

THE EASTERN **Graphic** THE LIVELY ONE

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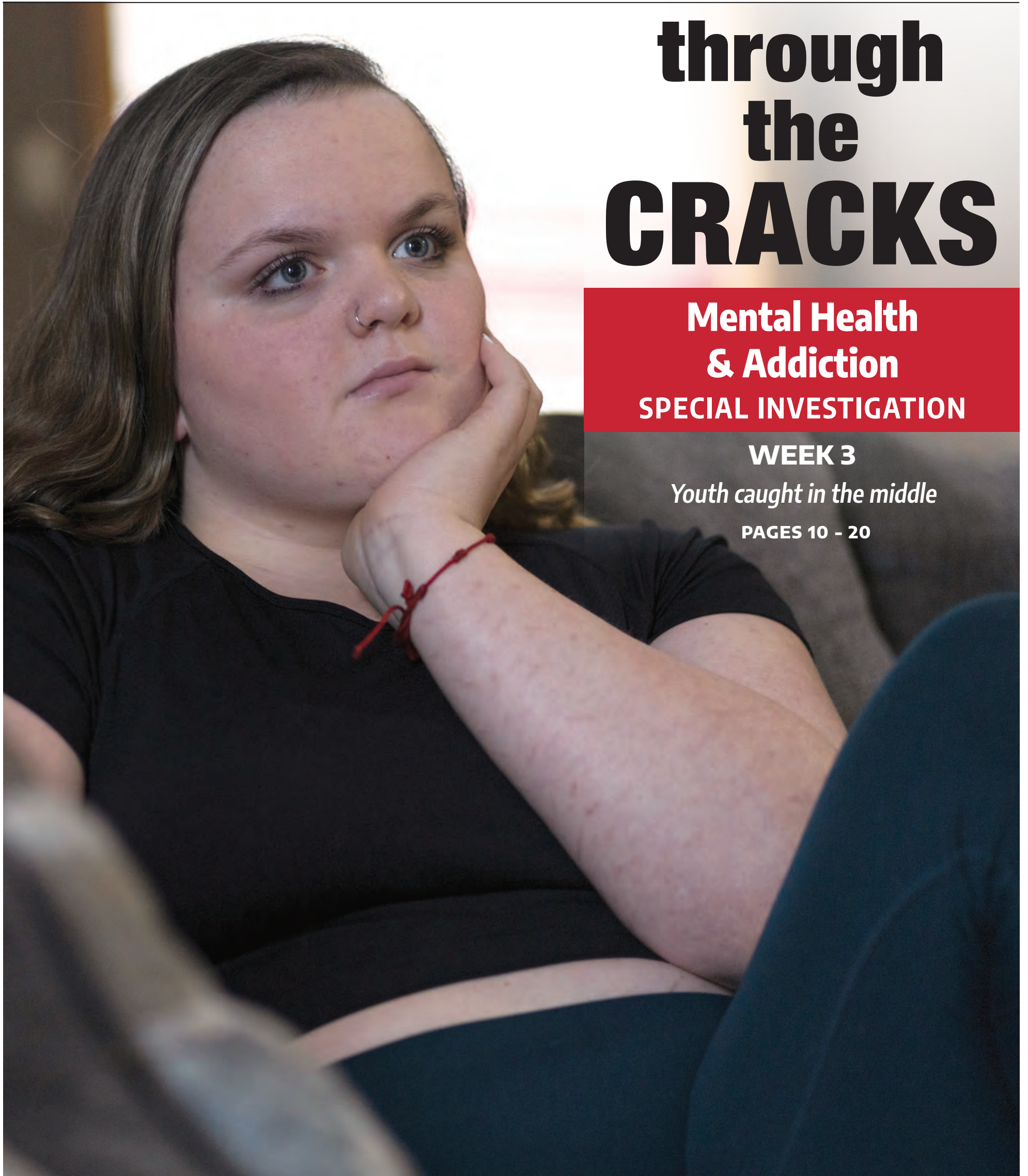
through the **CRACKS**

**Mental Health
& Addiction**
SPECIAL INVESTIGATION

WEEK 3

Youth caught in the middle

PAGES 10 - 20



After spending four years fighting for her life to survive leukemia, 13-year-old Autumn Newell is facing a second round of life-threatening illness - anxiety and depression.

Photo by John Morris Photography

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Fighting cancer was easier

Accessing appropriate in-person care proves a challenge for 13-year-old

By Rachel Collier

Local Journalism Initiative Reporter
rcollier@peicanada.com

After spending four years fighting to survive leukaemia, 13-year-old Autumn Newell of Montague is facing a second round of life-threatening illness - anxiety and depression.

"Cancer treatment was easier to access," says Stacey Newell, Autumn's mom. "It was handed to us. Where mental health, we had to go looking for it and we found out it was pretty much non-existent."

If mental health care was offered equitably to cancer treatment at the IWK, she said, her daughter would be surrounded by a well-co-ordinated team to guide her through treatment.

While programs may look plentiful on government's Bridge the gApp website, Newell says available services barely scratch the surface of her daughter's needs, and she has struggled for years to piece together meaningful support.

"The majority are Band-Aid solutions," said Newell. "She needs a consistent therapist who knows about trauma and treating youth her age."

Autumn has difficulty opening up about her mental health, so consistent, specialized and in-

“She’s 13 now but when she turns 15 or 16, if she hasn’t had help by then, I’m afraid she’ll turn to something else to cope, like drugs or alcohol.”

STACEY NEWELL

person support provides the most effective care.

From age four to nine, Autumn battled cancer including numerous rounds of chemotherapy. She witnessed other children with cancer suffer. Some passed away.

Newell suspects these pervasive, stressful experiences are the main cause of her daughter's struggles today.

Alongside biological factors like genetics, adverse childhood experiences and trauma are leading risk factors for developing mental health disorders such as anxiety and depression.

While the experience of chemotherapy, or treatment of any illness, can be the source of

trauma, so can neglect, abandonment, physical abuse, sexual abuse, emotional abuse, witnessing violence, witnessing death or even ongoing instances of betrayal or coercion by a caregiver.

Autumn isn't the only young Islander in need of enhanced support after experiencing negative stress, adversity, or trauma at an early age. In 2019 PEI's Child Protective Services (CPS) responded to 2,143 reports of issues worthy of investigation by the Department of Social Development and Housing - equal to seven every day of the year, including weekends and holidays. Issues that warrant investi-

gation include neglect, emotional abuse, physical abuse, sexual abuse, or domestic violence within the child's home.

The risk factors that would trigger a CPS investigation are only a fraction of the potential adverse childhood experiences or trauma Island youth may face.

Newell is concerned about what the lack of impactful care now will mean for her daughter's future.

"She's 13 now but when she turns 15 or 16, if she hasn't had help by then, I'm afraid she'll turn to something else to cope, like drugs or alcohol."

Newell looks at off-Island youth services, such as the IWK

Health Centre in Halifax with envy. "If it wasn't for the pandemic, I'd consider taking her to a specialized therapist available in Truro," Newell said.

Autumn has self-harmed on several occasions. "Whenever I feel upset, I feel like I have nothing else to do," she says.

Her crises became more acute in the spring of 2020 and involved self-harm, difficulty regulating emotions and suicidal thoughts.

"I think a lot of the time she won't act on what she talks about," said Newell. "But you never know if one of these times, she will. So, I have to take what she says seriously. She'll say



Autumn Newell, 13, wishes more youth were aware of mental illness and more compassionate toward those going through a hard time.

Photo by Rachel Collier

Stacey Newell says it is scary when she has to juggle keeping a vigilant eye on her daughter while balancing responsibilities like work and care for Autumn's siblings.

Photo by
John Morris Photography



things like, 'don't be sad if I die Mom.'"

Statistics Canada data shows, since 2000, intentional self-harm (suicide) is among the top three causes of death for youth ages 10 to 14. Suicide, cancerous tumours and accidental injuries consistently lead the annual ranking.

Suicide is the second leading cause of death for youth 15 to 24 since 2000, consistently following accidental injuries.

In 2019, 605 people, 24 years or younger, died of suicide across Canada.

On PEI, five below the age of 39 died by suicide in the same year.

