

Complex Care Transition Resource Guide

This general guide provides information on adult support services, funding and transition planning resources in Ontario for families supporting an adolescent with complex care needs (e.g., those who are dependent on others for care and decision making). An electronic version with active links is available at <http://www.sickkids.ca/Good2Go/Resources/index.html>. This information is up to date as of October 2013.

SUPPORT SERVICES AND FUNDING FOR SUPPORT SERVICES			
Resource	General Information	Key Websites and Contacts	Steps to Access this Resource
<p>Developmental Services Ontario (DSO)</p> <p>Ministry of Community and Social Services</p>	<p>Developmental Services Ontario (DSO) agencies can help adults with developmental disabilities find services and supports in their community. There are nine DSO agencies across Ontario. DSO also provides information and help with planning for the future. Supports may include:</p> <ul style="list-style-type: none"> - Residential Services and Supports - Community Participation Supports and Passport funding - Caregiver Respite - Person Directed Planning – help with goal setting and planning - Adult Protective Service Workers - Specialized Supports 	<p>Developmental Services Ontario: Website: www.dsonario.ca</p> <p>Ministry of Community and Social Services: Website: www.mcscs.gov.on.ca/en/mcscs/programs/devlopmental/index.aspx</p> <p>Toronto: DSO Toronto – Surrey Place Centre Phone: 1-855-DS-ADULT or (1-855-372-3858) Fax: 416-925-3402 Email: DSOTR@surreyplace.on.ca Website: www.dsotoronto.com/home/</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Visit DSO online to find your local office. Call to ask which assessments are needed to confirm eligibility. This is best done in late elementary school years. <input type="checkbox"/> Obtain a psycho-educational assessment through school board, hospital, or privately prior to age 16. <input type="checkbox"/> Contact local DSO at age 16, DSO will request documentation to confirm your child's eligibility (psychoed assessment, proof of identity). <input type="checkbox"/> If DSO determines you are eligible for services they will book a Support Intensity Scale (SIS) assessment to determine your family's support needs. <input type="checkbox"/> Waitlist are prioritized by urgent needs – Contact DSO if there is a significant change in circumstances such as a crisis or change in support needs.
<p>Respite Services</p>	<p>Respite Services staff are knowledgeable about respite options and funding. They can assist you in navigating the respite system for your specific situation.</p> <p>Funding differs for adults and children. Special Services at Home (SSAH) and Assistance for Children with Severe Disabilities (ACSD) are not available after age 18. Passport funding for adults (18 plus) can be accessed by registering with Developmental Services Ontario.</p>	<p>Respite support and information:</p> <p>Website: www.respiteservices.com E-mail: info@respiteservices.com</p> <p>Toronto: Phone: 416-322-6317 x 1</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Register by filling out a “Family Registration Form” online <input type="checkbox"/> Phone an Intake and Information Specialist for general information or a Respite Options Facilitator to get assistance with your specific situation. <input type="checkbox"/> Attend workshops on funding for respite, and respite options. Each local region will have workshops listed on the Respite Services website.

SUPPORT SERVICES CONTINUED...

Resource	General Information	Key Websites and Contacts	Steps to Access this Resource
<p>Health Care Connect</p> <p>Ministry of Health and Long-term Care</p>	<p>Health Care Connect helps Ontarians find a family health-care provider (family doctor or nurse practitioner). They can provide referrals to specialists, complete paperwork needed for 'proof of disability', and take care of basic health-care needs (e.g., flu shots, yearly checkups).</p>	<p>Health Care Connect</p> <p>Website: www.health.gov.on.ca/en/ms/healthcareconnect/public/</p> <p>Phone: 1-800-445-1822</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Make sure your child has a valid healthcard, their address is up to date with Service Canada and that they are not already registered with a family doctor. <input type="checkbox"/> Call the 1-800-445-1822 to enroll or enroll online.
<p>Community Care Access Centre</p> <p>Ministry of Health and Long-term Care</p>	<p>Community Care Access Centres (CCAC) connects people with health care and support in their community. Professional case managers from CCAC assess care needs and develop a custom plan. CCAC case managers will refer your child to professional services to meet their needs including nurses, physiotherapists, occupational therapists, social workers, dieticians, speech therapists and personal support workers.</p> <p>CCAC manages the needs of children and adults (18 plus) differently. If your child is currently with CCAC, when they turn 18 they will be transferred to an adult case manager and reassessed.</p>	<p>Community Care Access Centre</p> <p>Phone: 310 CCAC (2222)</p> <p>Website: http://www.ccac-ont.ca/</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Review website and speak with your child's health-care team to learn about CCAC. <input type="checkbox"/> Call 310-CCAC to connect with your local CCAC, some initial information will be reviewed over the phone. If the referral is appropriate CCAC will send professionals to assess your child's needs. You can contact CCAC any time and make a self referral for your child. <input type="checkbox"/> If your child already receives services through CCAC contact your paediatric case manager to learn more about any upcoming changes in services or assessments as your child approaches their 18th birthday.
<p>211 Ontario</p>	<p>211 is a confidential, free referral service that provides information on community and social services. Certified Information and Referral Specialists are trained to advise you about available programs and services. This service is especially helpful in crisis situations such as an immediate need for respite support, mental health counseling, or emergency housing. 211 does not provide these services directly but can link you to the appropriate service provider.</p>	<p>211 Ontario</p> <p>Website: www.211ontario.ca</p> <p>Phone: 211</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Call 211 to speak with a Certified Information and Referral Specialist or go online and use the website to search yourself for services and supports. This website is a good 'go to website' if you are having difficulty finding a particular type of service, support or funding for your child's needs.

