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Capacity and Consent As Your Child/Youth with Developmental Disabilities Becomes an Adult: Information for Parents and Caregivers

Summary: All parents want to ensure their children and youth to be safe, and raise them to be healthy adults. When one is a parent of a child with developmental and/or mental health challenges though, this can be more challenging. As they become young adults, they may increasingly want to assert their independence and autonomy. However, they may lack the capacity to make healthy decisions. Fortunately, there exist various ways to ensure that healthy decisions can continue to be made.

Case 1

Dave is a 17-year-old with autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). He has never liked the fact that his parents set limits on his video games, and as a result, says he will move out so that “then no one will tell me what to do.” Unfortunately, he is not yet capable of managing money nor does he have the skills necessary to live on his own. When younger, he would occasionally run away and police would bring him back. Since he is aged 17 now, the police have told his parents that they will no longer be able to bring him back unless they have a Power of Attorney for him.
What should parents do?

Case 2

Maya is a 17-year-old with mild to moderate intellectual disability who is dating an 18-year-old male. Maya wants to move out with her boyfriend when she turns 18.
However, her parents are worried that her boyfriend simply wants to take advantage of her. Their parents do not want her to move out with him.
What should parents do?

Introduction

All parents want to ensure their children and youth are safe and raise them to be healthy adults.
When one is a parent of a child with developmental and/or mental health challenges though, this can be more challenging. As they become young adults, they may increasingly want to assert their independence and autonomy. However, they may lack the capacity to make healthy decisions.
The good news is that there are many things that parents can do to help ensure that their children are cared for.

Short-Term Solutions for Finances

In the short run, parents often manage finances for their adult children by doing the following:

- Paying the adult's expenses (e.g. rent, bills) from the parent's own funds; and/or
- Joint bank account with the adult child, whereby the parent provides funds to pay for the adult child's expenses.

In the long run, however, there are other strategies that are preferable.

Usual Considerations

Ensure your own Will and finances are in order.

Are you the parent of the adult child?	YES ⇨	• Ensure your own Will is in order. • Review your financial plan to ensure your adult child with a disability will be as well cared for as possible, e.g. Henson Trust, etc.

Ensure that your adult child makes a Will.

Is your child age 18 and in Ontario?	YES ⇨	• If so, then your child is legally an adult. At this age, your adult child can make a Will (provided they have capacity). • See a lawyer, and have your child make a Will to deal with his/her assets -- just in case.

Register your child with MedicAlert's local "autism registry" or "developmental services registry".

Does your adult child have interactions with the police?	YES ⇨	• In the event that your child has problems such as running away, and needing to be brought back by police, consider registering your child with the local autism or developmental services registry. • The profile does not dictate a fixed plan, but rather it is meant to provide the police with helpful suggestions should they need to intervene with your child, e.g. your child's preferred nickname, favourite TV shows, food etc. By knowing these things, it will be easier for police to connect with your child, reduce anxiety and help with redirection.
Do you need to call the police?	YES ⇨	• If you do so, make sure you mention the registry to the police so that police can review it.

Navigate the system.

Learn about the local services in your area -- this is known as 'system navigation', and get connected to services that you need.

Does the youth or adult child have a developmental disability such as intellectual disability (ID)?	YES ⇨	• In Ontario, consider Developmental Services of Ontario. • In Ottawa, consider local agencies such as Service Coordination Support and Developmental Services Ontario Eastern Region.
Does the youth or adult child have autism spectrum disorder (ASD)?	YES ⇨	• In Ontario, consider the Autism Society of Ontario (ASO) • In Ottawa, consider Autism Ontario, Ottawa Chapter.
Is your situation complex and it is challenging to find help?	YES ⇨	• It might be helpful to have someone help you navigate the system. Contact your local service agency for information and support.

Are You Worried About Your Adult Child's Decision Making Ability?

Is Your Child aged 18 or above in Ontario?

