

The Right
to **Decide.**

Intellectual Disability and the Right to Decide

Resource #2: The Dangers of
Guardianship for People who have an
Intellectual Disability

This document offers several real-life stories of people in Ontario whose lives have been derailed by being placed under guardianship.



The Right to Decide Project – Overview

‘Legal capacity’ refers to people’s experience of being recognized as persons before the law, exercising rights, accessing the civil and judicial system, entering into contracts, making decisions about their own life and property, and communicating on their own behalf.

In many situations (for example, in the case of guardianship) substitute decision-making removes people’s legal capacity, i.e., the right to direct their own lives, including managing their money, making health-related decisions, and deciding where and with whom they live.

From 2018 to 2023, Community Living Ontario worked with five front line service organizations to understand how people who have an intellectual disability exercise their right to legal capacity – that is, how they make choices and decisions, and the barriers they face in doing so.

Our collaborative work uncovered many enablers of legal capacity, as well as many barriers. This resource is part of a series of documents that address this important issue.

Our local partners in the project were Community Living Dryden & Sioux Lookout, Brockville & District Association for Community Involvement, Durham Family Resources, and Community Living Windsor in partnership with Windsor Essex Brokerage for Personal Supports.

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For more information and resources related to this project, please visit our Right to Decide resource page.



The Dangers of Guardianship for People who have an Intellectual Disability

1. Britney Spears and Increasing Awareness of the Dangers of Guardianship

The Britney Spears case has focused a spotlight on the realities and risks of guardianship and other forms of substitute decision-making. Between 2013 and 2019, Ms. Spears' father, Jamie Spears, was both *conservator of the person* and *conservator of the estate* for his daughter.

As *conservator of the person*, Britney's father had control over his daughter's health care decisions (including medications), where she lived (including the ability to place her in a mental health facility), people she was able to see and talk to, and even what she was able to eat. As *conservator of the estate*, Jamie Spears had control over his daughter's money, investments, real estate, and other belongings.¹

In Ontario, these are called *guardianship of the person* and *guardianship of property*, and guardians have similar powers as conservators in California.

Conservators and guardians are supposed to support and protect people who have trouble understanding what might happen when they make decisions. They are also supposed to understand and respect people's will and preferences, and assist them to put their will and preferences into action.

Unfortunately, guardians and other substitute decision-makers can abuse the power they have over people they are supposed to support, which is what seems to have happened with Britney and Jamie Spears.

After Ms. Spears acted in ways that may have suggested a loss of decision-making capacity, her father was awarded conservatorship. He apparently used that position to:

- Force his daughter into performing, and took about \$500,000 each year from those performances.
- Invoice his daughter's estate for services that had no benefit for her, as well as for services that were never actually performed.
- Use his daughter's money to pay for things that only benefited Mr. Spears or his associates.
- Force his daughter to take medications that she did not want to take.
- Forbid his daughter to remove an intrauterine birth control device, and refuse her wish to have more children.
- Use technology to monitor Ms. Spears' communications and movements, even while she was in her own home.

The talk show host and public figure Wendy Williams is another high-profile example of a person who appears to have reduced decision-making capacity, and who has been poorly served by conservatorship laws.

In Ms. Williams' case, it seems that her bank refused to give her access to her own finances, out of a concern that she was being financially exploited by others.²

In a lesser-known but well-documented American case, Terri Black watched from the sidelines as a judge appointed her father's live-in caregiver as his legal guardian. This occurred despite the fact that the caregiver had thousands of dollars in gambling losses, refused to allow Ms. Black to see her father, and had transferred \$200,000 of the father's money to her own bank account while the father had reduced capacity. The legal guardian was later found guilty of theft and exploitation of a vulnerable person.³

These cases, and thousands of others across the United States, show the tensions and risks involved when someone's mental capacity is questioned, and when their right to exercise legal capacity is denied.⁴ Unfortunately, laws in both the United States and Canada place people at considerable risk of being neglected or taken advantage of while they are under guardianship. And while guardianship in Canada is regulated to a greater extent than in the U.S., examples of abusive or neglectful guardianships in Canada provide cause for serious concern.

2. Beyond Britney: Abusive and Neglectful Guardianships in Ontario

In 2015, ARCH Disability Law published several real-life examples of guardians who had power over financial and personal care decisions of people with cognitive impairments, and who misunderstood or misused that power.⁵ The following examples are taken directly from that report.

Leo is a person with an intellectual disability who “was involved in litigation which resulted in a financial settlement being awarded to him. A court appointed Leo's mother as his guardian for property and personal care, largely for the purposes of dealing with the financial settlement. Leo's mother administered and made decisions about the financial settlement funds. She spent the settlement improperly and failed to file reports as required by the guardianship order. No court or other public body pursued or monitored Leo's mother. Once the settlement funds were exhausted, Leo's mother vanished. No one was carrying out any guardianship obligations and responsibilities towards Leo. The mother refused to take any action to remove herself as Leo's guardian. The Public Guardian and Trustee was notified but did not take any action.”

Hazel is “a young woman who had been seriously injured in a car accident. She received a large insurance settlement, and her brother was appointed her guardian of property and personal care. Several years after the accident, Hazel had recovered and wanted to re-assert her autonomy and decision-making powers. Her guardian refused to accept that Hazel's condition had improved.”

