A Special Kind of Care

Office of the Child and Youth Advocate
Newfoundland and Labrador

December 2021

“Children’s rights are not an abstract concept and they define how well children can live their lives. At its most basic level, when children’s rights are upheld it can positively impact the trajectory of their lives.”

- Dr. Niall Muldoon, Ombudsman for Children, Ireland

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Message from the Child and Youth Advocate

The very nature of being removed and placed in a succession of caregiver arrangements places a child in a world where they have no natural home base within a trusted protective family relationship. Sadly, for many of these children and youth, the unfamiliar and unpredictable become the norm and life becomes fraught with challenges and uncertainty. A young person needs a sense of belonging, stability, continuity, and attachment in order to meet the challenges of their lives with a sense of hope for the future. All alternative care arrangements must address this, and must provide the emotional and physical safety for healing-centered care. Healthy, stable and nurturing relationships in a residential setting are incredibly important and provide the underpinning for all aspects of quality residential care.

This investigation involved a youth with significant disabilities who had been in the care of the Department of Children, Seniors and Social Development for most of her life. Her first out of home placement at two months of age was the first of 11 placements. These placements included a family placement, a long-term foster placement, trial adoptive placements, an emergency placement home, and staffed individualized living arrangements. In one placement, 75 different staff provided care for this youth within a six month period.

This investigation identified gaps in residential staff training, lack of residential staff continuity and consistency, poor implementation of resident programs, and deficiencies in collaborating with the various professionals involved in this young person's care.

These issues exist in various residential care settings throughout the province, and are not limited to this young person or the specifics of this investigation. The Department of Children, Seniors and Social Development must continue its work to address these issues on an urgent basis. As a duty bearer of children's rights, much rides on the Department's success in providing vigilant oversight and accountability for quality residential care to children and youth.

Jacqueline Lake Kavanagh
Child and Youth Advocate

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Introduction

The Office of the Child and Youth Advocate

Newfoundland and Labrador's Child and Youth Advocate is an independent Statutory Officer of the House of Assembly. She derives authority from the **Child and Youth Advocate Act**. The role of the Advocate is to protect and represent the rights, interests, and viewpoints of children and youth in Newfoundland and Labrador. This is accomplished through individual advocacy, investigations and reviews, systemic advocacy, and children's rights education.

United Nations Convention on the Rights of the Child

The Office of the Child and Youth Advocate operates from a children's rights framework. Children's universal human rights are articulated in the **United Nations Convention on the Rights of the Child**. Canada ratified this Convention in 1991 with written endorsement and support from all provinces and territories. The Convention is the most universally accepted human rights framework in the world today. It speaks to the social, cultural, economic, civil, and political rights of children. Children's rights are real and meaningful. When these rights are protected and respected, they help children live better lives and have improved opportunities.

Investigative Reviews

Section 15(1)(a) of the **Child and Youth Advocate Act** provides the Advocate with authority to receive, review, and investigate a matter relating to a child or youth or a group of them, whether or not a request or complaint is made to the Advocate. The Advocate may release a public report upon completion of an investigation. The purpose of the report is to present findings regarding the services provided to young people and to make recommendations that will help prevent similar incidents from occurring in the future.

The investigative report does not assign legal responsibilities or draw legal conclusions, nor does it replace other processes that may occur, such as investigations or prosecutions under the **Criminal Code** of Canada. It is intended to identify and advocate for systemic improvements and meaningful changes that will result in better responses, and enhance the overall safety and well-being of young people who are receiving designated services. It is not about finding fault with specific individuals.

The investigative process may include sworn interviews, review of documents and reports, file reviews, policy analysis, legislative considerations, consultation with experts, examination of critical issues, research, and other factors that may arise for consideration.

About this Investigation

This investigation was called after the Child and Youth Advocate received a request for advocacy on behalf of a youth with disabilities who was living in a staffed residential placement. It became apparent that the youth had been in a placement that was not adequately meeting her special needs. The investigation involved sworn interviews, a comprehensive review of case file documents, and an examination of relevant policy and legislation.

Children's Rights

The **United Nations Convention on the Rights of the Child** (UNCRC) and the United Nations Sustainable Development Goals envision an inclusive society in which health and education contribute to the well-being of all. To achieve this vision, children with developmental delays and behavioral, cognitive, mental, and neurological disabilities need greater access to health care, early childhood care, developmental services and education.