Are you worried about your adult child's ability to responsibly manage their Ontario Disability Support Program (ODSP) benefits?	YES ⇨	• If so, then ODSP has what's called "trusteeship provisions", as does CPP, that allows parents to receive and manage funds on their child's behalf without the necessity of obtaining guardianship.
Does your child have the capacity to grant a power of attorney?	YES ⇨	• In order to grant a power of attorney for personal care the grantor must: ◦ Understand whether the proposed attorney has a genuine concern for the person's welfare and ◦ Appreciates that the person may need to have the proposed attorney make decisions for the person. • If so, then your child can assign you (i.e. parents/guardians) as the attorney in a POA. • Note that it is your child's POA and not your POA.

Note:

- Your child is entitled to legal advice apart from the parent. Out of respect for your child's right to autonomy, it is recommended that your child be able to access their own lawyer to obtain their own legal advice about their options.

Brief Overview of Capacity / Consent Scenarios

Is the child aged 18 or above? AND Do you have concerns that your adult child has trouble with making healthy decisions?	YES ⇨	Does your child have capacity? • Capacity for personal care is being able to understand information relevant to a personal care decision; can appreciate the consequences of a decision or lack thereof. • Capacity for property and finances is being able to understand the value of their property/finances; understanding that the power to manage their property is being given to a third party (the attorney). If so, then your child has the option of assigning parent(s) as the attorney in a POA for a) personal care and/or b) financial matters. This is the easiest and preferred option. Having a good relationship with your child is important because your child must consent to this. A physician helps determine if the POA can be activated based on their observations.
⇩		
Is your child refusing to give you powers of attorney? AND Your child is competent?	YES ⇨	Is your adult child competent? • If your child is competent, then under the law, your child does have a right to make their own financial and personal care decisions, even if you do not agree. • Consider speaking to a professional or others in order to help you navigate this, e.g. improve communication or resolve differences with your child.
Is your child refusing to give you powers of attorney, AND do you have concerns about your child's capacity?	YES ⇨	Ask to have your child's Capacity assessed -- there is a list of Capacity Assessors on the Ministry of the Attorney General website. https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity/rosters/regional_map.php The Assessment, usually done after age 18, and which has a fee, will determine the capacity to manage two separate parts: • Is the person able to manage their financial assets? • Is the person able to manage their personal care?
⇩		
Does the Capacity Assessment show that your child is competent? NOTE: Mental capacity is not "all or nothing" -- a person could be: • Mentally capable of making personal care decisions, but not making a Will or Power of Attorney. • Mentally capable of making a Will, but not a Power of Attorney. • Etc.	YES ⇨	If it does turn out that your child is competent, your child does have the right to make their own decisions about: • Making a Will • Whether or not they assign powers of attorney or not. You may not agree with your child's decisions, but this is the law. You might consider seeing a counsellor or professional help with the situation.

⇩		
Has your child been deemed lacking capacity? AND Lacks a continuing (enduring) power of attorney for property or personal care	YES ⇨	A guardianship application can be made to the Superior Court of Ontario to appoint parent(s) (or others) as the guardian of • 1) Child's finances and/or • 2) Personal care (i.e. to make the financial and/or treatment decisions for the child over time). Guardianship is NOT necessary if the adult has a valid continuing (enduring) power of attorney for property or personal care). Note that guardianship terminates existing powers of attorney. Guardianship happens in a small number of cases and is a more extreme option. Guardianship will only be granted by a Court if there is no other less invasive solution (for example, the trustee provisions for ODSP and CPP). Parents will likely have to hire a lawyer in the guardianship process. They technically can be self-represented and don't have to hire a lawyer but it's not an easy process to navigate on their own. • The judge will determine if the caregivers can have guardianship over decision-making. • Note that the courts don't tend to grant this very easily because it is essentially removing the person's rights for decision-making.
⇩		
Is the person an adult who is assessed to not be capable of making the decision, and lacks powers of attorney or a guardianship appointment? Regarding the decisions to be made, are they health care or personal care decisions?	YES ⇨	If an adult is not capable, and there is no guardian or POA, parents do not necessarily need to proceed to Court to get Guardianship if the only issue is personal care decisions. For health decisions only, then under the Health Care Consent Act (HCCA), s. 20 allows for certain individuals that are entitled to make health care decisions in the following specific order: • A spouse or partner. • A child or parent, or a Children's Aid Society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. • A parent who has only a right of access. • A brother or sister. • Lastly, any other relative. https://www.ontario.ca/laws/statute/96h02#BK26 Otherwise, under the Substitute Decisions Act of Ontario (SDA), the Public Guardian and Trustee of Ontario (PGT) then becomes the guardian of that disabled person. It is much better to have someone assigned ahead of time, rather than have it default to a PGT. For more information: * A Guide to The Substitute Decisions Act – Ontario https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/pgtsda.pdf Note: Many families are unable to obtain Guardianship due to financial or other reasons.

