Dear Minister Simpson,

It is my pleasure to present the 2018/19 annual report of the Office of the Advocate for Service Quality (OASQ) reporting on the period of April 1, 2018 to March 31, 2019.

Before I outline the OASQ’s year in review, I want to acknowledge that I am a visitor to the xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations. I am thankful to the First Nations people in BC for allowing me to live, work, learn, and reconcile on their ancestral and unceded lands. I was grateful for the opportunity to participate in a workshop, “Building Bridges Through Understanding the Village,” with Kathi Camilleri. That workshop has grounded me in my efforts to learn more about the:

- Truth and Reconciliation 94 calls to action
- Impacts of colonialism
- Fifth principle of reconciliation

The fifth principle stresses the need to close the gaps in social, health and economic outcomes that exist between Indigenous and non-Indigenous people which will help create a more equitable and inclusive society. Continuing to learn about colonialism and reconciliation will remain priorities for me and my office.

Woven throughout most of the 275 calls to the OASQ is caregiver stress. When the lines of communication were opened, and parents were invited to collaborate and work together with Community Living BC (CLBC) and the service providers, the person at the centre ultimately received better support and service. When working together, both parents and professionals can be part of the solution to ensure the person is living the life that they want to live.

Last year I told you about Roxy, a young woman with a mental health diagnosis and Fetal Alcohol Spectrum Disorder, who was falling through the cracks. This year I heard many more stories like Roxy’s. Young people who are living with mental health issues, substance use and addictions, a developmental disability, and behaviours that pose a risk to themselves and others. They often end up in the emergency department of hospitals across BC. It is a complex and at times an ethical conundrum that the health authorities, the First Nations Health Authority, CLBC, families, and service providers are grappling with. At the end of 2018/19, Providence Health Care convened a meeting with me, CLBC, health authorities, and other interested parties where we began to think critically and work collaboratively to try and answer the question: where can Roxy go to receive the supports she needs that will better reflect a home and not a hospital?

Each story shared in this report is layered with problems about funding, service provision, communication, planning, and decision making. With the OASQ’s ability to be neutral and empathetic, and to truly listen and ask some difficult questions, we can often uncover the root cause of the problems and help find paths to move forward.

Over the coming year I will continue to work on building trusting relationships, solving problems creatively, and shining a light on systemic issues.

I look forward to our ongoing work together.

Sincerely,

Leanne Dospital
Impartial File Review
In November 2018 the Advocate initiated an impartial file review. There were unresolved issues with supports and services for a young person with a developmental disability being served by CLBC. As an independent and objective party, the Advocate may assess whether the processes impacting a person and their family have been respectful, thorough, and fair. The purpose of the review was to:

- Examine the evidence
- Determine if processes met the test of administrative fairness
- Attempt to get to the root cause of the issues
- Identify any learnings that may reduce the risk of recurrence and improve services

The resulting report with recommendations for the Minister will be finalized in the next fiscal year.

Health and Wellbeing Conference for Youth and Adults with Developmental Disabilities
The Advocate participated on the planning committee and attended this bi-annual, interactive conference. The event focused on practical strategies and partnerships to optimize the potential, quality of life, and health of people with a developmental disability.

Provincial Medical Consultant Services (PMCS)
Last year the Advocate described her advocacy work to ensure that these important services continued. The Ministry of Health conducted a review of PMCS and determined that they will not continue. They did, however, commit to exploring how best to meet the needs of people with a developmental disability.

275 People Helped
A core part of the Advocate’s work is responding to complaints and inquiries about services for people with a developmental disability. While helping people, the Advocate learns of some deeper and more systemic problems facing the community living sector. These problems are highlighted in the stories shared in this report and throughout the year.

BC CEO Network’s Professional Development Session: Best Practices When Collaborating with Families
In collaboration with Inclusion BC, the Family Support Institute, CLBC, and Community Living Society, the Advocate discussed self-determination and healthy approaches to difficult conversations.

Select Standing Committee for Children and Youth (SSCY)
At the invitation of the SSCCY, the Advocate provided a briefing about the current assessment and eligibility framework for children and youth with neuro-diverse special needs. Here are the minutes to the Advocate’s presentation. The Advocate highlighted that many parents described the transition experience as emotionally exhausting and full of uncertainty.

Community Outreach
The Advocate visited BC communities to:

- Connect with and listen to people in their home community
- Learn about issues and services unique in a community

This year, the Advocate visited 13 communities and made 56 connections with different community and government agencies in BC.