Despite her young age, Hazel's guardian “wanted her to remain in a nursing home with limited ability to travel outside, since he felt that this was the only way to ensure her safety. He allowed her very limited access to money, even though Hazel had ample funds available.”

“This curtailed her outside activities and limited her independence and ability to participate in the community. At times the guardian refused to spend money on necessary items such as

personal hygiene products, new clothes, and dental care, which compromised Hazel's dignity and health.

"Every step Hazel took to assert her autonomy was thwarted by her guardian. He refused to make arrangements for, or provide funds to pay for, a capacity assessment. Hazel's guardian claimed that she needed his permission to be assessed, and his agreement as to who performed the assessment. The guardian would not provide her with clear information about her finances to allow her to determine what type of alternative living arrangements she could afford.

"Even after Hazel obtained assistance from counsel, and underwent capacity assessments which confirmed her capacity to manage both her property and her personal care, Hazel's guardian opposed her. He was able to use the court process to delay her re-asserting her autonomy for almost a year after she had been found capable."

Michael, a man in his early forties, "was deaf and had an acquired brain injury. Michael's sister became a family member statutory guardian for property using the application process through the Office of the Public Guardian and Trustee.

"There were no conflicts between Michael and his sister as long as Michael's injuries restricted his ability to socialize or remain active in the community. However, when Michael became better able to assert his independence, and wanted to socialize and travel within the community, tensions rose.

"His sister was very uneasy about Michael travelling without an escort and she did not trust the friends with whom Michael wanted to socialize. Michael's sister assumed that he was

being taken advantage of and she felt that the only way to protect him was to restrict his ability to leave the facility she had placed him in for his own protection. To this end Michael's sister asked staff at the facility to 'watch' Michael, report his activities to her and make efforts to keep him away from the friends she did not approve of.

"Michael wanted to leave the facility and rent an apartment with a friend. His sister refused to release funds to allow Michael to pay rent. Michael felt that his sister was thwarting his attempts to become more independent, and that she was exercising an unreasonable amount of control over his daily life.

"Michael's sister did not understand the limits of her powers as guardian or the scope of her obligations. She felt that a guardianship of property gave her the power to control any and all aspects of Michael's life.

"Michael sought the assistance of a lawyer. His sister refused to speak to Michael's lawyer. She did not accept that Michael had any ability to retain a lawyer to assist him. Michael's sister effectively acted as a barrier to communication or resolution of the situation. To the extent that facility staff co-operated with her and refused to pass messages to Michael, she was able to use them to interfere with Michael's access to his own legal counsel.

"Michael's sister threatened to not repair his computer or TTY equipment, which would have greatly limited Michael's ability to communicate with his other family and friends. He felt he had to co-operate with his sister since it did not appear that anyone could intervene effectively to change or challenge his sister's behaviour."

3. Kathryn's Story

In the course of the Right to Decide project, we heard the story of a young woman named Kathryn. Kathryn's life had been derailed by her aunt, who had been her court-appointed guardian of property for several years.

Kathryn first came under guardianship of the Ontario Public Guardian and Trustee (OPGT) in 2016, following a capacity assessment that found her incapable of managing her finances. At some point, the OPGT obtained the court's approval to transition guardianship to her aunt.

Kathryn was the beneficiary of an inheritance from her grandmother, and also received funds from social assistance, the Passport program, and the Canada Child Benefit (for her children). While under the guardianship of her aunt, despite this income she experienced periods of homelessness and found herself having to beg for enough of her own money to survive.

Meanwhile, it seems that her aunt, as well as Kathryn's father, were using Kathryn's money to enrich themselves. It was several years before this was discovered, when her aunt was obliged to pass her accounts before the court. When financial irregularities were uncovered, the process of removing her as guardian was started.

During the same period, several of Kathryn's local support staff and a concerned lawyer had been working to address the negative issues that they had perceived in her life. They agreed that while Kathryn – like many thousands of people with and without disabilities – was susceptible to financial manipulation and scams, she understood how finances worked. She could do basic math and had the capacity and desire

to manage her own money. They also agreed that the official safeguards that had been put in place had failed her. Even worse, those safeguards were acting as a shield for theft, abuse, and neglect.

After the process to remove Kathryn's aunt as guardian was started, support staff helped her to prepare a budget to meet the requirements of the Public Guardian and Trustee (which is responsible for oversight of family guardians). They supported her to create financial goals for herself, which included putting money into a Registered Education Savings Plan for her kids' education. The organizations also helped Kathryn schedule and prepare for a second capacity assessment, because they were convinced that she had the capacity to pass one that was performed according to the official guidelines.

Kathryn did indeed pass her second capacity assessment. In August 2020 the Superior Court of Ontario terminated her aunt's guardianship over her, and acknowledged that she "is capable of managing her own property" and "can make property-related decisions on her own behalf." Further, the court ordered that Kathryn regain control of all her assets.

Kathryn's story shows the extent to which a few hours spent with the wrong capacity assessor can completely derail a person's life. It shows that Ontario's current system, overseen by the Public Guardian and Trustee and the Superior Court, can give control over a person's life to someone who will use that control to enrich themselves. It shows that, even if there was adequate education for and oversight of private guardians, this would address only some of the system's failings. It is a prime example of why changes are needed.

Notes

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Community Living Ontario is a non-profit provincial association that has been advocating with people who have an intellectual disability and their families for 70 years. We proudly work alongside more than 115 local agencies and advocate on behalf of more than 100,000 people across Ontario.

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