

Dear Parent/Caregiver,

When caring for adolescents who have a cognitive impairment, there are particular challenges when it comes to the transition process from pediatric to adult health care. It is important to remember that you are not alone in this process and that your pediatric and adult health care teams are available to assist you before, during and after the transition process. This information package was developed to facilitate the gathering of information and resources for adolescents who have a cognitive impairment.

When completing the various documents, please remember that if the adolescent is not able to read and understand the forms, he or she should not sign them. Many forms require the signature of a physician. In order to accelerate the process of the form completion, please complete the parents/caregiver sections before submitting them to the physician.

The information package *Transition from the Pediatric to Adult Health Care for Adolescents who have a Cognitive Impairment: 18 steps until 18*, was developed with the support of the EUREKA Fellowship, many wonderful parents and caregivers, Franca Kesic from the West Island Association for the Intellectually Handicapped, Pierre Frégeau and Associates (Attorneys), Danny JF Williams (Financial Security Advisor), as well as the Partnerships Office at the Montreal Children's hospital.

I hope that the information provided helps to support you through a smooth transition process.

Sincerely,

Heather Davies, N, MSc (A), CNN(C)

Nurse in Advanced Practice, Pediatric Neurology

Transition from Pediatric to Adult Health Care for Adolescents who have a Cognitive Impairment

18 steps until 18!

| <u>14-15 years</u> | Resources | Forms |
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| 1. Start obtaining a copy of the medical file including information such as: MRI, genetic testing, summaries or progress notes and rehabilitation reports (occupational therapy, physiotherapy, speech therapy) | Contact medical records MCH : 514 412-4408 | You will be required to complete an Authorization to release information form |
| 2. Register to find a family doctor | Government of Quebec Quebec Family Doctor Finder (GAMF) | |
| 3. Ensure a psychological evaluation is completed within 10 years of age 18 | If this is not available, Contact school, CLSC or hospital resources | |
| 4. Obtain a social insurance number (SIN) | Government of Canada 1 800 206-7218, option 3 | How to apply for a social insurance number |
| 5. Apply for federal and provincial Disability Tax Credit ¹ , provincial Supplement for Handicapped Children ⁶ , and Compassionate Care Benefits | Disability Tax Credit info Supplement for Handicapped Children info Compassionate Care Benefits info | Disability Tax Credit Certificate Supplement for Handicapped Children form Compassionate Care Benefits Application <i>These forms need to be signed by a physician</i> |
| 6. Apply for adapted transportation (if relevant) | Transports Québec info (in French only) Société de transport de Montréal Paratransit info 514 280-8211, option 4 | Application for admission to Adapted transportation form <i>These forms need to be signed by a physician</i> |
| 7. Obtain a disabled parking permit | Société de l'assurance automobile du Québec 514 873-7620, option 5, then 3 Disabled Parking Permit info | Disabled Parking Permit form <i>This form needs to be signed by the physician</i> |

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| <p>8. Obtain a medical exemption certificate, if the adolescent is not able to provide a photo or signature for Medical Care Insurance (Medicare) or passport</p> | <p>Régie de l'assurance maladie du Québec 514 864-3411</p> | <p>Medical Certificate (in French only) <i>This form needs to be signed by the physician</i></p> |
| <p>9. Seek assistance with a financial advisor who is very familiar with RDSPs to assist with the opening of a Registered Disability Savings Plan (RDSP) (REEI in French) as well as other financial issues.</p> | <p>Canada Revenue Agency (CRA)</p> | <p>Need to qualify first for the Disability Tax Credit¹ Financial and Social Aid links from the Montreal Children's Hospital; Financial Aid form; Many institutions offer RDSPs (ex. RBC, TD, etc.) but have no one with the necessary experience with these complicated plans to provide actual beneficial advice. Therefore, a financial advisor with RDSP experience is very helpful.</p> |
| <p>10. Apply for funding for transportation for medical appointments Residential Adaptation Assistance Program⁵</p> | <p>www.gouv.qc.ca 514 644-4545</p> | <p>Form (French only)</p> |

