

2022

WALKING THE TALK PROJECT

FINAL REPORT: FIRST STEPS TO IMPROVING YOUTH ENGAGEMENT & HEALTHCARE



Association for the Wellbeing
of Children in Healthcare



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Acknowledgements

Funding for the Walking the Talk project has been provided by the NSW Government through Multicultural NSW and the Australian Government through the Consumers Health Forum of Australia.

The Association for the Wellbeing of Children in Healthcare & Health Consumers NSW are funded, in part, by the New South Wales Ministry of Health.

Thank you also to Kelsey, Will, and Chelsea from YLab for their work designing and facilitating the Workshops, and synthesising the raw data from the Workshops.

Special thanks to the young people who collaborated on this project: Margherita Dall'Occo-Vaccaro, Ishvar Barani, Zoe Cushing, Zac Chu, Ethan Neish, Fulin Yan, Dominique Rose, Brielle Wenham, William Honon, Annelise Ryan, Felicity Palmer, Aristidis Tsoulakos, Devin Lam, Rebecca Yu, Aakriti Chhetri, Natalie Merchant, and Dion Stravroulakis.

Without you, Walking the Talk wouldn't exist!

Suggested Citation

Spongberg-Ross, I. (2022). *Walking the Talk Final Report: First Steps to Improving Youth Engagement & Healthcare*. The Association for the Wellbeing of Children in Healthcare & Health Consumers NSW, Australia. <https://awch.org.au/wp-content/uploads/2023/01/WTT-Final-Report.pdf>

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ISBN: 978-0-9943298-7-5

We acknowledge the Traditional Custodians of the land on which we all live and work throughout Australia.

We recognise their continuing connection to land, water, and community and pay respects to Elders past, present and emerging.

We acknowledge that sovereignty was never ceded.

This always was and always will be Aboriginal Land.

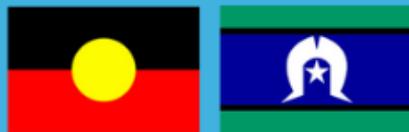


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Glossary

Adultism

Behaviours and attitudes based on the assumptions that adults are superior to young people, and entitled to act upon young people without their consent.

Ageism

Discrimination based on a person's age.

Autonomy

Freedom from external control or influence; independence; self-governance.

Co-design

A participatory approach to designing solutions, in which community members are treated as equal collaborators in the design process.

Engagement

Stakeholders actively involved in decisions, design, and delivery of systems, services, and processes that effect them.

Health Consumer

Any person who uses health services, as well as their family and carers. This includes people who have used a health service in the past or who could potentially use a health service in the future.

Health Literacy Environment

The infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services.

Holistic

In health, this term refers to care of the whole person, taking into account mental and social factors, rather than just the symptoms of a disease.

Intersectionality

A framework for understanding how aspects of a person's social and political identities (such as race, gender identity, sexuality, class, disability, age) combine to create different experiences of discrimination and/or privilege.

LGBTQIA+

Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, plus.

Shared Decision Making

Involves discussion and collaboration between a consumer and their healthcare provider. It is about bringing together the consumer's values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, in order to reach the most appropriate healthcare decisions for that person.

Telehealth

Consultation/appointment with a healthcare provider by phone or video call.

Young People

Walking the Talk defines young people as those aged 14-25.

TO OUR COLLABORATORS



We would like to acknowledge the young people who collaborated on this project, without whom the Walking the Talk would not have been possible.

Thank you for your time, energy, openness, and ideas!

thank you

Margherita Dall'Occo-Vaccaro

Ishvar Barani

Zoe Cushing

Zac Chu

Ethan Neish

Fulin Yan

Dominique Rose

Brielle Wenham

William Honon

Annelise Ryan

Felicity Palmer

Aristidis Tsoulakos

Devin Lam

Rebecca Yu

Aakriti Chhetri

Natalie Marchant

Dion Stravroulakis

The Walking the Talk project is a collaboration between the Association for the Wellbeing of Children in Healthcare (AWCH), Health Consumers NSW (HCNSW), and young people.

