WAITING FOR CHANGE

THE YOUTH ACTION COMMITTEE I 2016

A COLLECTION OF PERSONAL STORIES AND YOUTH-LED POLICY RECOMMENDATIONS TO ADDRESS THE ISSUE OF WAIT TIMES IN THE CHILD AND YOUTH MENTAL HEALTH SYSTEM.
WHO ARE WE?

The Youth Action Committee (YAC) is a provincial advisory and engagement committee of Children’s Mental Health Ontario (CMHO) and The New Mentality. The YAC is made up of youth aged 13-25 who work to reduce stigma and improve mental health services for children and youth through youth-led policy projects.

The YAC identifies major issues facing youth in Ontario who are experiencing mental health difficulties, and engages youth to find out how we can solve these complex issues. Following province-wide youth consultations, the YAC works together to report on its findings and generate youth-led policy recommendations to stakeholders who are responsible for change.

TO LEARN MORE VISIT:
thenewmentality.ca/yac/
thenewmentality.ca
kidsmentalhealth.ca

THIS ZINE IS WRITTEN BY THE MEMBERS OF THE 2016 YOUTH ACTION COMMITTEE. THIS ZINE HAS BEEN DESIGNED BY KIMBERLY CHEUNG.
In Ontario, there is no consistent information about how long children and youth have to wait to receive the mental health and addictions support we need. Children’s Mental Health Ontario (CMHO) estimates that several thousands of kids in a year wait for a year or more for help.

From our peers and personal experience, we agree that wait times are too long and when we’re waiting, our mental health is getting worse. We have to wait for weeks, months—sometimes years—for support that we need right now. We need this to change. We want to help, because our voices are important and needed in this conversation.

There shouldn’t be wait lists for services that we need now. So we have to work on making this a reality and we know that this will take time. But when there are wait times, we need to find ways to help each other manage our health as we wait.

To make a difference, we need a commitment from government and service providers to work together—and work with us—to focus on addressing wait times. We have four recommendations for how we can make change happen: two ideas to shorten wait times and two ideas for helping youth manage in the meantime.

"When I was 17 I was put on the waitlist for adult psychiatric care. I was told it would be a few months. Tops. I was on the waitlist for two years. And when I finally saw the Psychiatrist, he told me to "Go to church, and listen to the music" and to "not feel so sorry for myself". When he ended the session, I asked if I should come back, and he said no."

SHANNON NAGY, AGE 19
"I was four months away from turning 18 years old when I turned my (and my family's) life upside down. I was admitted to pediatrics for 2 days, then moved to the child mental health ward for a week. I was in no condition to be back at home, school, or work and yet I was expected to. Thus started my fight to try to finish school and stay sane and my mom's start to find affordable and suitable help for her unstable youngest daughter.

We were told during my discharge that I was being put on a list to see a therapist who is covered under OHIP and that that list was currently a 12 month wait. First we had to go through the EAP of our insurance. The intake appointment was done by a financial planner, not a counsellor, and my parents decided they were not a viable option. When we reached out to the local family resource agency, as recommended, we were told a minimum of 6 months waiting list, but because of my age (now only 3 months from turning 18) they would not put my name on the youth list, but they would also not put me on an adult wait list until I was actually 18.

We were told the same thing at the hospital. At this point everyone in my family felt completely hopeless and like the system was not designed to actually help struggling youth and their families. In the end I had to settle for a social worker that I never truly connected with that cost my already financially struggling family $150 an hour. It took us approximately 3 months of struggling to finally find paid help. The bonus to having gone to a private social worker was that I was able to continue seeing him after I turned 18 even if it was only for a couple extra sessions, and of course for a price."

Beth Nowosad, Age 23
BACKGROUND

“I essentially gave up on trying to access mental health services, because they were not available when I needed them the most. I felt like maybe my mental health issues were not that big of a deal and that I would just have to figure this out myself.”

NICOLE D’SOUZA, AGE 24

Why “Waiting for Change”? The 2015 Youth Action Committee knew from personal experience, and stories told to us by other youth across the entire province, that child and youth mental health wait lists were extremely long and impacting our overall well-beings. So, we hijacked CMHO’s annual conference, for the first Youth Summit—which we called “Waiting for Change”. We invited youth from across the province to speak up about wait lists. We wanted to know what issues we were all being systematically affected by and what solutions we had for conquering them. The feedback was overwhelming. This year’s Youth Action Committee wanted to make sure each and every youth’s voice was heard loud and clear. So, we continued gathering information among ourselves and at The New Mentality’s annual Disable the Label conference in July. And now, our (Ontario’s youth) voices are woven into each and every page of this Zine. Although the personal stories are from our YAC members, youth voices have been a key part in influencing the content, themes, and recommendations.