Article 23 of the UNCRC is specifically concerned with the unique rights of disabled children, in recognition of their vulnerability to segregation and discrimination. It states:

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which the application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.
3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.[1]

The UNCRC as well as the **United Nations Convention on the Rights of Persons with Disabilities** (CRPD) firmly establish that in order for children and youth with disabilities to thrive, they must receive specialized services. The CRPD offers a detailed outline of these unique rights which are designed to ensure disabled persons receive equitable treatment by

1 The United Nations. (1989). Convention on the Rights of the Child. Treaty Series, 1577, 3. Retrieved from: https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

government entities. It distinguishes equity and equality by emphasizing the principle that sometimes equal treatment can constitute discrimination.

Disability is an evolving concept and there are many definitions. The most widely accepted definition is stated by the World Health Organization as follows:

> Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.[2]

The CRPD preamble recognizes that disability results from the interactions between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. Therefore, while improving caregiver services and attitudes and removing environmental barriers may not improve a person's impairment, it will affect the degree to which the disabled person is able to fully participate in society.

Case Summary

This investigation involved a youth with disabilities who had been in the care of the Department of Children, Seniors and Social Development (CSSD) for most of her life. Her first out of home placement at two months of age was the beginning of 11 different placement settings. Some placements included siblings, while others did not. These different living arrangements included a family placement, a long-term foster placement, trial adoptive placements, an emergency placement home, and staffed individualized living arrangements (ILA).

This young person was diagnosed as a young child with a global developmental delay and was believed to function at the level of a four to six year old. Her pediatrician also suspected Post Traumatic Stress Disorder. She had complex social, emotional, and behavioral needs requiring specialized care. All aspects of her life were impacted due to the diagnosis of global developmental delay, and attention deficit hyperactivity disorder. Symptoms included poor emotional regulation, poor impulse control, trouble with attention and focus as well as obsessive and repetitive behaviors. This youth required assistance with basic activities of daily living such as appropriate hygiene, dressing, and preparing food.

Global developmental delay is defined as a delay in two or more developmental domains of gross/fine motor, speech/language, cognition, social/personal and activities of daily living,

2 Human Resource and Skills Development Canada. (2013). Federal Disability Reference Guide. Retrieved from: https://www.canada.ca/en/employment-social-development/programs/disability/arc/reference-guide.html.

affecting children under the age of 5 years. With a prevalence of 1%–3% of the population, global developmental delay is one of the most common conditions encountered in pediatrics. Genetic and structural brain abnormalities are the most frequent causes.[3] Children with these types of delays can experience difficulties with attention, learning, language, motor skills, social relationships, behavior, and other neuropsychological functions.[4]

For many years, this young person resided in contracted Level IV staffed residential placement resources. Child and youth care workers provide 24/7 care in Level IV staffed residential placements. Level IV resources are operated by both for-profit and not for profit entities under a number of service agreements with CSSD. These placements are intended for children and youth who have complex social, emotional, behavioral, developmental, or medical care needs as well as those who require a temporary emergency placement.

During this young person's time in staffed residential placements operated by the first residential care provider, she was noted to have displayed increasing and significant signs of emotional trauma including: increase in anxiety and frustration; self-injurious behaviour such as skin-picking; self-regulatory behaviour such as thumb-sucking, self-stimulation, rocking, humming, and screaming; and increased talk of suicide and harming others. Her pediatrician, her teachers, her social worker, and multiple allied health professionals were concerned that she was not receiving the care she required which was resulting in a deterioration of her health.

When this youth suffered a major medical crisis, she spent a prolonged time period in hospital. Upon release from hospital, CSSD arranged for a new residential care provider to deliver her care. The social worker had become concerned about the young person's deterioration, and the level of care in the previous placement.

There were significant changes for the young person with this new environment. She began helping staff with cooking, carrying out chores, and completing or assisting in her own personal care. Staff reported significant decreases in her aggressive and problematic behaviours. While some violent incidents occurred, staff were able to deescalate effectively. The new placement provider developed a staffing model involving a small and dedicated team to provide care for this young person. The time period of this investigation ended several months after the youth began this new placement.

3 Mithyantha, R., Kneen, R., McCann, E., & Gladstone, M. (November 2017). Current evidence-based recommendations on investigating children with global developmental delay. Archives of disease in childhood, 102 (11), 1071-1076.

4 Dewey, D. (2018). What is comorbidity and why does it matter in neurodevelopmental disorders?. Current Developmental Disorders Reports, Vol. 5, 235–242.