FUNDING AND FINANCES – GOVERNMENT PROGRAMS

Resource	General Information	Key Websites and Contacts	Steps to Access this Resource
<p>Ontario Disability Support Program</p> <p>Ministry of Community and Social Services</p> <p>Click here for a one page flyer version of the same information about ODSP.</p>	<p>The Ontario Disability Support Program (ODSP) helps adults with disabilities who are in financial need pay for living expenses, such as food and housing. This is called Income Support. Those on Income Support may also qualify for extra funding for special diets, incontinence supplies, transportation to and from medical appointments and some medical supplies.</p> <p>Those who are eligible for ODSP income support may also qualify for funding for items that are a necessity such as commodes, bath chairs, portable lifts with slings, hospital beds, and pressure relief mattresses. Speak with an occupational therapist (you can get one through CCAC or your local children’s treatment centre) and your child’s ODSP worker for more information about potential funding options.</p> <p>ODSP also offers Employment Supports that help people with disabilities who can and want to work prepare for and find a job.</p>	<p>Ontario Disability Support Program</p> <p>Ministry of Community and Social Services ODSP Website:</p> <p>www.mcscs.gov.on.ca/en/mcscs/programs/social/odsp/</p> <p>Website for locating your ODSP Office:</p> <p>http://appow.mcscs.gov.on.ca/OfficeLocator/index.aspx?lang=en</p> <p>Community Legal Education Ontario:</p> <p>Website link to ‘Disability benefits in Ontario: Who can get them, How to apply’:</p> <p>www.cleo.on.ca/en/publications/disabben/qualify-odsp#full</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Read through the booklet “Disability Benefits in Ontario: Who can get them, How to Apply” published by Community Legal Education Ontario. This will provide an overview of eligibility policies and the application process. <input type="checkbox"/> Start application process six months prior to your child’s 18th birthday. You can start online or go in person to your local ODSP office. Go online to locate your local ODSP office <input type="checkbox"/> Your local ODSP office will book an appointment to determine if your child is financially eligible once the initial application has been reviewed. <input type="checkbox"/> If your child is determined to be financially eligible, ODSP will provide forms that must be filled out by an appropriate medical professional. These forms state the nature of your child’s disability. Signed forms must be received by the ‘Disability Adjudication Unit’ within 90 days of the date they were provided to you. <input type="checkbox"/> If your child is deemed ineligible you can go through an appeal process.
<p>Assistive Devices Program (ADP)</p> <p>Ministry of Health and Long-Term Care</p>	<p>The Assistive Devices Program (ADP) provides funding support to individuals with long-term physical disabilities who need equipment. Equipment needs to be prescribed by an “ADP authorized” physiotherapist or occupational therapist. ADP may not cover the entire cost of equipment and will only cover certain brands/types of equipment from specific vendors.</p> <p>ODSP covers some equipment costs, if your child is on ODSP contact your child’s worker to check what costs are covered.</p> <p>You can also apply to charitable organizations for support. Please see the list of charitable sources of funding outlined by March of Dimes.</p>	<p>Assistive Devices Program</p> <p>Website:</p> <p>www.health.gov.on.ca/english/public/program/adp/adp_mn.html</p> <p>Toll-free: 1-800-268-6021</p> <p>Email: adp@ontario.ca</p> <p>Other Equipment Funding Sources</p> <p>March of Dimes Funding Sources for Adults:</p> <p>http://www.marchofdimes.ca/EN/programs/adp/Documents/ADP_alternative_funding.pdf</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Prior to your child’s 18th birthday speak with your paediatric equipment providers (e.g., seating clinics, AAC clinics) and ask for referrals to adult ADP authorizers. Speak with other adults with disabilities or other parents for recommendations. <input type="checkbox"/> Book an appointment with ADP authorizer for an assessment. There may be a wait time to get an appointment at an adult seating clinic or AAC clinic. <input type="checkbox"/> Ask the authorizer about other sources of funding and if they will help you apply.