Newell is disappointed that after years of trying to access quality mental health care services, her daughter's condition continues to deteriorate, leading to hospitalizations.

From 2018 to 2019, 292 children were hospitalized provincially due to mental disorders, according to Canadian Institute for Health Information (CIHI) data, accounting for a total number of 422 hospital admissions with a median length of stay of nine days. The vast majority, 260, were attributable to mood disorders such as major depressive disorder or bipolar disorder and "other disorders" which include conduct disorders, eating disorders and other behavioral and emotional disorders.

PEI's rate of youth hospitalizations, per population of 100,000, is the highest of all Canadian provinces, at almost twice the national rate. In 2018-19 the rate for rural youth was higher than urban, a trend seen across all provinces except Manitoba and Saskatchewan.

A CIHI information document explains that the high rate of hospitalization in rural areas is attributable in part to limited access to services.

Newell believes this applies to PEI. From her experience it's clear preventative, in-community, measures to support youth are



Autumn Newell encourages other youth to reach out for help if struggling. She says from experience, no matter how bad you are feeling it's important to remember things can get better.

Photo by John Morris Photography

far from adequate.

Information on the number of Island youth who present to an emergency department seeking access to in-patient bed to treat a crisis is less clear than hospitalizations, but the number is certainly higher.

A Health PEI spokesperson says in 2018 there were 505 instances of youth visiting an emergency department with mental health documented as the primary issue compared to the 422 hospitalizations. This is an underestimate because mental health may be ranked secondary if there is a more acute issue at play.

Youth hospitalization rates would be higher if more beds were available. In early 2021, Newell brought her daughter to the emergency department hop-

ing to keep Autumn safe and well cared for in the mental health unit. There were no beds.

Because Autumn is under 16, she could not stay in the emergency department without a parent. By late evening no bed had freed up. Newell faced staying overnight in the emergency department with her daughter or taking her home. She reluctantly drove her home.

This is not the only time Newell has been forced to juggle keeping a vigilant eye while balancing responsibilities of care for her other children.

"It's scary," the mother says.

Autumn has been granted a hospital bed in the past and says treatment received was beneficial. By being in a ward with other youth she realized she was not alone in her struggles. She

also found she could open up to some staff in the hospital environment.

Autumn wishes more youth were aware of mental illness. She believes it would allow for more positive discussions and a deeper understanding and compassion for those suffering. She says it's vital youth know they can reach out for help.

Jennifer Victor is guidance counsellor at Montague Regional High School. She says youth mental health initiatives have increased, pointing to efforts such as the student well-being team or the Insight program in Charlottetown. She says there is a lot of work being done with high school students at community mental health clinics as well.

But Victor also sees challenges, especially for those living in rural areas.

As an example, the Insight program is an excellent day program for students aged 13-18. Youth sharing similar issues, have access to cognitive behaviour and dialectical behaviour therapy. They do group work, individual work, and schoolwork, all in a very understanding environment.

Since 2016, 281 teens and family members have accessed the program's intensive services. This

averages about 60 students and family members per year.

It's a program Newell cannot wait for Autumn to attend. But the median wait time to enter the program is 243 days - about eight months. A school year is 10 months long.

Victor says Insight puts many rural students at a disadvantage. Parents are faced with the logistical and financial challenge of arranging travel to and from Charlottetown twice a day. Some can't make it work and the long drive is tiring for some students.

She suggests, a housing component for students or additional locations east and west would help. As would increasing the program's capacity.

After years of struggling to access needed services for Autumn, Newell took to social media over the summer of 2021. The response was overwhelming and after years of quieter advocacy Autumn was finally connected with a therapist and was offered a new schooling option through alternative learning.

Newell is happy for her daughter but concerned for families who aren't in a position to go public or battle the system effectively. She says Island youth cannot afford to wait years to receive necessary treatment.

Deep wounds require more than a Band-Aid

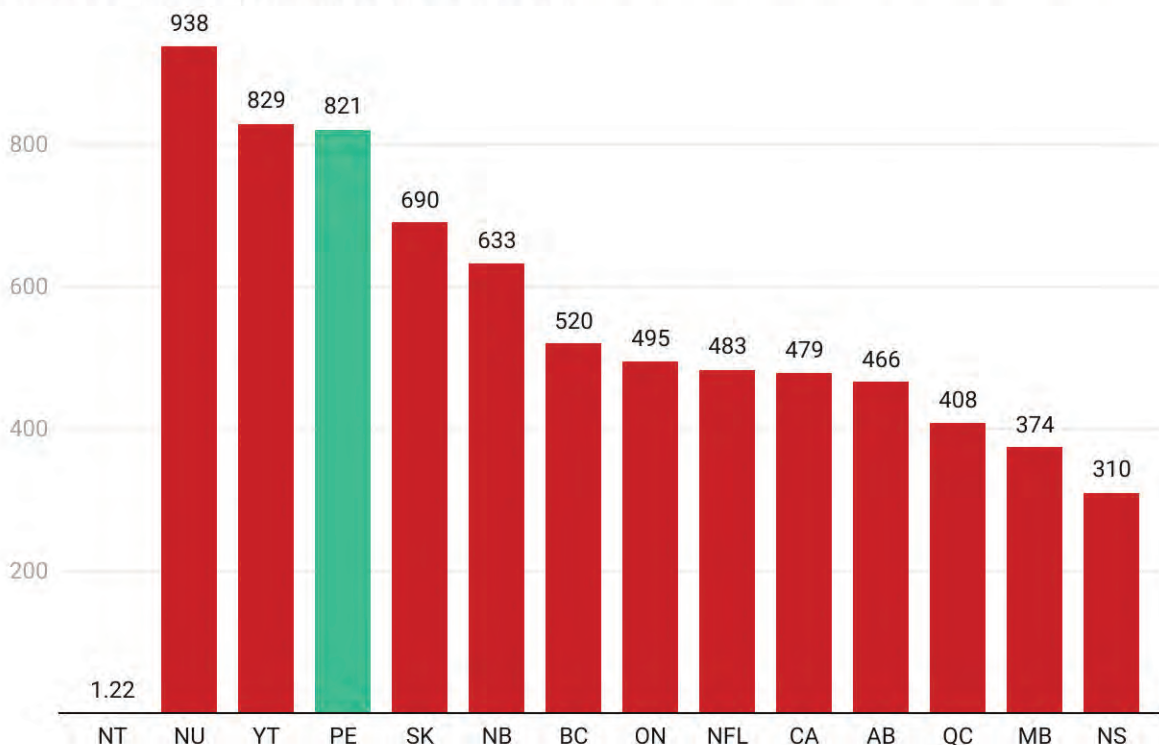
While Autumn Newell was able to access various programs, none provided the total level of care required. The following is a list of programming available for Island youth along with Autumn and Stacey Newell's experiences with the service.

- **INSIGHT** – 281 individual youth and family members have accessed Insight, a youth mental health day treatment program for students aged 13 to 18 located in Charlottetown, since November 2016. That's about 60 youth and family members per year. Autumn is on a waitlist for this program.
- **STRENGTH** - Over 300 youth have accessed Strength, a mental health and addictions residential program since spring 2015. This program does not apply to Autumn as she does not deal with substance misuse.
- **Strongest Families Online/Over the Phone Services** - In 2020 alone, over 500 Islanders accessed online or over the phone child and youth programs through Strongest Families for issues related to behavioural or conduct issues, anxiety or bedwetting. Autumn accessed this and it helped with her anxiety, but to a limited degree and for a short period of time. She still experiences severe anxiety and the program was limited to 12 weeks. Stacey Newell insists her daughter needs better, continued care with a provider she can count on.
- **Behavioural Support Team** - Over 200 families have received individual and group services from the Island's Behavioural Support Team since 2016. Autumn received support from this service but it was discontinued after it was determined her needs were beyond the scope of the program.
- **Student Wellbeing Teams** - Approximately 2,000 students received individual direct service through the 2020-2021 school year from the Student Wellbeing Teams. Autumn was in contact with the team but services were inconsistent and she did not feel comfortable sharing details with her multiple workers.
- **Community Mental Health** – Over 1,100 youth have been referred to community mental health per year from 2018 to 2020. Community mental health is intended to connect clients with group treatment, a specialist or private services that might better meet needs.

