1 **July 14, 2015 St. John's Session**

2

3 Honourable Felix Collins:

4 ... the issues and concerns around mental health and
5 addictions that have been, that was set up by the
6 House of Assembly some time ago. As I mentioned
7 earlier, I think this is the fourth session that
8 we've had in St. John's. We've had a number of
9 sessions across the province, and got consultations,
10 had been very open and frank, and that's what we want
11 you to be this morning, as well, to be open and
12 frank. Tell us your experience as you see them, and
13 we've been getting a lot of information and a lot of
14 feedback from the various groups around the province,
15 and hopefully at the end of the day that information
16 will help us to form a series of solid
17 recommendations that we can give back to the House of
18 Assembly after these consultations have ended. We've
19 always advised the people who've made presentations
20 to certainly be open, be frank, don't hold back.
21 It's important for us to know the facts as they are
22 and to understand the situation as it really is, and
23 we've had some very, very excellent presentations,
24 and I think certainly we've got a wealth of

1 information that at the end of the day that we'll be
2 able to use to make a series of recommendations that
3 will hopefully improve the whole system of mental
4 health and addictions, and the whole issue of mental
5 health and addictions in this province. And the fact
6 that an All-Party Committee has been set up by the
7 House of Assembly to do this work really indicates
8 how serious and significant an issue this really is,
9 and I hope that at the end of the day we'll be able
10 to provide some good results.
11
12 So, again, thank you for coming, and I'll
13 introduce Bruce Gilbert over here. Bruce is the guy
14 who keeps all this on the straight and narrow, so
15 I'll let him give the directions to you.
16 Dr. Bruce Gilbert:
17 You can hear me fine, right?
18 Unidentified Female:
19 Yes.
20 Dr. Bruce Gilbert:
21 My role is pretty basic, to keep the presentations on
22 time, keep the flow going, so that our three
23 All-Party Committee members can participate and don't
24 have to worry about that. I'll just say a couple of

1 things to get us going. You can find the washrooms
2 out here. We're not taking a coffee break. You can
3 go help yourself at any time during the day. We're
4 taking a 30-minute lunch break. We have 10 speakers
5 today. Some of them are 15-minute speakers and some
6 of them are 30-minute speakers, depending on what
7 they requested. The sessions are all recorded for
8 the purposes of getting a transcript, which will be
9 put up on line, and so, our Panelists can work with
10 the transcripts afterwards. The media is here.
11
12 For those of you that have asked that your
13 presentation not be recorded, they are honoring that.
14 We've talked to them about that, and yeah, I think
15 that's it. We're ready to do, so like our first
16 presenter is representing the Autism Society and it's
17 Scott Crocker. So you can go over here or you can
18 stand at this nonexistent mike, but if you do I'm
19 going to bring this over.
20 Honourable Felix Collins:
21 Well, welcome, Mr. Crocker, and we look forward to
22 your presentation. I should mention that we have one
23 other member of the Panel who will be joining us
24 momentarily, and he's got another commitment for the

1 first hour or so, but he should be here in about
2 three-quarters of an hour. Mr. Crocker, the floor is
3 yours, sir.
4 Scott Crocker:
5 Good morning. First of all, for the benefit of the
6 Committee, there's a brief overview of what I hope to
7 touch on this morning, the five key changes that we
8 believe can make a difference, who we are at ASNL,
9 what is Autism Spectrum Disorder, and what's the
10 relationship between Autism and mental health issues,
11 and what do we believe needs to change to address
12 priority needs. We believe critical solutions that
13 can be implemented immediately to improve the mental
14 health of persons with Autism and their families and
15 caregivers include the following:
16
17 . Screen all children for Autism between 30 and 36
18 months of age through the public health system;
19 . add medically-diagnosed anxiety to the criteria for
20 allocation of student assistant support to students
21 with ASD in inclusive classrooms;
22 . develop and implement a three-year comprehensive
23 action plan for effective training of all educators
24 and student assistants in the field about ASD and best

1 practice teaching methodologies;
2 . end the use of IQ70 as the sole criteria for service
3 provision to children, youth and adults, and add an
4 adaptive function measure to remove the
5 discrimination; and
6 · then create a central intake clinic for adults with
7 developmental disorders, including Autism.
8
9
10 I want to begin by acknowledging the important
11 work being done by the All-Party Committee. We all
12 understand the challenges presented to loved ones and
13 friends by poor mental health. Too many families
14 continue to be impacted each week. Today I
15 officially represent Autism Society Newfoundland and
16 Labrador. I could just as easily be speaking as an
17 individual, as a father, - I nearly lost one of my
18 two daughters to suicide five years ago - a
19 firefighter and a paramedic. Her attempt followed
20 many years of misdiagnosis, incorrect medications and
21 frequent prescription changes. It's easy to place
22 blame. There were some in the health care system who
23 did fail my daughter, but there were others in the
24 system who did recognize the errors. After the

1 attempt, a correct diagnosis was made, all
2 medications were removed immediately and it
3 ultimately saved her life and gave her a new life, a
4 whole life and a happy life.
5
6 Some of you may know I worked for 37 years as an
7 educator, 30 as a principal, in several of the
8 largest schools in the province. I can just as
9 easily be speaking as an educator. Mental illness
10 was a priority concern of my staff and I way back in
11 1995 when too many of our students were suffering but
12 had no access, certainly no timely access, to badly
13 needed support services. Educators live with these
14 challenges daily and provide individual and group
15 counseling as best they can. My guidance counsellors
16 and I advocated for services and supports for
17 students and families who trusted us for many, many
18 years. I remember speaking with and sending letters
19 to government ministers of the day 13 years ago,
20 detailing our perspective on the problems, our
21 concerns for students' safety and requesting the
22 placement of mental health advocates within a couple
23 of specific government departments.
24

1 We all know too many youth and adults have been
2 lost to suicide over the years. Many moms and dads
3 have not been as fortunate as I was, but despite the
4 suffering and the suicides, things remain the same.
5 Nothing has really changed until now, and today I do
6 have hope. This process you've invited us to engage
7 in gives me real hope that we've turned the corner;
8 that collectively we've been shocked into taking
9 action that begins to really address issues. Some
10 immediately, I hope, some in the near term and
11 perhaps some will come in the longer term. We have
12 the ability to develop an effective strategy that
13 will improve quality of life for the many that are
14 affected by mental illness. We can save lives and we
15 can save families. I've never doubted that for a
16 moment, but do we have the will to face the difficult
17 challenges? I certainly hope we do and I believe we
18 do.
19
20 Acknowledging the challenge has been an important
21 first step. It won't be easy. Forming the All-Party
22 Committee on Mental Health and Addictions is an even
23 more important step. The third step is most
24 important. We must create a provincial strategy, an

1 action plan with urgency and dedicate resources to
2 implementing real solutions that help improve
3 people's lives, give an opportunity for happiness,
4 enjoyment, strong lasting relationships, employment
5 and careers and suitable housing. It has to be a
6 provincial priority. This issue goes way beyond
7 challenges with budgets, financial resources and
8 deficits. Nothing is more important than providing
9 supports and services that guarantee quality life and
10 good overall health for residents of our province.
11 Nothing's more important. When reductions become
12 necessary, when cuts are to be made, mental health
13 supports and services must remain priorities that
14 cannot be reduced or eliminated. Some things are
15 just too important to family, the community and to
16 life. Some things will always be priorities, because
17 they're the right things to do.
18
19 Some may wonder why the executive director with
20 the Autism Society Newfoundland and Labrador is
21 speaking at a mental health forum. I speak because
22 Autism Spectrum Disorder is a mental health concern.
23 The standard criteria for diagnosing Autism are found
24 in the Diagnostic and Statistics Manual for Mental

1 Disorders published by the American Psychiatric
2 Society. The DSM-5 refers to a set of conditions
3 called Pervasive Development Disorders connected by a
4 symptom set, including impairments in reciprocal
5 social interaction and in verbal and nonverbal
6 communication skills, and by the presence of
7 restrictive, repetitive and stereotyped patterns of
8 behavior. These signs all begin before a child is
9 three years old and affect information processing in
10 the brain.
11
12 The three disorders known as the Autism Spectrum
13 Disorders are Autistic Disorder, Asperger's and
14 PDD-NOS, or Pervasive Developmental Delay Not
15 Otherwise Specified. The National Institute of
16 Mental Health in the United States also includes ASDs
17 in their database of mental and psychiatric
18 disorders. The diagnosis of an ASD is made by an
19 expert diagnostician or interdisciplinary team based
20 on the child's developmental history and direct
21 behavioral observation. This type of assessment
22 requires a high level of training and experience on
23 the part of the assessors. The diagnosis of an ASD
24 is typically made by physicians, child psychologists

1 and pediatricians in particular.

2

3 A very real concern for those with Autism is
4 comorbidity. Comorbidities are common, including
5 eating disorders, schizoaffective disorders,
6 gastrointestinal disorders, Epilepsy and mental
7 health issues. Studies have repeatedly found that 80
8 percent of those diagnosed with Autism also have
9 depression and/or severe anxiety. While most people
10 with Autism are diagnosed early in their lives,
11 Autism is not a childhood disorder, contrary to
12 popular myth. The prevalence of Autism among males
13 is higher than that for females. Four out of five
14 people with Autism are male, and people with Autism
15 enjoy the same longevity as people without Autism.
16 Raising children and youth with ASD and looking after
17 adult sons and daughters with ASD can be very
18 stressful for parents and caregivers. Without the
19 proper supports and services, including respite care,
20 parents and caregivers can often suffer from poor
21 mental health, as well, loss of employment, lost
22 careers, broken marriages. Lack of supports and
23 services create the very concerns that we are
24 discussing here today.

1 So, today I speak in my capacity as dad, educator,
2 citizen and Autism advocate. Autism presents
3 significant mental health concerns, and this has to
4 be recognized by the All-Party Committee. Autism is
5 the fastest growing developmental disorder in Canada,
6 and I personally believe it constitutes a public
7 health emergency. Success with reducing the impacts
8 of Autism requires a strategy, a clear action plan
9 and a commitment to resources and a timeline.
10
11 The Autism Society presented to the Mental Health
12 Commission four years ago in 2011. We contracted MUN
13 to complete a research project for us in 2012. ASNL
14 completed a Provincial Autism Needs Assessment in
15 2015. The Canadian Autism Spectrum Disorders
16 Alliance, or CASDA, has been working to secure the
17 Federal Government's commitment to the development of
18 a National Autism Action Plan. It completed Canada's
19 first ever National Autism Needs Assessment Survey in
20 2014. Of particular interest for this Committee is
21 that this CASDA study received a significant number
22 of responses directly from adults with Asperger's.
23 The level of mental health problems they reported was
24 significant. Their identification of issues related

1 to anxiety, depression, OCD and ADHD provides
2 dramatic insight into the need for more mental health
3 support services and transition planning for this
4 group of individuals with ASD. Concerns and needs
5 that were highlighted each time since 2011 remain
6 priority needs for the Autism community in
7 Newfoundland and Labrador. We believe action on
8 these priorities can significantly improve the mental
9 health of those with Autism and their families and
10 caregivers, and they include the following:
11 Recognition of ASD as a mental health condition and
12 programs, services, supports provided free of charge
13 to families and adult individuals as per the *Canada*
14 *Health Act*.
15
16 We repeatedly hear of families that cannot access
17 occupational therapy, speech language pathology and
18 have to go outside and get engaged personally with
19 their own finances and they cannot afford to do it.
20 And, you know, the question remains, when is
21 Government as per the *Canada Health Act* going to
22 cover the cost associated with critically needed
23 supports.
24

1 All children undergo a automatic screening and
2 assessment between 30 and 36 months by public health
3 within each regional health authority. There are
4 implications here for the training of public health
5 nurses, and the reason is because diagnosis and early
6 intervention is critical. We know it positively
7 impacts the lives of individuals and families
8 affected by Autism, and I repeatedly hear about
9 children that are not diagnosed until they've started
10 school or grade two or grade three and so on. Now,
11 there are many reasons for that. Sometimes it may
12 very well be lengthy wait lists. Sometimes it may be
13 moms and dads hoping that things are going to change
14 and going to improve, and they want to give it some
15 time, but we all know from a huge amount of research
16 that the earlier we get the diagnosis and the earlier
17 we start the intervention, the better quality of life
18 that individual will have.
19
20 Better assessment and diagnostic capabilities that
21 will flow from more personnel and more efficient
22 means of assessment and diagnosis. It wasn't so long
23 ago that we were complaining of wait lists that were
24 18, 20, 22 months long. In some cases, they may have

1 been because a doctor for some reason had to postpone
2 a scheduled appointment. Some cases, it may have
3 been because a family had an illness and couldn't
4 attend on a particular date. It doesn't really
5 matter. At the end of the day, it was 20, 22, 24
6 months before a diagnosis was finally made after a
7 referral. With the budget of, a couple of budgets
8 ago now, of course, more money was put into this
9 process and some more personnel, and perhaps more
10 importantly, how they were doing the process was
11 improved and changed, and we know that the wait lists
12 for diagnosis have now dropped significantly down to
13 around the nine-, ten-month range. We still want
14 better than that. We believe that everybody is
15 entitled to receive a diagnosis within a six-month
16 period. It's too critical and it affects your whole
17 life, so we need the diagnosis within six months.
18
19 Follow-up services in OT and SLP have unacceptable
20 high wait lists, 18 plus months in Eastern region,
21 and this is after we've added money and after we've
22 revised the system. Eighteen plus months in Eastern
23 region, longer elsewhere. They must be available
24 within a three-month period following a diagnosis,

1 since they're important components of the critically
2 needed early intervention.
3
4 Establish a minimum number of hours of ABA therapy
5 to be provided, and if it's delayed because of
6 lengthy or late diagnosis, extend it beyond age
7 eight, or beyond grade three. If a child for
8 whatever reason isn't diagnosed until grade one or
9 grade two, for heaven's sake, don't stop the ABA
10 therapy one year later, when others are getting it
11 from age three up until the end of grade three. So
12 establish a minimum number of hours, and then provide
13 that number of hours based on the starting point.
14
15 Establish an adult clinic for ASD and other
16 developmental delays in the province. There is no
17 such thing. I need to say that again. There's no
18 adult clinic for ASD and other developmental delays
19 in the province. And require that medical doctors
20 accept adult referrals for the purpose of diagnosis
21 and/or treatment. I just went through an experience
22 in the past couple of months trying to get two adults
23 in the Clarenville, what we call our Eastern region,
24 in to see a doctor for assessment, diagnosis and

1 referral, and we cannot find one. We cannot find one
2 in this province, not a psychiatrist, nobody. Now,
3 we're in the process of trying to establish one. A
4 group of people are at MUN and the Health Sciences
5 Centre to, and pilot it to see how it goes, but there
6 are a lot of adults with ASD in our province who
7 remain undiagnosed and cannot access the service and
8 the supports they need, and they are suffering, and
9 you know if they're suffering, their families are
10 suffering.
11
12 Provide better in-school supports and more of
13 them, and add to the criteria for student assistant
14 allocation to ensure success with inclusion and
15 student learning. Provide comprehensive in-depth
16 regular training, as per a three-year plan for
17 regular classroom teachers and structural resource
18 teachers, pervasive needs teachers and student
19 assistants. We are never going to make the school
20 system better with training that's ad hoc and all
21 over the place, just touching base here and there.
22 And I was in the system for 37 years, so believe me I
23 know, and we're never going to get any better if we
24 still focus our efforts on instructional resource

1 teachers. They're in the regular classrooms with
2 regular classroom teachers. We put a three-year plan
3 in place for implementing programs around LBGTQ
4 awareness. We did the same thing with team boards.
5 Now, for heaven's sake, we put a three-year plan in
6 place to teach people in the system how to use team
7 boards, and we can't do the same thing to teach
8 people how to effectively deal with children that are
9 in the school system and falling by the wayside, not
10 because teachers don't want to do it, because they
11 don't know the best ways to do it.
12
13 Establish and enforce a minimum number of days a
14 student can be removed from the school setting
15 because of behavior and safety concerns. Mandate
16 timely implementation of specific individualized
17 education plans for return to school, and when
18 children are at home provide ABA therapy and respite
19 care, so parents do not have to give up employment
20 and end their careers. Provide regular school work
21 to children who must stay at home. There's a
22 concept. Many of you would know children who for
23 whatever reason medically have to stay at home
24 sometimes. It may be they're undergoing treatment

1 for cancer. It may be surgeries, whatever. We
2 provide school work. It's collected and brought
3 back, there's regular intervals and things continue.
4 They're even tuition support programs provided by the
5 department. We don't do that when we say children
6 and young people with ASD cannot go to school.
7
8 Alternate schooling has to become a reality, and
9 be provided if and whenever a child or youth is
10 deemed too severe a safety risk to attend regular
11 school. This province and this country, confirmed by
12 the Court, has an obligation and a duty to provide
13 education to every single student, but we seem to be
14 able to exclude some for any of a number of reasons,
15 and I guess in this province it hasn't yet been
16 challenged. We have an alternate school here in the
17 city for people who've had difficulties with the law
18 or who are suffering some types of mental health
19 issues and so on, but there's nowhere for people who
20 aren't allowed to return to school with ASD because
21 they're deemed to be too severe a safety risk.
22
23 IEP meetings, transition meetings between grades,
24 between schools, between high school and

1 postsecondary schools, and/or the workforce, and
2 regulations around them, I believe need to be
3 included in legislation in the *Schools Act*.
4 Professionals have to be held accountable when and if
5 there's noncompliance.
6
7 Now, the only reason I have that there in slide 23
8 is because one of the main complaints I get during
9 the school year is from people who do not have
10 transition meetings occurring, and this is around the
11 province. It's not just one area, one school. This
12 is a fairly common thing, or a transition meeting
13 will occur, but then there's no follow-up, or an IEP
14 will be developed at the beginning of the year, but
15 then changes are made, but the parents aren't brought
16 in. There has to be a process that's in place and
17 guaranteed or it all falls apart, obviously.
18
19 Government must discontinue discriminatory policy
20 of using just an IQ test to deny services to people
21 with Autism; instead add to the criteria an adaptive
22 functioning assessment to determine needs of
23 children, youth and adults. Somebody somewhere some
24 time ago decided that a quick efficient way of

1 parting people to the left or to the right, for
2 service, without service, that kind of thing, was
3 going to be used based on IQ70, which is the
4 definition of an intellectual disability. And I will
5 say again, as I've been saying for two and a half
6 years now, intellectual disability has absolutely
7 nothing to do with Autism, and I've said I can bring
8 people in and show you who are going to university
9 and colleges and everywhere else and passing courses
10 and programs, but need someone with them during the
11 day at home to get them up, to get the hygiene in
12 place, to get the meals in place. They can't live
13 independently. They have IQs higher than many of us.
14 There's no correlation. I'm on a timeline.
15
16 Prepare a plan for independent living in the
17 community for people with Autism to the extent that
18 their abilities permit, and provide alternate-based
19 housing for individuals that require it. One of the
20 biggest concerns of many of the families I deal with,
21 aging families and their sons and daughters with ASD
22 are getting older too, is what's going to happen to
23 their children, and I don't have to say that or dwell
24 on it because you've all heard that many, many times,

1 I'm sure, and if any of you who are parents, or if
2 any of you have brothers or sisters, we can all
3 relate to that.
4
5 Implement and fund the research-based three-year
6 Continuing Professional Development Plan that ASNL
7 presented to the Minister of Health and Community
8 Services in the spring of 2013. It was based on
9 research of health care practitioners around the
10 province. It was done by Professional Development
11 and Conferencing Services at MUN. The cost is
12 $300,000 over three years. I can't imagine a better
13 way to spend $300,000 than to educate people in all
14 parts of the province who are crying out and saying
15 we don't know enough about, we need to know more.
16
17 The Autism Society believes its proposed solutions
18 will help. The five priority needs identified at the
19 beginning, and shown to you again here now, are not
20 cost prohibitive, and they will bring positive
21 results for many with ASD who experience significant
22 mental health challenges. These things are
23 achievable in the near, medium and longer term in the
24 context of a provincial strategy, but we believe that

1 these five can be done immediately, and we believe
2 they will have a profound effect on people at
3 different points in life. We're talking here about
4 young people, school-age children and adults.
5
6 ASNL, we advocate on behalf of all persons with
7 ASD. We say from the cradle to the grave. We're not
8 just about school children, or just about babies and
9 infants and so on, but the screening, so basic, so
10 simple, so not costly. We have kids not going to
11 school because of anxiety, ASD kids, medically
12 diagnosed, not anxious, medically diagnosed anxiety.
13 Cannot get it added to the criteria. I've been
14 trying for years. It's a mountain.
15
16 Develop and implement a three-year comprehensive
17 training program. Online training supposed to start
18 in September for the Atlantic Region. Great stuff
19 and it's going to help, but it's not even going to
20 come close to solving the problem. We need a
21 comprehensive training plan. IQ70, just get rid of
22 it. It's discrimination. I'm just waiting for
23 someone to invite me to court. And create a central
24 intake clinic for adults. The fact that it doesn't

1 exists is mind blowing. Thank you.
2 Honourable Felix Collins:
3 Thank you, Mr. Crocker.
4 Scott Crocker:
5 If there are any questions, I have 30 seconds.
6 Honourable Felix Collins:
7 Thank you. Thank you for that very well-prepared and
8 comprehensive presentation. Very realistic. Very
9 practical in your suggestions and recommendations.
10 Very informative, as well. I'm sure it will be very
11 helpful to the Committee at the end of the day. We
12 have some time for a few questions. So, Gerry, do
13 you want go first?
14 Gerry Rogers:
15 Scott, thank you so much, and we've been hearing from
16 parents with adult children of Autism in different
17 regions of the province, and their real grave
18 concerns about services for their adult children,
19 particularly what happens when their parents pass on.
20 So the issue of housing, housing, housing and
21 supportive housing has come up. Do we have, or do
22 you have any idea at all as to the numbers of kids
23 who are not in school because of problems within the
24 schools and the lack of services?