16-18 years

| | Resources | Notes and forms |
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| <p>11. Discuss resources for adult health care with medical team.</p> | <p>Neurologist, pediatrician, complex care team, gastroenterologist, respirologist, etc.</p> | <p>-Request that discharge summaries be sent to adult health care team at age 17; -Get first appointment date prior to the age of 18; -Waiting lists to obtain a first appointment may take one year.</p> |
| <p>12. Open a bank account for the teenager</p> | | <p>-Bank accounts should be opened before age of 18 as the parent has the legal right to do so; -Joint accounts that require only one signature is the ideal option.</p> |
| <p>13. Continue to obtain a copy of all pertinent health care information prior to age 18</p> | <p>Contact medical records MCH : 514 412-4408</p> | <p>If this has not yet been done, you will be required to place a request by completing an Authorization to release information form to release information.</p> |



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| <p>14. Ask for assistance with the transition process if needed</p> | <p>Social services at CLSC or hospital, and/or the advanced practice nurse: Heather Davies 514 412-4400 ext. 23267</p> | <p>Visit the Transition section on the Montreal Children's Hospital's website.</p> |
| <p>15. Attend a Parent Information Evening at the Montreal Children's Hospital</p> | <p>Karine Frisou-Dugas 514 934-1934 ext. 22504 transition.peds.adult@muhc.mcgill.ca</p> | <p>There is no charge and they are held in the fall and spring. Presentations are bilingual.</p> |
| <p>16. File income taxes for the adolescent before the age of 17</p> | <p>Canada Revenue Agency (CRA) Revenue Quebec</p> | <p>Even if adolescent not receiving an income, file taxes and declare income.</p> |
| <p>17. Prepare for curatorship or a will⁸ including preparing for estate planning and 'Henson Trusts'³¹</p> | <p>Contact a lawyer or notary: - Private lawyer: Barreau du Québec - Notary: Chambre des notaires du Québec - Legal aid: Justice Pro Bono</p> | <p>There are forms to fill in for curatorship: Medical assessment form Psychosocial assessment form These forms need to be completed by a social worker.</p> <p>A private lawyer can cost approximately \$3000.00.</p> <p>You may want to start thinking about family members/friends who you would like to name to play key roles in the dependant's life.</p> |
| <p>18. Explore community resources</p> | <p>Community resources such as:</p> <ul style="list-style-type: none"> • WIAIH (West Island Association for the Intellectually Handicapped), • CLSCs • Miriam Home for Respite Services, resources • Programs for young adults • Etoile de Pacho • Group interventions at TranXition Program at Lethbridge-Layton-Mackay | |

¹ A *totally* incapable person cannot make a mandate nor a will. A *partially* incapable person may be able to do so depending on their particular understanding. Usually wills serve for the parents more than the dependants, though they can be drafted for high functioning dependants. Wills have no say in the care of the adult dependant, only assets/property – this is why curatorship/tutorship are important.

| 18+ years | Resources | Notes |
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| Make sure you have completed all government forms indicated in the 14-15 years old and 16-18 years old sections | | Please remember that if the adolescent is not able to read and understand the forms, they are not to sign them (including your assistance with helping them put an X as a signature on the form). |
| Get to know the adult health care providers | | Including contact information for concerns between appointments, emergency care, resources |
| Place a request for financial assistance through the Social Solidarity Program⁵ (welfare), if the adolescent is not able to work | Emploi Québec Social Solidarity Program 418 644-1075 or 1 800 355-6557 | Social solidarity – Emploi Quebec Form This needs to be signed by a physician; The Supplement for Handicapped Children will end at 18 years old; This request will require a Medical Certificate. |

Helpful hints:

- Remember you are not alone in the transition process and if you are experiencing difficulties and concerns, contact your pediatric health care team for support.
- Please remember that if the adolescent is not able to read and understand the forms, they are not to sign them (including your assistance with helping them put an X as a signature on the form)
- The adolescent may no longer receive care in the pediatric setting (except in very rare and exceptional circumstances).
- In order to accelerate the process, please fill out all the sections of the forms for which you have the answers before submitting them to your physician.

KEY TERMS OR GLOSSARY

DISABILITY TAX CREDIT

The disability tax credit (DTC) is a non-refundable tax credit used to reduce the income tax you pay. It's available for people with a severe and prolonged physical or mental impairment, subject to approval by the Canada Revenue Agency (CRA).

'HENSON TRUST'

A 'Henson Trust' (sometimes called an absolute discretionary trust), in Canadian law, is a type of trust designed to benefit disabled persons. Specifically, it protects the assets (typically an inheritance) of the disabled person, as well as the right to collect government benefits and entitlements. '**Henson Trust**' (in common law) is a discretionary trust in Quebec (civil law).