Stacey Newell had asked for years that her daughter have regular access to a therapist and specialist. The option finally became available only after Stacey Newell began airing her grievances online. She says it should not take this type of desperate action to access needed care.

Rate of children and youth hospitalized for mental disorders, in Canada per province and territory

A comparison of the rate of youth and children hospitalized per 100 000 population across Canadian provinces and territories through the 2018-19 fiscal year. PEI has the highest rate of children and youth populations of all provinces.



Crude rate per 100,000 population. Mental disorders include organic disorders, behavioural and emotional substance related disorders, schizophrenic and psychotic disorders, mood disorders, anxiety disorders, personality disorders and other disorders such as eating disorders or other emotional behavioural disorders.

Chart: Rachel Collier • Source: Canadian Institute for Health Information. Care for Children and Youth With Mental Disorders, Data tables • Created with Datawrapper



There was always the looming threat that CPS was going to take Autumn West, pictured here in her youth, or her siblings away from her family while she was growing up. Her fears eventually came true. She now advocates for stronger supports for struggling families on PEI.

Submitted photo



If CPS and other social services were working to their potential, Autumn West says, they would be known as a source of support rather than the boogey man children lie to avoid being taken from their families.

Submitted photo

CPS boogey man

More supports needed to keep children in the home

By Rachel Collier

Local Journalism Initiative Reporter
rcollier@peicanada.com

The biggest fear for Autumn West and her five siblings growing up in Charlottetown was Child Protective Services.

"In our mind they were a looming threat. We were always afraid that they were going to take us away forever and put us with strangers," said West, now 24 and living and working in Nova Scotia where she found a work opportunity and what feels like a healthy distance from her past.

If CPS and other social services were working to their potential, West says, they would be known as a source of support that connects families with well co-ordinated supports like adequate housing, food, clothing and mental health care — rather than as the boogeyman children lie to avoid being taken away from their family.

The latest scientific research, compiled by the Harvard Centre on the Developing Child, shows that prolonged, pervasive and uncontrollable stress as a child leads to a variety of negative health outcomes later in life including mental disorders and addictions.

Parental addiction, neglect, poverty and food insecurity are examples of adverse experiences that can pile up, leading to these negative outcomes.

On the other hand, protective factors like safe, stable relationships and physical environments as well as stable supports like regular access to nutritious food can help mitigate the effects of harmful stress and prevent poor health outcomes even in the face of adversity.

Growing up, West's mother was addicted to several drugs including stimulants and opiates. At the age of three, to avoid foster homes, she and her two younger siblings moved in with their grandmother, herself in addiction recovery.

West's mom had two more children and maintained custody for several years with their father. But the family's fears eventually came true. Two half-siblings were moved by CPS into a foster home.

"It was awful. We didn't get to see our siblings anymore which was traumatizing," she says.

“

It was awful. We didn't get to see our siblings anymore which was traumatizing.

AUTUMN WEST

”

They were removed after it was determined the living environment with their mom was inappropriate because she was unable to manage her substance use disorder. Their father was not in a position to move away from their mother and their grandmother could not care for two more children in her three-bedroom duplex, already filled with four people.

West's family nightmare became a reality again when her oldest brother was placed in a group home. He dropped out of school just after completing junior high. West says unaddressed mental illness and ADD contributed to behavioural issues, all of which led to his departure.

"You want to vouch for a system that is getting kids out of toxic homes," she said, "But on the other hand there could be more resources to help the homes instead of just taking children away"

About 25 per cent of 704 children identified in need of focused intervention by CPS on PEI were taken from their home for some period between April 1, 2020 and March 2021.

Kelly Peck, provincial Manager of Children's Services, says taking a child out of the home is a last resort. The length of time a child is removed ranges from a week to months.

To prevent removal, families are referred to a variety of services: mental health and addiction supports, housing support and parenting courses, among others.

West knows that her family was referred to services, but she also sees that some supports recommended were difficult to access or simply did not meet her family's needs. She says a straightforward preventative solution would be to ensure families have a basic standard of living and stable housing.

A basic standard of living

Social assistance rates, or welfare, have been increasing on PEI since 2018. However, the most recent MayTree Welfare in Canada Report calculates, in 2020, Island families still fell below the local Market Basket Measure (MBM).

This marker identifies households whose disposable income is less than the cost of

“ There could be more resources to help the homes instead of just taking children away. ”
 AUTUMN WEST

a basket of goods and services that represent a basic standard of living in the area. If a household's income is less than 75 per cent of the local MBM, it is considered to be below the Deep Income Poverty Line.

A single parent with one child in PEI receives \$25,256 in annual social assistance support. While this figure is \$1,873 above the deep income poverty threshold for this family arrangement, it is \$5,921 below the local MBM calculation.

A couple with two children on PEI receive \$39,961 annually. This is also \$1,873 above the deep income poverty line, but \$5,921 below the family's poverty line (MBM).

In 2019, 22,000 Islanders, or 14 per cent of the population, lived with a low income, according to Statistics Canada. Eleven per cent, 17,000 Islanders, existed on income less than the MBM.

And 4.5 per cent or 7,000 were in severe poverty. West's family was counted among the poor when she was growing up. She believes it contributed to mental health issues both as a child and down the road for both she and her siblings.

“Our landlord was essentially a slumlord,” said West. “You know, we would get fleas or we would get bed bugs, there was just constantly something going on in the house.”

Kids at school noticed her clothes smelled, which contributed to social marginalization. The laundry machine in their duplex was often broken. There was no money to fix problems.

Food was another stress. “We never really ate a lot of meals together or anything like that. Just because we never had food.”

She remembers her siblings would fight for the sacred can of Ravioli often packed in food bank boxes that never stretched far enough for the family.

“I would hide it under my pillow and save it until I was really hungry,” she said.

One of her siblings suffered from celiac disease and required a gluten-free diet. This added another layer of financial strain.

With all of this going on, West says she was prone to self-harming as a teen.

Following her brother, West's younger sister also dropped out of school but more as a result of low self-esteem and learning style. The effects of poverty and stigma toward her mother's addiction contributed to this low self-esteem but her sister was also unaware she is dyslexic. Now in her 20s, she is working to complete her GED to better support her young children.

Because of her own struggles, West's grandmother did not advocate for psycho-educational analysis testing that may have helped create a more nurturing education experience and medical treatment.

The average wait time for these assessments over the past decade in PEI has been as long as 3.5 years. Wait times have decreased but still stand at more than a year and often require parental advocacy to the Public Schools Branch for a child to receive an assessment.

West does not take completing high school for granted and has worked hard to secure a managerial position with a retail chain in Nova Scotia. But if she had stronger financial supports and back up as she left high school, she suspects she might have continued her education and started working in a more meaningful field in line with her identity: social work.

Housing

West believes if financial support was paired with appropriate housing, her grandmother might have been able to house her younger siblings instead of CPS sending them to the country to live with a foster family. This would have provided her siblings a greater sense of a stable family relationship.

The PEI government owns 487 social housing units for families and offers 1,150 mobile rental vouchers to individuals or families eligible for social housing.