1 Scott Crocker:
2 No, the only number that I know is that there's about
3 150 who are being home schooled. What the department
4 say they cannot tell me is the breakdown, so that I
5 will know how many of them are at home because the
6 schools have refused to have them in school, or
7 because parents have simply been interrupted day
8 after day after day after day, and have simply given
9 up in frustration and withdrawn their child from
10 school. We know there's some religious education.
11 We know there's some things like that, but I contend
12 a large number is related to not being permitted in
13 school, or being interrupted constantly and sent
14 home, that sort of thing.
15 Gerry Rogers:
16 Yeah. So, do you think that that number of 150
17 doesn't catch the kids who've been constantly
18 interrupted and having to be sent home? Do you think
19 that 150 includes those kids, as well, or these kids
20 that are specifically registered as being home
21 schooled?
22 Scott Crocker:
23 These are registered as being home schooled. It
24 includes some of those.

1 Gerry Rogers:
2 Yeah.
3 Scott Crocker:
4 I have no idea what the number is on what we call, or
5 what the department calls partial day students.
6 Gerry Rogers:
7 Yes.
8 Scott Crocker:
9 These are kids or young people -- I always say kids.
10 I was in the system for years. These are kids who
11 are only permitted in for an hour a day, perhaps two
12 hours a day and sent home.
13 Gerry Rogers:
14 Yes, so, it doesn't catch those numbers.
15 Scott Crocker:
16 There's a whole host of students and we can't get the
17 status.
18 Gerry Rogers:
19 Okay.
20 Scott Crocker:
21 And there's all kinds of reasons why we're told we
22 can't get the stats. We know, for instance, there's
23 2,000 persons with Autism from birth to school
24 leaving age at 18. We know that, and we know that

1 there's some that remain undiagnosed, and we know
2 that there are some who are going through the process
3 of diagnosis right now, preschoolers, so the number,
4 and this is just birth to 18 years of age. I can
5 guarantee you there's that many or more from 18 up
6 into older adulthood.
7 Gerry Rogers:
8 So, the issue of the IQ70, where is that at in other
9 provinces?
10 Scott Crocker:
11 My understanding is that IQ70 is used, I'll say in
12 the Western World, but certainly across North
13 America. Ontario is moving away from it. BC has
14 been talking about it, but I think what's holding
15 everybody back is - well, I don't know this, but I
16 suspect is - they haven't done the investigative work
17 to figure out what the real cost will be. I have no
18 problem with IQ70 being there as an initial dividing
19 point. My request is simply that once you've said a
20 person who's getting supports and services, or who we
21 think should be, has an IQ above 70, then let's have
22 a social worker, or someone who works with that
23 family, do the assessment to figure out how well they
24 can function independently in society. If you or I

1 had a head injury and was admitted to a hospital, we
2 wouldn't be permitted out until an adaptive function
3 measure was done.
4 Gerry Rogers:
5 Right.
6 Scott Crocker:
7 But we just don't do it. Incredible.
8 Gerry Rogers:
9 And the issue of medically-diagnosed anxiety, can
10 that be done by a general family doctor, or are we
11 looking at another really long waiting list for that
12 diagnosis and assessment?
13 Scott Crocker:
14 When I was in the school system as principal for
15 many, many years and people applied for student
16 assistant support, if it was based on a medical
17 condition, the family doctor, there was a medical
18 certificate that the family doctor would complete.
19 Gerry Rogers:
20 Yes.
21 Scott Crocker:
22 So, I will say yes, that the family doctor can
23 complete the medical certificate.
24

1 Gerry Rogers:
2 Yes, and it's, I know we've heard many stories about
3 how difficult, how very, very difficult this is in
4 the school system and how very, very difficult it is
5 for families who are desperate for assistance in
6 trying to help their children. It is, yes.
7 Scott Crocker:
8 If a child has severe anxiety and gets up in the
9 morning and starts having the butterflies and starts
10 getting the bad stomach, - and we've all heard this -
11 and before they get out the door they, I don't want
12 to go, I don't want to go, and they start to cry and
13 this that and everything, or the parent finally gets
14 them there and within 20 minutes they have to leave
15 and go home again. Having one individual, a student
16 assistant, having one individual that that person
17 gets to know and gets a relationship with has proven
18 to make all the difference in the world at reducing
19 the anxiety around going to school. All of a sudden
20 there's a familiar face, and you can't say well, the
21 teacher is a familiar face because there's 25, 26
22 others and the individual time is very, very little,
23 but if you can get that person. But we can't even
24 get the criteria increased to include it.

1 Gerry Rogers:
2 Yeah, I have one quick question, one last quick
3 question. If you could point us to anywhere that has
4 best practices anywhere in the world, is there
5 anywhere that you could point us where you figure
6 this country, this jurisdiction, this city is getting
7 it right? Is there anywhere that you would see now,
8 this is the dream team?
9 Scott Crocker:
10 I guess my answer would be that there are some
11 private schools and facilities in Ontario, BC, even
12 in parts of the States and so on, which is where we
13 do a lot of our training with our program staff,
14 where in fact they are doing, but, it requires
15 resources certainly, right. There's no question
16 about that.
17 Honourable Felix Collins:
18 Okay, I'm going to cut you off there, Gerry. Chris,
19 you have a few questions?
20 Christopher Mitchelmore:
21 Scott, I thank you for your comprehensive
22 presentation and it really is solutions oriented, so
23 we like to see that from a Committee perspective, and
24 the Autism Spectrum Disorder comes up time and time

1 again. We've had other presenters across the
2 province while the Committee sat. The IQ test keeps
3 coming up. For me, it was really interesting to see
4 the wait time for occupational therapists and I know
5 that it's even worse in rural areas, because in St.
6 Anthony, for example, they have occupational therapy
7 vacancies for a number of months, so they bring in a
8 locum just for a very short period of time to get
9 service, so people in rural areas are really
10 suffering when it comes to getting the specialized
11 services that they need that are diagnosed with
12 Autism, so we grapple and deal with that every day.
13
14 I wanted to ask you some specific questions around
15 the screening of the children, like is this a
16 practice for 30 to 36 months in other jurisdictions,
17 you know, or is this to make Newfoundland and
18 Labrador best practice? Who's actually doing
19 screenings and things now? And you brought up that
20 this would be done through public health nurses, and
21 you said they would require training. Are some
22 trained now, or how does that process work?
23 Scott Crocker:
24 There are some who are doing the screening. I would

1 describe it as more of a movement that's following
2 all the research that's been done which shows how
3 good the results are, I guess, of early diagnosis and
4 early intervention. When I say the public health
5 system and public health nurses, what I'm really
6 talking about is a preschool health check. The
7 resources are out there in the communities around the
8 province. It wouldn't take very much effort, or very
9 much money wise, to do the bit of training, because
10 most of it at that point is based on observation, so
11 it really, any of us could become familiar with what
12 the symptom set is that starts to appear or to not
13 appear, whichever way, by two and a half to three
14 years of age. Getting that jump has consistently
15 shown over and over again tremendous results. So,
16 you know, at the end of the day my line is always you
17 pay now or you pay later. If you get it now, I can
18 guarantee you the resources and the support you'll
19 need later in school will be significantly less, but
20 it's so simply. When you think about the idea of a
21 public health nurse who's seeing the children anyway
22 and seeing them at a particular point in time and
23 doing that observation checklist and either noticing
24 concerns or not, it's an effective screening measure,

1 we believe, to help move the process along.
2 Gerry Rogers:
3 Great.
4 Christopher Mitchelmore:
5 Just, I guess, one more question, because the
6 supportive housing for people who have aging adult,
7 youth, kids, that's a big concern, and it seems like
8 we don't have anything here in Newfoundland and
9 Labrador to meet the needs of those after their
10 parents pass on. So what is the Autism Society or
11 what role do you see playing in trying to facilitate
12 and make something happen to help meet the needs of
13 those that are diagnosed, because it is going to be a
14 major challenge moving forward?
15 Scott Crocker:
16 Yeah. I mean at the moment it tends to be
17 institutions, seniors homes. There are some under
18 Eastern Residential Board and so on, there are some
19 homes in the communities where three or four or five
20 individuals may live with 24-hour care, 365 days a
21 year. There's waiting lists to get into some of
22 these, and these aren't just people with Autism, by
23 the way. These are individuals with other
24 developmental delays, as well. I know some families

1 who've taken the bull by the horns, I guess, and are
2 in the process of having like teaming up and having
3 places built, so that when they are no longer here
4 they'll be a place for perhaps two or three of them
5 who've gotten together. There's still the cost
6 that's involved and all that sort of thing. I've had
7 families come to me totally exhausted, both
8 personally and financially and wondering what to do
9 because a child is, not a child, a young adult, it
10 could be 35, 40 years of age, above IQ70, and there's
11 not even respite care being provided, so the
12 resources and the time that they have to be able to
13 spend a lot of time organizing and getting involved
14 with the type of thing we're talking about, there's
15 not a lot of that time out there because they're at
16 it, they're at it 24 hours a day, 365 days a year.
17 I've always been amazed at, for instance, - my last
18 comments - we will not pay a family with an adult or
19 younger, with a person of above IQ70, we won't pay
20 for respite care which I'll make a guess and say
21 what, $25,000 a year, $30,000 a year, max, but we'll
22 leave that family with no other choice than to go and
23 put the person in the care of Eastern Residential
24 Board where the cost is like $270,000 a year. Like

1 that doesn't, to me that's pretty powerful, but yet
2 we keep refusing, and I get the calls. We keep
3 refusing respite care day after day after day.
4 Honourable Felix Collins:
5 Thank you, Mr. Crocker, very much for a very
6 comprehensive presentation.
7 Scott Crocker:
8 Thank you.
9 Honourable Felix Collins:
10 Unfortunately, it's Bruce and my job to try to have
11 to cut off discussion in order to keep this think on
12 stream, and a presentation such as this lends itself
13 to a lot of questions and a lot of discussion, but
14 regrettably we have to cut it off at a certain point.
15 We're behind schedule. We have other presenters. So
16 again thanks, Scott, great presentation. Thank you
17 so much. Bruce?
1 Dr. Bruce Gilbert:
2 Okay, next up we have Frances Cole, the Atlantic

1 Manager of Roots of Empathy. So, Frances, you have
2 15 minutes. I'll just give you a five minutes
3 warning over there, so you'll know where you are in
4 your time.
5 Frances Cole:
6 Okay, thank you.
7 Honourable Felix Collins:
8 Welcome, Frances.
9 Frances Cole:
10 Thank you.
11 Honourable Felix Collins:
12 Thanks for coming this morning, and the floor is
13 yours.
14 Frances Cole:
15 My name is Frances Cole and I'm the senior mentor for
16 Roots of Empathy in Newfoundland and Labrador. My
17 Provincial Manager, Hazel Clarke, was ready to
18 present, but she's gone on holiday now since we got
19 delayed. She's no longer here, so I'm going to do
20 it. I want to speak about a Newfoundland woman. Her
21 name is Mary Gordon, and she had developed a program,
22 and I'd just like to refer you to in your package
23 there's a bio on Mary, not to read it to you. I'll
24 just highlight a couple of things. First of all, the

1 first sentence, born in Newfoundland. So Mary Gordon
2 is a Newfoundland woman. She's an award winning
3 social entrepreneur. She started off in Toronto, and
4 her parenting centres in Toronto are still on the go,
5 and she is recognized internationally. She's been
6 the recipient of many awards. She's had dialogues
7 with the Dalai Lama. She is - and I think that
8 speaks for itself - very well respected. She's had
9 three dialogues with His Holiness. She is an Ashoka
10 Fellow and an Ashoka Globalizer, and she has written
11 a book. It's called *Roots of Empathy: Changing the*
12 *World Child by Child*, and this is best seller.
13
14 So, Mary is no slouch, and she has developed this
15 fantastic program. She discovered that a baby is a
16 perfect teacher to help children learn about their
17 common humanity. Really, the heart of the program is
18 bringing attachment. When she worked in Toronto
19 early in her life, she discovered there was a lot of
20 neglect and abuse with the parenting, and she thought
21 well, why not use the parent-baby attachment and
22 learn from that. So she's found that this little
23 baby is a perfect teacher, and in our program our
24 little teachers have a uniform, unlike teachers and

1 principals, and this is what they wear in the
2 classroom as they go in. So, she highlights this
3 relationship between the parent and the baby, the
4 attachment. She uses it. Each program involves
5 students and their teacher, a trained Roots of
6 Empathy instructor and a mom and/or a dad with their
7 baby who's two to four months old. Over the nine
8 months, the instructor coaches the students to
9 observe the baby's development and to label the
10 baby's feelings, so the baby is the teacher and the
11 catalyst that the instructor uses to help children
12 identify and reflect on their own feelings and the
13 feelings of others, which of course leads to empathy.
14 Children watch love grow in the classroom. They
15 watch the confidence, security and emotional
16 attunement between the parent and the child.
17
18 Inspired by Mary's vision, Hazel and I have been
19 involved with community development work in the
20 province since 2005, during which time Roots of
21 Empathy has gone from a few programs that existed on
22 the southwest coast and in southern Labrador to more
23 than 100 programs throughout Newfoundland and
24 Labrador. We actually are the provincial managers,

1 but also Atlantic region.
2
3 So, why is this program beneficial and what does
4 research show about its effect? I will read the
5 mission. The Roots of Empathy Mission is to build
6 caring, peaceful and civil societies through the
7 development of empathy in children and adults.
8 Empathy is increasing being recognized as an
9 important characteristic and is being referred to by
10 some as the most important skill for the 21st
11 century, but Roots of Empathy's effectiveness is not
12 without research evidence, which of course is very
13 important.
14
15 Key research findings show that Roots of Empathy
16 children perceive a more positive classroom
17 environment by the end of their program, increased
18 sense of classroom belonging and peer acceptance.
19 Roots of Empathy children also exhibit an increase in
20 prosocial behavior. The research shows that Roots of
21 Empathy creates more caring and supportive children.
22 They're kinder, more likely to share and help their
23 classmates. These children in these classrooms where
24 the program takes place feel more supported by their

1 peers, by their teacher, and they feel a greater
2 sense of autonomy than other children. There is a
3 decrease in aggression. This is particularly
4 significant, given that children in the comparison
5 classrooms show increases in aggression across the
6 school year. I taught for 30 years and I can attest
7 to that. Aggression starts to increase. As spring
8 comes, it's even worse. The lovely thing that
9 happens when children have insights into how another
10 child feels or another person feels, which is
11 empathy, is that it provides a break against
12 aggression. You are not aggressive. You put
13 yourself in their shoes and you are much less likely
14 to be aggressive toward them. There's an increase in
15 social and emotional understanding. When compared
16 with other students, Roots of Empathy students
17 demonstrate significantly better understanding of
18 their own emotions and the emotions of others.
19
20 There's an increase in knowledge of parenting. We
21 do all kinds of things throughout the year in Roots
22 of Empathy, talking about Sudden Infant Death
23 Syndrome, never shake a baby, very powerful lesson on
24 that, so they learn, too, that parenting is not an

1 easy job. If you teach it at the grade seven, eight
2 level, they're not about to run out and think that
3 this is a great time to have a baby when you do a
4 whole unit on sleep and they realize they lose out on
5 sleep and that kind of thing. So there is a lot of
6 safety and parenting skills that they can bring
7 forward into their life as they become parents a
8 little later.
9
10 There's an increase in cognitive and emotional
11 empathy, but that's the research research, and I do
12 have put in your folders a sheet on the research, but
13 I like the more anecdotal research that comes out.
14 There's a letter there that was sent to a local
15 Atlantic coordinator after she did a presentation to
16 university students who were studying to become
17 teachers, and it's a very, very powerful letter, and
18 he attests to the fact that having Roots of Empathy
19 as a student when he was a boy in grade six changed
20 his life, and Mary Gordon actually has used that
21 letter. We sent it to her and she's used that letter
22 in presentations throughout when she's doing things
23 from Toronto.
24

1 We have things like parents reporting that their
2 Autistic grade three child received a birthday
3 invitation for the first time the year the class
4 participated in Roots of Empathy. I've done Roots of
5 Empathy in the classroom 10 years. I've got 10
6 beautiful, heartfelt moments, and when we have the
7 fourth day of training, we ask the instructors to
8 tell about their heartfelt moment in their class that
9 year, and then we get heartfelt moments sent to us
10 all the time. It's about children who come from
11 another country and are feeling very vulnerable, and
12 the baby smiles at them and they feel included.
13 We've got stories about children who are elective
14 mutes who speak for the first time to that baby.
15 We've got children with severe behavior problems,
16 very difficult throughout the whole time, but will
17 not miss a chance when the baby is there to join the
18 circle to come around the green blanket, which is
19 where the children all sit to observe the baby.
20
21 Mary has a very powerful story in her book that
22 I'm just going to read. I'll just sort of probably
23 paraphrase it a little bit to make it shorter. Page
24 5. Darren was the oldest child I ever saw in a Roots

1 of Empathy class, she says. He was a grade eight
2 student and had been held back twice. He was two
3 years older than everyone else and already had
4 started growing a beard. I knew his story. His
5 mother had been murdered in front of his eyes when he
6 was four, and he'd lived in a succession of foster
7 homes ever since. Darren looked menacing because he
8 wanted us to know that he was tough. His head was
9 shaved except for a ponytail at the top, and he had a
10 tattoo on the back of his head. The instructor of
11 the Roots of Empathy Program was explaining to the
12 class about differences in temperaments that day.
13 She invited the young mother who was visiting the
14 class with Evan, her six-month old baby, to share her
15 thoughts about her baby's temperament. Joining in
16 the discussion, the mother told the class how Evan
17 liked to face outwards when he was in the snugly or
18 the little pack and didn't want to cuddle into her,
19 and how she would have preferred to have a more
20 cuddly baby.
21
22 As the class ended, the mother asked if anyone
23 wanted to try on the snugly which was green and
24 trimmed with pink on the outside. To everyone's

1 surprise, Darren offered to try it, and as the other
2 students scrambled to get ready for lunch, he snapped
3 it on. Then he asked if he could put Evan in it.
4 The teacher, of course, was a little apprehensive,
5 but she handed him the baby and he put Evan in facing
6 towards his chest. That wise little baby snuggled
7 right in and Darren took him into a quiet corner and
8 rocked back and forth with the baby in his arms for
9 several minutes. Finally he came back to where the
10 mother and the Roots of Empathy instructor were
11 waiting and asked if no one has ever loved you, do
12 you think you could still be a good father. It's a
13 very powerful story, but it tells that in Roots of
14 Empathy children learn how important love is, how
15 important it is to know love.
16
17 So, I'll just go. I see my five-minute sign, so
18 we have hundreds and hundreds of those stories, and
19 Roots of Empathy helps make children more resilient.
20 It helps make them feel secure, and I personally have
21 had stories where children come clean with the fact
22 that there were ten-year old boys telling me they
23 have a pink fuzzy teddy bear on their bed. There's a
24 feeling a security in a Roots of Empathy classroom

1 and the teachers extend it. They keep going with it
2 and the class really, really benefits by it and all
3 children benefit by it.
4
5 So, basically what do we, why am I here, just what
6 do we want from the Committee? We just want an
7 awareness of the importance of not just programs that
8 deal with people who have developed mental health
9 problems and we know that's very vital, but we need
10 to be proactive in developing social and emotional
11 skills starting with children at a very, very young
12 age, and we believe that this will - It's a
13 preventative program.
14
15 Roots of Empathy is a program that takes place
16 over a full school year. We don't fly in for two
17 20-minute sessions. It gives the children the time
18 to really integrate the learning that takes place.
19 This can change children, can improve classroom
20 climate, can build more positive school environments
21 that nurture well-adjusted, more well-adjusted
22 citizens, citizens who care for one another and
23 respect each other's differences.
24

1 For the past four years the Government is helping
2 to fund support of Roots of Empathy through one-time
3 grants, and we've been very appreciative of the
4 wonderful support that we've received from several
5 ministries, Health and Community Services, Education
6 and Early Childhood Development, and the new
7 Departments of Senior, Wellness and Social
8 Development. We feel that Roots of Empathy offers a
9 pedagogy of hope, helping children find their voice
10 and often letting them share what's in their hearts.
11 So, we respectfully suggest that this program, which
12 has already impacted 18,500 children in more than 55
13 communities, be considered as a long-term part of the
14 provincial strategies and such receive the support
15 needed to work toward having programs in all schools
16 that want this program throughout Newfoundland and
17 Labrador. Thank you.
18 Honourable Felix Collins:
19 Thank you, Frances, and I have a quick question
20 before I go to Gerry or Chris. This is certainly a
21 fascinating story, Roots of Empathy. What is the
22 criteria that establishes where the program goes and
23 what communities and schools are involved, and so on?
24 How does that come up?