Executive Director Network Panel on Decision Making
The Advocate collaborated with the Family Support Institute, Public Guardian and Trustee, CLBC, Community Living Society and Home Society to provide training to service providers about decision making. The Advocate talked about self-determination and the application of legal decision-making tools.

Reimagining Community Inclusion (RCI) Initiative
The Advocate participated at the Partnership Table where she chaired the Healthcare working group. The group highlighted the need for improved access to health and mental health services for people with a developmental disability.

Adult Guardianship Training
The Advocate was invited to participate in the training along with CLBC, the Public Guardian and Trustee, and the Northern Health Authority. The Advocate developed and delivered training to health authority and CLBC staff in Smithers, Terrace, and Prince Rupert. She emphasized the importance of support when promoting self-determination.

Canadian Association for Community Living and People First of Canada: Policy Forum on Inclusion: What Gets Measured Gets Done
The Advocate attended the 9th annual federal policy forum which focused on exploring the importance of inclusion, not only as a philosophy, but as a goal that must be measured to be achieved.

Essentials for Ombuds
The Advocate successfully completed the five-day intensive training presented by the Forum of Canadian Ombudsmen and Osgoode Professional Development. She enhanced her skills in the areas of complaint handling, early resolution techniques and investigations.

BC CEO Network’s Professional Development Session: Best Practices When Collaborating with Families
In collaboration with Inclusion BC, the Family Support Institute, CLBC, and Community Living Society, the Advocate discussed self-determination and healthy approaches to difficult conversations.

2018/19 in Review
When helping youth and adults with a developmental disability and their families to resolve a complaint, the OASQ remains neutral and objective. It helps the involved parties find common ground and figure out the best way forward. We do this by practicing empathy, building trusting relationships, and helping with problem solving. Problems are sometimes resolved simply by pointing people in the right direction. Other times, the OASQ helps negotiate solutions by leveraging resources and working collaboratively. In all cases, the OASQ’s efforts centre around quality service for the person with a developmental disability.

Outcomes from the OASQ’s involvement might be:

- Improved services for people
- Better communication among the conflicting parties
- Modelling a good response
- Shining a light on systemic issues

People from the Fraser and Island regions of BC called the Advocate most often. Half of the inquiries were from the Lower Mainland. One-quarter of the inquiries were from the Island.

More than one-third of the calls were from families and 70% of these calls were from moms.

Parents often fill the role of caregiver, advocate, navigator, social coordinator, driver and case manager for their adult children with a developmental disability. This can lead to significant stress and exhaustion.

Most of society still expects that women will be the primary caregiver for their children. In addition, mothers who have a child with a disability work closely with community members, professionals and service providers to ensure the best support for their loved one. This can leave them feeling vulnerable and judged. Or as one mom described it, put under a microscope. Again, leading to increased stress in the family.

Who calls the Advocate for Service Quality?

<table>
<thead>
<tr>
<th>Who calls the Advocate for Service Quality?</th>
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<tbody>
<tr>
<td><strong>Family</strong></td>
</tr>
<tr>
<td><strong>Community and service providers</strong></td>
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<tr>
<td><strong>CLBC</strong></td>
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<tr>
<td><strong>Persons with a Disability</strong></td>
</tr>
<tr>
<td><strong>Other</strong></td>
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<tr>
<td><strong>Health</strong></td>
</tr>
</tbody>
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| 32%                                      |
| 26%                                      |
| 15%                                      |
| 12%                                      |
| 9%                                       |
| 6%                                       |
Issues

There are many reasons why a person might call the OASQ for help. The Advocate has sorted the issues into four main areas of concern:

- **Service**
  - No supports in local community
  - Complaints about service provision
  - Trust and communication

- **Transitions**
  - Youth transitioning
  - Ageing parents
  - Affordable and inclusive housing

- **Inter-Ministry Engagement**
  - Access to health and mental health services
  - Persons with disabilities (PWD)
  - Dental
  - Added care

- **Self-Determination**
  - Consent
  - Decision making
  - Adult guardianship
Setting goals will help foster independence, good health, and strong safeguards throughout the life of a person with a developmental disability. Goals may or may not require CLBC funded services and supports. However, when funded services are needed, they can be hard to understand and request. Funding may be denied or waitlisted until a crisis emerges.