FAQ

Q. My child is 19 year old and receives financial support from the Ontario Disability Support Program (ODSP). We are worried about him spending all his money on video games, or being taken advantage of by others.
A. In this scenario where a youth is only receiving ODSP, parents can be appointed as trustees for ODSP.

Q. My child has just turned age 18 and doesn't have the capacity to make healthcare decisions, nor to make a power of attorney. Can we continue to make healthcare decisions for our child?
A. Under the Health Care Consent Act, for most families with children who are transitioning to adulthood, and who don't have the capacity to complete a POA, then for personal care decisions, then the Health Care Consent Act allows the following to make decisions:

- a spouse or partner (defined as living with that partner for over a year)
- "a child or parent" or
- "a Children's Aid Society or another person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent."

In other words, for families where guardianship is not attainable, for health care decisions, there is already legislation in place that allows them to make health care decisions (provided the physician at the time of the decision determines the patient doesn't have capacity.)

Q. The Office of Public Guardian and Trustee (OPGT) is the statutory guardian of my loved one's property, however, I'd like to be the guardian of property instead. What do I do?
A relative of the incapable person (among other people)) may apply to the OPGT to replace them as the incapable person's statutory guardian of property.
For more information
https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/guardian_process.php

Case 1, Part 2

Dave is a 17 year old with autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). He has never liked the fact that his parents set limits on his video games, and as a result, says he will move out so that “then no one will tell me what to do.” Unfortunately, he is not capable of managing money nor does he have the skills necessary to live on his own. When younger, he would occasionally run away and police would bring him back. Since he is aged 17 now, the police have told his parents that they will no longer be able to bring him back unless parents have a Power of Attorney for him.

What should parents do?
A. Given that their child has a developmental disorder, parents can ensure that he is on the local police registry so that if police are called, they can understand some of the background situations.
If the child is aged 16, and if the child appears to have the capacity for decision making then the police cannot force a child to return home.
A diagnosis of ASD does not automatically cause any limitations on the person’s rights and capacity for decision making. An exception might be if someone appears to be irrational and in an acute mental health crisis.
Even with a diagnosis of mild intellectual disability, he may still have the capacity to make his own decisions. With a diagnosis of moderate to severe intellectual disability, most likely the officer would bring the youth back.
If parents want police to bring back an aged 16+ youth who is refusing to come back, then parents will need a power of attorney.
Is the child willing to sign over power of attorney to parents?
When Dave is in a calm state of mind, and not upset at his parents, parents can seek legal advice. They can explore whether or not he has the capacity to assign a power of attorney (POA) to parents.

- If YES → This is the easiest option, if the youth can sign it over to parents.
- If NO → Then there will need to be a determination of his competency.
- Is he competent?
    - Positive
        - I.e. is he capable of making his own decisions and understanding the consequences of those decisions?
        - If he is competent, then he would be able to keep his power of attorney and make his own decisions.
    - Negative
        - If a youth is not competent, in general parents would have to seek Guardianship.
        - For personal care decisions, parents would be next in line unless the youth has a spouse or partner. “Spouse” and “Partner” are defined in the Health Care Consent Act – generally need to live together at least 1 year. Boyfriend doesn’t qualify.