Findings and Recommendations

In completing this investigation, clear gaps were identified in the following areas:

1. Residential staff training
2. Residential staff continuity and consistency
3. Individualized residential programming
4. Collaboration

It is encouraging to note that CSSD identified these issues as well in its own internal Quality of Care investigation, and that efforts have begun in order to address these issues.The quickest route to positive changes to benefit young people is always the best path.This is vitally important because these issues are not unique to this youth or to this investigation and have been communicated to CSSD on other occasions.

When the Office of the Child and Youth Advocate completes an investigation, this process and the findings and recommendations are independent of any government department or agency and they come from a child rights analysis. These formal recommendations are tracked and reported publicly on an annual basis and therefore provide enhanced accountability from government entities.

Residential Staff Training

This youth's global developmental delay affected every aspect of her life and meant that she required nurturing caregivers with knowledge about her condition, and skill in responding to her special needs. Significant questions and concerns arose in the course of this investigation about the capacity of staff to provide the type of care this young person required, and whether they had received adequate and effective training.

Children and youth with delays and disabilities have a better chance of leading healthy and full lives when they are provided with quality and supportive care. Nurturing care has been defined as "a stable environment that is sensitive to the children's health and nutritional needs, with protection from threats, opportunities for early learning, and interactions that are responsive, emotionally supportive, and developmentally stimulating".[5] Medical professionals involved in this young person's care strongly recommended that she be cared for in a structured, predictable, and supportive environment, and partake in activities that would keep her engaged and interested in home, school, and community life.

Unfortunately, the care this young person received during the focus of this investigation did not meet her special needs as a disabled youth. Lack of proper staff training undermined the nurturing and structure she required to thrive. Staff turnover and instability also made it difficult to deliver and maintain training specifically relevant to her needs, because the knowledge was

5 Britto P.R., Lye S.J., Proulx K., et al. (2017). Nurturing care: promoting early childhood development. The Lancet, 389(10064), 91-102. https://doi.org/10.1016/S0140-6736(16)31390-3.

lost when workers did not return. Various professionals working with this youth indicated the residential staff appeared to have a general lack of understanding of global developmental delay. This investigation revealed evidence that the staff training program was ineffective and/or insufficient for a resident with global developmental delay. The UNCRC and the CRPD emphasize that equitable treatment of children and youth with disabilities requires specialized care and education.

Residential staff did not follow special needs programming for behavioral management, diet, and hygiene. Professionals working with this youth expressed frustration that despite explaining the young person's programs to various staff members, the individualized care plans were not adequately or appropriately followed, and at times were ignored.

Residential staff had a range of educational backgrounds. While some included child and youth care diplomas, as well as social work students, others had educational backgrounds with no direct connection to children, youth, and childcare. Several staff members noted they did not receive the Therapeutic Crisis Intervention or residential care program training from their employer until months after they had already begun working, and received no training specifically designed to care for young people with cognitive delay.

Our Investigators heard that staff did not feel adequately trained to care for this youth and did not know what to do during frequent violent outbursts. Staff reported being fearful of the youth as demonstrated in incidents where they locked themselves in a windowless office and thereby left the resident unsupervised in a crisis, or where they called police to intervene during behavioural escalations. The service provider's management and CSSD staff were aware of this troublesome practice of staff locking themselves away from the resident.

Staff reported distracting the youth with junk food to prevent behavioural escalation and this was contrary to behavioural and nutritional programming. They did not address some behaviours in order to avoid confrontation. Staff were suspicious the youth was planning violent attacks on them, and they attributed a higher level of cognition and reasoning to this resident than she possessed. However experts emphasized she did not have the cognitive ability to plan such actions. Staff believed the youth had the ability to communicate at a cognitive level that corresponded with chronological age. However, experts emphasized that even though her speech ability was high, comprehension was very low. This lack of understanding about the extent of the young person's special needs created significant difficulty in effectively responding to this young person's distinct needs.

Residential Staff Continuity and Consistency

This investigation revealed 75 different staff members cared for this youth over a six month period. This high number of staff, and in particular the use of unfamiliar casual workers, had detrimental effects on this young person's well-being.

This child experienced significant loss and interruption in her life with her separation from family and siblings as she was moved to various caregivers, communities, homes, and residential facilities. Staffing inconsistency undermined a sense of stability, relationship building, trust, and the presence of constant people who understood this young person and the programs that had been developed for her. Medical and other professionals expressed concern about this creating stress, frustration, and chaos for this young person. They believed that the lack of staff continuity and knowledge about this young person's programs and behavioural triggers did not support the youth's wellbeing and safety, nor that of staff.