We felt the need to bring to life the statistics that are constantly in the media, by adding our personal experiences. We are just a few of many more with similar stories. We wanted this to be a realistic representation of the system we know, and so the stories are not all negative, as some of us have had positive experiences in the system. Unfortunately, these positives are always overshadowed by how often we are let down by the system. And it all starts with being put on an indefinite list to wait for the help that we need now.
"Not only are clients being deprived of much-needed services while waiting, but the longer they wait, the less likely it is that they will connect with the services when they are finally available."

Ontario Centre of Excellence for Child and Youth Mental Health.

This Zine was made by youth, to be used by youth, and to influence government and child and youth mental health agencies to create positive change in our mental health system. It’s time our voices are heard.

"You wanna be progressive, look at our youth. Everyday youth are being told to wait. Wait to vote, wait to drive and even wait to go to the bathroom in school. Now we’re telling them to wait for life-saving treatment. We’re not even giving the future of our country a voice. We sit and see statistics we’ll talk about how tragic they are, about how to fix them. I have an idea, let’s ask the youth. They’re sick of waiting. Let’s give them a voice."

TRAVIS FRANKLIN, AGE 18
“Because I had waited so long, and was afraid of having to wait all over again, I had to settle for a social worker that I never truly connected with which in the end cost me time and energy and cost my family $150 an hour.”

BETH, 23
SHORTENING WAIT LISTS

WALK-IN SERVICES

“I remember walking into a walk-in clinic and being so hopeful that it would result in some kind of change that could turn my life around. When the counsellor brought me to a room, it looked like a counselling scene from a movie. The colour of the room seemed like it was an office space, there were no windows, two couches and beside each couch was your “therapist chair”. I did not feel comfortable at all and thought that if I came at a time where my mental health was not the best, being in this room would make me feel more anxious. The only positive thing I remember about the room was a little plant on the table. A part of me did not want to access this walk-in again, simply because of the environment it created, which did not seem that youth friendly or inviting.”

NICOLE, 24

Walk-in services allow youth to access mental health and addictions counselling without having to schedule an appointment. Youth can just show up and talk to a counsellor about whatever we need.

Flexible walk-in services are a way of providing easy and quick accessible care to children and youth who need it now, and can also lead to a potential path into longer-term services, if needed.

Based on the combined information from nine walk-in clinics in Ontario providing mental health services to children and youth, after attending a single session at a walk-in clinic:

- 93% of clients reported that “the consultation was helpful”
- 91% reported that they “felt hopeful after the session”
- At least 50% of clients attending walk-in clinics required no further services
- 68% of clients reported improvement in their presenting concerns

When walk-in services are not available, children and youth who might only need brief counselling end up on wait lists. This means that the struggles we’re facing will likely get worse as we wait, and could become quite serious. This also means that the wait lists are being made longer by adding people who really only needed walk-in services to begin with.

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SHORTENING WAIT LISTS

RECOMMENDATION

Every service area in the province, and the communities within, must offer weekly walk-in services.

HOW TO MAKE IT WORK

+ Integrate walk-in services as a crucial provincial strategy for managing wait times.

+ Agencies should hold semi-annual education sessions for their counsellors to emphasise the importance and value of walk-in clinics to ensure the care provided is consistent and effective.

+ Hire youth or recruit youth volunteers to create walk-in spaces that are youth friendly.

+ Work with youth to promote these services in schools, community organizations, and on social media.

+ Begin every walk-in session with a youth by explaining what the limits of the walk-in service are, and what next steps we should take if we require additional support afterwards.
SHORTENING WAIT LISTS

— COUNSELLING AND THERAPY SERVICES —

"When I was 9 and having extreme troubles with self esteem, hyper talkitivity, and focusing, I went to the doctor that diagnosed my brother, and father with ADHD, and there I was told "Girls can't HAVE ADHD." It wasn't until I was 14 and finally taken to a female psychiatrist that I was diagnosed with ADHD."