1 Frances Cole:
2 Yeah. In your package you will see, actually,
3 there's a thing there that says where we are in
4 Newfoundland and Labrador. Basically what happens is
5 when people come to us and say, phone us and say I'd
6 like to be trained as a Roots of Empathy instructor,
7 Hazel and I do proposals, get money from other
8 foundations like O'Neill Foundations, Sisters of
9 Mercy, Sisters of Presentation, Government, where we
10 can get money and we discover that oh, well, this
11 year we're planning to train 15 new instructors.
12 They come to us. They ask to be trained. It's often
13 we've got a lot of guidance counsellors in
14 Newfoundland and Labrador who really buy into the
15 program. They say it's the highlight of their week.
16 They feel that they're doing some good. They're
17 establishing relationships within the classroom. So,
18 we have a lot of those. We have social workers. We
19 have retired teachers, so then we train these. Then
20 we have, actually we've never had -- We have schools
21 phoning us, as well, principals. We'd like the
22 program. We have more schools wanting it than we can
23 provide instructors. Often a school will phone us
24 and ask for the program, but we don't have a lot of

1 extra instructors who are free of a school. We might
2 have a guidance counsellor at, like, for example,
3 we've got five programs at Holy Trinity. They've
4 really bought into it. They got this, the guidance
5 counsellor, the assistant principal, the resource
6 teacher. But a classroom teacher cannot do it, so it
7 needs to be one of the other people on staff or
8 somebody from outside, so it's a .... If we were
9 able to train more people, the schools are lined up
10 for the program. There's no doubt about that.
11 Honourable Felix Collins:
12 So, in terms of funding then and you mention your
13 responses and so on, but what's your funding
14 arrangement? How is the program funded? Is there
15 funding for the instructors? How is it funded? How
16 is it set up?
17 Frances Cole:
18 Instructors are not paid generally. They're in kind.
19 As I said, we have had money from Government, but we
20 do seek Monte Carlo. We seek foundations and it's a
21 little easier to get the money to train somebody than
22 to -- Nobody wants to pay the heat bill, the light
23 bill. That's a little more difficult. There's
24 mentoring involved. Every instructor who is in the

1 Roots of Empathy Program in the first year is
2 mentored. We need money for curriculum support, that
3 kind of thing. So, the money comes from different
4 sources.
5 Honourable Felix Collins:
6 Okay. Gerry?
7 Gerry Rogers:
8 Thank you so much. I've seen Roots of Empathy in
9 action and I just think it's incredible.
10 Frances Cole:
11 She's been to our big baby celebration.
12 Gerry Rogers:
13 Yeah, it's such a joy.
14 Frances Cole:
15 In May we bring all the babies together, 40 odd this
16 year, and we have a lovely little celebration.
17 Gerry Rogers:
18 It's really baby idolatry. It's really quite
19 wonderful, but also to see how excited the parents
20 are of the babies, and more often than not it's moms,
21 I guess, who go into the schools.
22 Frances Cole:
23 More often.
24

1 Gerry Rogers:
2 Yeah, some dads. This pedagogy of hope, I mean, what
3 better gift could we possibly, possibly give our
4 school systems and our children. That whole sense of
5 that pedagogy of hope. Is there any movement at all
6 to try and help, like for instances, Choices for
7 Youth have a single mom's club or a single parent's
8 club, and so, often parents, young moms who've had a
9 real hard time in their own lives, is there any
10 possibility of incorporating them a little bit into
11 the program? I would see it would be of great
12 benefit for them, too?
13 Frances Cole:
14 I can see what you're saying. The way we look at the
15 parents that we have in Roots of Empathy, obviously
16 we also have, we have a baby file, so we've got
17 people calling just saying I just found out I'm
18 pregnant. My baby's due in June, - because the baby
19 has to be two to four months old in October when the
20 program starts - I just found out I'm pregnant. My
21 baby's due in June. Can she or he be a Roots of
22 Empathy baby, so we got the babies lined up often.
23 Now, we will have parents from every socioeconomic
24 group. That is not a problem. The only thing that

1 we look for and the instructor will go and meet with
2 the parent beforehand and I've never come upon it,
3 but if they don't see that the parent has the
4 attunement and the attachment, that's our biggest
5 wish.
6 Gerry Rogers:
7 Yeah.
8 Frances Cole:
9 And if we have a single mom, a young mom, an old mom,
10 whatever, just as long as there's the attachment.
11 That's what we're looking for because we have to show
12 that, to show the love, to show how important, and we
13 always the baby, and we'll say in the classroom, look
14 how the baby has just turned to the mom. Why is he
15 turning to his mom, and the children will say because
16 he feels safe with his mom or his dad, so it's
17 attachment that we're looking for.
18 Gerry Rogers:
19 Yes.
20 Frances Cole:
21 So, it doesn't matter.
22 Gerry Rogers:
23 So there's an acceptance and an eagerness on behalf
24 of the school boards?

1 Frances Cole:
2 Absolutely.
3 Gerry Rogers:
4 That's great. So one of your big problems is core
5 funding then?
6 Frances Cole:
7 Core funding, yeah, so that we can make plans, right.
8 Like you always say well, if we get the funding for a
9 training next year, if, if, but if we had, if we were
10 a line item kind of thing then we could make plans
11 and sooner.
12 Gerry Rogers:
13 Yes.
14 Honourable Felix Collins:
15 Chris?
16 Christopher Mitchelmore:
17 Thanks, Frances, for this presentation. I guess
18 previously I did a lot of volunteer work with Junior
19 Achievement and how they delivered programs on the
20 Great Northern Peninsula, and we did outreach to, I
21 guess, finance the particular programs through
22 corporations, and I see you have a charitable number,
23 so you do do outreach, I guess, to businesses and to
24 others to try and fund programs, because I'm just

1 looking at the delivery and I see there's a real gap
2 on the Great Northern Peninsula. There was only one
3 program delivered in all the schools north of Deer
4 Lake, so is that a capacity issue and the fact that
5 you just don't have the network there, or?
6 Frances Cole:
7 No, we are certainly, we are accepting -- Right now
8 I'm interviewing for new instructors and references
9 and all that jazz, and we do say to them that we'll
10 do the approval later on in August, because that's
11 something that we want to do, make sure that we are
12 getting instructors from all over the province. We
13 don't want it to be here to the overpass kind of
14 thing. So, no we're not really, we've got two, I
15 think we've got a couple from western region who've
16 applied this year, so, we're only training 15, so
17 it's not a come first. It's not that kind of thing.
18 We will try to spread throughout the province, and we
19 will have people from Labrador, as well. We have
20 candidates, applications, I guess I should say.
21 Christopher Mitchelmore:
22 Yeah. No, I just go to the point that it was very
23 difficult, I guess, for the Junior Achievement, that
24 we had to be very proactive on the ground to be able

1 to get into the classrooms and to secure that, but
2 the importance of being able to do that prevention,
3 or that awareness on financial literacy, as well as
4 what this type of program would offer, I think would
5 have tremendous benefit to the students, to the youth
6 and the communities, so thank you for raising it.
7 Frances Cole:
8 Thank you.
9 Honourable Felix Collins:
10 And, Chris, I want at this time to mention we've been
11 joined by Kevin Parsons, the MHA for Cape St.
12 Francis. And welcome, Kevin. Do you have any
13 questions, by the way? [Recording fades]. Maybe I
14 shouldn't ask this. What support, cooperation or
15 connection does your program have or support from the
16 Department of Education of the province? Any
17 interconnection, any involvement there?
18 Frances Cole:
19 I'm sorry, I'm not getting what you're asking?
20 Honourable Felix Collins:
21 Well, what kind of support do you get or what kind of
22 recognition do you get from the Department of
23 Education?
24

1 Frances Cole:
2 Do you mean dollars?
3 Honourable Felix Collins:
4 Yeah, dollars and other (inaudible).
5 Frances Cole:
6 Yeah, well over time we've met, of course, many times
7 with different departments and we've had $89,000
8 (inaudible) services. Mary Gordon had a license
9 agreement with the Department of Education. We have
10 written a letter to the Department of Education
11 asking for an additional $27,000 for this upcoming
12 ... [microphone not working].
13 Honourable Felix Collins:
14 Thank you very much.
15 Frances Cole:
16 But they've very, very supportive. They do admire
17 the program, like the program.
18 Honourable Felix Collins:
19 Thank you very much for your presentation. Ladies
20 and gentlemen, we're over time, as usual, because
21 it's almost impossible to cut off discussion on these
22 topics, but we were due for a 15-minute break. I'm
23 going to ask you if you could keep it down to about
24 five, seven minutes or so, so we can come back and

1 get on schedule. Thanks and we'll have a short
2 break.
3 (Off the Record)
4 Dr. Bruce Gilbert:
5 You have 30 minutes. I guess you're going to share
6 your mike. I'll give you a ten-minute warning and a
7 five-minute warning just so you know where you are,
8 and take it away.
9 Honourable Felix Collins:
10 Thank you, Lisa. Welcome, and we're certainly
11 looking forward to hearing you. By the way,
12 congratulations on your new appointment to CEO of
13 Stella's Circle. It's a great appointment and we
14 look forward to seeing much of you. The floor is
15 yours.
16 Lisa Browne:
17 Thanks very much and I'm thrilled to be at Stella's
18 Circle and almost at my six-month mark now and
19 learning lots every day. We're thrilled to be able
20 to be here and with me is Denise Hillier, who's our
21 Director of Clinical Services. I'll start the
22 presentation and give an overview of Stella's Circle
23 and then Denise will speak more specifically around
24 mental health and addiction. I have to remember to

1 click.

2

3 So that's Stella's Circle. We have about 125
4 staff members. We're governed by a volunteer Board
5 of Directors and we also have a foundation board
6 which raises funds to allow us to do some of the work
7 that we do. Our operating budget is about $8 million
8 and we serve 1,000 people a year. So, we're a fairly
9 large organization in the scheme of things.

10

11 In terms of our funding, our funding comes from
12 many different sources, from the Department of Health
13 and Community Services through Eastern Health, from
14 Advanced Education and Skills, Justice, Education,
15 Corrections Canada, and of course we raise our own
16 funding as well, and I say we have a stellar history,
17 which is very true. Our organization actually
18 started about 70 years ago with Emmanuel House
19 through Stella Burry and has since grown quite
20 substantially since then, and I'll go through some of
21 our offerings throughout the presentation.

22

23 So who do we serve? We serve adults, with the
24 exception of one program, which I'll reference later.

1 So adults who face many barriers to fully
2 participating in our community, and those barriers
3 can be for any number of reasons, certainly for
4 mental health and addictions, poverty, homelessness,
5 unemployment, involvement in the criminal justice
6 system, illiteracy, and most often it's a multitude
7 of issues and not just one. So people who have very
8 complex needs. And so, as you can see, we serve a
9 very wide variety of people within the province.
10
11 And what services do we offer? When I first
12 started with Stella's Circle, one of the challenges I
13 had was actually describing all of the services that
14 we offer. They always say you should have an
15 elevator pitch. Well, our elevator needs 40 floors
16 to kind of cover all the services that we offer
17 because they're so varied, but they make perfect
18 sense. And they make sense because it really started
19 by recognizing the needs of participants and the
20 services then flowed to address the gaps within the
21 community, so it's very participant-focused in terms
22 of what we offer.
23
24 So in general we use this info graph to kind of

1 describe our work and we have really three lines of
2 business. We say that we offer real help, real homes
3 and real work. So in terms of real homes, and the
4 province is very much getting into the housing-first
5 philosophy, something that we have lived by for many
6 years, I would say that we're certainly a national
7 leader in terms of housing, and we offer safe,
8 affordable homes, and provide support services to
9 people as well. We have about 76 units and we work
10 with about 35 landlords to provide safe homes for
11 people.
12
13 We also have a resource centre, which anybody can
14 take advantage of in terms of getting assistance
15 around housing, and we also operate Jess's Place,
16 which is for women who have gone through addictions
17 and need a transitional housing. So that's under
18 Real Homes.
19
20 And then under Real Work, we offer employment,
21 pre-employment programs, we offer work experience
22 through our social enterprises, like the Hungry Heart
23 Café, like a commercial cleaning business, we have a
24 Trades Helper Program, and we also offer Adult Basic

1 Education, Level 1, which is often a precursor prior
2 to going into employment programs, and we also have
3 what we call CanDo Enterprises. So this is really
4 almost like a temporary employment program where
5 people with complex mental health issues can come in
6 and get paid for work and they're hired into the
7 community and do work. It might be for an hour a
8 week, it could be for up to 15 hours a week.
9
10 So you're seeing the start of the circle in terms
11 of housing and offering employment and finally real
12 help, in which we offer residential, community and
13 correctional-based counselling through our Community
14 Support Program, and our Just Us Women's Program,
15 which is for women who have a criminal justice
16 involvement, and we work with women in the
17 Clarenville correctional facility as well and try to
18 help ease the transition from that facility into the
19 community, and we certainly would work with women in
20 other facilities in Atlantic Canada as well, and of
21 course Emmanuel House where Stella Burry really
22 stated the organization, which offers residential
23 counselling for a four-month period. And so that's
24 really Denise's area in terms of that real help and

1 she'll speak a little more about that later.

2

3 Social aspect is also very important to us, and so
4 we offer things like an inclusion choir, which is
5 very popular, started in 2008, available for dates,
6 and the idea behind the choir is that it's open to
7 anyone, our participants and our staff and it's a
8 weekly opportunity to get together and share the joy
9 of singing, and almost acts as quasi-support group in
10 some ways. And we also partner with many
11 organizations, specifically CHANNAL, to offer a
12 shared, what we call a shared space, which is
13 essentially a coffee house once a month. We provide
14 supper to participants and participants can get up
15 and sing or do karaoke or some sort of musical
16 adventure, because our social support is so
17 important.

18

19 So how do we know that we're good? What's our
20 evidence of success? And there's certainly anecdotal
21 evidence, testimonials, that sort of thing, but we've
22 also got some really solid proof, I think, that we
23 are doing good work. I mentioned our CanDo Program,
24 which is our temporary employment program, and there

1 was a social return on investment study or evaluation
2 done on that in 2012, which indicated that we saved
3 $1.77 in savings to other systems. So by working
4 with people within their homes, for example, or
5 working with people and trying to engage them and
6 help them and support them, we can avoid costs that
7 are incurred in other systems like the health system
8 or like the justice system. So that social return on
9 investment, for example, which is a really important
10 concept to us, we avoided $268,000 and the justice
11 system 18,000, and that was looking at that CanDo
12 Project.
13
14 Just last year, for example, for the fiscal year,
15 120 people secured employment, which is very
16 impressive, and a lot of those people would have been
17 considered "unemployable" in the past, but when you
18 provide certain supports and work that works for
19 them, then they certainly can make a contribution,
20 which we all say the best social program is a job,
21 and without a job you can't really have good mental
22 health in a lot of ways.
23
24 We also have a evaluation of our Community Support

1 Program, a pilot project, so this data unfortunately
2 is old but it's what we have, which really show that
3 within our Community Support Program, when you
4 identify people with complex mental health needs and
5 other needs, you work with them in their homes to
6 support them, we absolutely can increase their
7 quality of life and decrease the
8 institutionalizations that they face, unnecessary
9 institutionalizations is what I should say, in terms
10 of hospitalizations and incarcerations.
11
12 Before Denise gets into specifics around mental
13 health issues, I just thought I would kind of, I
14 guess, repeat some of the messages that I brought at
15 the pre-budget consultation, and certainly speak to
16 the value of community services, and I think most
17 people in the room would probably be supportive of
18 community services, but just to say there is
19 definitely such an important role within the
20 community sector for organizations like ours. We
21 have a flexibility that allows us to be able to be
22 very responsive to needs and to be able to change our
23 program offerings relatively quickly based on needs
24 and gaps, so the role of the community sector is so

1 important in this area.

2

3 Our focus on mental health and addictions, this is
4 something that's really been strong in the last few
5 years for sure and we would certainly encourage that.
6 It's just so important, and as you'll see from
7 Denise's presentation, we are dealing with
8 increasingly more complex issues that people are
9 facing.

10

11 Coordinated approaches, I mentioned the large
12 number of funders that we get support from. They
13 each have their own way of requesting funds, their
14 own evaluation, so we spend a fair amount of time
15 responding to each funder individually, and what one
16 funder might want from an evaluation perspective is
17 very different from another one, but yet nobody will
18 fund things, like somebody to work on our databases
19 or somebody to work on evaluation, so we must deliver
20 on evaluation three or four different ways, but
21 there's no funding to do that. Similarly in terms of
22 administration, for example, we have 125 people. It
23 serves to reason that we would need at least one HR
24 person but, again, we need to dig deep for those

1 sorts of resources ourself.

2

3 We are very much in support of the Affordable
4 Housing and Homelessness Strategy and in fact we
5 would consider ourselves a leader in that area.
6 Poverty Reduction as well, very supportive of that in
7 terms of the coordinated approaches that the province
8 has been taking.

9

10 Multi-year end appropriate funding, I mentioned
11 the evaluation as one example. Multi-year of course,
12 when you know that you're getting funding for two or
13 three years makes a big difference in terms of how
14 you plan your services, how you evaluate and what
15 you're able to do. Right now we go year to year.
16 Our employees are employees for year to year and so
17 the challenge of having annual funding is a fairly
18 significant one. And I might suggest that the
19 efficiency is not there when you have annual funding
20 versus multi-year funding.