According to her health care team, the frequent use of unfamiliar caregivers led this young person to become increasingly dysregulated and hypervigilant to her surroundings. This increased her triggers for caregiver conflict which again increased the overall level of stress in the home and likelihood for challenging behaviours and violence. This type of response is frequently seen in dysregulated children with developmental delay and therefore should have been anticipated and mitigated by those responsible for her care.[6]

Individualized Resident Programs

This young person's diagnosis of global developmental delay presented significant and broad ranging behavioural challenges which included violent episodes. Effective behavioural management was essential. A medical professional working with this young person stated that challenging behaviour is not a medical or psychiatric diagnosis in a young person with a global developmental delay; rather, it is a symptom of an environment that is not meeting that young person's needs. The behaviours were based on impulse and reactions, and could usually be managed by avoiding known triggers and situations.

A behavioural management specialist concluded that many of the challenging behaviours occurred at home during unstructured time. A behavioural plan provided staff with a number of tools and specific activities that would give structure to this young person's life and respond to specific behaviours. This included detailed instructions on triggers and programming. These programs included ways to manage escalating behavior, hygiene strategies, emotional awareness, and regulation approaches, and daily activity schedules. Some of this involved visual aids and charts that reportedly went missing from the home. Reports indicated that the resident sometimes damaged them or they were simply lost. Unfortunately, behavioural tools tailored to this young person were not used consistently. According to the behavioural expert,

6 Marquis, W. A., Noroña, A. N., & Baker, B. L. (2017). Developmental delay and emotion dysregulation: Predicting parent–child conflict across early to middle childhood. Journal of Family Psychology, 31(3), 327-335.

most violent incidents could have been avoided if behavioural programming had been followed.

The structured program for this youth also included a healthy eating plan and positive food related activities. A dietician developed a menu and included visual aids and strategies so the youth would become involved with meal preparation and planning. This would benefit this young person by increasing her self-confidence, participating in family-like activities, encouraging her to try foods as she prepared them, and setting the foundation for her to improve her dietary and life skills.

Part of the plan involved eating meals together at mealtime with staff in a family-like atmosphere. This did not always happen and she often ate alone or in front of the television. Meals were often prepared in bulk, frozen, and thawed in the mornings. When staff brought their own meals due to budget constraints in the home, this young person sometimes became upset when she could not have the meal staff ate or the junk food she demanded. Staff reported she became obsessed with food, and they attempted to calm her by providing her with the unhealthy choices. She experienced a dramatic weight increase. Staff reportedly removed food from the refrigerator and locked it away out of her access, and just left milk, water, and a snack in the refrigerator.

Shared mealtimes with children provide an opportunity for family rituals, nurturing relationships, and shared connections. The dinner table is a chance to reconnect and talk about the day. It is also a time for sharing responsibilities for activities such as setting the table, loading the dishwasher, and cleaning up. This young person did not have the routine and opportunity to connect with others over mealtimes. The culture and practices around food for this young person were deficient: the dietician's programming was not followed, staff attempted to soothe her with food that was not part of her dietary plan, she often ate alone, and she was frequently unhappy with the meals provided to her. The dietician was rarely consulted.

The failure to use behavioural management programming at home contrasted sharply with this young person's experience at school where the behavioural programs were implemented. Teachers and educational staff eliminated surprises and created predictability where possible, which was an important strategy for this young person. School was structured, consistent, and staffed by professionals with an understanding of how to work with young people with cognitive delays. While there were some isolated violent outbursts at school, they were rare compared to at home. School reports indicated an eager helper, particularly for students with physical disabilities, and a student who enjoyed vocational education activities. One teacher said that this young person liked the daily updated visual schedule, liked to know what was going on, what would happen next, and would follow the schedule throughout the day.

This investigation revealed that residential staff were either unaware of the programming, unsure of how to use it, or chose not to use it. They did not understand the importance of programming to this young resident's wellbeing.

Collaboration

Children and youth in care often require significant levels of interventions which are frequently quite complex. When these children live in staffed residential care, it is important for the service provider to be committed to inter-disciplinary collaboration. Such resources provide obvious benefit to the young person, but also to the staff who are entrusted to provide direct care in a home-like environment. This is demanding work with high stakes. When collaboration works well, the combined value and impact of the resources can exceed the impact of each service delivered individually.