FUNDING AND FINANCES – GOVERNMENT PROGRAMS CONTINUED...

Resource	General Information	Key Websites and Contacts	Steps to Access this Resource
<p>Disability Tax Credit</p> <p>Government of Canada</p>	<p>The Disability Tax Credit (DTC) is a non-refundable tax credit used to reduce amount of income tax payable for eligible individuals. To be eligible, a person must have a severe impairment in physical or mental functions. The impairment must also be 'prolonged'.</p> <p>A qualified practitioner must fill out the appropriate paperwork. Click on the Canada Revenue Agency's website on the "Definition of Disability and List of Qualified Practitioners" to learn which practitioners qualify.</p> <p>A supporting person may be able to claim all or part of a dependant's Disability Tax Credit providing that both the supporting person and the dependent were residents of Canada during the tax year.</p>	<p>Eligibility Criteria for Disability Tax Credit:</p> <p>Website: http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/qlfd-prcts/whts-eng.html</p> <p>Definition of Disability and List of Qualified Practitioners:</p> <p>Website: http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrm/cmpltng/ddctns/Ins300-350/316/glssry-eng.html#qualified</p> <p>Disability Tax Credit Application - Form T2201</p> <p>Website: http://www.cra-arc.gc.ca/E/pbg/tf/t2201/t2201-12e.pdf</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Review eligibility criteria to determine if your child qualifies. <input type="checkbox"/> Review the 'list of qualified practitioners'. Book an appointment with one of the health-care providers that meets the definition of a 'qualified practitioner' to have them fill out the Disability Tax Credit Application. <input type="checkbox"/> Download and print the Form T2201 and ask a qualified practitioner to fill it out. Be sure to include any documentation about date of onset. If your child had the disability in previous tax years but you had not registered for DTC you may be able to claim back money paid in taxes from these previous years. <input type="checkbox"/> Send the original signed form in to Canada Revenue Agency as soon as possible. You can submit the form any time throughout the year.
<p>Registered Disability Savings Plan (RDSP)</p> <p>Government of Canada</p>	<p>A Registered Disability Savings Plan (RDSP) is a federal tax-supported savings approach that is intended to encourage people to save for the future needs of a person with a disability.</p> <p>The Government may contribute Canada Disability Savings Grants of up to \$3,500 a year, for up to 20 years, depending on the amount of contributions made to the RDSP.</p> <p>The Government may also pay a Canada Disability Savings Bond of up to \$1,000 a year, for up to 20 years, into the RDSPs of low-income and modest-income Canadians. No contributions are necessary to receive the bond. Earnings accumulate tax-free until money is taken out of the RDSP. People with disabilities must be 49 years old or less in order to receive grants or bonds.</p>	<p>Information on RDSPs</p> <p>Ministry of Community and Social Services</p> <p>http://www.mcscs.gov.on.ca/en/mcscs/programs/social/what/rdsp.aspx</p> <p>Canadian Revenue Agency</p> <p><i>General summary:</i></p> <p>http://www.cra-arc.gc.ca/tx/rgstrd/rdsp/bt-eng.html</p> <p><i>Detailed Summary on RDSPs</i></p> <p>http://www.cra-arc.gc.ca/E/pub/tg/rc4460/README.html</p>	<ul style="list-style-type: none"> <input type="checkbox"/> To be eligible for the Registered Disability Savings Plan your child needs to first qualify for the Disability Tax Credit. <input type="checkbox"/> Most banks provide RDSP programs. You can ask at your local branch for more information. You may want to ask for a staff member who has had previous experience setting up an RDSP. Consult with other parents and/or adults with disabilities to find a financial advisor or bank employee with knowledge about RDSPs.