21

22 We also have, as you know, a focus on social
23 enterprise such as things like the Hungry Heart Café,
24 and I did notice, I was in Toronto recently and the

1 Government of Ontario put something into place so
2 that from a tendering perspective, with the Pan Am
3 Games, for example, 20 percent, I think it was, of
4 tendering must come from a social agency, social
5 enterprise. So, for example, KLINK Coffee, which is
6 an organization for ex-offenders, and they roast and
7 make coffee, they have partnered with a private
8 sector business to offer coffee to the Pan Am Games,
9 so you can imagine what that will do for that
10 organization in terms of revenue and bringing it back
11 into that organization.
12
13 So that's some of the high level messages. I
14 should also say in terms of government committees,
15 like Crime and the Mental Health Advisory Committee,
16 we would certainly love to have a place at those
17 tables, or someone within our organization to be on
18 those two committees. We feel like we have a lot to
19 offer, particularly the Crime, the Committee on Crime
20 and Community Safety, the Premier's Committee, and
21 the Provincial Mental Health and Addictions Advisory
22 Council, particularly with the crime issue in terms
23 of our role and our knowledge, particularly with
24 women involved in the criminal justice system and

1 transitioning to the community is extremely
2 important, and we have a lot to offer in that way.
3
4 So Denise now will continue in terms of mental
5 health specifically.
6 Denise Hillier:
7 Thank you, Lisa. Thank you for the opportunity to
8 speak today. I'm just going to touch a little bit
9 on, highlight some of the things that are working
10 well, give a few examples of some of what we've been
11 able to pull out of the work that we're doing at
12 Stella's Circle, particularly with working with
13 individuals who have some really complex mental
14 health challenges and long histories of
15 institutionalization, and then make a few kind of
16 suggestions around, I guess recommendations then,
17 highlighting some of the gaps that exist.
18
19 So in terms of some of the things that we know are
20 working well, the government's kind of done some
21 great work in the area of rent supplements, and our
22 housing division has certainly been key in working
23 with, in partnership with government around those.
24 Poverty reduction, we know the Poverty Reduction

1 Strategy, we hear it when we are discussing with
2 other provincial partners. They talk to us about our
3 Poverty Reduction Strategy and how impressed they are
4 with what this province has done. Another piece of
5 work that's I think the key in terms of government is
6 putting traditionally office-based staff in the
7 community, and we can certainly give some examples of
8 some great partnerships that have come.
9
10 One example is our Just Us Women's Program, which
11 for a number of years had a social worker from Mental
12 Health and Addictions work in partnership with our
13 social work staff to deliver addictions treatment for
14 women, and we think those kinds of partnerships
15 certainly need to continue and need to be enhanced.
16
17 Within our own organization, some of the work that
18 we've engaged in, kind of a, a bit of a technical
19 term here, it's called dialectical behaviour therapy
20 or DBT for short, but it is a form of therapy that
21 helps people regulate emotions, so people who have
22 had histories of self-harm in particular, and we went
23 down this road about five years ago when we were
24 really struggling to meet the needs of some of the

1 individuals we were working with in the community and
2 we explored and had a knowledge of DBT, but it wasn't
3 being offered here in this province, and so we looked
4 at what was happening in Toronto, specific with CAMH,
5 and we had discussion with Correctional Services
6 Canada, which has offered those kinds of treatment
7 programs in their institutions in other places, and
8 we went down that road of starting DBT here in
9 partnership with Eastern Health. It's been a great
10 partnership and we initially ran DBT groups starting
11 three years ago here in the community with Eastern
12 Health.
13
14 The demand has grown, and I would add that there
15 are other people who were involved in the training
16 that we brought here five years ago who are also
17 doing it at the Janeway, but we began running groups
18 with Eastern Health three years ago. The demand was
19 so high that we actually now run those groups
20 individually. So Eastern Health runs them and we run
21 them, but we run them in partnership and have two
22 team meetings that occur during the year that we
23 bring everybody together to talk about what's
24 happening, so I think an example of some really good

1 work that can happen when we're all talking together
2 and working on the same page.
3
4 The inclusivity that Lisa mentioned, so choir and
5 shared space, we know that partnering with people and
6 shared space, an example with bringing CHANNAL to
7 work in partnership with us and pull people together
8 for, to give people an opportunity to really create
9 their own community, has been important. NAVNET, and
10 I think you've heard perhaps in some presentations
11 about NAVNET, but that whole coordinated approach to
12 delivering services in the community, and we sit on
13 that committee as well as a co-coordinator.
14
15 So I just wanted to highlight a little bit with
16 our Community Support Program, and that's, I know
17 that Eastern Health also has a Community Supports
18 Program. We had our name first. Even though we've
19 debated making some change, but -- so it is a program
20 that started really as a result of women, although we
21 now work with both women and men, but we were looking
22 back in around 15, 16 years ago, at the high numbers
23 of Newfoundland women with complex mental health
24 issues who were serving time in federal prisons, and

1 Correctional Services Canada asked us to work with
2 them at that time and really look at what was
3 happening, and we looked at other parts of the
4 country and how, I guess, women with complex mental
5 health issues and correctional histories were being
6 served there and realized that we certainly had some
7 big gaps here in this province, and that started us
8 down the road to developing a community support
9 program, which is predominantly funded by Health as
10 well as some funding from Correctional Services
11 Canada.
12
13 The program was expanded to include men because we
14 realized that those with complex needs were also
15 falling through the cracks here, and it really is a
16 program that looks at the individual, the kinds of
17 support they may need. It recognizes that housing is
18 the first priority and then in order to help people
19 really be part of their community, that they need
20 supports and services in the home, in the community,
21 and we wrap the supports and services around them.
22
23 The average participant right now is 44; about
24 half are female. We work with 40 individuals in that

1 program. It is an intensive case management program,
2 half female, half male. The average CSP participant
3 has two diagnoses but I would say that there are
4 participants in that program who have up to six and
5 seven diagnoses. The average participant also has
6 two physical health conditions that cause them some
7 challenges and typically that might be something like
8 diabetes. As well, I think every individual in that
9 program is single; 26 percent have children and 90
10 percent minors, either in care or with, or being
11 raised by other family members. The typical
12 participant is also unemployed, and 64 percent have
13 never attended high school, or attended and never
14 graduated from high school, and 80 percent have one
15 addiction, and we include smoking as an addiction.
16 So, but if you look at that, you realize how complex
17 the individuals can be and some of the challenges
18 that they may face, and some of the individuals
19 certainly coming into that program have had up to
20 about ten years of institutionalization, either
21 prison or, and/or hospital.
22
23 So, I guess the past three years we've had
24 somebody help us with database, and Lisa mentioned

1 that as a challenging area, because our clinical
2 programs, up until three years ago, had no database,
3 had no way to track things other than on paper, so it
4 was really difficult to kind of, I guess, show proof
5 of what we knew we were doing really well. And so as
6 an example, you can see here that at least we can
7 look at something now and see who is our most, I
8 guess what is the most common illness that, in this
9 group that we're working with at CSP, and so you see
10 schizophrenia, schizoaffective disorder being kind of
11 number one, followed by issues of anxiety, and it's a
12 bit hard to see from this angle here but bipolar
13 would be next. So, and like I said, at least two
14 diagnoses would be your typical, and some people have
15 up to six, seven diagnoses on record.
16
17 This one here as well is a bit difficult for me to
18 see from this angle, but this is just an example of
19 one individual. We're trying to do some tracking
20 over time, because one of the things that we do get
21 asked is how do we know that we are reducing
22 unnecessary institutionalization stays and how do we
23 know that we're improving quality of life, because
24 that's what we set out to do in this program. So

1 this is an example of one person's
2 institutionalization history, which would include
3 both in custody as well as in psychiatric hospital,
4 and you can tell certainly over time, some of this
5 tracking was on paper because our database didn't
6 start till three years ago, but it's pretty accurate
7 statistics, and we've been trying to go back and
8 really track the change in people's lives, so that
9 you can see here that one individual, and certainly
10 in the early years, and I think that that one starts
11 back about five years ago, had a lot of time in
12 provincial custody and that certainly reduced over
13 time.
14
15 One of the other things that we know when working
16 with individuals who have really complex histories is
17 that change is going to be slow and relationship
18 building is going to be slow, and one of the things
19 we always say is key to working with individuals is
20 building healthy trusting relationships. We know
21 that if people haven't had that during their lifetime
22 it's not going to happen overnight, and change won't
23 happen overnight.
24

1 Again, just to highlight a case example, but I
2 guess it's about the change that can occur and when
3 it occurs when we work in partnership with each
4 other, so this is just an example of a male with a
5 number of diagnoses on record, certainly a history of
6 being through a variety of systems, including foster
7 care and the justice system and our health care
8 system, but somebody who was able to identify some
9 positive goals when we started to have some
10 conversations with him. What we felt and what we
11 know has been really helpful with people who have
12 been institutionalized for long periods of time such
13 as this individual, it has to be slow, and so we sent
14 our staff in to actually take him out on day passes
15 from the hospital, and we've done this in other case
16 examples as well, but really try to give some gradual
17 introductions to community and what the community
18 could look like for him. So there were a number of
19 systems that had to sit at the table to really do the
20 planning for this individual, and we've also planned
21 similar cases where we've had to work with AES to
22 secure an apartment for somebody and let them do
23 gradual visits to their apartment to get used to it
24 and then gradually do some overnight stays. So

1 similar to this, we had to help, work with this young
2 man to navigate a return to school, a return to his
3 community, to help identify family, because that was
4 what he wanted, that would work with him, and we work
5 with what it is that the individual identifies that
6 they need to help them live successfully in the
7 community, and in this case it was gradual overnights
8 with the family as he transitioned to out of
9 hospital. That took about a year, the transition,
10 but it ultimately has resulted in a year in the
11 community so far very successfully.
12
13 So just to highlight some of where we feel the
14 gaps are, adult children with cognitive or physical
15 disabilities who live with aging parents, and it
16 would certainly be our housing division that I know,
17 and you've probably heard this story at the
18 presentations, we typically work with people who have
19 mental health diagnosis and addictions issues. Our
20 housing program certainly has been inundated over the
21 past number of years with calls from aging parents
22 who are really struggling to find a place and
23 supports for their children, because they are so
24 concerned about what will happen after they go, and

1 our program, our housing division ultimately ends up
2 referring them to other programs and organizations
3 because it's again a group that there's a gap.
4
5 Just in terms of home care for those who age
6 poorly, what we find, and I know studies have shown,
7 typically people who have extremely complex mental
8 health issues will live lives that are anywhere from
9 10 to 20 years shorter than those of us who do not
10 have complex mental health needs, and what we find is
11 that people in their 40s and into their early 50s are
12 struggling with severe physical health challenges
13 that require a lot of care and sometimes they're
14 falling through the gaps in terms of getting that
15 care.
16
17 Quite similar, I say here mental health training
18 and facilities, caring for those with physical health
19 challenges, because we end up having people who
20 require support because of their physical health but
21 they also have mental health challenges, and we
22 sometimes encounter situations where people who are
23 working in homes, and it might be seniors homes, are
24 not trained in how to also deal with the mental

1 health challenges at the same time that they're
2 supporting the physical health challenges. And we
3 certainly had a case where we had an individual who
4 went into care and we ultimately sent our staff in to
5 help train the staff there in the seniors home about
6 schizophrenia so that they could more adequately
7 respond to the individual who had moved into their
8 care.
9
10 Transitions from youth to adult and adult to
11 seniors, and specifically I think our biggest
12 challenge has been with the youth to adult system and
13 what we've seen is that because an individual turns
14 18 or they turn 21 and come into our adult system,
15 all of a sudden, they had 24 hours' support a day and
16 now they're qualifying for 20 hours a week and I
17 can't figure out how that happens overnight but it
18 does.
19
20 Access to medical practitioners, particularly in
21 the downtown area, critical. The nurse
22 practitioners, certainly through New Hope, have been
23 a godsend to many of the participants we work with,
24 but there's now a wait list and they're no longer

1 taking new patients, and we find that that's a
2 struggle, and it's also a struggle because sometimes
3 there are few doctors in the downtown area and then
4 not all doctors want to take people who have complex
5 mental health issues on their caseload.
6
7 Transportation remains a problem because people
8 require a set number of appointments in order to get
9 access to bus passes, and stigma again is huge for
10 individuals.
11
12 All right, I'm down to five. I think I'm on the
13 last slide. So what do we need to do? We need to
14 combat stigma. We need education and awareness and
15 we need to include employers. Lisa mentioned some of
16 the statistics on 120 people finding employment
17 through our Employment Division last year, and it's
18 key that we deliver the message to employers that
19 people who face barriers to successful community
20 living can get out there and work and live meaningful
21 lives and have meaningful jobs and earn their own
22 money. It also includes working with those in our
23 own health care system and educating people there.
24 We need to look at the policies and services that

1 impact those transition stages because just because
2 an individual has a birthday shouldn't change the
3 kinds of services, supports that they need.
4
5 We need to educate those who support seniors in
6 the area of mental health, and I mentioned the
7 example of the support that we did. But, we talk
8 about an aging population. Well, we also have an
9 aging population of people who have mental health
10 challenges and we need to be able to educate people
11 and be sure that we're all working together on that.
12
13 We need to continue to develop and grow programs
14 that build on partnerships, and I touched on DBT, but
15 even the programs around community inclusion and
16 making people feel like they really indeed are part
17 of this community and we need to do that together,
18 and I do feel strongly that community is where it
19 needs to begin. And we need to recognize the link
20 between health and poverty and ensure that those who
21 are marginalized have access to medical programs, and
22 I think I've given some of the examples throughout.
23
24 And that would be it from our end, other than your

1 questions. Thank you.
2 Honourable Felix Collins:
3 Thank you. Any questions from the Panel?
4 Christopher Mitchelmore:
5 Thanks so much for your presentation and providing
6 such an overview of comprehensive services that you
7 provide. For me, I sat as a director with the
8 Canadian Community Economic Development Network, so
9 social enterprise is a big component of what we
10 believed in in pursuing how much value you can add to
11 the community in terms of creating jobs. So your
12 comment that the best social program is a job and I
13 truly believe that and I think we have to find ways
14 to provide employable services to people and across
15 the province in other areas, that social enterprises
16 can truly be enlarged. There are opportunities.
17
18 And the comment you made from what the provincial
19 government in Ontario is doing, because it's a
20 positive process, and I think that's something that
21 we should take note of and look at that. In terms of
22 your services, how long is the wait list for some
23 people to get access to service because obviously
24 there's big gaps, even with what you do, and I guess

1 it varies depending on the program but particularly
2 around housing I would think that you have a long
3 extensive wait list.
4 Lisa Browne:
5 It's difficult to have a wait list for housing per se
6 because people's circumstances change daily, but
7 suffice to say if everybody moved out of our
8 facilities today, we would fill it tomorrow. Like,
9 our turnover is fairly quick when that happens, so I
10 can't give you a specific number. We would certainly
11 have a number from our Community Support Program,
12 which tends to be about 25 right now on the wait list
13 for our Community Support Program, so people with
14 very complex mental health issues, and that number
15 stays fairly consistent, I think, Denise.
16 Christopher Mitchelmore:
17 Is there any plan to, like, expand your housing
18 component or?
19 Lisa Browne:
20 We are actually working on two apartments within
21 Naomi House, Naomi Centre, and those will be for
22 women who have traditionally used Naomi Centre and
23 need a little bit more support. So we are, through
24 federal funding, we're working on developing those

1 two additional ones. They're the only ones at the
2 moment, in addition.
3 Kevin Parsons:
4 Then it comes to your educational programs and stuff
5 like that, I notice that 64 percent doesn't have a
6 high school. Is there any programs or what kind of
7 programs are you offering to people to try to get at
8 least their high school diploma and stuff like that,
9 because I know you're very successful with your job
10 rates at 120, which is excellent, but I'm sure that
11 if the education part came up a little bit more that
12 we could probably even secure more jobs for people.
13 Lisa Browne:
14 And that 64 percent is just within the Community
15 Support Program alone.
16 Kevin Parsons:
17 Yes.
18 Lisa Browne:
19 And this is one of the challenges of evaluation,
20 because we have one database for housing, one for
21 advanced education, and one for community support, so
22 some of our challenge is there. But we do offer
23 Adult Basic Education, Level 1, within our Cabot
24 Street facility, and we also offer a number of

1 employment programs. For example, our Discover
2 Skills Program, which is a pre-employment program, a
3 couple of months long, and it consists of four days a
4 week. Two days are in-classroom sessions, two days
5 are work experience. So participants could be placed
6 at the Hungry Heart Café, they might be in a
7 commercial cleaning business, or they could be in our
8 Trades Helper Program. So the education component is
9 quite vital, you're right, for many of our
10 participants.
11 Denise Hillier:
12 And I guess I would just add in terms of the
13 Community Support Program, certainly high numbers of
14 people there who haven't finished high school.
15 Certainly in some cases classroom settings don't work
16 and one of the programs that we do actually have
17 there that's been highly successful is called
18 Stella's Pride, and it's actually a work group that
19 occurs every week, it's three hours, but one of the
20 jobs that occurs is through a rags program where
21 people actually cut materials that are then bagged in
22 large bags and sold to, as an example, Metrobus and
23 various garages around the city, and so those people
24 are earning a wage through that program and there's

1 always a meal component built in. So sometimes it's
2 not about kind of stepping up the education piece.
3 Sometimes what people want is some meaningful work,
4 and so that program has been hugely effective for
5 participants in that program.
6 Kevin Parsons:
7 You're doing a fantastic job because exactly what you
8 said there that time, once a person can get a job or
9 have some employment, it gives them a real purpose,
10 so it's huge, and the education part of it, as we all
11 know, is huge for anyone. So anyway, thank you for
12 your presentation.
13 Honourable Felix Collins:
14 Gerry?
15 Gerry Rogers:
16 Thank you. The work that you're doing is just so
17 incredible, and I know what's happening is that the
18 more you do, more and more and more is downloaded
19 onto you as well to continue to do that work and help
20 people who are needing it. Some of the gaps that you
21 are filling in are quite amazing, considering the
22 resources you have as well. We're hearing a lot from
23 different organizations about the need for multi-year
24 funding and how important that is. How can you plan

1 and how can your staff plan? Also, that issue of
2 funding for evaluations as well, nobody wants to give
3 that kind of funding and core funding is so hard to
4 get and then you're constantly scrambling for program
5 funding. We're hearing a lot as well about parents
6 of adult children with persistent needs and how
7 difficult that is. I have referred a lot of people
8 to Stella's Circle, people who call my office looking
9 for help, and particularly around supportive housing,
10 and of course I know that you can't meet their needs
11 and that somehow though there's a sense that, oh,
12 it's all taken care of because Stella's Circle can do
13 it and Choices can do it, but in fact your wait lists
14 are so great as well.
15
16 What's happening, because I know that folks like
17 you and The Gathering Place, what happens to people
18 when they can't get access to the type of help that
19 they need, whether it be supportive housing, whether
20 it be seeing a psychologist or a social worker? What
21 happens to them if they can't get access to that kind
22 of help in a timely manner?
23 Denise Hillier:
24 I would say sometimes what we see is that people end

1 up institutionalized, and, I mean, just to touch on
2 that one again, I'm back to transition, but I do, I
3 guess, recall a case because it just so bothered me
4 that we had somebody who transitioned, I think it
5 might have been at the age of 21, because there had
6 been a service agreement in place, but we learned
7 more after the fact, I guess, but it was someone who
8 received 24-hour support and turned 21 and received
9 40 hours and within a year were serving time at a
10 federal institution. And I think that that's what
11 happens when people don't get the service or get wait
12 listed for far too long.
13
14 What I will say is that the inclusion piece of
15 activities that we do certainly where we try not to
16 say to people that you sit on a wait list and you do
17 nothing for a year, but if there's a piece of
18 anything we can do, if it's social inclusion or
19 sometimes through employment services we get people
20 linked to an employment counsellor, an employment
21 support person, that we will try to help them
22 navigate all the other systems that they're likely
23 trying to navigate while they may be looking or
24 considering going back to school or getting to work.

