

## News Release

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## CHANGE NEEDED TO ENSURE CHILDREN AND YOUTH WITH SPECIAL NEEDS AREN'T ISOLATED AND INVISIBLE

VICTORIA -- A girl with special needs stayed – alone, hungry and confused – for many days beside the body of her dead mother. This distressing case must act as a catalyst to improve the quality, accessibility and effectiveness of the province's services to children with special needs, B.C.'s Representative for Children and Youth said today in releasing an investigation report into the incident.

"While that incident in itself is so deeply disturbing, my investigation found that details of this girl's life circumstances prior to her mother's death were equally troubling," said Mary Ellen Turpel-Lafond. "The neglect of her needs for a very long period of time before her mother's death was significant, and she was all but invisible to service providers who should have been focused on her well-being.

"If there had been a plan in place to ensure high visibility, the harm caused to this girl by being left with her deceased mother would likely have been prevented, and her life before her mother's death would have been much richer and more dignified."

The report, *Isolated and Invisible: When Children with Special Needs are Seen but Not Seen*, fully details the sad results of the breakdown that can occur when parents of children with special needs do not receive the essential support of service providers and their communities.

Turpel-Lafond said that today in B.C., there are not enough supports available for parents and caregivers unable to navigate the spectrum of services or the complex system serving child and youth with special needs.

"The child-serving system needed to do much better for this girl and, in the future, much better for other families who have children with special needs. This is not the only child in British Columbia we are letting down in these ways."

The Representative's in-depth investigation determined that there was no comprehensive plan for this child's development or for her future. There was instead piecemeal provision of inadequately monitored care and support, confusion about roles and responsibilities, and no meaningful assessment or planning.

The Representative's investigation began after a 15-year-old girl with Down syndrome was found on Sept. 14, 2010 by neighbours, alone with the body of her mother, who had been deceased for many days.

The mother had complex medical needs of her own, struggled with addictions and lived in poverty and isolation. Toward the end of her life, she could barely walk. She could not look after her own health care, let alone seek help for her daughter. These challenges meant that providing a full life for her child was overshadowed by striving for their basic necessities of life. It also meant that other service providers who *should* have had a singular focus on the well-being of the daughter were instead oblivious to the girl's needs, her existence overshadowed by attention to her mother.

The Representative's four recommendations include a call for a detailed strategy to ensure that children and youth with special needs are receiving services they require, and a review of the plans for all children and youth transferred from Community Living BC to the Ministry of Children and Family Development (MCFD) services.

Also of significant concern was that the mother's income assistance file was closed with no follow-up with the family. In circumstances where it is clear that a single parent with a child with special needs is struggling financially, all efforts need to be made to make sure the child's well-being is a priority. "It is shocking that income assistance benefits could be cancelled, knowing these circumstances, without any contact with the family or to MCFD," said the Representative.

The report contains a recommendation that policy be put in place so that income assistance to families with dependent children or youth with special needs can't be terminated without reviewing first with MCFD and that personal contact must be made with the family, including a home visit to ensure other effective supports are in place.

"These essential changes don't require grand schemes of reorganization or governance, but we do require solid, cost-effective, accountable programs that improve outcomes for vulnerable children," Turpel-Lafond said. "These children deserve clarity about who does what, and programs that require child protection social workers, special needs workers, therapists, physicians and teachers to work together with an intense joint focus on the child.

"All children with special needs must be given full opportunities to live fulfilling and rich lives," she said. "When parents or caregivers face challenges of their own, others must take on the responsibility to help provide these opportunities. This must be done sometimes in partnership with the community and sometimes with the active intervention of government."

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**Note**: In this report, care has been taken to avoid identifying the girl and her family by name, photo or location. Out of respect for the girl now and in her future, and for the ordeals she and her family have been through, the Representative requests that others also respect the privacy of the girl and her family members. As well, because the girl is now a child in government care, the *Child, Family and Community Service Act* prohibits identifying her.

**Note**: The full report, "Isolated and Invisible: When Children with Special Needs are Seen but Not Seen", is available on the Representative's website ( www.rcybc.ca ).

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