The goal of the project was to engage with young people (14-25) from a diverse range of backgrounds to identify and target gaps in current resources and practices of youth engagement within the healthcare system, with a focus on the COVID-19 pandemic. This includes any areas of improvement within AWCH & HCNSW's systems and processes. We aimed to support young people to voice their thoughts, ideas, and opinions, and collaborate with them to make optimal youth engagement and health advocacy a reality.

ABOUT US



The Association for the Wellbeing of Children in Healthcare (AWCH) is a national not-for-profit organisation that advocates for the needs of children, young people and their families within the healthcare system.

Health Consumers NSW (HCNSW) is a membership-based, independent, not-for-profit organisation promoting and practicing consumer engagement in the NSW health sector. HCNSW creates meaningful partnerships between consumers, the health sector, and policy-makers.



PROJECT OVERVIEW



The “Walking the Talk – designing youth advocacy with young people” project is a collaboration between The Association for the Wellbeing of Children in Healthcare (AWCH), Health Consumers NSW (HCNSW) and young people (aged 14-25).

The main objectives of Walking the Talk were to:

- Engage with a diverse group of young people, creating and fostering a welcoming and safe space to share experiences, ideas, opinions, and thoughts
 - Listen to young people’s experiences with the healthcare system and health engagement
 - Collaborate with young people to identify ideas and solutions to address the issues brought up through these experiences
- Identify and discuss young people’s experiences with regard to COVID-19, identifying issues, themes, and examples of resilience
- Develop a Youth Engagement Strategy for AWCH & HCNSW based on the findings of the engagement process

Through the work done by AWCH and HCNSW a substantial need has been identified for engaging with young people more effectively and co-designing engagement strategies, processes and priorities with them. This need is particularly salient within engagement with young people belonging to marginalised groups such as culturally and linguistically diverse communities. Walking the Talk aimed to begin to address this gap, laying a foundation for future youth engagement and health advocacy.

Prior to engaging with the young collaborators, a [White Paper](#) was created in order to gain insight into the current landscape of youth engagement and advocacy, as well as the needs and desires of young people in Australia. This offered a sound foundation for our engagement, to ensure we were using best practice in the lead up to asking our collaborators how to improve *future* engagement.

PROJECT OVERVIEW



The aims of the white paper included identifying ‘young people’ as a distinct group, exploring current information about their experiences and priorities, identifying key themes and gaps within current youth engagement resources, and lastly, identifying actions to be taken by Walking the Talk based on the findings. This was achieved by reviewing current, relevant data regarding young Australians, current academic information, relevant models of youth engagement, and current youth engagement resources, drawing out themes and gaps within each area in order to shape the next steps of the project.

It was found that young people in Australia continue to face numerous challenges and barriers to engagement, both as health consumers, and behind the scenes within engagement design. Further, many young people continue to feel unheard and dismissed in society, particularly in the midst of the COVID-19 pandemic. The literature reviewed mirrored these findings, identifying several areas of consideration for youth engagement. Several common themes were identified within current youth engagement resources such as mutual trust and respect, accessibility, and flexibility.

Four main gaps were identified, offering areas for opportunity for Walking the Talk. The gaps identified were:

- The need for an intersectional lens with regard to young people’s identities, experiences, and needs
- The need for improved follow up and sustainability of engagement
- The need for improved collaboration and sharing of power between adults and young people
- The need for improved acknowledgement of young people’s work as co-designers/producers/authors

These findings assisted the project in choosing focus areas and designing optimal engagement processes prior to gaining insight from our collaborators.

STEERING COMMITTEE

The project also created a Steering Committee of experienced professionals to help guide our approach and ensure best practice before we engaged with young people.

As one of the main objectives of Walking the Talk was to gain insight into how we can improve youth engagement, we were required to rely on current knowledge and understanding to design and implement our engagement process. One way we ensured this was by bringing together various professionals with both personal and professional experience with youth engagement. The insights gained from the Steering Committee assisted the project in recruitment, design, and implementation of engagement processes.

Thank you to all members of the Steering Committee for your time, knowledge, and insights that helped to shape this project.