SHANNON, 19

For a significant number of children and youth, we need more than walk-in services to receive the needed level of support in managing our mental health. Counselling and therapy services involve more in-depth mental health support, over a more extended period of time. For these services to be effective, children and youth need to be able to work with a counsellor or a therapist who is a good fit for our personal needs, allowing us to feel safe.

Recent data shows that anxiety disorders are the leading cause of emergency department visits for mental health disorders among children and youth; such visits have significantly increased over the last decade. Meanwhile, evidence supports the use of well-established anxiety treatments—like cognitive behavioral therapy and exposure-based therapy—which we know can be delivered in community settings like child and youth mental health centres.

For counselling and therapy to be effective and make positive change in our lives we need to feel safe in the environment we’re in and with the person we’re with, our counsellor or therapist. When counsellors and therapists are not a good fit, meaning we do not feel safe to open up about what is really going on in our lives, we can become resentful, fall deeper into depression, and time thinking about sessions become clouded with anxiety. For a therapeutic relationship to be successful there must be mutual trust and respect. So, as an example, if we say we do not feel comfortable and therefore would never be able to trust a male counsellor, listen to us because when you put us with a male counsellor, it makes things worse.

2 Canadian Institute for Health Information. (2015). Care for Children and Youth with Mental Disorders. Available at: https://secure.cihi.ca/free_products/CIHI%20GYN%20Final%20for%20pubs_EN_web.pdf
SHORTENING WAIT LISTS

COUNSELLING AND THERAPY SERVICES

“I am an abuse survivor, so I don’t feel safe opening up and being alone with male doctors. I specifically requested and was told I had a female doctor waiting for me and when I got to the hospital I found a man sitting at a desk and he said he would be seeing me. They never called me, or sent me a letter or emailed to let me know they changed my psychiatrist.”

SHANNON, 19

Being able to open up about past experiences, whether it be personal or professional, is a great way to build trust, so knowing hobbies/interests and past clients served would be incredibly beneficial to matching youth with counsellors and therapists who fit. Positive progress in our own mental health journeys means having trusted counsellors and therapists who see us for who we are because we finally felt safe enough to let someone see.

RECOMMENDATION

Increase the number of counsellors and therapists in every service area in Ontario so that a child or youth who requires counselling is able to access this care.

HOW TO MAKE IT WORK

+ Provide youth with some choice of who their counsellor or therapist is and offer bios of available counsellors and therapists, including photos, their methodologies, and basic facts about them (gender, hobbies, interests, and populations served like LGBTQ or homeless children or youth etc.) to help ensure youth are starting their treatment program on the right foot, with individuals we will feel safe with.

+ In cases where the next available counsellor or therapist is someone who the child or youth knows would not allow for a healthy supportive relationship, we should maintain our spot on the list until someone who is a good fit becomes available. In cases where an agency only has a single support staff, the child or youth should be supported in connecting with another agency.

+ Under no circumstances should a child or youth be removed from a list because we turn down beginning treatment with a particular counsellor or therapist.
HELPING YOUTH
MANAGE THE WAIT

"If there is a waiting list for a counsellor or treatment at least offer youth something; anything! Whether a drop-in or a peer support program. Don't leave youth to cope on their own."

ZARA ANUCHA, AGE 24
HELPING YOUTH MANAGE THE WAIT

PEER SUPPORT GROUPS

“I have been in a New Mentality group for six years this fall. I am currently the oldest in the group, and have been in the group the longest. My group is VERY tight knit. We all watch out for, and support one another. We have helped one another through breakups, exams, family stress, college/university applications, and life and death crises. All of those that were apart of the group at the time took suicide prevention training together. In the past, we have had youth come up and express harmful thoughts, and we didn’t know how to help the youth. Now we have the knowledge to get that youth to help and support!”

SHANNON, 19

A Kids Help Phone survey found that teens who would consider getting help for a mental health issue were most likely to reach out to a friend for support⁴. Peer support is all about youth helping youth in healthy ways.

The reality is that we will first talk to our friends about our mental health issues; it’s easier opening up to people our age who are experiencing similar things.

It’s important for agencies to support youth in developing peer support networks so that we can help make sure youth are supporting each other in ways that are safe and healthy—particularly as we are waiting to access the professional care we need.