No Supports in Local Community

River loves celebrations and remembers everyone’s birthday. He lives in his grandfather’s former home with his cousin. He knows everyone in his small rural community, but his relationships aren’t deep. River’s grandparents attended residential schools. Since his grandfather passed, he’s struggled with his daily living skills, depression and isolation. There are no community, community living, health or mental health services or supports in River’s community. The closest services are in a town that is a one hour drive away. River had connected with a community living organization in town but was not receiving any funded services. When River’s service provider called our office, they were concerned for his wellbeing and safety. The OASQ helped facilitate a conversation with River, his service provider, and CLBC that helped create a better understanding of River’s situation and initiate a service request. River is now receiving some services and a funding request is outstanding for additional needed support. The OASQ continues to raise the concern about a lack of supports for CLBC-eligible people in their home community.

The OASQ receives a notable number of complaints about the quality of service being provided by CLBC-contracted service providers. These include communication, staffing, and program challenges. The OASQ recognizes that service providers are also facing ongoing challenges about recruitment, retention, and staff training. Service providers come to the service relationship with a significant amount of knowledge and expertise about people with a developmental disability. Families come to the relationship with significant knowledge and expertise about the person receiving the service. Building strong relationships with families takes time and trust. When working together, both parents and professionals can be part of the solution and ensure person-centred service.

Complaints about Service Provision

In his 60s, Carl enjoys his senior coffee discounts and sleeping in so that he can watch his morning game shows from bed. In her 80s, Carl’s mother, Anna, continues to visit Carl in his group home a couple times a week and accompanies him to appointments. As he has aged, Carl’s needs have been changing including more ageing-related health concerns. The OASQ received a call from Anna saying that she was concerned about Carl’s increased falls and bruising. She was worried about his safety and had told the group home manager about her concerns, but it didn’t seem to change. The OASQ reached out to the CLBC office to discuss Carl’s options. The goal was to address his changing needs and to connect him with Health Services for Community Living (HSCL) at the regional health authority. The OASQ had several productive conversations with the service provider and Anna about developing a communication plan moving forward.
Transitions

Over a person’s lifespan, transitions come and go. For people with a developmental disability, transitions require ongoing person-centred planning, supported decision making and an engaged support network. However, transitions can be difficult to plan for and respond to and often end up as a crisis. Understandably, it is during these times of transition that the OASQ will receive complaints.

Youth transitioning to adult services requires significant planning. That’s why it remains a focus for CLBC and inter-ministerial partners. Youth and their networks are increasingly requesting more inclusive and person-centred supports. Year after year CLBC indicates the request for funded services outweigh available resources. The OASQ hears from youth and their families about funding challenges. Their biggest frustration is when eligibility, planning and collaboration has occurred, yet they do not get the needed services.

With shortages everywhere, the OASQ receives a significant number of calls related to housing. These include issues related to:

- Homelessness
- Needing to move
- Finding a better fit
- Stressed caregivers

The lack of affordable options that support the unique needs and do not isolate people with a developmental disability is at a crisis point.

One transition that can be anticipated is ageing. A joint report by CLBC, Ministry of Health, and SDPR—Aging with a Developmental Disability, 2017—emphasizes that getting older can look and feel different for someone with a developmental disability. The report highlighted that ageing-related (e.g., health) challenges may happen earlier and more quickly than for other people. The combined experience of age and disability can result in extra discrimination or isolation. In addition, a parent or other caregiver may not be able to provide support anymore because they are ageing too.

Eligibility when Concurrent Disorders are Present

By her mother’s account, Ally was pushed through the education system with little support. Ally’s parents paid for a private psychologist’s assessment that did not confirm CLBC eligibility. Within a year of turning 19, Ally (similar to Roxy) was living on the streets in Vancouver. After ending up in the emergency department of the local hospital, she received treatment for concurrent disorders. The clinicians supporting Ally suggested calling the OASQ for help. The OASQ gathered information and talked with CLBC and the Health Authority to get their perspectives. We learned about their efforts to assist Ally and her mother, then assisted all parties to collaboratively find a way to provide the supports needed. Ally was eventually found eligible for and is receiving CLBC services. She also continues to receive mental health supports and now has a place she calls home.
Inter-ministerial engagement remains an important part of the work of the OASQ. Families are confused about who does what and struggle to grasp what services and supports could be possible. Collaborative inter-ministerial and person-centered planning is the answer to this challenge. The OASQ sees the necessity of collaboration on the frontline and at leadership levels. This can play an important role in helping government and community partners to clarify the issues, encourage clear and respectful communication, and promote accountability and fairness.