Case 2, Part 2

Maya is a 17 year old with mild to moderate intellectual disability who is dating an 18 year old male. Maya wants to move out with her boyfriend when she turns aged 18. However, her parents are worried that her ‘boyfriend’ simply wants to take advantage of her and do not want her to move out with him.

Q. What should parents do?

A. From a relationship perspective, parents can ensure that they (continue) have a strong, healthy relationship with their daughter. It helps to meet her emotional needs, and validate her wishes, hopes and dreams. They need to know how to empathize, validate and accept her feelings so that she feels that they love her no matter what. They can ask about the ‘competition’, and ask, “What is it about your boyfriend that makes you want to be with him?” And then parents can try to meet those needs so that she does not need to turn to him.
When their daughter is in a calm state of mind, and not upset at parents, parents can seek legal advice. With the help of legal advice, they can explore whether or not their child has the capacity to assign a power of attorney (POA) to parents.

- If YES → This is the easiest option, if the youth can sign it over to parents.
- If NO → Then there will need to be a determination of his competency.

- Is the youth competent? I.e. is the youth capable of making their own decisions and understanding the consequences of those decisions?
    - If the youth is competent, then they can keep their power of attorney and make their own decisions.

Note also

- A person with capacity can appoint a power of attorney for personal care if they are 16 years of age or older.
- A person with capacity can appoint a power of attorney for property if they are 18 years of age or older.
- For health care decisions, if the health care professional providing treatment determines that an individual is not capable of making treatment decisions, then the health care professional must obtain consent from the legal substitute decision-maker. If there is no court-appointed guardian or valid power of attorney, then the health care professional must obtain consent from the person's substitute decision-maker. The hierarchy of substitute decision-makers is set out in the Health Care Consent Act. OPGT will become involved if no person on that list exists (or if there is more than one equally ranked person and they cannot agree).
- For property decisions, unless there is some other informal mechanism available (like the ODSP trustee provisions), the only options are Guardianship or involve the OPGT - unless there is a valid power of attorney (which means the POA was made at a time the youth had capacity).

Readings and Resources

Handle with Care: Who Can Make Decisions for Your Disabled Adult Children
https://nelliganlaw.ca/article/estates-law/handle-with-care-who-can-make-decisions-for-your-disabled-adult-children/
Resource for POA: POA forms and informational guide at the following link:
www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf
Resource for Guardianship: Ministry of the Attorney General website on dealing with mental incapacity at the following link: www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/

Looking for Legal Advice in Ontario, Canada?

Law Society Referral Service: Looking for a lawyer? Looking for up to 30-min. Of free legal consultation? Contact the Law Society Referral Service at https://lsrs.lsuc.on.ca/lsrs/ or by calling 1-855-947-5255 or 416-947-5255.

About this Document

Written by the health professionals at CHEO, including Isabella Mentina, Pro Bono Ontario (PBO) at CHEO Triage Lawyer. Pro Bono Ontario (PBO) at CHEO is a Medical-Legal Partnership created to help low-income families resolve legal problems that may prevent them from focusing their full attention on caring for a sick child.
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Resources for Families in Canada

Autism Canada:
https://autismcanada.org/
Connectability:
https://connectability.ca/en/

Resources for Families in Ontario

Developmental Services Ontario
https://www.dsontario.ca/

Autism Ontario:
https://www.autismontario.com/
Learning Disabilities Association of Ontario:
http://www.ldao.ca/
Learning Disabilities Association of Ottawa:
https://www.ldaottawa.com/

Resources for Families in Ottawa, Ontario

Case Manager

Service Coordination
https://scsonline.ca
Developmental Services Ontario (DSO)
https://www.dsontario.ca/agencies/dso-eastern

Legal Resources

Reach Canada
https://www.reach.ca/
Nelligan Law
https://nelliganlaw.ca/
Kenneth Pope
http://www.kpopelaw.com/