1 Gerry Rogers:
2 And what's happening with our women in the prison
3 system?
4 Denise Hillier:
5 The numbers are high again.
6 Gerry Rogers:
7 Who's in jail?
8 Denise Hillier:
9 A lot of drug-related and a lot of remands, about 75
10 percent maybe remands, for women. I can't speak to
11 men. And we're there, still there. We do two days a
12 week of addictions and we alternate between trauma
13 program and anger management groups as well as
14 individual --
15 Honourable Felix Collins:
16 I'm going to have to intervene again now because we
17 have three more speakers. I'd like to get them in
18 before lunch because they've made arrangements to be
19 here before lunch and to put them off till after
20 lunch I think would not be fair. Thanks so much for
21 your presentation. One thing we found in these
22 consultations, we didn't have to have these
23 consultations to find this out, but there are some
24 groups out there doing some great work and obviously

1 Stella's Circle is one of them and your work in the
2 community is legendary, actually, and we thank you so
3 much for the contribution. You identified some gaps
4 that we found in all the consultations we go through,
5 adult children with aging parents. That's been
6 coming through, all through. The transitions from
7 youth to adult, we've heard this, and of course
8 access and wait lists for medical practitioners. So
9 thank you so much for your presentation and keep up
10 the good work.
11 Dr. Bruce Gilbert:
12 Okay. We have Ed Sawdon. Ed, are you going to come
13 up here or are you going to sit over there? Your
14 choice.
15 Ed Sawdon:
16 Sit here.
17 Dr. Bruce Gilbert:
18 Okay. Ed has a 15-minute time slot. Ed, if you keep
19 an eye on me, I'll give you a five-minute warning.
20 Take it away.
21 Honourable Felix Collins:
22 Welcome, Ed. The floor is yours and you're on the
23 clock.
24

1 Ed Sawdon:
2 For those of you who don't know me, my name is Ed
3 Sawdon. Some of you are familiar with me already.
4 I've been a mental health consumer since 1975. That
5 was around the same time I had ulcerative colitis and
6 I've had to deal with it over the decades and I'm
7 still dealing with it. I also have various physical
8 health programs too on top of that, and I'm also a
9 volunteer and advocate, volunteer board member of
10 CMHA, as well as the Pottle Centre. I wanted to be
11 here and before I speak I gave your staff person,
12 Gillian, correspondences from former or current
13 Ministers of Health from various provinces like
14 Alberta, Saskatchewan, Manitoba, Quebec, New
15 Brunswick, and Nova Scotia, and also from your former
16 colleague, the Honourable Jerome Kennedy, the former
17 Minister of Health and Community Services, the former
18 Premier of Ontario Dalton McGuinty, as well as the
19 Federal Opposition Health Critic, Libby Davies.
20
21 Now, I'm advocating for mental health drug
22 coverage. Since 2003 I've advocated for a
23 universally accessible pharmacare program or a
24 national pharmacare program, to not only Newfoundland

1 and Labrador, but also for all of Canada. In spite
2 of the overwhelming support from Canada's ten
3 provinces and three territories, Canadian disability
4 in poverty-related organizations and agencies,
5 Canadian Medical Association, most Canadians and even
6 Canadians from different political affiliations,
7 unfortunately our current federal government has
8 abandoned its leadership role in the now former
9 National Pharmaceutical Strategy and in creating a
10 national pharmacare program and has left Canadians
11 with 14 federal and provincial, territorial drug
12 programs.
13
14 Unfortunately, not all Canadians, including some
15 of our province's mental health consumers, have
16 access to a private or public drug coverage. While
17 it is true that hospitalized Newfoundlanders and
18 Labradorians have our medications covered by our
19 provincial medicare program, MCP, in our health care
20 institutions, it's good that they're covered but when
21 they are released from the hospital it's a different
22 story for some people.
23
24 In its 2009 letter, the former Federal Finance

1 Minister, the late Honourable James Flaherty writes,
2 "Under the *Canada Health Act*, all necessary drug
3 therapy administered within a Canadian hospital
4 setting," and that includes the Waterford,
5 "provincial and territorial governments are
6 responsible for the administration of their own
7 publicly funded prescription drug programs when
8 they're released from the hospital. Most Canadians
9 have access to insurance coverage for prescription
10 medicines through public or private insurance plans.
11 The federal, provincial and territorial governments
12 offer varying levels of coverage with different
13 eligibility requirements, premiums and deductibles.
14 The publicly funded programs generally provide
15 insurance coverage for those most in need based on
16 age, income, and medical condition."
17
18 Yes, it is true that the Newfoundland and Labrador
19 Prescription Drug Program, otherwise known as NLPDP,
20 has five drug plans, The Foundation Plan for those
21 residents on income support, children under the Child
22 Youth and Family Services, and individuals under
23 supervised care; The 65Plus Plan for those residents
24 who are now receiving the federal Old Age Security

1 and Guaranteed Income supplement benefits; The Access
2 Plan; The Assurance Plan; and The Select Needs Plan
3 for residents who have Cystic Fibrosis and Growth
4 Hormone Deficiency. But while the provincial
5 government has made modest improvements in our NLPDP,
6 there is no special drug plan for those residents who
7 have long-term mental health issues.
8
9
10 One must keep in mind that Newfoundlanders and
11 Labradorians have to be eligible for any one of the
12 five provincial drug plans. One must ask themselves
13 what happens to those individuals irrespective of age
14 or social status who don't qualify for any of the
15 NLPDP drug plans, and who don't have access to other
16 public or private drug programs. For example, what
17 happens to seniors living on Canada Pension Plan,
18 OAS, and a low to moderate retirement pension, who
19 have no drug coverage and simply cannot afford high
20 cost premiums into a private plan? For those mental
21 health consumers who are eligible for the access or
22 the insurance plans or have access to certain private
23 plans, the individuals' high co-pay amounts may deter
24 them from getting their medically-required drugs.

1 Now, there's also two points that I didn't mention
2 here and I need to mention them. There are people
3 who are currently covered under one of the province's
4 drug plans, and certain medications are not covered
5 under the provincial drug formulary. For example,
6 2009, I sent an email message to the former premier,
7 Danny Williams, and the former Minister of Health and
8 Community Services, Ross Wiseman, that I found out, I
9 don't need it but I found out that other mental
10 health consumers who require the anti-depressant
11 Cipralex, or the generic name is Escitalopram, don't
12 get coverage, even under special authorization.
13
14 Let me go back. Currently, there is one drug that
15 is not covered under the drug plan for those
16 residents who have schizophrenia or are being treated
17 for bipolar, Abilify. I think that's how you
18 pronounce it. Some of these drug names are hard to
19 pronounce. But anyways, Abilify, I believe it is.
20 It's not covered under the drug formulary and most
21 private insurance coverages don't cover it as well.
22 So what happens to them and what happens to people
23 who through, for family, personal reasons, are going
24 to find work in another, what happens to their drug

1 coverage when they're out of province? Does the
2 Newfoundland and Labrador Prescription Drug Program
3 cover those people who need newer prescribed drugs in
4 other provinces like Ontario or Nova Scotia? Does
5 your drug plan cover you when you're out of province?
6
7 Since Canada nor Newfoundland and Labrador have no
8 universal drug program, I have been advocating for a
9 specialized mental health drug plan, ever since our
10 province, Newfoundland and Labrador, had the
11 2004-2005 Mental Health Strategy. So this isn't new.
12 I've been advocating this for over ten years.
13
14 Outside of Newfoundland and Labrador, there are
15 two provinces who provide a specialized mental
16 health-related drug plan, British Columbia and Prince
17 Edward Island. I was quite surprised about PEI.
18 Under the British Columbia PharmaCare Program there
19 is Plan G for clients of mental health service
20 centres for whom the cost of medication is a
21 significant barrier to treatment.
22
23 In Prince Edward Island, their provincial
24 government provides a community mental health drug

1 program. This program is for long-term psychiatric
2 patients living in the community who require long
3 acting injectable antipsychotic medications. In
4 provinces such as Alberta and Quebec, residents can
5 get universally accessible drug coverage for their
6 various physical and mental health conditions,
7 provided they have no other private or public drug
8 plans. And just like Newfoundland and Labrador,
9 people in British Columbia, Manitoba, Ontario, New
10 Brunswick, Nova Scotia, PEI, and Saskatchewan can get
11 access to public coverage, provided they meet certain
12 eligibility requirements that are based on income or
13 annual drug costs or family size or age. Mind you,
14 Ontario has a Special Drugs Program for those
15 residents with schizophrenia who require the drug
16 Clozapine.
17
18 In Canada's three northern territories - Yukon,
19 Northwest Territories and Nunavut - their
20 non-aboriginal residents can get most, if not all,
21 their psychiatric drugs through their Chronic
22 Diseases and Conditions Program. Federally,
23 Aboriginal and Inuit, veterans, military personnel,
24 RCMP, and the federal government's approved refugees,

1 can get their psychiatric drugs covered by a federal
2 drug plan.
3
4 By having a specialized mental health drug
5 program, the government and society can prevent
6 certain mental health consumers from falling through
7 the cracks of our country and province's social
8 safety net. It can also prevent certain residents
9 from being readmitted into the Waterford Hospital or
10 other provincially administered hospitals, which in
11 the long term it costs our government much more in
12 tax dollars since the hospital meds are covered by
13 our public medicare system than by having a far more
14 less expensive universally accessible pharmacare
15 program or a mental health drug plan.
16
17 We know that mental illness does not discriminate
18 and a public drug plan should not discriminate
19 either, and by having such a program we can improve
20 mental health consumers' quality of life and in many
21 cases reduce poverty. If our province is serious
22 about reducing poverty through the Poverty Reduction
23 Strategy and helping people's coping skills, both
24 mentally and physically, or helping people go through

1 the recovery process, then I say us Newfoundlanders
2 and Labradorians need a public pharmacare program.
3 Thank you.
4 Honourable Felix Collins:
5 Thank you, Mr. Sawdon.
6 Ed Sawdon:
7 Thank you very much.
8 Honourable Felix Collins:
9 A few minutes for questions, and, Gerry, we'll start
10 with you.
11 Gerry Rogers:
12 Thank you, Ed, and I know you've written many letters
13 to the editor about this as well and have been
14 championing this cause for a long time, and I think
15 it sums it up so well when you say that we know that
16 mental illness does not discriminate and a public
17 drug plan should not discriminate either. And I
18 think it'd be kind of interesting, because all the
19 premiers are meeting here now this week, and just
20 wondering if they will be talking about a national
21 pharmacare, that whole issue, because it's so clear,
22 it makes so much sense, and then the trickle-down
23 effect in terms of how that will affect a provincial
24 pharmacare program.

1 Ed Sawdon:
2 I'd like to comment on that. I agree with you
3 wholeheartedly. I mean, I've been calling for a
4 renewal of the 2004 National Health Accord which our
5 federal government has just put aside, cast aside. I
6 believe the provincial government, working with other
7 provinces and territories, should call for a,
8 re-introduce the National Pharmaceutical Strategy and
9 we should also call for a national pharmacare program
10 because it's vitally important, because I believe all
11 Canadians, no matter where you live, work or
12 whatever, whatever your social status is, we should
13 be all treated the same. It should be like universal
14 medicare. When you go from province to province you
15 get comparable medical benefits or coverage for
16 hospitalization and doctors' fees and so on and so
17 forth. The same rules should apply with our drug
18 programs.
19
20 Some provinces are more generous than others.
21 Unfortunately, the federal government hasn't helped
22 matters. They've dumped the issue onto the provinces
23 and territories, which I don't think is right. The
24 federal government needs to play a leadership role in

1 this. The fact that they cut federal transfers,
2 federal health transfers, to not only Newfoundland
3 and Labrador but throughout the whole country,
4 they're cutting $36 billion, isn't going to help our
5 province and other provinces' situation.
6
7 I mean, imagine if they didn't cut that benefit.
8 Maybe we would have a new Waterford and maybe we
9 would have a pharmacare program and an improved home
10 care program, and there's so many needs, but yet the
11 federal government seems to be what, dump the problem
12 onto the provinces. I don't know if it's fair to say
13 that they're deficit downloading. Sounds familiar,
14 because the previous federal government did that back
15 in the 1990s.
16
17 But health care concerns all of us. I mean, when
18 it comes to pharmacare, it can make it a matter of
19 life and death, and if the health care profession and
20 the government wants to save taxpayers' money, I
21 believe provincially and nationally you got to invest
22 in a pharmacare program because if you don't it's
23 going to cost you a lot more in the long term.
24

1 And it's not just a political issue; it's a moral
2 issue. I mean, we shouldn't leave anybody behind. I
3 don't believe in that. I believe in inclusion, I
4 believe that we're all valued members of society and
5 that we're all equal and we should get comparable
6 equal treatment when it comes to pharmacare as well
7 as other aspects of health care.
8 Honourable Felix Collins:
9 Any further questions from the Panel?
10 Christopher Mitchelmore:
11 Just a brief question, I guess, Minister. I mean,
12 certainly we've heard that as well from our second
13 presenter, that access to medication is so critical
14 and important. Throughout many of our consultations
15 we've heard about the NLPDP and how certain
16 medications need to possibly be added or how they get
17 special authorization or how that process -- that's
18 been raised time and time again. I just wanted to
19 clarify and ask a question about the British Columbia
20 PharmaCare Program, the Plan G that you have
21 mentioned, because it's talking about those who have
22 a barrier, obviously like a financial barrier, to get
23 treatment. So like in Newfoundland and Labrador, my
24 understanding is that the insurance plan, if somebody

1 has a financial barrier, if they have high costs of
2 medication, then they would get access to insurance
3 program with a co-pay that they can afford.
4 Ed Sawdon:
5 Yeah. Going to that specific point, I believe that
6 supports for people, outpatients in other words,
7 supports for outpatients who have been released from
8 the hospital, I believe that the supports, including
9 the Newfoundland and Labrador Prescription Drug
10 Program, and there's other supports out there too
11 that we all know of, like housing, like
12 transportation assistance, like home care or
13 specialized care in the community, it should be
14 patient focus. The person who's leaving the hospital
15 shouldn't have to go and run around to a federal or
16 provincial program and see if they qualify. It
17 should be set up even before the patient is released
18 from hospital so that that way their medical care
19 continues and is uninterrupted and they don't have to
20 worry about all the stress and anxiety about how are
21 they going to ever possibly pay for all or part of
22 their medical uninsured medical expenses, including
23 drugs.
24

1 Honourable Felix Collins:
2 Okay. We'll move on, Mr. Sawdon.
3 Ed Sawdon:
4 Thank you.
5 Honourable Felix Collins:
6 Thank you so much for your presentation.
7 Ed Sawdon:
8 Thank you, thank you very much.
9 Dr. Bruce Gilbert:
10 Okay. We have Patrick Hickey. Patrick, I don't know
11 if you want to go here or here. Okay, you have 15
12 minutes. Keep your eye on me and I'll give you a
13 five-minute warning. Take it away. Thank you.
14 Honourable Felix Collins:
15 Thank you, Mr. Hickey, for coming today. I certainly
16 recognize the name. You've gained name recognition
17 and deservedly so for your contribution that you've
18 made to this issue in recent times, and we're
19 certainly looking forward to hearing from you this
20 morning. The floor is yours.
21 Patrick Hickey:
22 Thank you, Gerry, for encouraging me to come. I plan
23 to just give a brief overview of sort of mental
24 health from the youth perspective and sort of end

1 with just a closing statement. It's a bit
2 (inaudible).
3
4 I'd like to start though with a few statistics
5 gathered from my own school which you may have heard,
6 but I think they'll be valuable for your notes. So
7 in October of this school year, in 2014, I did a
8 survey in my school, Holy Heart High School, of 1,000
9 students to gain some data on mental health in our
10 own school. So a few stats that we actually
11 generated ourselves. Twenty-two percent of the
12 students that we polled were currently diagnosed with
13 a mental illness, 85 percent of the students had
14 experienced severe anxiety, 85 percent suffered from
15 anxiety, 53 percent had suffered from severe anxiety,
16 78 percent of students had their school performance
17 affected by a mental health issue, excuse me, 35
18 percent of our students had admitted to using drugs
19 to deal with their depression or anxiety, 45 percent
20 of students were not currently happy with their body
21 image, 53 percent of students believe that stigma is
22 the reason we don't talk about mental health, and 68
23 percent of students feel that they are unable to help
24 themselves or others who are suffering from a mental

1 health issue. So that kind of puts it into
2 perspective, I guess, how real an issue it is in our
3 schools and amongst our youth.
4
5 In terms of mental health affecting youth, I have
6 no (phonetic) experience myself, so I will speak sort
7 of generally on the issue, and to do so, youth spend
8 most of their time in schools. We go to school five
9 days a week. Everything we do is revolved around
10 school from a young age until we're almost 18 years
11 old. And so within schools, mental health in
12 schools, it's sort of split up into counsellors and
13 classrooms.
14
15 I'm sure you've heard from the NLCPA, the current
16 counsellor-to-student ratio in schools is 1 to 500.
17 So with 1,000 students in my school, we had two
18 guidance counsellors, and any time of day when you
19 walked by the guidance offices, there's a line-up of
20 at least three or four people waiting to get in to
21 see the guidance counsellor. This could be an issue
22 with your schedule, having to get a course changed,
23 but that's for about one week at the beginning of the
24 school year and from then it's mostly mental health

1 issues, self-esteem issues, various social conflicts.
2
3 And so, I'm sure you've also heard that the NLCPA
4 is recommending we reduce that ratio from 1 to 500 to
5 250, so that would have four counsellors at my
6 school, would reduce the wait times and definitely,
7 probably also improve the quality of care that
8 students are getting from our counsellors.
9
10 Moreover, the psychologist ratio is currently over
11 1 to 1,000, so we don't even have one psychologist
12 for my school, and believe me there's a need for one
13 in our school alone, but our psychologist I believe
14 is responsible for three schools in the city, which
15 is at times definitely not sufficient to meet the
16 needs of students in our schools.
17
18 I'll get back to that side of things in a minute,
19 but then within the classroom, I went through 13
20 years of the public school system without ever
21 learning about mental health whatsoever within the
22 classroom, period. I never learned anything. I'm
23 not even in a position to probably speak here today
24 because, like everyone else here, I have no

1 qualifications at all. It's almost ironic that you
2 know my name because all of the things that I have
3 done over the past 12 months I should never have had
4 to do or attempt or even think about, and that's
5 something I think about quite often.
6
7 But within the classroom and education within the
8 province, and what I'm speaking of now is
9 extrapolated from the youth group that I started,
10 which encompasses every high school in the city, no
11 students in that group who represent every high
12 school in the city has ever learned about mental
13 health in school. That's from kindergarten through
14 grade 12. We do do courses where we think it could
15 be incorporated, especially in high school, which is
16 where we all were when we discussed this. We have a
17 healthy living course. There are second level and
18 third level biology courses, and these are offered in
19 every school across the province, where you could
20 incorporate the simplest black and white thing about
21 mental health to at least get some awareness out
22 about it, not even necessarily to educate us but just
23 to put that in our ear so we're more familiar with
24 it. But just putting it in high school wouldn't be

1 sufficient because we all know about stigma and how
2 it's developed and waiting until high school I think
3 would be too late, but I personally believe if we
4 were to implement something obviously in association
5 with the school boards, I think you would have to
6 start in high school. If you were to start in
7 kindergarten today, you would already miss 12 years
8 of students, but if you start in grade 12 or a third
9 level course today, everyone would get caught there
10 and you can work your way down to the bottom of the
11 ladder. But even in junior high we need to take
12 mandatory health courses, again every student in the
13 province would take these. A health course, and you
14 don't actually learn about mental health at all,
15 period, nothing. You learn very little in that
16 course, to be frank, but you learn nothing about
17 mental health, which is equally as much a part of our
18 bodies as physical health. And you can even start
19 this in kindergarten, primary school, just learning
20 about emotions and the body and mind, but it's
21 definitely something -- that was the top issue that
22 our youth group identified that's missing currently
23 for youth regarding mental health in the province, at
24 least in the city definitely.