Government benefits are crucial in providing financial means for a young adult/adult with a significant cognitive impairment as they are not able to support themselves with a job. Government legislation for disability benefits generally has a means test; therefore assets that the young adult owns can affect the benefits that the young adult receives. In other words, a lump-sum payment in the form of a bequest can have a significant impact on the young adult's access to provincial benefits. The assets in the 'Henson Trust' do not have an impact on the young adult's/adult's government benefits and therefore can be accumulated for future use. This is possible as the young adult/adult has no right to the assets of the trust as it is under the discretion of a chosen trustee (often a family member).

REGISTERED DISABILITY SAVINGS PLAN (RDSP)

A registered disability savings plan (RDSP) is a savings plan that is intended to help parents and others save for the long term financial security of a person who is eligible for the disability tax credit (DTC). Contributions to an RDSP are not tax deductible and can be made until the end of the year in which the beneficiary turns 59.

RESIDENTIAL ADAPTATION ASSISTANCE PROGRAM (RAAP)

The Residential Adaptation Assistance Program provides financial assistance to owners of homes occupied by a person with a disability to carry out essential, functional and cost-effective adaptations. Examples include installing an outdoor access ramp, remodelling a bathroom, widening door frames. A report must be obtained from a CLSC occupational therapist showing that the disability is significant and persistent.

SOCIAL SOLIDARITY PROGRAM

Once the young adult is 18 years, he/she is no longer entitled to handicap allowance. If the young adult has a severe limited capacity for employment they are eligible for the social solidarity program through Emploi Quebec. A medical certificate must be completed to apply for this program. If the young adult has cash resources that exceed the permitted exceptions, the application for financial assistance will be refused.

SUPPLEMENT FOR HANDICAPPED CHILDREN

The purpose of the supplement for handicapped children is to provide financial assistance for families to help with the care and education of a handicapped child. The impairment or mental function disability must significantly limit the child in carrying out life habits for a period expected to last for at least 1 year. The supplement for handicapped children is the same, that is, \$195 a month, for all children who meet our eligibility criteria, regardless of family income or type of handicap. That amount is not taxable and is indexed in January of each year.

SUPPLEMENT FOR HANDICAPPED CHILDREN REQUIRING EXCEPTIONAL CARE

Receiving the supplement for handicapped children does not automatically mean that your child is eligible for the supplement for handicapped children requiring exceptional care. The supplement is exceptional financial assistance paid to families in exceptional situations. The eligibility requirements are based not on a diagnosis but rather according to the severity of the child's limitations in performing life habits. Only children who have multiple serious handicaps or who require complex care at home based on set criteria are eligible for additional financial assistance.

WILLS AND MANDATES

When a young adult/adult is incapable of managing their own property, a mandate permits one or more people to manage this property while the young adult/adult is still alive. A will is a document that details how property will be distributed after death.

Incapacity: A person is unable to care for himself or his property. There are different degrees of incapacity. It can be partial or total, temporary or permanent. For young adults who have a cognitive impairment, the incapacity is permanent however it may be partial or total. A psychological evaluation assists with the determination of whether the incapacity is partial or total. A psychosocial evaluation is necessary to determine the young adult's ability to act independently.

Mandate: When the young adult is declared incapacitated a protection mandate is necessary. A mandate is necessary for young adults with a cognitive delay. This is not the same as a power of attorney which permits others to act on a person's behalf even though the person may be capable of managing their own affairs. The person or persons (for young adults often a parent or sibling) in charge of the mandate are referred to as the mandatary. The mandatary has two responsibilities: looking after the well-being of an incapacitated person and managing the person's property. Before a mandate can become official it requires a judgement from the court.

Will: A will is especially important for parents of young adults/adults with a cognitive impairment in order that their detailed wishes for their assets and the care of the young be clarified.

COMPASSIONATE CARE BENEFITS

Those government benefits are eligible to you if:

- You are a family member of the person who is critically ill or injured or needing end-of-life care, or you are considered to be like a family member;
- Your regular weekly earnings from work have decreased by more than 40% for at least one week because you need to take time away from work to provide care or support to the person;
- You accumulated 600 insured hours of work in the 52 weeks before the start of your claim, or since the start of your last claim, whichever is shorter. For example, 600 hours is equivalent to 15 weeks of work at 40 hours per week;
- A medical doctor or nurse practitioner has certified that the person you are providing care or support to is critically ill or injured or needing end-of-life care.