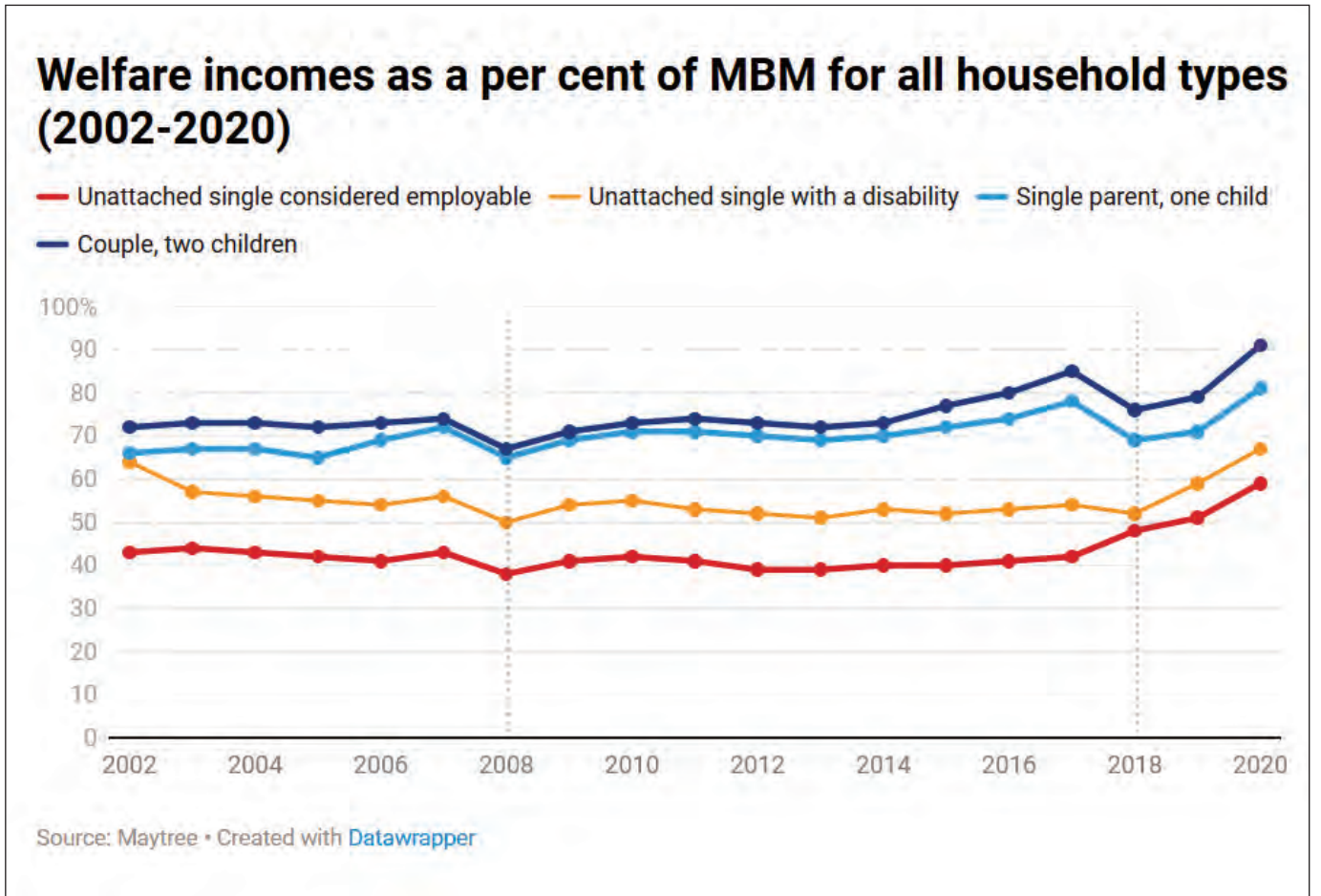
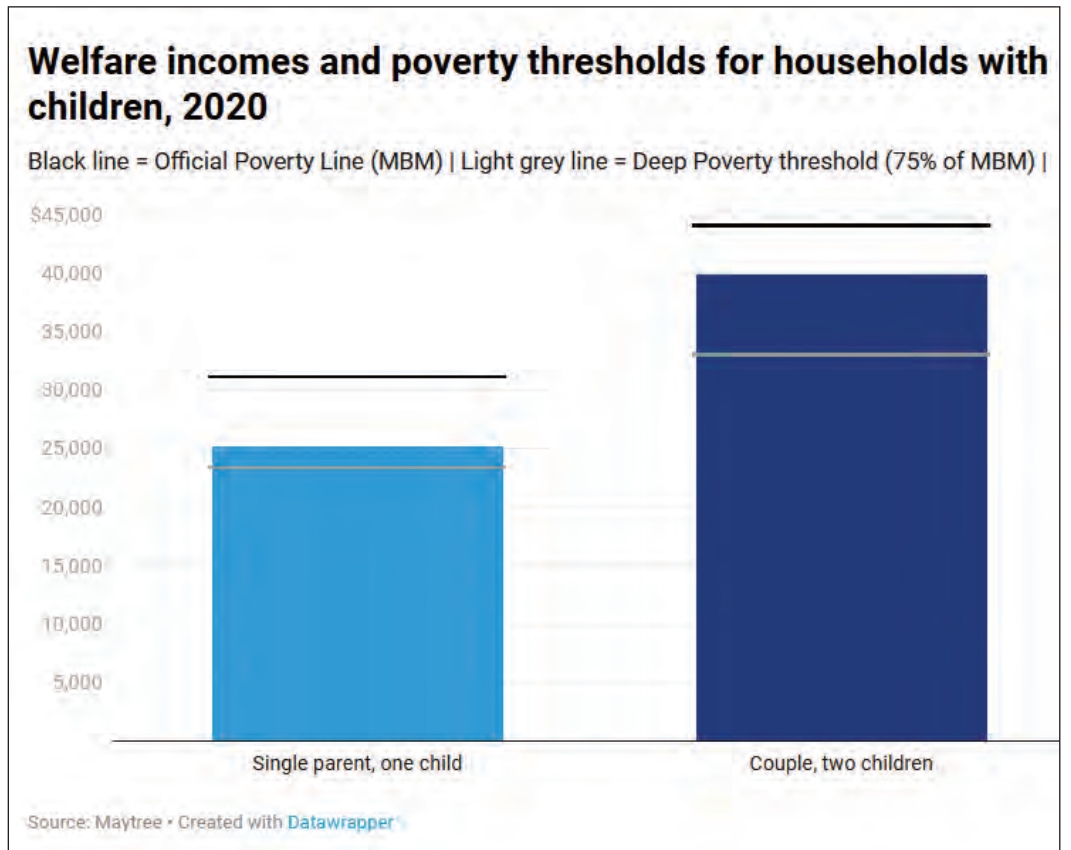
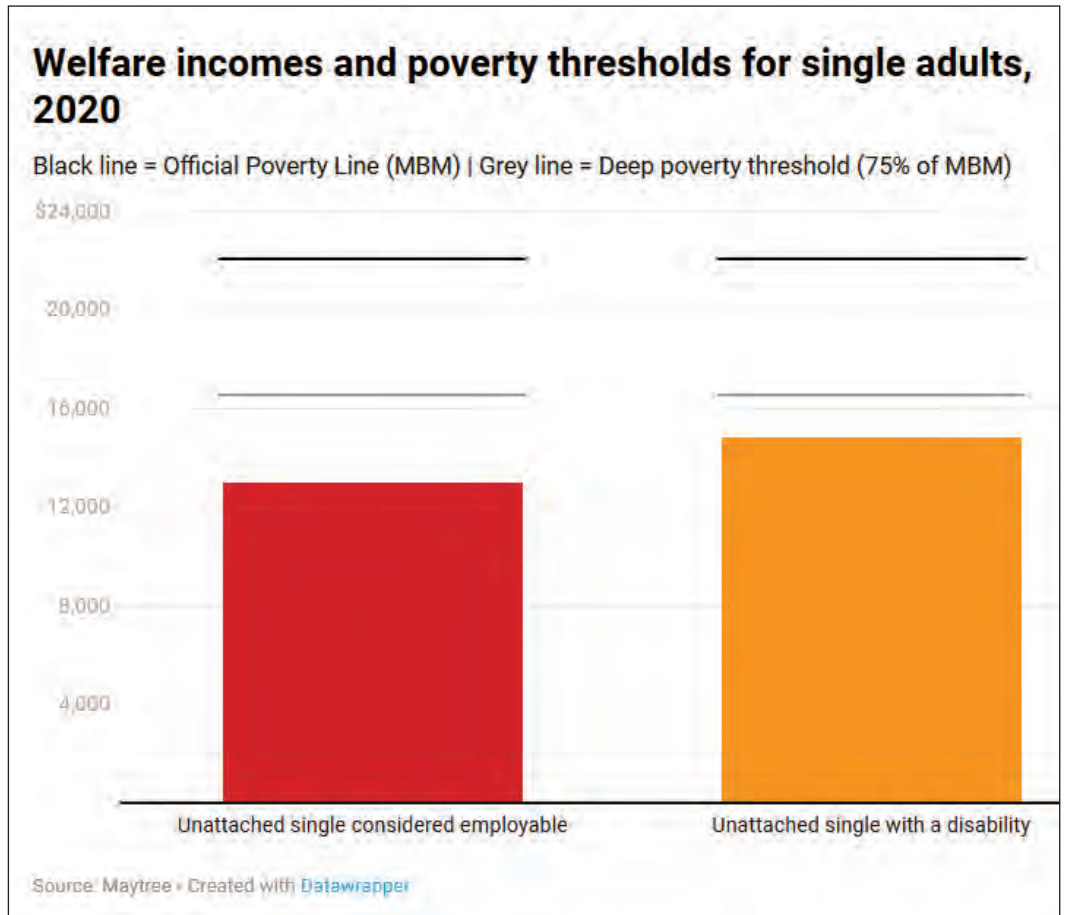
There are currently 260 families waiting for a placement that suits their needs according to the department's website. There is a need for 88 seniors units as well. The total number has decreased drastically since it being over 1,000 in early 2020.