Children and youth with global developmental delay benefit significantly from the involvement of a variety of professionals in their care. Due to the multi-faceted issues in caring for a child with this type of disability, a multidisciplinary team is important that ideally may include social work, medicine, psychology, occupational therapy, and speech therapy. Other allied professions such as a behavioral specialists or dieticians may be included in a child or youth's team. It is well-established that caregiver training, psychosocial interventions, and caregiver support make a substantial difference to a child or youth's ability to thrive and develop to their full potential.

In this case, and despite the many professionals involved with this young person, the full value of multi-disciplinary expertise and contributions was not realized. Guidance and direction was not always followed nor integrated into planning and interventions with this youth. Unfortunately, the professionals were not always engaged in follow-up consultation when problems arose.

Recommendations

Recommendation 1

The Department of Children, Seniors and Social Development ensure the policy pursuant to Section 68(1) of the **Children, Youth and Families Act** include the requirement to share information necessary for the planning and care of children and youth in staffed residential care. In the case of children with disabilities and complex needs, this information must include all known exceptionalities and include information from former care givers. Information should be communicated prior to placement whenever possible.

Recommendation 2

The Department of Children, Seniors and Social Development ensure that all children and youth with exceptionalities and who live in Level IV residential care are cared for by child and youth care workers who have received training specific to the special needs prior to or soon after working with the child. Such training may either be through a formal training program, through in-service training with the child or youth's healthcare team, or a combination of both.

Recommendation 3

The Department of Children, Seniors and Social Development undertake an audit process with residential care providers of children and youth to ensure the best level of care is delivered. This audit should include at a minimum:

i. Determine whether staffing practices ensure recruitment of qualified staff, and appropriate and adequate training programs for these staff.

ii. Determine whether budgetary allocations appropriately fund the recruitment, retention, and training of qualified caregivers.

iii. Determine whether budgetary allocations for food are appropriate for quality nutritional requirements of children and youth in residential settings. This may require engaging a dietician to assess the costs for quality nutritional requirements for various age groups.

Recommendation 4

The Department of Children, Seniors and Social Development ensure that residential programming meets the needs of children and youth in care, that this programming is implemented in a timely and consistent fashion, and that service providers adhere to programming plans. The Department may consider the potential benefit of a dedicated position, beyond the assigned social worker, to be responsible for detailed review and follow up of planned interventions and programming at staffed residential placements in order to ensure programming meets the needs of the children and youth in care and that necessary follow up and consultations occur.

Conclusion

The **United Nations Convention on the Rights of the Child**, and the **Convention on the Rights of Persons With Disabilities** are clear that children with disabilities require increased supports both for the person with a disability as well as their caregivers. Caregivers play a central role in facilitating children and youth's access to developmental interventions and must be adequately supported.

The **Convention on the Rights of the Person with Disabilities**, Article 5, addresses the issue of children with disabilities who are in the care of government agencies. The convention states that where immediate family is unable to care for a child with disabilities, government must undertake every effort to provide alternate care within the wider family, and failing that, within the community in a family setting. Unfortunately, this young person's placement in a staffed residential care home with a rotating staff model that resulted in 75 different staff circulating in and out of her life in a short period of time did not reflect a family setting. CSSD rightly facilitated a change to a new residential service provider, but this chaotic staffing practice was not constructive and should not have been able to continue.

Children and youth in residential care are in the legal care and custody of the manager of the Department of Children, Seniors and Social Development. While the Department engages a service provider to deliver residential services on its behalf, it is ultimately responsible for the well-being of the children in its care. Residential staff provide the first line of daily care for these vulnerable young people. However, these staff must be appropriately recruited, trained, and supported in order to provide the best level of care possible to these residents. This is an important responsibility of the service provider that must be taken seriously.

This investigation reflects an individual young person's experience at a specific point in time. However, the identified issues are broader and more systemic in nature than this one case. They have arisen in other complaints and concerns which have been brought to the attention of the Office of the Child and Youth Advocate. They have also arisen in other Canadian jurisdictions where quality of care in residential care settings for young people has come under scrutiny.

Appendix: Investigative Process

Documents Reviewed

Department of Children, Seniors and Social Development
Protective Intervention File
In-Care File
Provincial Office Documentation

Department of Health and Community Services
Regional Health Authority File

Department of Education
School District File

Investigative Interviews

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