Fiona Robards
Flinn Donovan
Kawsar Elmir
Laura Griffin
Mae Rafraf
Lauren Gatt
Allison Hutton
Pratibha Singh
Bianca Louise Webb

THANK YOU!



+

YLab.

METHODOLOGY

The engagement phase of Walking the Talk consisted of three workshops with our collaborators. These workshops were conducted online, over three weeks.



AWCH & HCNSW commissioned **YLab** to work alongside us to design and facilitate the workshops. We designed **3 online workshops** aimed at optimising collaboration and creating a welcoming space for sharing lived experiences, opinions, and ideas.

Each Workshop was 3 hours in length and involved a combination of presentation of information and activity outlines, collaborative but individual work through adding to a shared document, and both small group and whole group discussions and sharing.

YLab.

"YLab is a co-design and consulting social enterprise that brings together young people with diverse lived experiences and partners to design solutions to complex problems.

Our model for co-design brings together those with lived experienced and technical expertise to design tailored and lasting solutions and shape a better world for young people."



Admiring the Problem



Workshop 1 focused on collaborators' experiences with the healthcare system, services and organisations. This included the following prompting questions:

- What are some barriers you face when accessing health services as a young person?
- What part of health services do you wish young people were a part of designing? Why?
- What difference might be seen if young people were involved in designing health engagement?

The first half of Workshop 2 focused on digging deeper into the themes/issues identified in Workshop 1. Collaborators were asked to think "But why?" in order to trace back through to the core of each issue. This allowed for more critical thinking and drawing out of core issues for which change can be advocated for.

Then Workshop 2 focused on collaborators experiences with regard to the COVID-19 pandemic. This included the following prompting questions:

- What were some of your experiences accessing health services during the pandemic?
- What are some of the issues and barriers that you face **now** due to the COVID-19 pandemic?
- How has the pandemic changed/impacted how you use/engage with health services?

Building Solutions



From Workshops 1 & 2, themes were drawn out and synthesised. These themes were then presented to collaborators in Workshop 3, where they were then asked to indicate which themes they felt were most important to address. Based on collaborators votes, four themes were selected to focus on; ageism and adultism, consumer and provider relationships, accessibility, and finances and eligibility.

From here, we asked collaborators to brainstorm ideas to address each of the four issues. Collaborators were asked the following questions:

- **How might we...**change the way young people, their networks, health workers communicate... **so that...**young people are heard and have agency over their health care needs?
- **How might we...** advocate for increased accessibility to health services for young people...**so that...** they have the help they need in the way they need when they need it?
- **How might we...** increase ease of access to health services...**so that...** young people understand the services that are available to them and can afford to use them?
- **How might we...**reimagine youth consumer and health provider relationships...**so that...**young people feel safe, cared for, and confident in their health providers?

Synthesis of Findings



From here, the insights were synthesised into four main Sections for this report.

- Section I: Young People's Experiences with Healthcare & Health Engagement
- Section II: Young People, Healthcare & Resilience in the Face of COVID-19
- Section III: Building Solutions for Youth Healthcare
- Section IV: Improving Our Work with Young People

