# Youth stakeholders: Investing in them will help us to beat NCDs

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Maia Olsen speaks at the Interactive Hearing on NCDs in New York, July 2018 © NCD Child

As International Youth Day nears, on 12 August 2018, there are two important policy commitments which will hopefully culminate in better and much-awaited patient health care: the United Nations High-Level Meeting (HLM) on noncommunicable diseases (NCDs) and the renewed commitment to the Alma Ata Declaration. The turn of the century has seen the rise of the notion of "youth engagement" and as we move towards renewed commitment, I reflect on where it all began this year, key gaps that should inform what are deemed to be historic events, and advocacy resources developed by youth to ensure specific recommendations of youth are considered by governments to truly and inclusively advance progress on NCDs.

Like many others around the world, I usually avidly follow the World Health Assembly (#WHA71) from afar – taking in the different resolutions, following the conversation on Twitter, thinking about what I would say if I was inside the Palais. This year was different – for one, I had the opportunity to attend in person, but more importantly, the dialogue about and with youth was a marked change from previous years. It was electrifying and a signal of change to come.

### WHO's Director General – Acknowledging the need for fair youth integration

For example. Director General, <u>Dr Tedros Adhanom Ghebreyesus</u>, is possibly the first leader at a <u>United Nations (UN) organisation to openly acknowledge what he termed during his opening address as the "exploitation" of young interns at the <u>World Health Organization (WHO)</u> [1]. This has led to health insurance benefits and support from the <u>Welcome Trust for paid internships</u> [2] for talented youth from resource-limited countries. But the lack of institutionalisation around inclusion of youth experts is still a glaring gap, and salaried internships are not enough.</u>

As a young person attending the WHA, you are still relegated to an observer role in a tightly packed and far-removed gallery. You will not be a part of your country's delegation even though you reached out to it multiple times (that's me, yes), nor will you have any speaking opportunities. You will rarely bump into policy-makers, unless by sheer luck or if you are fortunate to be part of organisations such as <a href="NCD Child">NCD Child</a> [3], which firmly place youth inclusion high on the agenda.

Experience has taught me that youth side-lining and exclusion will probably be the case for youth at the HLM on NCDs itself and similar gatherings, "Unless we create and advocate for a seat at the table". These words of golden advice and more were offered in a session by world renowned NCD expert and leader <u>Dr Sania Nishtar</u> [4] during the NCD Child Town Hall discussion during WHA71, which I co-facilitated. Dr Nishtar's advice undoubtedly signified the winds of change for youth engagement and intergenerational learning.

## Heeding advice: Youth's specific recommendations for the HLM

NCD Child sought to walk the talk by encouraging its youth delegates to bring their creativity, ideas, diverse experience, and energy forward for the session. The end result? A real, robust and riveting discussion versus the traditional WHA side-event, panel discussions (hint 1 for organisers of the HLM on NCDs). Instead, the floor was open and dissatisfaction for ZERO YOUTH PARTICIPATION in the recent draft WHO NCD High Level Commission Report kicked off the discussion. Dr Nishtar eloquently responded, "Focus your efforts and give us specific recommendations on NCDs." And so we have heeded the call, galvanised and put together a list of 10 key recommendations for the upcoming HLM on NCDs [5]. On the advocacy side, it was excellent to see NCD Child take contributions such as recommendation 6 (strong support for taxes on tobacco and sugary beverages) and recommendation 9 (institutionaliing the role of youth advocates ensuring a firm place at the table on the list)!

Other lessons from WHA71 are that we rarely hear from the audience, nor is the playing field level (hint 2 for organisers of the HLM on NCDs). However, as youth delegates we equalised relationships where both the young and young-at-heart significantly shaped key messages:

"While we discuss youth engagement and related mechanisms for ensuring meaningful participation, we **should not consider youth as a single homogenous group.** It's a challenge but we need to ensure we include a wide range of perspectives when discussing health interventions – this is particularly the case when we consider NCD prevention and how to tackle the social drivers of risk." - Liam Sollis, Policy and Advocacy Manager, Plan International, United Kingdom (UK).

"I felt that we didn't really talk much about financing of NCDs and the voice and perspective that youth could have towards this issue. This is critical and flagged in the commission report." - Helen Seibel, Associate Director, Global Community Investment, AstraZeneca.

"My intervention was concerned about when to be involved and related expectation to make a difference. I said that even if young people were strongly present and ready to participate at the High-Level Meetings, this will not bring much of a difference. Because, as we all know, these events are usually ceremonial to officially approve a predetermined outcome" - Basem Mohamed, Consultant, WHO (Health Workforce).

The most powerful intervention during the session was the voice of youth advocate **Maia Olsen**, a cancer survivor championing NCD prevention and management with Partners in Health:

"As a childhood cancer survivor and person living with a severe primary immune disorder, I am very aware that my story has had much more to do with bad luck and genetics than with prevention of the modifiable risk factors. As privileged as I am, I've still faced significant challenges in accessing life-saving treatment and the costs and burden stacks up with a chronic disorder I didn't ask for nor could have prevented.

It is important that we continue to seek out ways for young people living with the full spectrum of NCDs and across all geographic settings – especially those most marginalized – to be included in discussions and efforts around policy change. How do we work together on that?"

While observing so many sessions during WHA71, it was Maia who hit the nail on the head by focusing on what these strategies, commissions and jargon mean for the patient and specifically, for young patients. A key area of meaningful youth engagement is the next steps after the shop talk is over, so keep tuned for a progressive grouping of youth to drive bold action: our recommendations simply must be taken on board!



### **About the Author**

Dr Shakira Choonara (@ChoonaraShakira [6]) is an award winning health researcher and influential public health activist. She is also the 2017 Woman of the Year in Health (South Africa) and attended the World Health Assembly in 2018 on behalf of NCD Child [7].

### Featured:

Related Link: NCD Child [7]

Youth Recommendations for the UN High-Level Meeting on NCDs [5]

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#### Links

- [1] http://www.who.int/dg/speeches/2018/opening-world-health-assembly/en/
- [2] https://twitter.com/wellcometrust/status/998880243120328704
- [3] http://www.ncdchild.org/
- [4] http://www.sanianishtar.info/
- [5] http://www.ncdchild.org/media/1347/07-2018-youth-recommendations-un-hlm.pdf
- [6] https://twitter.com/ChoonaraShakira
- [7] http://www.ncdchild.org