But Green Party MLA Karla Bernard is uncertain about the numbers, considering the increase in housing units does not match the decrease in the waitlist. She has also heard from numerous constituents who have waited years on the registry only to find out they have been removed without their knowledge.

The Department of Social Housing and Development attributes the decrease to new housing builds and families accepting mobile rental vouchers. Rental vouchers are not available to those on social assistance.

Beyond reducing poverty and housing issues, West believes better awareness might motivate Islanders to push for solutions and reduce the harmful effects of stigma on young children, and by extension help prevent mental illness and addiction.

“No one deserves to grow up in these conditions and with a supportive community, the cycles might be broken more often and more easily,” West said. “Everyone knew that our mom was a ‘junkie’. Some parents wouldn't let us play with their kids.”



“ I can't even wrap my head around when my partner does kind things for me, just out of the goodness of his heart and not because he has to. I have to remind myself, he's not a group home staff. ”

TAYLOR WILSON

Children face years of instability under CPS

By Rachel Collier

Local Journalism Initiative Reporter
rcollier@peicanada.com

After escaping a highly traumatic childhood with her mom and her partner in Montague, Taylor Wilson spent the better part of her adolescence living in a group home in Charlottetown.

Now 24 and living in Nova Scotia, Wilson says no child or teen should live under such institutionalized conditions for an extended period of time.

“The staff don't love you, from the very get-go they tell you that ‘we're not your parents,’” she said. “It's like you are growing up in an artificial environment with no real love.”

Safe and stable relationships, especially with an attentive caregiver, are proven to show significant positive effects on a child's health outcomes later in life.

At 11, Wilson spilled information to a nurse at the QEH pertaining to a chronic history of sexual and physical violence as a young child. Disclosing the details led to an investigation and removal from her parents' custody. Wilson says this was absolutely for the better.

She spent some time with a foster family, but it wasn't a good fit. She felt betrayed when she disclosed parts of her family history, but was not believed.

For three years she moved between foster families and group homes, and by age 14 she started a long four-year haul in the group home in Charlottetown. There was regimented discipline, but what was lacking was an unconditional caregiver-child relationship.

She says it caused profound effects that she is still working to overcome.

The ideal of finding children stable family environments is reflected in CPS's mandate policy. It states: “All efforts will be made to sustain the family and the significant relationships of the child. If it is not possible to do so, the Director of Child Protection must be diligent in planning for the child's future stability in a permanent family environment.”

Yet it is common for Island children to live in instability for extended periods. In 2020 between 15 and 20 were living in a group home longer than a year.

“I can't even wrap my head around when my partner does kind things for me, just out of the goodness of his heart and not because he has to. I have to remind myself, he's not a group home staff,” she said.

Wilson rebelled against rules that forbid normal social interactions, like visiting friends.

“I remember the police showing up to the door of my friend's house. We were having a sleepover and I was in full face mask and I had to get in his cop car and be driven back.”

She appreciates the importance of a group home knowing where residents are at any given time. However, staying out with friends beyond curfew, in the outside world, is typically managed by an adult with a more stable and caring relationship to a teenager than a City Police officer, she says.

“Some children thrive in a group home setting while others prefer and succeed best in a foster-parent setting,” a government spokesperson said in written response from the Department of Social Development Housing last July.

Kelly Peck, Provincial Director of Children's Services followed up on the statement during an interview.

“Our priority is always to try and match the children in the group home with placements in a foster home if it's possible,” she said, “But we really do need more foster parents that are able to take children with varying needs.”

Some children, she says, have specific needs,

such as autism or Down syndrome. Others may have mental health or behavioural issues.

Peck says recruiting parents across the Island, including those willing to foster older children and teens, is ongoing. According to the department, a case plan is created for each child in care that includes therapeutic services such as counselling, along with medical services with physicians, dentist, optometrists, etc.

There are five group homes with a total of 40 beds across PEI. Each home has a counsellor assigned to provide therapeutic services through the department's Family Ties Program.

Wilson says while group home services and support may sound impressive, in reality mental health care is lacking.

“A lot of my behaviour was based around just having undiagnosed post-traumatic stress disorder,” said Wilson. “It wasn't until I was 18, that I got the official diagnosis that I started actually being able to identify how my mental illness was ruining my life.”

Once diagnosed she was prescribed medication and referred to other types of therapy to help deal with PTSD. She did not receive a psycho-educational assessment until she was 18.

“It has helped me so much,” she said. It opened up the availability of some disability supports and allowed her to think differently about how she can set herself up to succeed in life.

She would like to see youth in the system access these assessments sooner.

Psychological assessments are often completed through the Public Schools Branch, said a representative from the Department of Social Development and Housing. Now, when a significant wait time is identified, the director of Child Protection approves assessments to be done privately and assumes the cost.

The Department of Social Development and Housing spent \$78,000 on psychological assessments for children in care in the 2020-21 financial year.

Wilson still wonders if addressing her mental health and learning issues at an earlier age might have helped her manage her behavior to a point where a stable relationship with a foster family or adoption might have been more easily facilitated. She wonders if her relationships and resilience would be stronger today.

“ We need to stabilize our teams and our workforce so that they are better able to support children and families. ”

KELLY PECK

Massive turnover hinders CPS

By Rachel Collier

Local Journalism Initiative Reporter
rcollier@peicanada.com

PEI's Child Protective Services hopes to expand its mandate, amid severe difficulties retaining staff and a high volume of cases requiring investigation.

Provincial Director of Children's Services Kelly Peck says an expanded mandate will improve service in the long run. It's hoped prevention and early intervention will be incorporated into the Island's Child Protection Act.

She says reincorporating more preventative work seems like a “no brainer.” The idea is that CPS staff will have better ability to engage with families and help them build a circle of support before a point where more intrusive CPS interventions are necessary.

But to do this successfully it will require more staff. And CPS already has a massive issue in retaining workforce.

In 2019 about 40% of staff (CPS did not supply a specific number) left permanent positions. Thirty-eight per cent departed in 2020. And as of the middle of last October, 20% left in 2021.

“Our priority right now is doing everything we can to reduce the number of staff turnover, even just moving between positions. We need to stabilize our teams and our workforce so that they are better able to support children and families,” she said.

She added a stabilized workforce will prevent clients having to retell their story, and staff from having to quickly catch up to speed in a crisis.

A request for the department to provide the average caseload for CPS social workers was refused. Peck would only say the workload is appropriate for current staffing levels.

However, from April 1, 2020 through March 2021, Child Protective Services received 3,800 reports of suspected children at risk. Of these, 2,143 were flagged by a team of five workers for issues warranting a CPS investigation.

The CPS investigation team consists of 29 full-time equivalent social workers, if fully staffed, with the support of seven case aids and six admin staff.

Investigations are intended to be completed within 30 days. Eight per cent or 172 of 2,143 CPS investigations passed this timeline in 2020-2021. The reasons include but are not limited to waiting on information from other service providers and waiting to close an investigation until it's confirmed referred supports are being provided. Another reason is staffing and caseload challenges, according to the department.

Focused interventions following investigation were required in relation to 704 children and 636 parents. These investigations are supported by 16 full-time social workers, if fully staffed, supported by four case aids and three admin staff.

Peck says part of the reason for such a high staff turnover is the difficult nature of working with families in crisis, which she hopes can be minimized by expanding the department's mandate.



Kelly Peck, Provincial Director of Children's Services, says reincorporating more preventative work seems like a “no brainer.”