COLLABORATORS

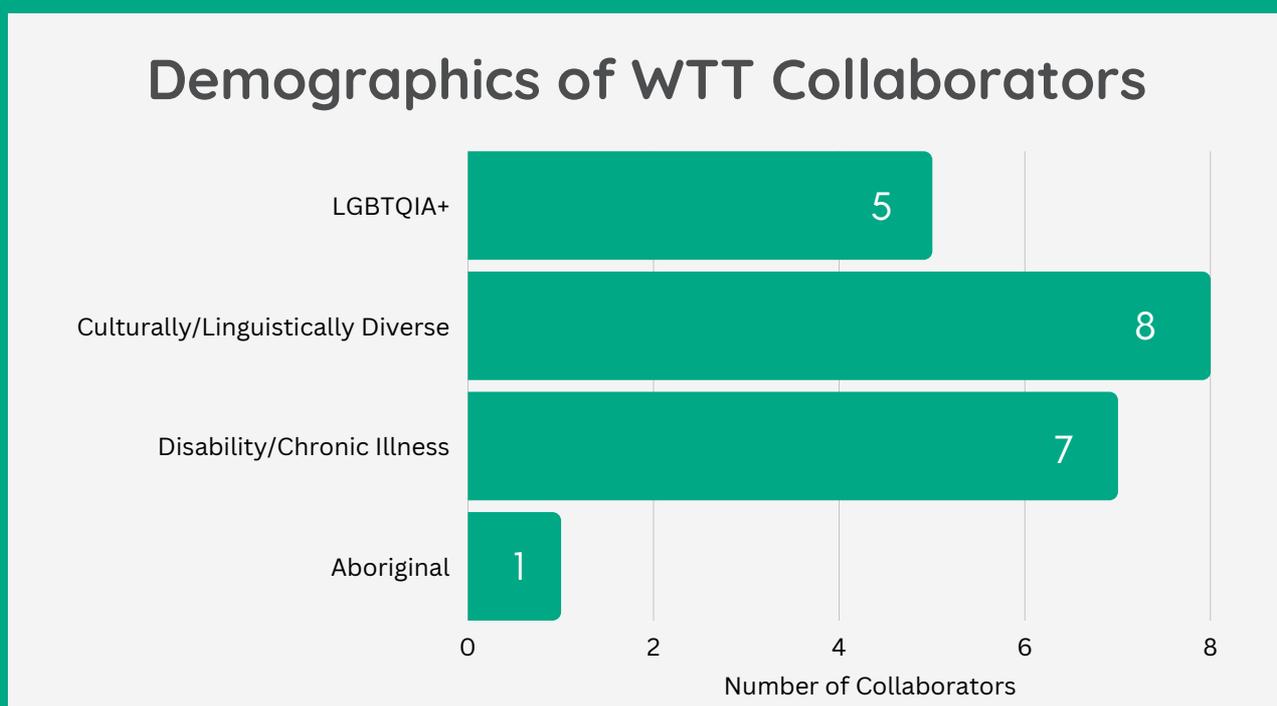
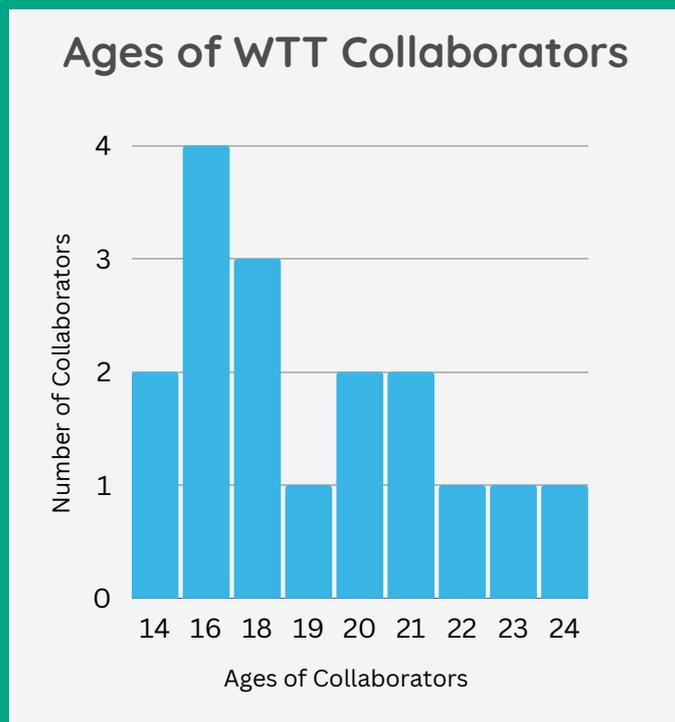
Seventeen young people contributed to this project, ranging from 14 to 24 years old.

Walking the Talk recruited young people to collaborate on the project through various means including organisational networks and social media.

Some demographics questions were included in the application process for collaborators in order to capture the overall diversity among the group.

Demographics included:

- 8 collaborators were from culturally and/or linguistically diverse backgrounds
- 5 collaborators identified as part of the LGBTQIA+ community
- 7 collaborators reported having a disability and/or chronic illness
- 1 collaborator was Aboriginal



COLLABORATORS

The majority (14) of Walking the Talk collaborators were located in New South Wales, most commonly the greater Sydney area. Three collaborators lived interstate.



