address: Suite 5, Granville Professional Centre, 500 Granville, Summerside, PE, C1N 5Y1
Currently accepting referrals: Yes
Typical referral wait time: less than 1 week
Language in which service provided: English
Formal assessment services provided: ADHD, adult ADHD, behavioural/emotional, career/vocational, cognitive/intelligence, learning disability
Relevant areas of practice: abuse; addictions; ADHD/attentional problems; anger management; anxiety; attachment issues; assertiveness; autism spectrum disorder; behavioural problems; blended/step family issues; body image; conflict resolution; depression; disabilities; grief/loss/bereavement; habit change; health issues; loneliness; obsessive compulsive disorder; pain management; parenting; personal growth/wellness; phobias/fears/panic; post- traumatic stress disorder (PTSD)/trauma; psychotherapy; rehabilitation; self-esteem; separation/divorce; sexual issues; sleep disorders; social skills; stress management; workplace issues.
Services provided to: individuals; couples; families
Age-groups served: school-aged children; adolescents; adults

I practice cognitive behavioural therapy and emotion focused therapy.

This entry last updated: 21 May, 2015