HELPING YOUTH MANAGE THE WAIT

RECOMMENDATION

Establish a formal peer support group or network in every community in Ontario—using Ready... Set... Engage!⁵, created by The New Mentality, as a working model in terms of safety, adult allies and genuine youth engagement.

HOW TO MAKE IT WORK

✚ Enlist an adult ally or adult allies who are passionate about youth engagement and peer support—who are able to let the youth lead, while providing us with the guidance and support we need.

✚ Outline clear roles and responsibilities within the peer group to make sure members understand the boundaries of what is and can be expected to ensure a safe and healthy space.

✚ Train members in the peer groups to be youth leaders—for example, providing basic crisis and suicide prevention training so that we can help each other stay safe and work with adults to get to the help we need.

“Accessing peer support groups and wellness workshops by Mental Health Disability Services at my university helped me from going into a deeper spiral while waiting for services. The informal meet up group session were useful even though it wasn’t one-on-one counselling. Having a space to go to vent and make connections with other students going through similar things helped keep me hopeful despite going through a dark period. Wellness strategies and mindfulness workshops gave me new tools to cope with the stress and anxiety I felt.”

ZARA ANUCHA. AGE 24

HELPING YOUTH MANAGE THE WAIT

SERVICE NAVIGATION

"I aged out of my old counseling place after being there for eleven years. I spent a few months without support of a counsellor, then a friend pushed me in the direction of the local abused/struggling women’s shelter, for counseling. There I was told upfront that there would be a three month wait list period. BUT they offered to have me see a crisis worker for the three months, if I needed the support RIGHT NOW. I think that’s a very important, and amazing feature for them to have! It helped me get used to the building, while I was getting help stabilizing and staying safe while waiting."

SHANNON, 19

Youth are not experts in what resources are available in our communities. We show up at community mental health agencies looking for help and guidance towards what services we can access. We may not know all the services an agency offers or what other agencies or services are available or still exist.

In cases where there are language, cultural, and/or geographical barriers—we and our parents find it a challenge to know what to do.

We need to be able to rely on agencies to help us get the right services for us—and this includes when we age out of the child and youth system.

A survey from Parents for Children’s Mental Health found that 76% of families indicated it was very or extremely difficult to know where to find help; 62% found it very or extremely difficult to coordinate different plans and care teams.6

Research has found that in as many as 60% of known cases, poor transitions in services lead youth to disengage from their care.7

HELPING YOUTH MANAGE THE WAIT

RECOMMENDATION

Dedicate more human resources at child and youth mental health agencies to helping children, youth and our families navigate the system, even when that means connecting us with services at different agencies.

HOW TO MAKE IT WORK

✦ Take an inventory and create a list of all services that exist—within the agency and elsewhere—including walk-in services, peer support networks etc., which may provide assistance as youth wait for more significant support. Help connect youth with these services, rather than just providing information about them. And be honest about the length of wait times.

✦ Provide alternatives and suggestions for immediate help when care is needed urgently.

✦ Identify youth who will be transitioning in the next 12-18 months and help us prepare for engaging with the adult sector, including introducing us to the appropriate services.

✦ Educate and support counsellors so that they are in a position to work with youth (including transitioning youth) in accessing other community resources.
“I finally got the courage to go and seek support for my mental health. I decided to go to the walk-in that was in my community. At the end of the session, I was told that if I wanted to access services there would be a wait list, but I could use the walk-in whenever I needed to. It was also mentioned to me that I should use my university’s counselling services as their wait list was probably shorter. I found out where the counselling services at my university was and signed up.

A few months later I was able to have a counselling session. This ended up being very similar to the walk-in. Once again I was told that because I’m not a high need I would be on a wait list, and it could take a few months to be seen. It was then recommended that I use the same walk-in that I went to originally, because their wait list may be shorter. I explained that the walk-in had told me the same thing as the university and the counsellor told me that I should tell them that the university has a long wait list.

This is something that I feel should be addressed among service providers so youth are not sent in a circle, and it should not be their responsibility to inform service providers about how long other’s wait list are.

NICOLE D’SOUZA, AGE 24
SUMMARY AND CONCLUSION

In summary, this Zine includes four different ways to improve Ontario’s child and youth mental health wait times: Walk-In Services, Counselling and Therapy Services, Peer Support, and System Navigation. You heard personal stories from different youth across the province, and hundreds of youth voices were intricately interwoven within each and every page.