SECTION I



WORKSHOP 1: YOUNG PEOPLE'S EXPERIENCES WITH HEALTHCARE & HEALTH ENGAGEMENT

"What part of health services do you wish young people were a part of designing? Why?"

"What are some barriers you face when accessing health services as a young person?"

"What difference might be seen if young people were involved in designing health engagement?"

THEMES



In the first two workshops, collaborators came together to “Admire the Problem”. This involved collaborators looking at prompting questions regarding healthcare, and consequently sharing lived experiences, thoughts, and opinions.

This phase of work provided an opportunity for the team to think critically about, and better understand and articulate the challenges, barriers and issues facing young people when it comes to accessing healthcare services. YLab understands that identifying and deeply understanding those challenges and barriers is crucial in order to then design tailored and targeted solutions for, and with, young people. During the “Admiring the Problem” workshops, the co-design team drew from their lived experience of accessing and receiving support from the healthcare system, including during the covid-19 pandemic.

The following themes emerged from the collaborators experiences...

AGEISM & ADULTISM

Adultism and ageism manifest in the healthcare system in many ways, including dismissal and disbelief of young people's experiences, biased assumptions about young people's behaviour and health, distrust of young people, and a lack of acknowledgement of young people's autonomy and agency. Young people have expressed the serious consequences to health and wellbeing that ageism and adultism have.

1. When young people aren't taken seriously or not believed, it can lead to scary, life threatening situations when it comes to health conditions and accessing health care including receiving no treatment, incorrect treatment, and misdiagnosis.
2. Often staff will talk to parents or caregivers about the health of young people, rather than to young people themselves.
3. Staff and providers make assumptions about the health and wellbeing of young people without asking or checking in with young people.

“

“My friend dialled emergency services after an asthma attack (severe) and the paramedic was unsure whether to **trust** that he was indeed not prank calling them.”

”

“We are **not taken as seriously** as we should be. Doctors often prefer to talk to our parents, rather than us.”

”

“Staff **think they know** what my worries are but they don't, and they don't ask me.”

“

“[There is a] Misunderstanding of the **autonomy** young people have over their own bodies.”



CONSUMER/PROVIDER RELATIONSHIPS

Young people want better relationships with their health care providers and practitioners. The most difficult elements of these relationships indicated by young people were empathy, trust, communication and continuity.

1. Language barriers, complex terminology and medical jargon makes communication difficult.
2. Lack of empathy when disclosing certain news to young people and family causes upset with practitioners.
3. Privacy and non-disclosure breaches cause distrust between young people and practitioners and staff.
4. Lack of continuity and regular communication with patients further isolates young people from services.

“

“There can be a **language barrier** to accessing health care for young people and also for people from culturally and linguistically diverse backgrounds.”



”
“Doctors, nurses and specialists need to assess the room more and **see how the patient and their family is feeling** and then determine on how to present news and/or information.
READ THE ROOM!”

ACCESSIBILITY

Young people need practical access to health services. Young people indicated that location, long wait times of a strained system and lack of preventive care were some of the most difficult parts of access.

1. There is a lack of rural based doctors and service locations, particularly a lack of specialists in rural areas. Recent changes to Medicare include the discontinuation of rebates for long consultations via phone, causing further barriers to care for those living rurally.
2. Long wait times and infrequent appointments make accessing care more difficult.
3. Services need to improve how they inform young people of various aspects of access (i.e. Medicare card, Centrelink concession, Medicare Benefits Schedule, AHPRA).
4. Young people feel there is a lack of peer support in youth services, so they have to rely entirely on clinical support.
5. There is not enough preventative support for young people accessing mental health care.



“(It’s) **Very hard to access** mental health support unless for mild anxiety and depression or when in crisis. There is no middle ground support/prevention before crisis”

“There are **no doctors** in **rural** New South Wales.”

1. Schubert, S. (2022, 6 July). *Medicare rebate changes disadvantage rural Australians, doctors say*. ABC News. <https://www.abc.net.au/news/2022-07-06/medicare-rebate-changes-disadvantage-rural-australians/101210532>

ACCESSIBILITY CONT.