The CHANGE MAKER

Weaving change
Weaving chances to change
Weaving is the process of combining warp and weft components to make a woven structure

By Paul MacNeill
paul@peicanada.com

In 2001 Carlene Donnelly began work with a small Alberta non-profit, CUPS Calgary, providing front-line services to some of the city's most vulnerable residents.

Early on the Vernon River native recognized clients were forced to repeat their complex stories, often involving trauma, at every step in accessing services. Donnelly identified 13 separate CUPS entry points, for everything from housing to mental health and addiction treatment, child family services, legal, and healthy relationships.

No one was looking after the clients' bigger picture. She knew there must be a better way. After being named CEO in 2003 she set about redefining how front-line services are delivered, while growing CUPS into a multi-million-dollar, silo busting, non-profit, unlike anything in PEI.

If there is anyone capable of weaving together disjointed and seemingly disparate care efforts into a well-



Carlene Donnelly, CEO of CUPS Calgary, says a key to any successful mental health and addiction system is the sharing of data between departments, agencies and non-profits to ensure clients receive the best care without having to repeat their story multiple times. Submitted photo

coordinated, client centred teamwork - Carlene Donnelly is it. She's already done it.

Among other accolades, CUPS was named one of Canada's top 10 Canadian Impact Charities by Charity Intelligence Canada four years in a row, 2017 through 2020 under her direction. The award recognises efficiency and innovation.

PEI talks of co-ordinated, client centred care. In many ways the Island's social services system is where CUPS was more than a decade ago. Clients bounce around service to service, repeating their stories. Sometimes they access redundant support, other times they leave an inappropriate service frustrated while a solution may exist next door. A chronic staffing crisis in Child and Protective Services means that clients often are forced to repeat their stories to a new social worker. It can occur multiple times.

And that's just one area of government. "What I love about it is that we did build our entire program, really on the science," said Donnelly who speaks with a rapid-fire delivery streaming together insight, analysis, data points and corporate strategy - often in a single breath.

Every client entering CUPS is taken through a 40-minute assessment called the integrated care assessment tool, a questionnaire developed by CUPS in partnership with the University of Calgary Faculty of Nursing. Data from Harvard University Centre of the Developing Child, which CUPS has a partnership with, and Alberta's Palix Foundation were instrumental in its creation.

See page 16



Over the past 20 years Carlene Donnelly has grown CUPS Calgary into one of Canada's leading frontline service providers by embracing the power of data to enhance services to the most vulnerable.

Submitted photos

“

We do better at the service level and community level, creating a care plan for them that is not just picking them up and taking them to a detox or to a shelter or to emergency department.

”

CARLENE DONNELLY

The CHANGE MAKER

continued from page 15



“It’s not a formal clinical tool, but it gives us enough information to know what the priorities are to at least start a care plan with that person,” she says. The tool assesses a client’s strengths and weaknesses and potential capacity to face adversity.

Donnelly says clients often experience epiphanies when they recognize that their mental health or addictions are a predictable side effect of adversity, such as childhood trauma.

“It is incredible to hear their stories, because they will say to you, I thought I was just a screwed-up person or a mixed-up person,” she says. “It is the first time in many ways, and I hear this all the time, they feel forgiveness for themselves.”

These epiphanies, paired with an evidence-based plan showing how an individual can make lasting change, is powerful motivation. “So they do the work. They show up and do the work.”

The intake session provides clients with a one-stop-shop for accessing all potential entry points of service. Services, whether delivered directly by CUPS or

a service provider the organization partners with, share the same client information.

It’s the type of simplified entry point and co-ordination that PEI can only dream of, with its labyrinth of disconnected programs and services. While PEI nibbles away at the edges of systemic change, Donnelly’s created the technology and processes that could allow PEI to quickly make a massive leap forward into current best practices.

To her, everything is interconnected. Housing. Mental health and addiction. Family. Childhood trauma. Education. Employment. Transportation. Without effective, comprehensive, and interconnected intervention, she contends, issues become generational.

When these are disconnected, it creates a primary impediment to delivery of impactful programming.

Donnelly earned an undergrad at UPEI with a major in psychology, a Masters of Education from UNB, and a Master’s in Business Administration from the University of Phoenix. She

recognizes that no organization - government, non-profit or community - can do everything. When a range of players with different expertise co-ordinate and contribute to the same cause it can be massively beneficial.

CUPS was born in an era of austerity when the Alberta government offloaded frontline services to non-government organizations. Today it employs 200, including: doctors, nurses, psychiatrists, counsellors, care coordination specialists, and educators. Half of its annual \$18 million budget is fundraised through corporate donors. Donnelly says this funding is achieved thanks to extensive community engagement campaigns.

But if history is any guide, adopting a new service model might be a difficult sell to both health care workers and the public. The key, Donnelly says, is for all partners to know what their strengths are, and engaging the right solution at the right time. Transparency is imperative. She talks often of ‘knowing where



your lane is' and views CUPS as supporting, not competing, with other service providers.

She believes street level service providers, tied to non-profits or other community programs, are best able to meet the needs of complex mental health and addiction populations.

"We do better at the service level and community level, creating a care plan for them that is not just picking them up and taking them to a detox or to a shelter or to emergency department."

Other players have important roles too, such as government's oversight of funds.

"If we can respect where each other's expertise stop and start, right there and then we have more of a coordinated service," she says.

Meaningful data sharing is key to any effort at change. It's an idea that is talked about, but not implemented here.

"Health systems improve when they monitor and evaluate what is being done, and openly share better ways of doing things," states PEI's 2016 Mental Health and Addiction Strategy, which set out an ambitious roadmap for improving the level of care over 10 years. "Improvements and innovations are maximized by

good quality, well organized data that makes it possible to identify and respond to the diverse needs of specific populations with targeted services and supports," the report states.

But the vision of an interconnected, responsive system has gone largely unmet, with little evidence of cooperation or coordination between government departments and agencies, specifically as it relates to the sharing of data.

Solutions proffered involve creation of phone lines to tell people where to go, a system those with lived experience say is of little benefit. Navigators are

hired to send clients to the front door of services, but there is little data to track results of these interventions.

With access to clear data, not only is CUPS better able to direct clients to appropriate services but the organization is able to identify and fill gaps in care.

"What I have done is say where do the services of, let's say Health PEI, stop and start and for what population? And for what needs, then how do we complement that and actually become an asset to you. This isn't a competition," she says.

Donnelly uses the example of a man who visited the emergen-

cy room 36 times the previous year. CUPS has built relationships with three Calgary area hospitals so when a person arrives who does not need medical care but has nowhere else to go, CUPS is called.

CUPS was able to provide the individual a short-term housing solution in a shelter, which grew into a full-time apartment. The client has lived there for more than a year. It is a system that provides far greater supports at significantly less cost than ER visits, Donnelly says.

Donnelly added that service follow up data would be particularly beneficial to rural areas such as PEI. Research shows that rural areas have distinct cultures that affect what services are most beneficial and how solutions are tailored to serve the population.

"They need to have a voice and a platform to talk about the needs of that particular community. They really do," said Donnelly. "And that is something that people have to understand. If that isn't led by the community, no matter what government or any other resource tells them, it's not going to be as effective."

While Donnelly says CUPS is not perfect, it is effective at providing necessary intervention and programming to individuals, families, and children, with the added benefit of helping to prevent generational issues.

"It is a work in progress that is increasing coordination and navigation to the better. We are far from perfect. There's still lots of cracks and issues. But the conversation continues with the right people at the table."



CUPS Calgary's 40 minute assessment tool helps individuals identify their strengths and what they could improve within the four major pillars of resilience. After the assessment individuals have a better, evidence-based, understanding of how they can most effectively build resilience and promote long lasting life change.

What's good data?

Government's limited view stalls potential solutions

By Paul MacNeill

paul@peicanada.com

Carlene Donnelly believes technology can help improve delivery of mental health and addiction treatment, especially in rural communities. And the CEO of CUPS Calgary says an Island-based virtual platform could play a pivotal role in the effort.

But broadening the PEI government's understanding of what effective data collection is - and how it can support service delivery - is 'challenging', says Eddie Francis, CEO of the Charlotte-town-based platform called Neeka Health Canada.