The Advocate fosters this by building trusting relationships with:

- CLBC
- Ministry of Children and Family Development
- Ministry of Health
- Health authorities
- Office of the Representative for Children and Youth
- Public Guardian and Trustee
- Service providers
- Community organizations such as Inclusion BC and the Family Support Institute

The OASQ is engaged by families, service providers and government agencies. It helps youth and adults with a developmental disability solve problems involving:

- Health and mental health services
- Discharge planning
- Persons with disabilities (PWD) benefits
- Transitions from children services
- Decision making

Getting to the Core of the Issue

Lilly lives in a CLBC-funded home share and loves family outings to local community events. She has diabetes, receives counselling support from mental health through the Health Authority, and PWD benefits from SDPR.

Lilly’s mother contacted the OASQ because there were concerns about Lilly’s diet which was impacting her diabetes management and care. Mom explained their experience and described the case conference meeting they had attended. She also provided information about the plan to help Lilly manage her diet and diabetes.

Three months after the plan was agreed to, the family continued to find evidence of Lilly not following the diet plan. Her diabetes symptoms were worsening. After hearing Lilly’s mother’s concerns and efforts to resolve the problem, the OASQ reached out to CLBC, the home share provider, the CLBC-contracted service provider, and the nurse and counsellor with the Health Authority. Through many conversations with all parties involved, it was discovered that Lilly’s counsellor was not consulted on the original plan. The counsellor advised that Lilly required different supports to address her mental health related needs which had a direct impact on her diet. As this was new information, the OASQ worked to ensure that the team collaborated with each other and included mental health going forward.
Self-Determination

The OASQ is often brought in to complex situations to help sort out confusion about what is in the best interests of a person with a developmental disability. In all cases, it is best to ask the person themselves. However, it becomes complicated when the person may require support in decision-making and the person’s support network is unsure what the best decision is.

Self determination is not related to IQ or age. It is related more to opportunities to make one’s own choices. When the OASQ is told that a person has the mental age of an 8-year-old, we explain that that does not consider the lived experiences of the person and opportunities they’ve had to learn and make choices.

Michael Wehmeyer says that, the more opportunities for a person to make “real” choices that affect them directly the more self-determined they will become.¹ This perspective is built into BC’s Adult Guardianship laws which state that there is a presumption of capability once a person becomes an adult and that they have the right to self determination. It is also a core principle of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which further states that:

- Persons with disabilities have the right to recognition everywhere as persons before the law
- Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life
- Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity²

But, as a wise mother once said, we cannot abandon people to their own autonomy.

Being self-determined is not black or white. People with a developmental disability may need support making decisions in certain areas of their lives and not in others. And often, support is needed to promote and encourage a person’s autonomy. That support may include:

- Interagency collaboration
- Respectfully questioning or challenging a person’s choices
- Suggesting the person take more time to consider their choices
- Discussing the consequences and options to ensure the person’s decision is an informed one

The OASQ’s role in these challenging cases is as a connector, advisor, and problem solver. We listen, remain neutral, ask difficult questions, and question power dynamics. We work with all parties to remain person-centred and trauma-informed, and help find a path forward.

Operations

Leanne was appointed by an Order in Council in April 2016. She reports directly to the Minister of Social Development and Poverty Reduction.

The Office of the Advocate for Service Quality (OASQ) was established in 1992 and since then has encouraged accessible, transparent and accountable services for people with a developmental disability. The OASQ acts as a neutral third party and steps in to help solve problems and find solutions to concerns and complaints.

The OASQ is a small and self-sufficient office of two people located in Vancouver and serving the province.

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<th>Description</th>
<th>Annual Budget</th>
<th>2018/19 Actuals</th>
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<tr>
<td>Total Expenses</td>
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<td>240,066</td>
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<tr>
<td>Total Salaries and Benefits</td>
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<td>211,000</td>
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<tr>
<td>Total Operating Costs</td>
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Contact

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Website: gov.bc.ca/AdvocateForServiceQuality

Twitter: @ASQ_BC

In Vancouver call: 604-775-1238
In Victoria call Enquiry BC: 250-387-6121
Elsewhere in B.C. call Enquiry BC: 1-800-663-7867

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Places the Advocate has visited

Victoria
Powell River
North Vancouver
Vancouver
Kelowna
Surrey
Mission
New Westminster
Toronto
Terrace
Smithers
Ottawa
Prince Rupert

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