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April 9, 2009

Family's Heartbreaking Plight Sheds Light on Deeper Issues

From Day One it's been all about what Kaylee Wallace won't do. She won't go to school, she won't walk, she won't live a typical life. One of the first suggestions was not to feed her. It seems there has been very little about what she might do, what she could become and that her life, while following a different path, could be just as fulfilling, just as wonderful and just as valued as any other. The take away message has been that a life with a disability is a fate worse than death.

The Wallace family, and many that have come before them, have found themselves in a heartbreaking predicament. They are told by medical professionals and experts that their daughter's life is in immediate peril. That efforts to support her are futile, that the family should leave her be and let her die with dignity. Families, under pressure, often sleep-deprived and in the throes of emotional trauma rely on their trusted doctors to provide them with unbiased information. They rely on their doctors to treat their children, not just with dignity and respect, but to treat their medical conditions. Life-and-death medical decisions are being made on a particular perspective of quality of life. If your child is not expected to follow a particular path perceived by others as typical development then the quality of their life is brought into question.

As a family-based, national association which advocates for people with intellectual disabilities and their families, the Canadian Association for Community Living is concerned that this tragic situation is another example of a child's treatment being defined and determined by disability. Joubert Syndrome is not described as a terminal illness. The breathing difficulties often associated with the Syndrome are more commonly known as apnea which is a highly manageable condition – one that most people with Joubert Syndrome outgrow. It is hard to get an accurate account of the specifics with Baby Kaylee. Joubert Syndrome, as with many disabilities, doesn't not have one predictable outcome. Yet, the focus of Baby Kaylee's short life has been that imminent death was the only outcome.

The active devaluation of the lives of persons with disabilities is a disturbing trend. Misinformation about disability is a real concern for individuals and families who live with disability. The lack of public discussion about the impact of devaluation makes people with disabilities and their families extremely vulnerable. The perception that a life with a disability is not worth living is perpetuated in the media interest surrounding the Wallace family and other similar stories. The increased demand for prenatal testing and the pressure prospective parents experience to terminate when an "anomaly" is detected risks leading us down a dangerous road reminiscent of our eugenic past.

Baby Kaylee may not survive. If that heartbreaking outcome is to be her reality it should not be because she hasn't received all of the treatments and health supports she deserves.

For more information contact Anna MacQuarrie 416-602-3015

The Canadian Association for Community Living is a national association of 40,000 members, 400 local and thirteen provincial and territorial associations for community living, working to promote and achieve the full inclusion of people with intellectual disabilities in all aspects of community life.

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