TRANSITION PLANNING RESOURCES

Resource	General Information	Key Websites and Contacts	Steps to Access this Resource
<p>Transition Planning</p> <p>Ministry of Education</p>	<p>Educational rights of youth with special needs:</p> <p>Young people can stay in the school system until 21 years of age in Ontario (depending on the preference of you and/or your child). Note that</p> <p>School principals are required to make sure a transition plan is created, as part of the Individual Education Plan, for each exceptional student who is 14 years of age or older.</p>	<p>Transition Planning Resource Guide: www.edu.gov.on.ca/eng/general/elems/ec/speced/transiti/transition.pdf</p> <p>Ministry of Education Website: Special Education</p> <p>http://www.edu.gov.on.ca/eng/parents/speced.html</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Review information on website about your child's educational rights. <input type="checkbox"/> Review the Transition Planning Resource Guide. This document explains in detail how to create a transition plan, what should be included and provides examples of plans. <input type="checkbox"/> Speak with the principal about his/her role as a "Transition Planning Team Lead" and create a Transition Planning Team. <input type="checkbox"/> Obtain copies of key documentation such as psychoeducational assessments, Individualized Education Plans (IEPs), report cards and assessments. <input type="checkbox"/> Book regular meetings with Transition Planning Team to create a transition plan.
<p>A List of Planning Organizations</p> <p>Not funded or supported by the Government of Ontario</p>	<p>The organizations included in this list have websites that help caregivers of a person with a disability plan for the future. Many of these organizations have been formed by families of people with disabilities.</p> <p>Most of these organizations have some free resources on their website. Many of the groups also offer some free advice and planning support. Please note that some ask for a fee for services or sell products such as life insurance or books on planning.</p> <p>SickKids does not endorse or recommend these products or services. These links are provided for information purposes only. Caregivers are encouraged to ask questions and make informed choices before purchasing services or products for their family.</p>	<p>Planning Organizations</p> <p>The Special Needs Planning Group Website: www.specialneedsplanning.ca E-mail: graemetreeby@sympatico.ca Phone: (905) 640-8285</p> <p>PLAN Toronto Website: www.plantoronto.ca/ Phone: 416-232-9444</p> <p>Other "PLAN" Groups: PLAN Institute: http://institute.plan.ca/ PLAN Canada: www.plan.ca</p> <p>Families for a Secure Future Website: www.familiesforasecurefuture.ca</p> <p>Life Trust Website: www.life-trust.com/</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Review the information and articles on the websites provided. This information is best reviewed early when your child is young but can be used at any time to help you plan for the future. <input type="checkbox"/> If interested in further information or services call the organization to get information about: <ul style="list-style-type: none"> - Types of services offered - Types of products sold - Cost of services - Amount of time services will be offered and how frequently - References from other families that have used these services.

TRANSITION PLANNING RESOURCES CONTINUED

Resource	General Information	Key Websites and Contacts	Steps to Access this Resource
<p>General Resources on Estate Planning & 'Henson Trusts'</p>	<p>Caregivers have special needs when it comes to estate planning. Leaving an adult with an inheritance may end up disqualifying them from social assistance programs such as the Ontario Disability Support Program (ODSP). Many parents have used financial planning methods such as leaving assets in a "Henson Trust" to ensure their child will not be disqualified from ODSP and will still be able to benefit from their inheritance. The resources listed here explain some of the steps parents of children with disabilities have taken to ensure a secure future for their child.</p> <p>When setting up an estate, creating a will and/or setting up a Henson Trust it may be a good idea to hire professionals to assist. Finding a professional with experience in this specific area is important. Caregivers are encouraged to ask questions and make informed choices before purchasing services or products for their family.</p>	<p>Information on Estate Planning and Henson Trusts</p> <p>Estate Planning for Individuals with Disabilities Published by York Support Services Network https://yssn.ca/wp-content/uploads/2012/09/15-Estate-Planning.pdf</p> <p>What can you do to enhance the quality of life for a family member with a disability? Consider a Henson Trust Published on Reena Website: http://www.reena.org/sites/default/files/InformationBrochures/hensontrust.pdf</p> <p>Finding a Lawyer</p> <p>The Law Society Referral Service</p> <p>Website: http://www.lsuc.on.ca/find-a-lawyer-or-paralegal/</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Review articles on estate planning and Henson Trusts. <input type="checkbox"/> Review the "Special Needs Planning Group" website listed in this resource under Family Created Planning Organizations. <input type="checkbox"/> Contact other parents who've set up Henson Trusts for referrals and more information. The List of Planning Organizations provided in this resource has several parent led organizations listed that you may contact. <input type="checkbox"/> Contact The Law Society Referral Service and ask to be referred to a lawyer that specializes in trusts and estates. They may have the qualification of "Trust and Estate Practitioner" (TEP). Explain that you are a parent of child with a disability are seeking to set up a Henson Trust. <input type="checkbox"/> Ask lawyers specific questions about their history in setting up trusts, if you can speak with another family that has worked with them, associated fees and what they would recommend in your specific circumstance.