1
2 But going back to the counsellors, if you were to
3 go to your school's guidance counsellor and get
4 referred to a GP or to a psychologist or eventually
5 you needed to see a specialist, from my personal
6 experiences, everyone who I've been talking to over
7 the past 12 months or so, the shortest wait time I've
8 heard of to see someone is four months, which might
9 sound pretty good but, I mean, these issues aren't
10 negligible, they're not trivial. Oftentimes they're
11 quite serious and four months can be too long, and
12 I've also heard of wait times of over 15 and over 16
13 months to see a specialist, unless you admit to being
14 suicidal at the time when you're requesting an
15 appointment. Then you'll be seen to immediately.
16 But if I was suicidal yesterday and today I'm being
17 referred, I will wait 16 months, which is -- it is
18 what it is and it could be much worse. You could
19 have to wait five years, but, you know, four to 16
20 months, that's what it is now.
21
22 So then you look at in between these wait times,
23 between being referred and actually seeing someone,
24 and we've seen a lot of good work here with Bridge

1 the Gap from Eastern Health, which the government
2 supported, and that's sort of symbolic, I think, of
3 how technology is a good way to engage youth and
4 service youth, or serve youth rather. And also I
5 think school in-services are a great way to do a lot
6 of things for mental health, and obviously that's
7 where I focused a lot of my efforts within my own
8 school and for all the schools across the province,
9 but you shouldn't have a 16-year old student
10 dedicating over a year of his life to organize this.
11 It should probably be done from the school board or
12 schools themselves, again through the school board or
13 through the provincial government. Something should
14 be in place so that you don't have a 16-year old
15 planning an event for every high school in the
16 province regarding mental health, because of the wait
17 times. Obviously if the services were perfect, there
18 wouldn't be a need for any of this.
19
20 And so, I'd just sort of like to end with, I
21 guess, a template that I always keep in mind whenever
22 I approach any initiative, and it's sort of three
23 steps that are progressive. So you start with
24 awareness and you progress to education and you end

1 with action, one, two, three, and you can't skip from
2 awareness to action. You can't skip awareness and
3 start at education and go to action. And if you
4 start with education and then go to awareness and
5 then action, you won't have success, but I think
6 those three steps in order really work. And so in
7 terms of -- and you can apply this to anything. I
8 look at it with environmental issues, mental health
9 issues, anything, but in terms of mental health with
10 youth and in the school, if you start to bring
11 awareness to mental health in schools, which is the
12 best way to get to youth, you eliminate the stigma
13 just having a definition, having to know what
14 depression is in Biology 2201 or 2202, whatever the
15 course is called. That will create some awareness
16 and reduce the stigma. And plus, if you start to
17 actually educate people, like really educate them,
18 the whole spectrum of what mental health is, well
19 then people will be knowledgeable but you'll also
20 start to identify problems and issues within people's
21 own mental health, which leads you then to actually
22 taking action and then you will have to see to these
23 problems and help people overcome their mental
24 illnesses, mental health issues, or to help any given

1 any individual reach their maximum potential when it
2 comes to their own mental wellness. And those steps
3 again have to be followed in order, but as you create
4 more awareness, more people will start to become
5 educated, and as you educate more people there will
6 be more problems.
7
8 Obviously we've seen a lot of good work happening
9 here over the past year, year and a half, regarding
10 mental health, and this committee itself is great,
11 but it all really has to keep pushing forward because
12 the potential which lies in each of those three steps
13 exponentially grows as more people sort of are
14 becoming aware and knowledgeable and then there's a
15 need for action to be taken.
16
17 So that's everything I've prepared. Quite simple,
18 I guess. It's obviously a big issue, something a lot
19 of people are working for and there's still a lot of
20 work to be done, but it's very encouraging to see
21 everything that's been happening and I hope you guys
22 have some questions, and when you eventually go
23 through everything you've compiled, I hope that youth
24 don't get left behind. Starting with the young

1 people I think is the best way to approach this issue
2 and definitely I'd like to reinforce the idea of,
3 like, an education reform for mental health in the
4 province is definitely something that's needed, I
5 think.
6 Honourable Felix Collins:
7 Thank you, Patrick, very much. Okay, we got a few
8 minutes for questions. This end?
9 Kevin Parsons:
10 Patrick, thank you for your presentation. Patrick,
11 it was excellent actually. Yes, and I agree with you
12 100 percent. I mean, I think that when we look at
13 mental health and even addictions and everything
14 else, the earlier we start and educate people, the
15 stigma itself and the problems that we incur always
16 starts at a younger age and it seems like they keep
17 snowballing and getting worse and worse, so you're
18 doing a great job. I just want to say I agree with
19 you 100 percent. It's something that we should be
20 working at, even like you said, from kindergarten
21 right on through. So I want to just let you know
22 that I fully agree and support what you're saying
23 there this morning. Thank you very much.
24

1 Honourable Felix Collins:
2 Chris?
3 Christopher Mitchelmore:
4 Patrick, thanks so much for coming out today. I had
5 the opportunity, I guess, at one of the round tables
6 in St. John's here to sit with a counsellor who
7 raised the issue of the number of students as well as
8 one of the youth representatives who sit on the
9 committee, so it was really empowering to see young
10 people involved and engaged and part of the
11 discussion, and I think that it is somewhat
12 concerning but I think it is empowering that you took
13 it upon yourself and gathered all of these people to
14 create the group and the organization to develop this
15 awareness and education and take action. But it
16 really does need to be a collaborative approach, so
17 there must be some breakdown somewhere when it comes
18 to the school board and government to really make
19 this something that is more cohesive and is across
20 the province so that the outreach is done when it
21 comes to mental health and addictions awareness. So,
22 can you provide some advice or what's actually
23 happening with your group in terms of succession
24 planning or how government and the school board can

1 be a bigger partner or player in making this happen
2 so that we can get the message out to other schools
3 in other areas so that more positives can happen,
4 because the statistics that you started off with were
5 extremely alarming to hear for me as a young person
6 in Newfoundland and Labrador?
7 Patrick Hickey:
8 Sure. Well, I think coordination is needed.
9 Currently it seems like the only people who are
10 really trying to do something are actually within the
11 schools and mostly the students. We don't have the
12 answers. I don't have the solution. It's such a
13 complex issue. There's no, like, one simple answer
14 and such a broad issue, but I definitely think there
15 does need to be coordination between, like, the
16 students, the teachers, the board, and government to
17 get something in place. Whatever that thing is, I
18 think it will take a round table of representatives
19 from each demographic to sit down and I suppose more
20 clearly define the issue and then work towards the
21 solution, but I think it's important that the
22 government, if this is something that they decide to
23 dedicate themselves to, to have youth at the table
24 and it really has to be sort of a 50/50 thing going

1 forward, not only to clearly define the issue but
2 also to, I guess, create a sustainable and effective
3 solution.
4 Gerry Rogers:
5 Patrick, thank you so much. And, no, it shouldn't
6 have to have been a 16-year old to do this, but thank
7 God you did. Like, absolutely thank God you did.
8 And I think that what you folks did at Holy Heart,
9 and then across the province, is you issued a huge
10 wake-up call, a huge wake-up call to all of us,
11 because it makes us say, my God, what are the gaps in
12 services, what can be done. My question is, when we
13 look at those stats and what we've been hearing
14 across the province as well is this increase in
15 depression, increase in anxiety, particularly around
16 our young people. What's going on? Like, what's
17 happening?
18 Patrick Hickey:
19 Sure. Obviously anxiety and depression are the two
20 most common mental illnesses within students at my
21 school anyways, or my past school. A lot of the
22 people -- or you hear often that it's attributed to
23 sort of the busy schedule, always going from A to B
24 and not having time for self-care. I do think that

1 sort of if we were a bit more cognizant of ourselves
2 and the idea that we all have mental health............... I
3 went to a national youth conference in November on
4 mental health run by the Mental Health Commission of
5 Canada, and so there were 130 students there, I
6 think, from across Canada who were supposed to be, or
7 who were, rather, sort of the leaders in mental
8 health in their own communities, and the first
9 question they asked us just by a show of hands was
10 who here has mental health, and I think I was the
11 only person in the room who raised my hand.
12
13 So, like, young people aren't really aware that,
14 of what mental health is, and I think that again
15 links back to the issue of a gap in our education
16 system, which is what we've all, has always come to
17 the surface at the Metro Youth Group that we've
18 established. Before I even got involved with this, I
19 wasn't even aware of my own state of mental health,
20 so it's something obviously you hear all the time, it
21 goes untalked about due to stigma and other reasons.
22 But I think the main reason for this would just be
23 you really don't know what's going on up here until
24 something bad happens, and we almost wait for tragedy

1 or an issue to really provoke any action.
2 Gerry Rogers:
3 But do you have any, even personal theory, as to,
4 like, when you're speaking with your friends and some
5 of the work that you've done, why we see such an
6 increase in anxiety and depression? Why are young
7 people suffering more? Like, what's happening?
8 Patrick Hickey:
9 I think more today than in the last (phonetic) years?
10 Gerry Rogers:
11 Yeah. Is it really an increase or is it that we're
12 more talking about it? But people talk about it as
13 if, like, there's this tsunami of anxiety of
14 depression, that there is more, and if so, like,
15 what's going on?
16 Patrick Hickey:
17 I think it comes down to two things. I think there
18 is a bit of a paradigm shift currently with more
19 people are starting to understand what mental health
20 is, and I think that lends itself to more people
21 understanding their own issues, but I do think again
22 with the pace of life always increasing and becoming
23 so fast, I think that that would be the most obvious
24 answer anyways in youth. You have students who,

1 students I personally met who you have swimming at
2 five in the morning before school. You go to school
3 for eight hours and then after school you might have
4 another sport, a music lesson, homework, and I think
5 the pace of life along with this paradigm shift, that
6 there may have been just as many ten years ago who
7 just didn't know what they were going through, and I
8 think it's a mix of both.
9 Honourable Felix Collins:
10 Thank you, Patrick. Certainly your contribution that
11 you've made in the last year or so and the youth
12 perspective that you bring has opened a lot of eyes,
13 a lot of ears, and I don't think I'd be reluctant at
14 all to say that the youth perspective that you bring
15 will certainly occupy a prominent consideration in
16 the recommendations of this Committee going forward.
17 Thank you so much for your presentation.
18 Dr. Bruce Gilbert:
19 Okay. Next up, Mary Walsh. Mary, you can have the
20 podium, you can have the chair over there.
21 Mary Walsh:
22 Probably the podium.
23 Dr. Bruce Gilbert:
24 Podium?

1 Mary Walsh:
2 I'll try to be fast and I'll just be 15 minutes
3 because then everybody can go to lunch at 12:30.
4 Dr. Bruce Gilbert:
5 Whatever you need.
6 Mary Walsh:
7 Okay, great, thank you.
8 Dr. Bruce Gilbert:
9 Good to see you.
10 Mary Walsh:
11 Thank you. Good to see you. Hi, my name is Mary
12 Walsh.
13 Honourable Felix Collins:
14 Mary, thank you very much for coming this morning.
15 Thank you so much.
16 Mary Walsh:
17 And I serve on the Minister's Committee with Mental
18 Health and Addiction, and also I was with Clara
19 Hughes and Howie Mandell this year doing the Bell
20 Let's Talk Day, and I've had experience trying to
21 access care in this province and in other provinces.
22
23 First of all, I'd like to say that as a member of
24 the Minister's Committee the really frustrating thing

1 is people from Eastern Health and people from, who
2 provide services, come and they make, they say we're
3 doing this, this, this, this, and this, and it's
4 great. I mean, the policy, it's great. But when you
5 try to get in, there's like a fortress mentality.
6 You'd think they'd be saying come in, come in, we've
7 got mental health services in here that maybe you
8 could access, but, no. I always think that mental
9 health is the red-haired stepchild of the health
10 services and addiction is the red-haired stepchild of
11 mental health, and so where are those two new
12 addiction centres that we've been talking about for
13 so long and why if we're building a new Waterford
14 Hospital do we have less beds, because 30 or 40 years
15 ago we thought it was inhumane to keep people locked
16 up in a hospital, to give them hospital care when
17 they suffered from mental illness, and now we put
18 those people in jail. I don't know what happened to
19 us. Did we lose our sense of compassion in the last
20 40 years?
21
22 But according to the police chief in Calgary, 50
23 percent of people he has in jail in, 50 percent of
24 the people who are in jail in Alberta are suffering

1 from mental illness or severe brain trauma.

2

3 Howard Shaffer, who's the federal guy, says that
4 it's more like 67 percent, 67 to 80 percent, some of
5 the numbers of people who are in jail suffering from
6 mental health issues and severe brain injury issues
7 also. And the Elizabeth Fry Society says that 80
8 percent of the women who are in jail in this country
9 have an addiction issue. So we're just locking
10 people up and nobody cares, I guess, in some way.
11 And so it always is money, isn't it? It's like, oh,
12 we've got this policy and we've got that policy and
13 everything is going to be hunky-dory, and then what
14 we do is we don't .... Try to get help at the
15 Janeway. Like, one in six children in this country
16 who need mental health care, that's how many get it,
17 one in six. Can you imagine if one in six children
18 with leukemia in this country received care? One in
19 six of people, of children who are seeking care,
20 that's who get any kind of mental health care.

21

22 And then they talk about best practices and best
23 practices as far as anybody knows is pharmaceuticals
24 and therapy, and yet nobody gets therapy. There is

1 no therapy, I mean, unless you have enormous amounts
2 of money. Of course the rich are fine. The rich
3 will always be fine, I guess, but for the middle
4 class and the poor, God help the poor, because they
5 don't get in anywhere. I've been down to the
6 hospital for six kids (phonetic) and they don't, I
7 mean as far as I can see, they don't, I don't know if
8 they provide psychiatric services at all. I know
9 they're fabulous with broken bones and they've done
10 -- I mean, God knows, I brought my child there when
11 he was growing up. But in terms of psychiatric
12 services that are available to children in this
13 province or children in this country, it is sadly,
14 sadly missing. So, and being on the Bell Let's Talk
15 Committee is like we're making people more aware and
16 we're educating them and everything, but then the
17 services aren't there.
18
19 So, it's like, I love Mr. Hickey's thing of
20 awareness, education and action. I think we have to
21 take action now. I don't think we can wait to make
22 more people aware. (Applause). Yes, what about the
23 people who need help now? What about the people who
24 can't access services for whatever reason? Like,

1 Mr. Baggs said at the very first meeting, he stood up
2 and he said if people don't want to work in mental
3 health care, then don't, like, get another job, but
4 don't always be there trying to build a wall and not
5 let me in and also make me feel bad that I'm seeking
6 help and seeking services, and that has been my
7 experience, trying to access care in this province
8 and also in Ontario.
9
10 They've got more money in Ontario obviously. They
11 have more facilities, but I don't know if they're
12 doing a better job of it. My being on both those,
13 being on the committee and being with Bell Let's Talk
14 has made me very hyperaware of just the radical lack
15 of services in this country generally.
16
17 When we said we were going to close down our
18 hospital for mental health 30 or 40 years ago, we
19 said that we were going to provide community care,
20 and of course Stella Burry and Choices for Youth are
21 two great services that the community does provide,
22 but it's not nearly enough. And I don't understand
23 why we now accept that we put people with mental
24 illness and addiction in jail, where 40 years ago we

1 couldn't accept that we put them in hospital. I
2 don't understand where our thinking has gone. I
3 think that we've just forgotten. We lock them away
4 and we put them in solitary confinement until they
5 lose their mind completely, and we just forget, we
6 forget it.
7
8 Anyway, that's all. I didn't want to go on much
9 further than that. That's all I wanted to say. I
10 know it's great that we're all talking about it. I'm
11 so glad that there's an All-Party Committee. It's
12 just that we need to take action. Money needs to be
13 spent. Research needs to be done.
14
15 My friend, Louis Bernard, died of his mental
16 illness and his doctor said to his father, well,
17 we're just throwing a bunch of drugs at him, hoping
18 that something will work. It was very, very honest
19 of that doctor to say that and I appreciate that, but
20 at the same time I don't appreciate that there's no
21 -- where is the research? Where are the research
22 dollars to help the one in five Canadians who
23 struggle with mental illness? We really have to get
24 that money out there. Anyway, thank you very much.

1 Honourable Felix Collins:
2 Thank you, Mary. Any questions from the Panel for
3 Mary?
4 Gerry Rogers:
5 Yes, I do. Mary, thanks so much. So if you were
6 queen of the mental health world here in the
7 province, and sometimes I think that you are, and I
8 know the incredible work that you've done and the
9 yelling and screaming and stomping of feet, and also
10 the incredible informed analysis that you have done,
11 do you have any concrete directions that you think
12 that we need to go in in the province, like some
13 concrete things that you think should be done first
14 off? Like, what needs to be done immediately? What
15 needs to be done long term?
16 Mary Walsh:
17 There are always concrete things that need to be done
18 and there are always concrete things that can be
19 done. Say the problem of homelessness, the Canadian
20 Commission for Mental Health just did a long study
21 that proved beyond a shadow of a doubt that if you
22 get housing first, that housing first actually does
23 work, that if you give people a house -- don't wait
24 for them to get off heroin, don't wait for them to

1 get their lives together. If people have a house and
2 a place to live, they are kept out of hospitals and
3 institutions that cost -- of course we only talk
4 about cost because somehow or other the merchants and
5 the conservatives took over completely, so now we
6 only talk about everything. We even talk about
7 poetry and its cost and how very, very fundamental it
8 is to keeping the economy going. But anyway, and I
9 can't stop myself from always going back to cost, but
10 cost is so effective.
11
12 We spend the least of any G8 country on research
13 in mental health, Canada does. We need to change
14 that. We need to spend the money. We need to find
15 out, there's all kinds of interesting things that are
16 happening. Now there's a whole anti-pharmaceutical
17 response. The psychiatric community is going through
18 a whole new way of looking at mental health, but
19 still there are no answers and because the kind of
20 money is not there to do the research, because we --
21 leukemia, we do the research.
22
23 Macular degeneration, I have macular degeneration
24 and it's the leading cause of blindness in North

1 America, and so people, the drug people of course put
2 an enormous amount of money into doing first trial,
3 second trial, third trial, because we're getting old,
4 so, so many people have macular degeneration so
5 they'll need this drug, so they came up with
6 Lucentis, which they're charging $15,000 or something
7 a shot for.
8
9 But when the need is there, then when the voices
10 rise up, then the people will respond, but we can't
11 keep hoping that drug companies are going to do our
12 work for us because there's all kinds of new ways,
13 because even best practices says that drugs aren't
14 the answer, and there's all kinds of new research
15 that shows that drugs may not be the answer at all,
16 that they may only be a very short-term answer,
17 leading to long-term therapy and things like that.
18 Sorry, Gerry, I thought I could be short about this
19 but I'm not.
20
21 Really, basically, more money, more passion, more
22 commitment, and we are the people and our government
23 represents us. They're not there for the
24 pharmaceutical companies. They're not there to save

1 money.