Young people need health services that are accessible to them and their specific needs.

1. Young people need space for the intersections of their identities (including age) and their health difficulties when accessing health services.
2. Young people want holistic approaches that can be used to mitigate a wider range of barriers they may face.
3. If health services had young people designing them, young people feel they would be:
 - Better at prevention and proactive services
 - Accessible online and used more effectively from remote places
 - Accessible to those who have limited support networks

“(It should be) **Accessible** to those who have no family ties and are living independently as young adults”



“

“(Make) space for the **unique** difficulties young people who have different **intersections** may face”

INCLUSION, COMMUNITY & ENGAGEMENT

Young people want welcoming and accepting environments for their healthcare needs. The following suggestions were made by collaborators:

1. Support groups would allow young people to be in regular contact with people with common experiences in the health system. While support groups exist for particular chronic illnesses and disabilities, the notion of more general peer support groups and networks, to offer support for aspects of healthcare such as system navigation, was popular.
2. More inclusive and accessible environments are necessary for youth engagement (LGBTQIA+ specific supports, cultural diversity, youth disability representation).
3. Young people need flexibility in how and when they can access services, with decision making powers to decide when they are ready to discontinue/finish.
4. Young people want health services to cultivate welcoming and accepting spaces - physical environments need to be functional and inviting for young people.



“

“Many medical practitioners... don't get a sense of **inclusivity of LGBTQ+ communities.**”

”

“If you're part of the community, and you're going to a health provider, it is helpful to know that you're not going to someone who's **intolerant**, and has sort of **preconceived notions**”

NAVIGATING THE SYSTEM



"I felt like a **tiny person** in front of a **massive skyscraper**"

Young people need the skills to navigate the health system independently. Young people expressed that not everyone has equal support networks to help navigate a very complex system.

1. Not all young people can have, or want to have parents/caregivers help them navigate these systems.
2. Costs need to be explicit prior to accessing services + lists of bulk billing practices and language translations of this.
3. Young people would like to see the normalisation of teaching young people about the healthcare system before they reach young adulthood, where they will be navigating the system for themselves.



"(You need) overwhelming **navigational skills** to properly access various health services."

SERVICE FEATURES

Young people want to be able to advocate for themselves within the system. The collaborators had a lot of feedback regarding feedback processes.

1. This indicated that young people have a strong desire to use their autonomy within the health system and create change to have services that function for young people.
2. Young people want health staff and practitioners to practice trauma informed care and have sensitivity.
3. Young people need knowledge regarding healthcare complaints processes. Further, power dynamics cause young people to not feel able/comfortable making formal complaints about healthcare providers.



"Who do you **complain** to if something happens? (We want) **Support and info** around this"

“

“If people can't access or afford it [healthcare] **what's the point** of working on the other things?”

FINANCES & ELIGIBILITY

Costs of services and health treatment is a big concern for young people, and the recent changes to Medicare have caused significant anxiety around billing and fees.

1. Many GPs no longer bulk bill, creating a lack of options for young people and also limiting practitioner/consumer relationships because these changes make continuity hard.
2. Most free services are crisis services, there are few free preventative options.
3. Mental health treatment is very expensive, with psychiatry services often costing between \$400-\$700 for a first appointment, and Medicare only covering 10 psychology sessions per year.
4. There is significant frustration regarding how eligibility criteria is decided for services such as the NDIS, including how young people with chronic illness/disability are perceived.

”

"All the GPs in my area no longer bulk bill - so there is a **lack of options** if you can't pay, and **no continuity of care** due to always having to change."





“(You feel) that **someone else deserves** the care you would get **more than you do.**”

STIGMA & NEGATIVE PERCEPTIONS

Stigma is a major issue throughout the health system, creating an added barrier for many young people. Young people opened up about their struggle with stigma in the health system.

