

## Extensive Needs Service – Family profile

### Quote for media materials

“As a mother, I have done everything I can for my children and it’s still not enough. Available resources are greatly limited, waitlists are long, being selected for funding is akin to playing the lottery, and costs to procure private services are high. Extensive Needs Services is helping prevent us from losing our kids and our home. Rory’s therapy is vital to her life and the wellbeing of our entire family.”

### Rory’s story

Aurora, who goes by Rory, is a smart, sweet and kind three-year-old. She lives with her mom, dad and baby brother. She is diagnosed with Autism Spectrum Disorder (ASD), is non-verbal and has sensory sensitivities.

When frustrated and unable to communicate, Rory consistently bangs her head, often so violently that she must be taken to the hospital. This includes hitting her head on walls, appliance, furniture and the floor, picking her fingernails, pulling her hair out, stabbing her eyes, and throwing herself down the stairs. She has an average of 500 incidents of self-injury in a 24-hour period. She has had burst eye capillaries and bruises, often throwing up to due to the severity of her injuries. At a recent Emergency Department visit at Sick Kids, the family was told that brain damage is inevitable if Rory’s behaviours continue. She has also inflicted harm towards her parents, baby brother – requiring Children’s Aid Society to become involved – and other family members.

Rory has severe problems with transitions, becoming overwhelmed when away from her mother, Jamie. Rory has difficulty feeling comfortable with therapists for the first few meetings, taking away from the efficacy of these sessions. Countless health care professionals, including Nova’s Ark, Autism Canada, CAS and Urgent Response, have advised the family that she would benefit from immediate and consistent occupational therapy and speech-language pathology, up to two to three sessions of both per week. However, available resources are greatly limited, waitlists are long, being selected for funding is akin to playing the lottery, and costs to procure private services are high.

As Rory’s needs have increased, Jamie has made the difficult decision to quit her full-time job to care for her daughter, as no daycare or school will or can administer care. Making ends-meet on one income and physically protecting every family member is becoming more and more difficult. Multiple agencies agree that urgent help is vital and know what course of treatment would save Rory’s life, but her family’s situation is impossible. Credit cards are maxed out and relatives have given what financial support they can offer. Their family is having to choose between paying for their mortgage, bills, groceries or Rory’s therapies. “As a mother, I have done everything I can for my children and it’s still not enough.”

The Grandview Kids’ Extensive Needs Service, delivered in partnership with Holland Bloorview Kids Rehabilitation Hospital, Michael Garron Hospital and Surrey Place, provides clinical services to children with extensive needs and their families through individualized treatments to enhance capacity, reduce challenging behaviours and treating underlying health concerns. ENS is imperative for children like Rory, who experience frequent visits to emergency departments and urgent care, and whose families have exhausted existing service options, but continue to have unmet needs. Co-occurring behavioural, medical, psychological and social needs create a dilemma that, without intervention, puts the integrity



of the family at risk. These families will now have the resources for sustained intervention and support that they require to help their children live life at their full potential.

The impact of ENS is significant and immediate. “Extensive Needs Services is helping prevent us from losing our kids and home. Rory’s therapy is vital to her life,” Jamie reflects. They are equipped with child and parent skills to support meaningful functioning and participation in the home. High-risk behaviours are becoming drastically reduced through the provision of integrated and timely clinical services. There is an overall prevention of further deterioration of health through the development and implementation of service plans. Jamie shares her family’s story because she “wish[es] someone who is going through what I have was able to help tell me where to go.” ENS offers the life-saving intervention required not only by at-risk children, but their families as well.