2

3 I remember when hospitals used to be called
4 hospitals. They were run by doctors, and then all of
5 a sudden -- I can remember when they were called
6 corporations and then it was a CEO running it,
7 somebody who didn't -- and once upon a time we cared
8 about each other for a brief period, I know, and so
9 doctors ran hospitals and hospitals were there to
10 serve people, and our government is here to serve us,
11 and so one in five of us suffers from mental illness,
12 so we have to up our game and we have to put the
13 money where our mouths are and we have to do the
14 research and we have to find the answers.
15 Christopher Mitchelmore:
16 Mary, I just, I think going back to the point of
17 putting people in jail, I mean, really resonates
18 because the lack of services or access to service is
19 pushing people with addictions issues or mental
20 health issues to seek incarceration. I have
21 constituents that have reached out to me. There's no
22 methadone access on the Great Northern Peninsula.
23 These people at the end of the day, I know one of
24 them committed a crime so they could get incarcerated

1 so they could get access to the services that they
2 needed, and the cost of that and to the overall
3 system and what that does to a person, an individual,
4 to be able to get their life back on track, it's
5 incredible that services don't exist where they're
6 needed when it comes to mental health and addictions,
7 and that we're pushing people to go to the criminal
8 system to seek the services, so that's a real
9 challenge. And I guess I wanted to raise that
10 because where you sit on these committees in that
11 role around the minister's level, are these types of
12 things talked about as to how we can get more
13 services in the community so that people aren't
14 pushed to go to the prison system to seek
15 incarceration?
16 Mary Walsh:
17 It's just shocking to me that the incarceration
18 system is the system that is looking after our people
19 who suffer from a disease, from an illness, that
20 that's where they have to go to seek help, that the
21 medical system is not open to them and the only place
22 that they can get help is through a system that is
23 not trained. We saw what happened to Ashley Smith.
24 People who are prison guards are not trained to look

1 after people with mental illness, and so the
2 tragedies happen one after another after another, and
3 I don't know what it will take until people recognize
4 that the services, putting the services in place will
5 in the end, I mean, I hate to just go back again to
6 the money situation, but it costs so much less to
7 have a methadone program on the Great Northern
8 Peninsula than to keep probably even that one guy in
9 jail for how long.
10
11 And is methadone the answer? I mean, we all leapt
12 on the methadone thing and we started putting 16-year
13 olds, 17-year olds on methadone, a lifetime program.
14 It's like, come on, could we not send them to a rehab
15 centre first? The money would be more expensive up
16 front and there'd be no great pharmaceutical payoff,
17 so. I mean, I'm not entirely, but something should
18 be done. Some services should be available that that
19 person feels that they could access.
20
21 And Gerry asked a question about young people and
22 depression and anxiety and it's because people are
23 faced with hopelessness. I remember going to
24 Sheshatshiu in 1986 when the overflights were on and

1 there were a lot of young people in Sheshatshiu
2 attempting suicide because they saw no future for
3 themselves, because they saw a world that was closed
4 against them. They saw them losing themselves,
5 losing their own culture, losing what was important
6 to them, and yet having nothing offered for them to
7 grasp onto, and I think that in an increasingly
8 conservative business-modelled world, I think our
9 children are going, where do I, where do I go? Where
10 do I fit? And that, I think that that -- I'm not
11 blaming all mental illness on capitalism, but I think
12 that as we embrace more and more of the, that may the
13 best man win and I've got mine, Jack, and you get
14 yours, I think it does have a severe cost, and one of
15 those costs is that our children are becoming more
16 anxiety-ridden and depressive. Anyway, I have
17 nothing to back that up at all.
18 Honourable Felix Collins:
19 Mary, thank you so much for taking the time to come
20 and make your presentation today. It's certainly
21 appreciated.
22 Mary Walsh:
23 And thank you for having me. Thank you.
24

1 Honourable Felix Collins:
2 Folks, we're going to take a lunch break. We have a
3 half hour scheduled but we're going to try to cut the
4 lunch break. We have a half hour scheduled but if we
5 can cut it to 20 minutes or so, keep it close to
6 that, so remember be on the clock and when we call
7 you back because people are here to make
8 presentations, they have schedules to follow as well
9 so we have to try to accommodate them. So we'll take
10 a quick break.
11 (Off the Record)
12 Honourable Felix Collins:
13 Good afternoon. I trust you've all had a chance to
14 have a little refreshment and a bite to eat, bathroom
15 break, whatever else was required. Okay, Bruce.
16 Dr. Bruce Gilbert:
17 Okay, I'd like to welcome Chad Perrin, Program
18 Manager Adult Residential Care with Caregivers
19 Newfoundland and Labrador, I think.
20 Chad Perrin:
21 Yeah.
22 Dr. Bruce Gilbert:
23 Take it away, Chad. You're down in my book as having
24 30 minutes. You have a Power Point, you got your

1 flicker there?
2 Chad Perrin:
3 Yeah.
4 Dr. Bruce Gilbert:
5 You're good to go? I'll give you a ten-minute and a
6 five-minute warning with a card, just so you know
7 where you are on your time.
8 Chad Perrin:
9 Yeah.
10 Dr. Bruce Gilbert:
11 If you want to have some engaged conversation try and
12 save a few minutes.
13 Chad Perrin:
14 Okay.
15 Dr. Bruce Gilbert:
16 Thanks.
17 Honourable Felix Collins:
18 Welcome Chad, thanks very much for coming today. The
19 floor is yours, sir.
20 Chad Perrin:
21 Okay. As has already been mentioned, my name is Chad
22 Perrin, I'm a program manager with Caregivers and I'm
23 also a registered social worker here on the island.
24 We offer, Caregivers offers a lot of different

1 services. My program's focus is a specific group,
2 adults with intellectual disabilities and supporting
3 them in the community. So, intellectual disabilities
4 is the very first disorder identified in DSM 5.
5 That's the book psychiatrists use when they're trying
6 to diagnose any type of mental disorder, covered
7 under the heading neurological disorders.
8
9 The needs of this service population impacts many
10 different aspects of government-funded services
11 including health care, inclusive of mental health,
12 the criminal justice and income support. While the
13 primary purpose of this presentation is to identify
14 the impact, the needs of these individuals may have
15 on the mental health system, it's impossible to avoid
16 the discussion as to how these individuals are
17 supported in the community. Those two particular
18 components, the mental health service provision, as
19 well as community supports, are inextricably linked
20 as we're going to discuss during the course of the
21 presentation.
22
23 So, probably the first thing to talk about is how
24 many people we're talking about that may present with

1 this particular disability. There haven't been a
2 tremendous number of studies to identify the number
3 for Newfoundland specifically. So in order to
4 identify that number we have to take a look at
5 national studies to determine prevalence. In one
6 study, they mentioned approximately 10.37 out of
7 1,000 will present with intellectual disabilities.
8 Other studies equate it to about three percent of the
9 population with about one percent of that being in
10 the adult range. There's a couple copies of those
11 research papers in the appendices in the binders I
12 gave you guys.
13
14 Estimates of the proportion of adults with an
15 intellectual disability who have a dual diagnosis, so
16 that means not only do they have an intellectual
17 disability but they also have a mental health
18 disorder, a psychiatric, anxiety or mood disorder or
19 other, would be about 30.6 percent. So, when you're
20 talking about numbers, let's take three percent of
21 the 500,000 people in Newfoundland. You're talking
22 about 15,000 people in the province who present with
23 intellectual disabilities. If you're taking 30.6
24 percent of that number, you're looking at around

1 5,000 people who will present with co-occurring
2 disorders. Of the 15,000, about 10 to 15 percent of
3 that number will present with an intellectual
4 disability with what we refer to as challenging
5 behaviours. So, physical aggression, self-harm
6 behaviours which can be anything from hitting
7 themselves to putting themselves in danger by running
8 into traffic, not understanding the long-term effects
9 of what they're doing. Those kind of things. About
10 10 to 15 percent of that population are going to
11 present with what we refer to as challenging
12 behaviours.
13
14 So, for people with profound and multiple
15 disabilities, when you're talking about people who
16 present with co-occurring disorders, the prevalence
17 occurs probably higher, according to one of the
18 papers that are in your appendices there. So,
19 knowing that many people in the province are
20 affected, it's important to review what we're
21 currently doing for the service population of the
22 community.
23
24 So, this is a very brief, and this was something I

1 made up. This isn't something the government has
2 currently in existence right now, but when I was
3 trying to explain to my staff how services are
4 available in the community, this diagram kind of
5 presents an outline for what you would see. So, I'll
6 take a few minutes and identify each of them and some
7 of the challenges that we see at each point going
8 forward and how, I think, we can provide some more
9 care and quality care to the service population as
10 well as identifying the various impacts that this
11 service population has on the mental health system in
12 general.
13
14 For independent living, for this group, I mean,
15 you're talking about individuals who are really high
16 functioning. They're usually able to have some
17 semblance of work because of how high functioning
18 they are. They may or may not live independently.
19 They may live with families, they may live in a
20 supportive-living apartment. They're sometimes aided
21 by family or friends and they're sometimes able to
22 live completely independently, based on whatever
23 their needs are.
24

1 With this service population, when you're talking
2 about difficulties that they may experience, I think
3 we've already talked about today the difficulty that
4 we have in community housing across the island. It's
5 been really challenging for people who are able to
6 live independently because they may not need a
7 tremendous amount of support, but they might need
8 someone to check in on them every once in a while.
9 So we don't really have that type of supportive
10 environment where they could go and live on their
11 own. And even if they could live on their own,
12 housing costs in Newfoundland and Labrador have
13 skyrocketed in the past few years. So, even if they
14 could go out on their own, they can't afford to go
15 out on their own because the housing costs that have
16 increased.
17
18 And for those people who are rather
19 high-functioning and can go about the day-to-day,
20 there are some daytime programs that exist here in
21 the community that provide a really valuable service,
22 the Longside Club is one example, the Pottle Centre
23 is another. They do some excellent work, however,
24 they are woefully underfunded and there aren't a lot

1 of options outside of those for daytime services. So
2 children and youth are able to stay in the school
3 system until the age of 21, and that is what, for
4 want of a better term, is their vocation. It's their
5 education. When they become adults what you fill
6 your time with or what you do for your day-to-day
7 becomes challenging. You can't go to a movie every
8 day. You can't go to Tim Horton's every day. You
9 want meaningful interactions and vocation, if you're
10 able to. And for those who are not able to, who
11 aren't independent enough to be independent living,
12 you want some form of day service where they have
13 some meaningful interactions to their day so they're
14 not home all the time.
15
16 So, the importance of some of these day programs
17 is apparent when you're looking at some of the
18 service population and the lack of that available
19 service is woefully difficult, in St. John's,
20 especially, and in rural Newfoundland is much worse.
21
22 Supportive living is when you have staff who are
23 able to support an individual to remain in their
24 homes in the community. So, they could be living,

1 again, they could be living in an apartment on their
2 own, they could be living with family and by
3 providing qualified staff and support you're able to
4 maintain them in their placements in the community.
5 So, you really want to be able to do an appropriate
6 evaluation for families with children or adults who
7 present with challenging behaviours but those
8 evaluations currently are based on home-support
9 evaluations. Largely service administration for this
10 group is done by home support. So if you have an
11 adult who presents with challenging behaviours, then
12 you would do a home support evaluation to determine
13 how much support they may get and then you'd probably
14 be getting a home support worker who may or may not
15 be qualified to be able to provide the level of
16 behavioural support that family or that individual
17 may need.
18
19 Providing qualified, trained professional staff to
20 assist with managing personal care, behavioural needs
21 and/or advocating for additional services is going to
22 be the key to being able to maintain these placements
23 at home before they get into some form of
24 institutionalized setting or other community setting.

1

2 The Alternate Family Care Program, if you guys
3 aren't familiar with the service, the best way to
4 explain it is it's the adult version of foster care.
5 So, if an adult who is not able to look after
6 themselves, the Alternate Family Care Program, they
7 function as another family who has agreed to take on
8 this individual and look after their care in a
9 family-type environment. So, they will try, they
10 usually try to be flexible in the type of environment
11 they look after. They usually provide some support
12 in terms of behavioural management, challenging
13 behaviourism but the goal is to try and keep them
14 living in the family environment for as long as
15 possible, if their family is unable to provide care.

16

17 AFC homes, like foster homes, have been more
18 difficult to recruit in recent years with more of
19 them closing than there are opening and with more
20 homes closing and retention strategy struggling, the
21 number of homes keep diminishing, and keep
22 diminishing and keep diminishing to the point where
23 you have no choice but to look at other strategies in
24 terms of providing community support. Aside from

1 that, not every individual with intellectual
2 disabilities would be a good candidate for an AFC
3 home. If they present with extremely challenging
4 needs, then putting them in this home will only
5 stress them out and the families, because if their
6 needs are so high they may need another form of care.
7 So we need some means by which we gauge what type of
8 bed is this person going to, what level of support do
9 they need?
10
11 My wife and I, for example, used to provide care
12 under this family model. It's a fantastic program.
13 So I can speak both to its benefits as well as its
14 challenges when the needs of the person you look
15 after become more than your own particular family can
16 handle, right?
17
18 Respite support is a type of staffing support. So
19 you have the families who are looking after these
20 individuals, as well as the potential alternate
21 family care providers. Respite support is intended
22 to give the families a bit of a break when they're
23 dealing with really challenging behaviours. So,
24 maybe they might go on vacation somewhere or they

1 might take a weekend break if they've been looking
2 after them all week or they might take a break for a
3 couple of weeks. So that gives the family a bit of a
4 respite to be able to look after themselves, do their
5 own personal care and then make sure that they're in
6 the right mindset to be able to provide quality level
7 care for these individuals.
8
9 Again, similar principles as the difficulties we
10 have with the AFC homes, with the reduction in AFC
11 homes comes the reduction in the capability to
12 provide respite. So, and if you have very few
13 respite options available, that leads to the burnout
14 of AFC homes and families looking after individuals
15 in the community because they don't have an ability
16 to be able to separate themselves from this care.
17 And if the individual presents with challenging
18 behaviours and you're living this 24/7, it will lead
19 to placement breakdown very quickly. So, if we were
20 able to develop a more structure environment, or
21 availability, at least, for respite services in the
22 community, then maybe we might be able to build on
23 retaining those placements in the community, either
24 living independently or living in supportive living

1 arrangements.

2

3 The co-operative apartment program is another
4 great service that the island offers. It was
5 intended to be a transitionary program. So if an
6 individual needs to get stabilized because of their
7 challenging behaviours, once they're stable then they
8 would go out into the community. That was the
9 primary purpose of the program. The focus was on
10 skill teaching, independent living rather than a
11 permanent residence because they wanted to ensure
12 that they could stabilize these individuals to a
13 point and then once they were stable then they could
14 go out into the community.

15

16 There's a couple of things around the current
17 co-operative apartment program that the standards
18 themselves don't really match with the type of
19 standards they have across the rest of the country.
20 In your binder that I gave you guys, in Appendix 6,
21 is Ontario standards that they have, and we'll talk
22 about that in a little bit, but that would be a
23 relatively simple fix, which would be to look at the
24 standards that we have for the co-operative living

1 apartments and then try and put in place some of the
2 quality assurance matrix that other provinces have.
3 But the primary issues with the co-operative
4 apartments is trying to identify their mandate. What
5 we need in the province is to identify how are we
6 going to handle these adults long-term.
7 So, if we're going to keep the co-operative
8 apartments in their current mandate, which is as
9 transition that's fine, but then we're going to need
10 to identify what are the long-term options for these
11 adults, because this is not, their intellectual
12 disabilities is not a disease from which they will
13 get treatment and then forever be cured. This is who
14 they are and this is who they will be into their
15 lifetime and it's not a bad thing, but if they need
16 support going into the future then we need to plan
17 for how are we going to meet that level of care.
18 So, if we want to utilize co-operative apartments as
19 a long-term solution, that's fine, we may need to
20 look at the standards for that and how we're going to
21 adjust their mandate and make sure the support boards
22 are fine with that. But, or maybe we want to keep
23 them in their current mandate in terms of as a
24 transition placement and then identify what we're

1 going to do long-term, but it's one thing we need to
2 look at in terms of the continuum and how we're going
3 to provide care for the service population.
4 By far, the largest service provider for long-term
5 care on the island are personal care homes or
6 long-term care homes. So, the Regional Health
7 Authorities have, as you guys, I'm sure know, they
8 have the personal care homes, long-term care homes as
9 well the protective community residences, or how I
10 know them as the dementia care bungalows. So, often
11 adults with intellectual disabilities will be placed
12 in this form of care, largely because their care will
13 likely not diminish. They'll forever need care. So
14 that's not the fault of any particular person or
15 group of people, it's just in our current system
16 that's the only part in our system that is designed
17 for long-term care. So if someone's going to need
18 care, go in this long-term and that would usually
19 lead to referral to a personal care home or a
20 long-term care bed. The difficulty is, you have
21 people in their 20s or 30s or 40s going into these
22 long-term care beds that were designed for the
23 elderly, right, so. And I don't have any data to
24 identify what percentage of those beds are taken up

1 by the service population, but even if we could free
2 up 30 to 40 percent of those beds it would allow for
3 some infrastructure development to be able to manage
4 that service for the elderly as well as go back to
5 focusing on the individualized service that we wanted
6 for this service population.
7
8 This is taken from the position statement on the
9 website for the Newfoundland and Labrador Association
10 for Community Living. So, I'll just read it as it
11 is. In the 1980s the Newfoundland and Labrador
12 government committed to community living and
13 deinstitutionalization. Newfoundland and Labrador
14 Association for Community Living worked in
15 partnership with government to close several
16 institutions and individuals with intellectual
17 disabilities were assisted to move from the Waterford
18 to community living under the Rights' Future project.
19 The success of these individuals has been recognized
20 internationally as leading progressive social policy.
21
22 In the early 1990s group homes were also closed.
23 Individualized program planning and innovative
24 community based options were developed and personal

1 care homes, nursing homes were never advanced as
2 appropriate housing options. Since that time, home
3 support ceilings and funding freezes have created
4 crises in the community. Throughout the province,
5 especially in Labrador where there is an inadequate
6 housing stock and support service availability.
7 Despite principle commitments and a history of
8 successful community living and research that
9 demonstrates that institutional placements are not
10 appropriate for adults with intellectual
11 disabilities, in Newfoundland and Labrador today,
12 individuals with intellectual disabilities are being
13 placed in long-term care centres and personal care
14 homes.
15
16 ILAs, aside from personal care homes and long-term
17 care beds, are where a large number of adults with
18 intellectual disabilities are being placed right now
19 and it is an extremely wide berth of type of care
20 that's being provided, largely because the service
21 standards that the service providers are falling
22 under, it falls under home support which the
23 standards for home support were not designed to meet
24 this type of long-term residential type care or to

1 meet the needs of the individual. So, you have, I
2 don't know how many home support agencies around the
3 island, but most of them provide some form of this
4 care, without a whole lot of education or standards
5 or outcome measurements for them to know what they
6 should be doing to provide this level of care.
7 If we were able to utilize this type of service model
8 effectively, we could assist with maintaining a high
9 quality of life for adults with intellectual
10 disabilities who present with more complex needs than
11 any of the other previous continuum options may
12 present. One of the things that our program has
13 done, which is different than other programs which
14 exist on the island is the level of support we
15 provide to the staff as well as the training that we
16 insist the staff are required to have. So, it's not
17 just putting the staff in the home and then waiting
18 for the social worker and the behavioural management
19 specialist to manage it, they need clinical support
20 doing their day-to-day, are you doing your job
21 effectively? How am I going to help you do your job
22 well? They need to, someone needs to follow up to
23 make sure the staff are following the behavioural
24 support plan, because behavioural management

1 specialists are intended to be consultants. They're
2 intended to, here's the plan, I need you guys to
3 follow this and then they need the data from their
4 records to be able to find out, okay, is this working
5 or is this not in their roles as a consultant. So,
6 you need someone who's going to provide that clinical
7 level of support to the staff, to make sure that the
8 behavioural support plan is being followed up on and,
9 but with this high number of individuals who present
10 with co-occurring disorders, as well, you need to
11 have the ability to have someone in the organization
12 that's looking after them to be able to do the
13 assessment piece. Identify what you're seeing in the
14 home and then explain that to everyone involved, so
15 psychiatry, the family doctor, occupational therapy,
16 the behavioural management specialist, the family,
17 who are extremely invested in trying to find out
18 what's going on and hoping that they're going to get
19 better and get to a point where they can have a high
20 quality of life. So, if you can have an agency that
21 can do that, then that might help identify an area
22 where we could be providing long-term care.
23
24 Where we're seeing the challenges right now in the

1 mental health system, first of all, is a lack of
2 availability. As I've already mentioned, there
3 aren't a number of long-term care beds available in
4 the province and even then, the long-term care beds
5 that this service population are filling up are the
6 wrong type of long-term care beds for the service
7 population. So, we need to try and create a service
8 continuum that's going to be able to accommodate the
9 size.
10
11 Aside from that, there is a tremendous amount of
12 psychiatric hospital beds. So, if you have Jimmy who
13 is 35 years old and presents with an intellectual
14 disability, and all of a sudden begins to present
15 with challenging behaviours and the family can no
16 longer look after him because mom has been beaten
17 three or four times now, dad's been beaten three or
18 four times now and they simply can't look after him
19 properly, they have to bring him to a hospital and
20 he'll sit in this hospital bed, usually, in the metro
21 area or even in the Avalon area it may mean that
22 person is taking up a bed at the Waterford Hospital
23 which is only intended for short-term stay but
24 because of the lack of available resources, that

1 person might be in that bed at the Waterford for
2 weeks, months. I've heard of more than a year for
3 one particular resident at the Waterford and that
4 takes away from the mental health resources we have,
5 which aren't a tremendous amount, right now. So, if
6 we can identify some of these other types of
7 community resources, that could help free up
8 resources in the mental health system, in the
9 hospitals.
10
11 Aside from that is, in terms of managing these
12 individuals in the community, is access to psychiatry
13 in the community. Psychiatrists in the community
14 right now are overwhelmingly overworked. They have
15 really high caseloads and especially in rural
16 Newfoundland and even when you're talking about, not
17 even rural Newfoundland, if you're talking about
18 metropolitan areas like Corner Brook and Grand Falls,
19 you could be waiting - I'll give you an example. So,
20 if a resident presents with, they're beginning to
21 hear voices and wondering if the medications need to
22 be reviewed, you could be waiting six months to see
23 your own psychiatrist to whom he is already assigned.
24 Right, like the wait times are exceptionally long and

1 it comes from having a tremendously high caseload as
2 well, right, but if we can manage that then we may be
3 able to work towards maintaining some of these
4 community placements longer.
5
6 Funding is, obviously, I know a few people have
7 talked about today, the difficulties we have, because
8 of the limitations we have in our current fiscal
9 environment. So, there are a number of different
10 funding sources for this service population. There
11 is the community supports, home support budget which
12 was never designed to look after this service
13 population but that's where the large portion, for
14 ILAs, this budget comes from.
15
16 Income Support. So, the Department of Advanced
17 Education and Skills, the welfare system, because
18 these individuals can't work, they will not be able
19 to work, some of them, some of them will be able to,
20 especially the independent living group and some of
21 the supported living will be able to work but for
22 those who can't work, then they'll largely be on the
23 Income Support system or if you have a Co-operative
24 Apartment Program because those programs are already

