

Supports – or Surgery?

Debate is raging throughout North America about Ashley – the young girl with a severe disability whose parents sought surgical intervention to arrest her puberty and stunt her growth to ease their ability to care for her in future. The announcement comes years after the surgery actually was performed in 2004.

Their actions have unleashed a fury of controversy and raise profound questions that shake the very foundations of humanity. Groups representing persons with disabilities, medical associations, ethicists, news commentators and just about anyone with an opinion is expressing it.

Canada experienced its own version of this debate in 1993 when Saskatchewan farmer Robert Latimer killed his daughter Tracy. She had a severe disability as a result of cerebral palsy. Robert Latimer claimed that his actions were a form of mercy, sparing her future pain and suffering.

Ashley's circumstances are actually somewhat more complex because she was not

killed by her parents. Her infantilization cannot be equated with infanticide – though some may argue that it is effectively a form of death.

The ethics of the Ashley case will long be debated. But the morality discussions mask the bigger story to this story. It can be summarized in a nutshell. There is something drastically wrong when radical surgical intervention and even death are seen as better options than the system of disability supports currently in place.

Families with children with severe disabilities receive precious little assistance. While there are far more services available than in the past, these are still in limited supply relative to need. In addition to shortages, the current system of disability supports is plagued by myriad problems.

Disability supports refer to a cluster of goods and services that include technical aids and equipment, and personal services that provide attendant care and homemaker assistance. The various supports are currently organized as

discrete programs. In most provinces, there is no common access point even when different services are delivered by the same department.

The problem of multiple entry points creates a need for another form of support, known as ‘navigational assistance,’ to help families identify the package of aids and services appropriate to their circumstances. But navigating the maze is just the beginning of the long and winding road. Families must then qualify for these supports – at which point they encounter a new set of complexities.

The individual programs that comprise the disability supports system have distinct eligibility criteria. Each requires medical certification and assessment by designated professionals, such as psychologists, audiologists or speech therapists. Applicants must pay for these assessments – often without assurance that they actually will qualify for the support.

Equally problematic are the long wait lists not only for assessments by professionals but also for the services they provide. There is a shortage of professional services in all fields, especially in rural and remote regions of the country. Wait lists of 12 months for occupational therapy, 16 months for physical therapy and in excess of 24 months for speech and language therapy are not uncommon in some provinces.

Simply put, there are not enough disability supports to meet the wide-ranging need for assistance. To make matters worse, many programs explicitly exclude certain categories of disability, particularly when they involve behavioural and psychiatric disorders.

Families fortunate enough to qualify for services often must supplement this assistance

with additional help for which they must pay – sometimes up to tens of thousands of dollars a year. The financial burden is made more onerous by the fact that some caregivers must give up all or part of their income to care for a child with a severe disability.

But money is only one side of the equation. Most caregivers just need a break. They require respite to take some time for themselves. Even being able to work a few hours or days a week provides relief for some caregivers who worry about their financial circumstances or job security. But the relief itself is in short supply.

There are solutions to these problems. They include sufficient investment and revamped delivery. Governments must invest in the supply of disability supports to ensure that more aids and services are available to families and that parents have access to adequate respite so that they can continue to be good caregivers.

Provinces, in particular, must reorganize the provision of supports to reduce duplication, ease eligibility and assist parents in navigating the complex maze that the delivery systems themselves effectively create. This task is not the impossible dream. Jurisdictions like Québec have gone a long way to redress eligibility and delivery problems through its one-stop Office for Disability Issues – though there is still a relative lack of services.

Perhaps the more insidious and difficult problem is the one that goes beyond financing and delivery. It is the problem of a society that does not easily make a place for persons with disabilities. It is a society that creates physical barriers of access and emotional barriers of attitude. It is a society of stairs – and stares.

Supports must replace surgery. Equally important, the inherent worth of all human beings, including persons with disabilities, must be recognized and valued. Ashley's story is both cautionary tale – and slippery slope.

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