"This platform could enhance existing supports and programs and offer a turnkey, data-driven, solution that would put PEI on the map as a global leader in digital peer support technologies," says Francis.

The problem is government's antiquated view of data collection. For instance, Health PEI launched Bridge the Gapp, a directory website of mental health and addiction programs and services, and positioned it publicly as an important new data source. Senior officials bragged about the website.

In reality, the only data collected is basic Google analytics, which does not allow for immediate treatment interventions or client interaction. The Graphic requested user data from the site and it shows insignificant engagement. In one month it attracted only 439 users and



Neeka Health Canada CEO Eddie Francis says trying to convince the provincial government of the potential benefit to programming through effective collection and utilization of data has been 'challenging.'

during an 11-month period in 2021 recorded a minuscule 33,000 page views. In a five-month period in 2021 only one 'Have Your Say' survey was completed.

This is where the Neeka app is a potential solution, especially in rural communities, says Donnelly, a pioneer in the use of data to make navigating

large, complicated mental health and addiction systems easier.

She believes technology can overcome a common reality of rural existence - high demand for services but little local delivery. Most people, however, do have cell phones and are familiar with how to use apps. Rural internet capacity is also increasing.

Neeka focuses on peer support and primary care services. Its competitive advantage is overcoming the major stumbling block to building any comprehensive solution - how to make electronic records created by different companies or government get along in a virtual world.

Neeka's platform empowers individuals to decide what records are important for them to see, be it electronic medical records, personal items like banking information or government programs and services. Virtually any type of record can be housed on the platform, which works seamlessly, regardless of creator or format and overcomes technological and corporate silos that dominate health care delivery.

Neeka's app essentially acts as a trusted middleman, bringing all the various items of importance to an individual together in one place, while at the same time building structure and connectivity with peers, friends, and family members.

"We're taking the redundancy away from different technologies and making it efficient from a consumer point of view," says Francis, of Charlottetown.

The app's true value proposition is the high level of engagement created with a user. A trial with the NHL Alumni Association was so successful the app will be rolled out to all alumni members and their families this summer. The platform takes the best of social media - design and proven ability to engage users - and combines it with best-in-class security and versatility to deliver a tailor-made solution for every client.

Despite its NHL Alumni success, efforts to pitch government on a larger Island-based trial, specifically targeted toward youth, have not gained traction within the PEI bureaucracy.

A trial would highlight Neeka's ability to collect data from clients interacting with the app and respond in real-time: Did you take your pills? Did you book your appointment? Did you walk a kilometer? Did you interact with your peer supports? If a potentially serious issue is flagged, it can be acted upon in real time and triaged to the appropriate medical professional. In a rural community, with limited access to specialized treatment, this type of interaction is potentially transformational, especially for people who may be hesitant to reach out for support or treatment.

"You can have the most beautiful app or platform around. But if you don't get engagement and utilization, it will not be an effective tool for individuals struggling with transitioning," Francis says.

"We want to help the individual on the journey and make that difficult situation as streamlined as possible."



Dr Tina Pranger of Stanley Bridge says PEI's formal mental health and addictions care program is lagging at incorporating input from those with mental illness into policy and program development. Submitted photo



Dr Michael Gardam Health PEI's CEO was initially hired as a consultant with the mission to help empower local decision making. He has not lost sight of the goal since moving into the role of CEO. Submitted photo

Top-down approach

Health PEI imposes programming on rural communities

By Rachel Collier

Local Journalism Initiative Reporter
rcollier@peicanada.com

While researching for her book, *Beyond the Asylum*, which traces the history of mental health care in PEI from 1846-2017, Dr Tina Pranger of Stanley Bridge found that PEI follows most Canadian mental health care trends - but is consistently a decade behind the rest of the country on implementation.

In some ways, she says, this is still true today.

"We're still very much profession focused," said Dr Pranger as an example of the Island lagging identified best practices. "It's the professionals and the bureaucrats who decide what kind of services we need. We don't do much in the way of consulting with people who live with mental illness."

Dr Pranger studied incorporating people with mental illness into policy and program development to earn her PhD in social sciences and health through the University of Toronto in the early 2000s. In the same decade she also worked as a mental health consultant to PEI's Department of Health and Wellness.

She says a movement toward involving those with mental illness in program and policy development in Ontario started in the '80s and '90s, but still has not gained traction on the Island.

She noted, there are some examples of programs that seem to be guided strongly by client input, notably some of the Canadian Mental Health Association programs, but she sees room for improvement particularly within the formal health care system.

The idea of incorporating patient or client input into program development is on the radar of Health PEI and the Department of Health and Wellness. But implementation is spotty.

Health officials told a legislative committee those with lived mental health experience were consulted in development of a mobile mental health model, which first proposed pairing police officers with mental health clinicians on every call. The model was moved forward despite a recommendation from a group of 18 stakeholders not to include

“It's the professionals and the bureaucrats who decide what kind of services we need. We don't do much in the way of consulting with people who live with mental illness.”

DR TINA PRANGER

police on every call.

Documents later presented to the Standing Committee of Health and Social Development indicated only four participants with lived experience were interviewed Island-wide.

After harsh criticism, the Department of Health and Wellness backtracked and later implemented a model where police are only called when needed.

Developing culturally informed mental health programs with rural communities rather than for them is a growing evidence-based trend.

Dr Michael Gardam, CEO of Health PEI, recognizes the importance of local decision making and tailored programming.

In a February 2021 interview with The Graphic he compared PEI to Ireland where he has worked previously.

"What would work in Dublin definitely was not going to work in Cork. And what worked in Cork was not going to work in Limerick. So, we set standards that everybody was going to work on, then it was up to them to figure out how they were going to get there."

A year later Health PEI was not able to answer how this has worked out on the ground with Island mental health programming. Have local leaders been given the tools and incentive to create local tailored programming that may increase acceptability and accessibility of services in rural areas?

In the interview in 2021 Dr Gardam did note, change would not happen overnight but as the result of an accumulation of small changes and shifts over time.

Meanwhile, median wait times to access community mental health in Montague reached eight months, or 243

days, in 2021.

Joanne Donahoe, the new Executive Director of Health PEI's Mental Health and Addictions points the finger at individual choices rather than programs not meeting local rural needs. In effect, she is proving Dr Pranger's contention that PEI is still a top-down system.

"Someone will stay in a waitlist because rather than a group, they'd like to see their preferences, but prefer one-on-one," said Donahoe. "We provide that choice to stay on the waitlist, but we do offer other services in the interim."

Some group therapies such as CBT therapy to treat anxiety and depression are proven to be just as effective as the equivalent one-on-one counselling options and are available on PEI. But group therapy is underutilized says Dr Javier Salabarría, Medical Head of Mental Health and Addictions for Health PEI.

"The general public is either unaware of it," he said, "and that's our job to educate them, or they're hesitant about it. They've never done it before because it's something new and something different."

The fishbowl effect, where everybody knows everything about everyone is known to impact acceptability of services in rural communities. It can be harder for patients to trust confidentiality will be maintained through private sessions with a therapist, much less group sessions. People are less likely to seek treatment in a fishbowl situation if they suspect other community members may hold negative attitudes toward mental health issues or treatment options.

A former Health PEI staff member told The Graphic limited available hours can impact how long clients remain on a waitlist.

She added group therapy options are often inconvenient. When scheduled during the day, working people tend to be unavailable and those who are not working tend to have issues affording transportation. Issues with leadership can cause high staff turnover, also impacting wait times.

The Graphic requested staff turnover and job vacancies within community mental health. After multiple requests, Health PEI released recent group therapy schedules to the Graphic. It showed in January and February no group therapy options had been offered by the province in Eastern PEI.

In March no CBT or DBT group therapy options were scheduled in Eastern PEI. Four of five regular addiction support or recovery group sessions were scheduled for mid-day or early afternoon.

Community mental health services are triaged based on the presence, severity and complexity of mental illness symptoms as key determinants. Someone triaged as a top priority for community mental health services typically has access within three to seven days depending on the client's availability.