1 currently funded. But if we were able to do a
2 review, as a province, so how many people do we have
3 that are receiving the care somewhere in this
4 continuum, and identify what, how many beds or how
5 many placements we need at each particular level, you
6 could probably have an overall savings across, in
7 terms of the provincial budget, if it was a
8 coordinated effort because right now you've got three
9 or four different departments that are all affected.
10 You've got the Department of Advanced Education and
11 Skills, you've got the Department of Health,
12 Corrections are largely involved because this service
13 population, due to their mental health concerns or
14 their intellectual disability will largely end up in
15 the correctional system because they don't understand
16 the permanence of their actions and so you've got
17 multiple departments that are all affected and then
18 all trying to work together without a clear
19 understanding of how are we going to support this
20 person long term.
21
22 So, in terms of providing supports in the
23 community, what we suggest right now, for the people
24 who are providing support are largely home support

1 workers. Home support workers have a focus on
2 personal care or disorders that affect the aging
3 population. So, workers for adults with intellectual
4 disabilities have a completely different set of
5 competencies and we'll refer to them as Direct
6 Support Workers because that's what they're called in
7 the literature. So, in Appendix 4 in your binder,
8 there's an organization in the United States and
9 Canada called the National Association for Persons
10 with Developmental Disabilities. They've already
11 done the research. They've already identified the
12 competencies these staff persons should have, and
13 they actually have a certification process for you to
14 be a certified Direct Support Professional. So in
15 the white binder are the service standards for what
16 type of competencies those type of works should have.
17 But ensuring the staff have appropriate training will
18 ensure they have an understanding of the best
19 practice in the field. It will create an environment
20 of professionalism and they will be able to manage
21 the behaviours and the challenges that they're seeing
22 in the field and this goes back to the point I was
23 making a few minutes ago about service coordination
24 support. Even if you have direct support workers who

1 are appropriately trained, they still need support in
2 their day-to-day job. They need to have a
3 coordinator or a manager or someone who is overseeing
4 the home to make sure everything's being looked after
5 so that the appointments are being attended, the
6 petty cash is being looked after, the individual is
7 getting to their psychiatry appointments or making
8 their psychiatry appointments, or coordinating with
9 the family, coordinating with the social worker,
10 behavioural management specialists from the health
11 authorities. There has to be someone who is
12 providing support for the frontline workers to make
13 sure that they're doing their actual job and that
14 they know how to do their job, if they're not sure.
15 Right now, most of the agencies that are providing
16 care in terms of infrastructure don't have that.
17 Caregivers developed that ourselves because we knew
18 that going forward, this population needed more than
19 they were currently getting so we developed it
20 ourselves but if we're going to utilize the ILA
21 structure as kind of a mandate going forward, then I
22 think we need to identify some quality assurance
23 measure that's going to make that work.
24

1 In Ontario, and it's up to you guys whether you
2 want to follow this model or not, but I use this as
3 an example. They developed an Act called the
4 Services and Supports to Promote the Social Inclusion
5 of Persons with Developmental Disabilities Act,
6 SIPDDA. So that Act outlines the supports that this
7 service population are going to get and then there's
8 also provincially legislated quality assurance
9 measures in Appendix 6. So if you're getting funding
10 from the government, to provide care of any level, of
11 any kind, if it's supported living, if you're
12 providing a day program, if you're providing
13 residential care, then there are standards that exist
14 to provide that level of care, so those standards are
15 outlined in Appendix 6 in your workbook.
16
17 I think I'm going back there now. Personal
18 Sensory Assessment, there we go. Caregivers uses an
19 assessment, I know a gentleman from the University of
20 Chicago named John Lyons, he developed this
21 assessment called the Adult Needs and Strengths
22 Assessment and we utilize that to try and communicate
23 what we're seeing to service providers. So, one of
24 our residents, for example, was presenting with

1 symptoms of psychosis. He would present at ER, they
2 would say, no, it's not, so we had difficulty, even
3 advocated with management to try and explain, he
4 needed more help. So, we were able to utilize this
5 assessment, the ANSA, to give to the psychiatrist and
6 explain from a clinical standpoint what we were
7 seeing, and then they were able to treat him
8 appropriately.
9
10 So, if we're able to get some of these ILA
11 agencies or other agencies to be able to adopt this
12 assessment approach then we can work towards
13 communicating with other service providers, in terms
14 of training, identify what we see and getting these
15 individuals the support they need.
16
17 In terms of, when you have any agency who's
18 providing care to a government, what you want is to
19 be able to have, what I refer to as matrix, you want
20 some level of reporting to show how are we providing
21 care for these people. Are they getting better? Are
22 they getting worse? What do you see in terms of the
23 type of care that they are presenting with or that
24 they need? So, outcome measurement becomes extremely

1 important. Dr. Lyons developed this system called
2 the Transformational Collaborative Outcomes
3 Management or TCOM that we've been utilizing and it
4 kind of gives human services frameworks an ability to
5 manage that type of outcome level that you're seeing.
6 That's where the ANSA framework came from. The new
7 Mental Health Treatment Centre for Children and Youth
8 here in this province, they're using the child
9 version which is called the CANS, framework
10 (phonetic) is the same. And the idea is you build
11 the infrastructure so that it will identify what's
12 going on and review the outcomes, and he used to tell
13 me this all the time when I was talking to him, you
14 can't manage what you don't measure. If you are
15 looking after hundreds of people and you're not
16 measuring how they're doing, you're measuring how
17 you're going to help them and whether what you're
18 doing is working, then how do you know you're doing
19 well? How do you know you shouldn't change what
20 you're doing? You can't manage what you don't
21 measure. So, having an outcome management or outcome
22 measurement for any service provider providing care
23 for the government, I think is important to ensure
24 that the government is getting what they need in

1 terms of service provision.

2

3 So, this is a listing of recommendations that I
4 had. It's entirely up to you guys whether you follow
5 or not. A lot of this is based off what I've seen in
6 some of the other jurisdictions that we have across
7 the country. They have a particular departmental
8 division, are responsible for individuals with
9 intellectual disabilities and/or neurological
10 disorders. We could review the feasibility or the
11 necessity, it may not be necessary, maybe we could
12 just have some adjustments to what we have, but
13 establishing quality assurance measures for this
14 service population that you're providing here on
15 behalf of the government.

16

17 Ken Fowler provided a report to CYFS in 2008 and
18 it was a review of all the types of children who were
19 in care. Now, it doesn't have to be Ken Fowler, but
20 if we could have a review of the Regional Health
21 Authority's community support case files to identify
22 how many individuals we're looking at, what level of
23 care they require and what recommendations that
24 individual might have and we can identify how many

1 beds do we need at each point of the continuum and do
2 we need anything else that we don't currently have?
3 Like, what does literature, maybe we need something
4 that's not in our current continuum. Maybe we need
5 to build something else, what does literature say.
6 So, a review would be fantastic in terms of trying to
7 identify that and that would, again, help with
8 identifying the number of beds needed at each level.
9
10 Issuing an RFP for essential service providers to
11 establish a professional service agreement
12 relationship with the existing service providers,
13 because, as I said, there are a number of ILA
14 providers across the province, all providing
15 different levels of care, because standards don't
16 currently exist. So, if we could create a provincial
17 standard for this service population, and then issue
18 that in an RFP so that we could have different
19 agencies providing care, then we might be able to
20 create that longer-term type of support that we feel
21 that we need for the service population and develop
22 an outline for supported living guidelines and
23 service delivery for intellectual, for individuals
24 with intellectual disabilities, because, again, if

1 you're able to provide support in the community then
2 you'll likely be able to avoid the higher cost of an
3 institutionalized form or you know, a residential
4 type placement.
5
6 In conclusion, I want to underline the point that
7 we can do more for these at-risk persons. We can do
8 more to support them, we can do more to support their
9 families and if we do this in a systematic manner,
10 with a coordinated effort, we could do it within the
11 fiscal restraints that the government is currently
12 facing, given our budgetary constraints. All of
13 this, while improving the quality of care of these
14 individuals receive and increasing the expectations
15 placed on the organization that serve them. By
16 supporting these at-risk persons, we can reduce the
17 overall impact they present to the mental health care
18 system while ensuring they still get the care that
19 they deserve.
20
21 Thank you for your time. Any questions?
22 Honourable Felix Collins:
23 Questions? Gerry?
24

1 Gerry Rogers:
2 Chad, thank you very much for that. That was very,
3 kind of thorough and comprehensive and thanks so
4 much. So, I just want to double-check with you, so
5 at this point for ILAs, we have no standards for
6 professional qualifications?
7 Chad Perrin:
8 They do have standards but the standards they are
9 following are home support standards.
10 Gerry Rogers:
11 Right.
12 Chad Perrin:
13 So, they don't really speak to the type of care that
14 they're getting.
15 Gerry Rogers:
16 Yes, yeah.
17 Chad Perrin:
18 So, if you have a home support agency who's providing
19 care under an ILA setting, then, they're home support
20 agencies, so when the Regional Health Authorities are
21 doing their review, it's based on home support
22 standards.
23 Gerry Rogers:
24 So, and so Caregivers has a number of ILAs?

1 Chad Perrin:
2 Um-hm, across the province.
3 Gerry Rogers:
4 Yeah, what are your greatest challenges?
5 Chad Perrin:
6 The greatest challenges are trying to get the Health
7 Authorities to understand, all three of them,
8 actually, because they will all argue, you don't need
9 behavioural aides, which is what we refer to as our
10 direct service workers, you don't need behavioural
11 aides, you need home support workers because the rate
12 of pay is different. So it's a little bit more
13 expensive for them to see on their budgets and,
14 again, the home support budget was not designed for
15 this level of care. So trying to explain to the
16 Health Authority you need staff who are trained, you
17 can't have home support workers in home doing this
18 care, they have to be trained to look after them.
19 You can't put staff in a home and leave them to their
20 own devices and think that things are going well.
21 Someone has to be looking after the staff and looking
22 after the individual. You need oversight, all of
23 which they don't feel that they can afford or that
24 they need. So, it comes down to trying to argue what

1 level of care these individuals are getting. So,
2 those are probably my biggest challenges right now,
3 is even just trying to get the Health Authority to
4 understand that they actually need this. All three
5 of them fight me on that.
6 Gerry Rogers:
7 So, and can you talk to me a little bit because we've
8 heard from so many parents of adult sons and
9 daughters with persistent mental health issues or
10 developmental delays who they know that their
11 children are going to need help and also, I don't
12 know if you were here when Scott Crocker was here
13 from the Autism Society talking about the same kind
14 of thing?
15 Chad Perrin:
16 No.
17 Gerry Rogers:
18 So, people are talking about supportive housing which
19 is very different, in some ways than the ILAs. Just
20 talk to me a little bit about, I know what the
21 differences are, but what kinds of directions are we
22 going into? Is it more ideal to have people in a
23 sort of a group home setting with the ILAs or
24 individually housed with supports, with your

1 experience?
2 Chad Perrin:
3 In my experience it goes back to what the needs of
4 the individual are and it goes back to a proper
5 assessment of the individual to understanding what
6 their needs are and having a continuum of care where
7 you can put them where their own needs are going to
8 be met. So, for example, I go back to this report,
9 but Ken Fowler's report for CYFS in 2008, he referred
10 to an assessment they could do, they'll do the
11 assessment on the individual. That assessment will
12 gauge the level of care the individual needs and then
13 you can identify where in the continuum you're going
14 to put them based on that level of care, on that
15 assessment.
16
17 I would propose the answer would be that type of a
18 tool because it's the adult version of the child
19 version he was talking about, right?
20 Gerry Rogers:
21 Yeah.
22 Chad Perrin:
23 Right, and it's the same developer, John Lyons, all
24 from the same framework, but you would need to have

1 that continuum of care developed first to know where
2 you're going to put this individual. So, I would
3 love for individuals to stay with their families,
4 like, for example, my youngest is on the spectrum. I
5 would love to know that he'll be able to stay with us
6 forever. I mean, I could be wrong, he could go on
7 his own but I would want to know that we would be
8 able to look after him or that we would be able to
9 provide his care, long-term and like the same things
10 with families, like you want to make sure that if
11 they want to look after their care that they are able
12 to do so for a longer period.
13
14 So, you need to ensure that there's a system in
15 place, in terms of supportive living, in terms of
16 staffing support, in terms of providing their care so
17 the families can still have their life and know that
18 their family individuals are looked after. And if
19 you can do that, I think you'll find that families
20 will be able to get by. Like, again, right now, if
21 you have a mom and dad and one of their children
22 presents with autism and they are on the severe side
23 of the spectrum disorder and present with challenging
24 behaviours, a placement, like, they may not be able

1 to stay home because they can't look after their
2 care. Whereas if you were able to put in some
3 supports in home, in terms of qualified staff who are
4 trained to manage behaviours, and you have someone
5 overseeing their care, doing an assessment,
6 collaborating with the social worker and the
7 behaviour management specialist, and the psychiatrist
8 on behalf of the family, I think you'd see that
9 people would be able to maintain in the home longer
10 and I think that's kind of an individualized decision
11 that families need to make on their own in terms of
12 what can they handle and what does the person that
13 you're talking about need, based on what they're
14 presenting with.
15 Honourable Felix Collins:
16 Chris?
17 Christopher Mitchelmore:
18 Chad, I think you gave a very thorough overview of
19 the different types of care, levels of care that
20 exist. I think one of the things that you
21 highlighted, and we really need to get a better
22 understanding of, obviously, is the matrix, the
23 number of people who are in long-term care, in
24 personal care homes that are likely inadequately

1 housed and receiving not an adequate level of care.
2
3 I know of people in my own district that are in
4 their 30s and 40s that are either in personal care
5 homes or long-term care and they're not getting the
6 services, it's not the ideal setting but they are
7 very limited in their options because the family
8 supports of these other types of housing options no
9 longer exist or, so it is something that we need to
10 have a broader discussion on. So I thank you for
11 putting forward the presentation. I don't really
12 have a question, more of a comment.
13 Chad Perrin:
14 Well, I'll give you an example. In the news I think
15 it was last year, that they mentioned about the
16 number of people in long-term care and personal care
17 homes who need antipsychotic medications. Now, I
18 have no data to support me because we haven't done a
19 review of them, but I wonder how many of those
20 individuals are people with intellectual disabilities
21 who present with mental health concerns. Right, if
22 there's a number of them who are taking up personal
23 care homes and long-term care centres, then maybe
24 they need the antipsychotic medication, I don't know,

1 but is the personal care home or the long-term care
2 home the place for them?
3 Honourable Felix Collins:
4 Kevin?
5 Kevin Parsons:
6 Chad, I live in a district that's pretty close to St.
7 John's and you wouldn't think it would be an issue
8 but in my district there's a lot of problems with the
9 home support part and getting staffing and getting
10 the people that are qualified to do it. Is it an
11 issue because of the number of hours that are
12 supplied for this or is it a pay issue?
13 Chad Perrin:
14 There's a number of things. There isn't a program,
15 per se, on the island to train people to work with
16 this population. So, there's the Child and Youth
17 Care Workers certificate program, for example. We've
18 been working with Keyin College to try and develop a
19 similar-type program. So the best you would be able
20 to get would be Community Studies or Education and
21 Psychology, so that's the first piece behind it.
22 Now, we actually had to, we were talking to an online
23 training platform and they have curriculum that we
24 were going to implement in terms of being able to

1 give our staff the training they need to get ready
2 for work with this population, but an agency kind of
3 has to take that on themselves. They have to train
4 up their workers themselves to get them ready for
5 this work because the pre-existing education doesn't
6 exist. That's one part of it.
7
8 The other part of it is funding issues. So, the
9 Health Authorities want to pay the home support
10 worker rate, not understanding well, these are
11 behavioural aides or direct service workers,
12 whatever, Ontario calls them Direct Support Workers.
13 So, you have these people, it's a different level of
14 education, different type of skill set, different
15 type of work expectations these people are going to
16 have from home support, so it's different and a bit
17 more expensive, and you also need to be able to
18 provide home support. Not home support, you need to
19 provide oversight so it's more expensive and the
20 Health Authorities are reluctant because it comes out
21 of the support budget and so there's a number of
22 different challenges.
23 Honourable Felix Collins:
24 Thank you Chad, very much for your presentation.

1 Gerry Rogers:
2 Just one quick question. Can you talk a little bit
3 about the types of day services that you think would
4 be helpful?
5 Chad Perrin:
6 It would be great if we could build on, the Pottle
7 Centre is doing fantastic work.
8 Gerry Rogers:
9 It would be great if we could build on a little bit
10 on what they do. The Pottle Centre, what we need in
11 terms of a day centre is a day service with
12 structured programming, so someone who's coordinating
13 it with activities. There are some vocational
14 programs here on the island and again, they probably
15 need a bit more funding in order to bulk them up, but
16 you need some other programs and enough funding to be
17 able to properly support it. So if we could support
18 these and you need to be able to emulate those
19 programs across the island. So, we have the Pottle
20 Centre and the Longside Club here in town, they need
21 a bit more funding to be able to provide the level of
22 care that they want and I'm sure that they could
23 speak about what type of things they'd love to have
24 in terms of their daytime programming but you need

1 similar programs across the island.

2

3 I know VON does some day time programming work.
4 They could probably, again, speak to things they
5 could do if they had a bit more funding but if we
6 were able to build on some of the programs that we
7 offer, in terms of activities and the level of
8 intervention that they get from them trying to build
9 on their independence, I think you'd see a marked
10 difference in the service population.
11 Honourable Felix Collins:
12 Chad, thank you very much for your presentation, and
13 taking the time today to come and present to us.
1 Dr. Bruce Gilbert:
2 I believe we have one more presentation, is that
3 correct? Are we done?
4 Honourable Felix Collins:
5 That concludes our presentations for the day. Thank
6 you so much to all of you who stayed with us this
7 time. Your presentations are insightful, informative
8 and I'm sure that at the end of the day they will go
9 a long ways towards our deliberations and
10 considerations for recommendations to help improve
11 the systems as best we can. But you can still make
12 input. I will repeat that again. You can still make
13 input if you want to, either online or by email or by

14 (inaudible) on the website BeHeard. And if you have

15 an opportunity to do that, by all means do so.

1 Again, thanks so much for coming out today. Anybody
2 have a question?
3 Michelle:
4 (Inaudible - not by microphone)?
5 Honourable Felix Collins:
6 Well, I can't speak for what the parties want to do
7 leading up to an election.
8 Michelle:
9 (Inaudible - not by microphone).
10 Christopher Mitchelmore:
11 I think, Michelle, the point you've raised is a very
12 good point and as All Parties we have meetings where
13 we can bring forward that, discuss it and see if it's
14 something that we feel, moving forward, we would take
15 upon us. So we certainly take your suggestion. We
16 can't answer that right now.
17 Michelle:
18 (Inaudible - not by microphone).
19 Honourable Felix Collins:
20 Yes, as the Committee moves forward and as the
21 consultations sort of wind down, we will be
22 determining the future direction, future steps for
23 the Committee. There's a lot of collaboration and
24 collation of information we got. We got a ton of

1 stuff that's come at us, and it's all good stuff and
2 there are a lot of things, as mentioned already, can
3 be expedited rather quickly; some of it is long-term.
4
5 As regards to actual plans and where we go from
6 here, I'm suggesting to you that we've got some work
7 to do to see how that falls in place over the next
8 few weeks.
9 Michelle:
10 (Inaudible - not by microphone). I mean, we should
11 carry this information forward, no matter who gets
12 in. (Inaudible).
13 Honourable Felix Collins:
14 That's the basis and focus of an All-Party Committee.
15 It's nonpartisan and the intention here is to follow
16 through and come up with a set of recommendations
17 that any government, hopefully, can pursue and, so,
18 that's the benefit of an All-Party Committee. It
19 doesn't hinge on what happens in November. So,
20 thanks very much for your comments, we certainly
21 appreciate it.
22
23 (All-Party Committee Public Hearing Concludes)
24