Now it’s your chance to use this Zine to make the change we all need!
Name: Nicole D'Souza, Co-Chair  
Age: 24  
Hometown: Scarborough

**Why is mental health and having your voice heard important to you?**
Mental health is important to me, because there is still so much that needs to be done to support youth who are experiencing mental illness and negative mental health, as well as adding more cultural pieces in this conversation. It is important to me to have my voice heard, because there may be other youth who have similar experiences to me and if we work together with youth we can create a system for youth.

Name: Beth Nowosad, Co-Chair  
Age: 23  
Hometown: Keswick

**Why is mental health and having your voice heard important to you?**
Mental health is important to me because there is still so much stigma behind having a mental illness and I was a teen who kept silent for a very long time until I broke. Having my voice heard is so important to me because I don't think anyone needs to break before getting the help they need, so if I can help at least one person by having my own voice heard it is worth all the pain and suffering the system may have caused me in the past.
Name: Chizara Anucha  
Age: 24  
Hometown: Toronto

**Why is mental health and having your voice heard important to you?**

Mental heath and access to mental health services is very important to me. When young people are healthy mentally they can reach their greatest potential. Youth have expertise that can be used to transform the mental health system. Hearing their voices is essential for making positive changes.

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Name: **TRAVIS FRANKLIN**  
Age: 18  
Hometown: **THUNDER BAY**

**Why is mental health and having your voice heard important to you?**

Mental Health is important because it’s something that affects everyone daily. It’s a part of our daily lives and it’s often not well taken care of sadly for some that has caused hardship and loss. As someone connected to mental health in particular a youth and someone going into that field it's important for my voice and the voices of other to be heard on this issue so we can come to understand it and prevent further harm from bad mental health and flourish with good mental health.
Name: Cherish Dorothy Elizabeth Diane "Moskotaywenene" Bluecoat
Age: 20
Hometown: Big Trout Lake ON, Lives in Thunder Bay

Why is mental health and having your voice heard important to you?
Having my voice heard is important to me because when I was dealing with mental health and addictions (STILL dealing with) I had NO IDEA there was people out there to help. I had no idea there was other youth like me suffering in silence I thought I was the only one. Speak up! Be heard! No one is ever alone in the battle of mental health and addictions. Mental Health is important to me because I want no one to ever suffer in silence and if I could speak up and be heard YOU CAN TOO!

Name: Shannon
Age: 19
Hometown: Orangeville (rural area)

Why is mental health and having your voice heard important to you?
I was first diagnosed at age 5. And it was never really explained WHY I was feeling the way I was. And I ended up getting worse and worse. Until I was 14 and I was just ending a long term abusive relationship, I was at risk of hurting myself, and I hated myself. I felt like I was yelling into a void for help, but no one heard. I don't want any other youth to have to go through that. I don't want any other young impressionable youth to have to be silenced, or excluded from their treatment plans like I was. That's why I take up space and speak up now.
Name: Matt
Age: 20
Hometown: Brampton

Why is mental health and having your voice heard important to you?
Mental health is important to me because I have struggled for many years with very little help. It is important for me to have my voice heard because I don’t want others to have to experience what I did.

Name: Caralyn Quan
Hometown: Toronto

Why is mental health and having youth voice heard important to you?
I have met so many inspirational youth, young adults, and adult allies through my work at The New Mentality, many of whom have struggled with their mental health. I think mental health is important for everyone, and having youth voice heard is important because often youth have a different view that can really transform how we think about mental health, the system, and how we can all work together to support people with mental health issues and mental illness.
Name: MARY-ANNE LEAHY
Hometown: OAKVILLE, ON
Why is mental health and having youth voice heard important to you?
In order to create a mental health system that works for our young people we need to listen to their experiences and ideas for change. Through my work with The New Mentality I have seen the powerful impact that youth can create when their voices are heard and respected.

Name: Chris Langlois
Hometown: TORONTO, ON
Why is mental health and having youth voice heard important to you?
We’re slowly moving toward committing to mental health as a priority in our health care and child and youth service systems. But, if we don’t make a significant and dedicated effort to learn from youth about what’s working and what’s not—about what they really need—we’ll continue to miss out on one of the most important sources of information we have as we aim to make meaningful progress. We owe it to them to listen and to work together.
Children’s Mental Health Ontario
Santé mentale pour enfants Ontario

THE NEW MENTALITY
DISABLE THE LABEL

START