Some of the symptoms and associated factors that may indicate a person should receive more urgent assignment would include:

- Significant risk to self or others that can be safely managed in a community setting,
- Significant changes in mood or activity, and significant deterioration in basic functioning,
- Irrational or overwhelming debilitating anxiety,
- Aggression, agitation and disorganized behaviour.
- Co-existing medical conditions, alcohol or substance problems and physical or intellectual disabilities that may increase the severity of a person's mental health symptoms,
- Social and environmental vulnerabilities and lack of supports (social determinants of health) that may increase the severity of a person's mental health symptoms.
- Recent discharge from a mental health inpatient setting or emergency department due to psychiatric/mental health crisis.

Psychiatric wait times community mental health

PEI's average and median wait times for psychiatric care vary significantly between community mental health locations.

Location	Average wait in days		Median wait in days	
	2019-2020	2020-21	2019-20	2020-21
McGill Centre	65	51	39	28
Montague	174	225	107	101
Richmond Centre	215	115	170	43
Summerside	13	90	6	35

Table: Rachel Collier • Source: Health PEI • Created with Datawrapper

General wait times community mental health

PEI's community mental health wait times are near national targets overall, but average and median waits vary significantly by location. Some individuals have waited as long as eight months.

Location	Average wait in days		Median wait in days	
	2019-20	2020-21	2019-20	2020-21
Alberton	26	22	20	14
Evangeline	53	42	27	21
INSIGHT	118	199	101	243
McGill Centre	14	10	11	7
Montague	98	102	49	35
O'Leary	29	23	23	15
Richmond Centre	92	92	60	102
Souris	107	83	34	26
Summerside	78	51	28	26

Table: Rachel Collier • Source: Health PEI • Created with Datawrapper

Mental Health and Addiction complement: 17 per cent vacant

Health PEI's Mental Health and Addiction staff complement, excluding physicians, is 17 per cent vacant. This is five per cent higher than the health authority's overall rate. FTE means full-time equivalent.

Location	FTE	Vacant FTE	Vacant FTE (%)
Hillsborough Hospital	158	27	17
Provincial Addictions Treatment Facility	61	9	14
Prince County Hospital	61	9	14
Queen Elizabeth Hospital	45	7	16
Richmond Centre	26	6	24
Lacey House	10	5	52
Addictions, Youth S'Side	22	4	20
Talbot House	10	4	40
McGill Centre	42	3	8
Schools	39	3	13
Mental Health, 75 Fitzroy Street	5	2	40
Mental Health, Youth Ch'Town	9	2	23
Kings County Addictions Centre	10	2	15
O'Leary Health Centre	2	1	50
Western Hospital	3	1	33
Allan Shaw Building	5	1	11
16 Garfield Street Charlottetown	2	0	15
35 Douses Road Montague	16	0	0
St. Eleanor's Place	9	0	0

This data is accurate as of Feb 28, 2022. Data excludes physician and temporary positions. HPEI created several FTE positions recently at Lacey Residence and Talbot House contributing to high vacancy rates. Thirty-seven per cent of Mental Health and Addiction vacancies are due to temporary leaves.

Table: Rachel Collier • Source: Health PEI • Created with Datawrapper

HPEI Mental Health and Addiction vacancies by profession

Psychologists, nurse practitioners and social workers have the highest vacancy rates among Health PEI's mental health and addiction staff. Data excludes physician vacancies.

Profession	Vacant FTE (%)
Psychologist	38
Nurse Practitioner	33
Social Worker	23
Licensed Practical Nurse	19
Technician/Clinician/Assistant	19
Registered Nurse	17
Admin/Clerical/Superv/Secretaries	15
Manager/Program Officer	14
Occupational Therapist	9
Service Worker	8
Cook/Baker	0
Maintenance/Trades	0
Personal Care Worker	0
Residential Care Worker	0
Registered Nurse-Educator	0

This data is accurate as of Feb 28, 2022. Data excludes physician and temporary positions. Thirty-seven per cent of vacancies are due to temporary leaves.

Table: Rachel Collier • Source: Health PEI • Created with Datawrapper



Rural trends like closeness to nature, a sense of responsibility to community and a tight knit society can all contribute to an individual's wellbeing but on the other hand they can create barriers to positive health outcomes. Photo of a serene day in Murray Harbour by Heather Moore



Many Islanders turn to nature for renewal. The advantage of living in rural PEI is that we are never far from nature and the countless calming scenes just like this one situated on a red dirt road surrounded by water, trees and wildlife. Heather Moore photo

The good and bad of rural life on mental health

By Rachel Collier

Local Journalism Initiative Reporter
rcollier@peicanada.com

Group dynamics and stigma

Drive off the ferry in Wood Islands after a trip to the mainland and it does not take long to observe potential mental health benefits of living on the Island.

Stretch your legs with a stop at Panting's Shore; seals will bob their heads 50 meters of gentle waves away, sparrows will zoom in and out of their nests in the cliff. You may be the only person in sight. Drive on.

Pick up groceries at Butler's Clover Farm in Murray Harbour. Chat with someone you know about where you have been, what you are up to now and, oh, how are your parents, kids?

Notice church after church as you carry on; they are sources of community and support for many. If you bust a tire, you likely either know how to fix it, or someone will pull over to help.

Rural trends like closeness to nature, a sense of responsibility to community and a tight knit society can all contribute to an individual's wellbeing, says Laura Friesen. She's a rural Albertan studying and researching mental health in rural Canada as she works to complete her PhD through the University of Alberta.

But, she says, the very things that bring mental health benefits can also cause barriers.

Geography

Thinly-spread populations are tied to fewer available and less accessible services.

Barriers like trips over the bridge for health care or long waits for services are common to rural Canada and impact mental health.

Geographic remoteness and tight-knit communities create challenges retaining health care professionals from away. They may feel less than fully accepted. They may be physically isolated from their support networks of friends, family, and professional colleagues abroad.

It can be more important for rural people to remain a group insider than it is for people in urban areas, said Friesen. There are fewer social support networks available if a rural resident is ostracized. This can compound the effects of stigma, especially in a rural fishbowl. Everyone tends to know everything about everyone in small towns. Anonymity can be more difficult to achieve.

Individuals will avoid trying certain services because they fear others may have negative attitudes toward it.

Communities with strong cultures, including Christian or Indigenous cultures, may be hesitant to try or promote new professional services if they seem to ignore or devalue their wisdom.

Negative attitudes toward mental health services can stem from the common rural tendency to value self-reliance.

Industry

Physically and financially risky work like farming or fishing is common in rural PEI. Injuries are hard to avoid, and a bad season is financially and emotionally crushing. Meanwhile, self-employed fishers or farmers and their employees are less likely to have high quality private health care benefits than white collar workers in urban areas. This creates a potential barrier to top-quality care. These are some of the factors which can play into low availability, accessibility and acceptability of mental health services in rural areas, said Friesen. And it means fewer rural residents access the right service at the right time.

"They may go to ministers, physicians, like general practitioners or family doctors, friends, family, bars," Friesen said. "And that can be important. It can be supportive, but sometimes it can actually exacerbate mental health problems." In some cases it can lead to additional trauma.

All ages affected

While the difference in overall prevalence of mental health issues between rural and urban Canada isn't entirely straightforward, a trend in severe outcomes, including deaths, is.

Mortality rates caused by self-harm (suicide) and alcohol related diseases increase directly in line with geographical remoteness in Canada, according to a massive Statistics Canada analysis of data between 2011 and 2015.

People across age ranges living in rural or remote areas were more likely to experience a hospital stay for self-harm compared with those in urban areas, in part because there may be fewer community services in rural areas, according to CIHI. Similarly CIHI reports that higher rates of hospital stays due to harm caused by alcohol may indicate poor access to community-based care to prevent or manage harm.

PEI has a higher rate of hospital discharges per population for mental health and addictions treatment compared to all other provinces and Nunavut according to the latest 2019 CIHI data. The province had a higher rate of hospital stays for harm caused by substance use per 100 000 people compared to the national average. Only BC and the three territories had higher rates.

The rate of hospitalizations for youth experiencing mental health crisis is higher even in rural PEI than in the Island's urban hubs, according to the Canadian Institute for Health Information. It's a trend seen in all provinces except Manitoba and Saskatchewan.



More than 2,100 people are involved in the fishing industry on Prince Edward Island. It is a competitive business but the people who take part in it faithfully support community and fellow fishers when the need arises. Heather Moore photo

through the CRACKS

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