1. Mental health stigma is a significant barrier for young people when trying to access support. Young people are often being labelled as attention seeking or dramatic and some health professionals often perpetuate these stigmas.
2. Many young people feel they cannot reach out for sexual health support or speak 1:1 with health care staff for many reasons including (but not limited to) privacy concerns, shame, lack of knowledge of how/what to say.
3. A recurring feeling young people brought up throughout every workshop was feeling like they didn't deserve the care they need because someone may need it more.
4. Young people want information for the standards and procedures for under-18s accessing health services, and information about consumer charter of rights and what you should expect from healthcare systems.



“(There is) **massive stigma around mental health,** particularly diagnoses of complex trauma, personality disorders, and chronic suicidality”

SECTION II

WORKSHOP 2: YOUNG PEOPLE, HEALTHCARE & RESILIENCE IN THE FACE OF COVID-19

"What were some of your experiences accessing Health services during the pandemic?"

"What are some issues or barriers that you face now due to the Covid-19 pandemic?"

"How has the pandemic changed how you use and/or engage with health services?"

OVERVIEW

One of the main goals of the Walking the Talk project was to gain insight into young people's experiences during the pandemic.

While the collective trauma of the global COVID-19 pandemic has touched all demographics, it is important to understand the specific impacts on specific groups, including young people.

Young people were underrepresented in the discussions regarding COVID-19 and its impacts, including within media coverage. Further, when young people were included in media coverage of the pandemic, many media outlets used stereotypes and negative sentiments in their coverage.¹

The impacts of the pandemic can be seen in all aspects of young people's lives including healthcare, education, employment, finances, housing, social support, and safety. Additionally, young people face long term effects in many of these areas including:

- adverse effects from disruption to education
- consequences of unemployment on long-term employment prospects and finances
- access to secure housing
- mental health²

"[It's] **Harder to connect** socially with others."

"My body has **deconditioned** quite a bit, meaning I'm a lot more limited in what I can do now compared to what I could do before."

"Every health related process seems to **take longer**, from obtaining a referral to waiting list, to actually seeing a healthcare provider!"

"[The pandemic caused a] **Loss** of social confidence."

1. The Foundation for Young Australians. (2020). *Examining the representation of young people by Australian news media in the first six months of COVID-19*. <https://www.afy.gov.au/DocumentStore.ashx?id=75065acc-0e97-4881-a2ed-dc48ec003b27&subId=698462>

2. Australian Institute of Health and Welfare. (2021). *COVID-19 and Young People*. <https://www.aihw.gov.au/reports/children-youth/covid-19-and-young-people>

THEMES

In Workshop 2 of the Walking the Talk project, we asked our young collaborators the following questions:

- What were some of your experiences accessing Health services during the pandemic?
- What are some issues or barriers that you face now due to the Covid-19 pandemic?
- How has the pandemic changed how you use/engage with health services?

Four main themes emerged from Workshop 2:

- Fear, Isolation & Avoidance
- Lack of Safety & Care
- Accessibility
- Communication & Technology

“

"Actual support and advice with being COVID positive was **limited** (or at least felt like it, especially for youth in school)."

”

"Chronically ill young people are **questioned** [about the legitimacy of their condition(s)]"

“

"[You] **Feel a burden** to healthcare unless you are in a crisis."

”

"[I] Felt like **others** may **need** health services **more**."

FEAR, ISOLATION & AVOIDANCE

“I was **scared to go out** since many people were coughing **without masks** at the peak of the pandemic.”

It was deeply evident that young people are still experiencing the effects of the COVID-19 pandemic. These effects are being experienced across their physical, social and emotional well-being.

1. Health anxiety was prominent for most young people, expressing that avoiding going out as much as possible (as instructed during pandemic) is still something many young people do.
2. Heightened hygiene awareness was also strongly expressed, and having higher expectations of this from health care professionals was important to young people.
3. Young people experience strong feelings of loss towards their personal and social lives because of the pandemic and the subsequent consequences of the lockdowns.
4. Young people want to connect to their health care providers and the world around them, but are too scared and have too much distrust in the health system.

“I have a constant FOMO [Fear Of Missing Out] if I miss anything outside related. I **don't want to waste my life inside** when I already spent nearly 12 months in lockdown.”

“(I) **Couldn't feel safe** or find a safe space”

LACK OF SAFETY & CARE

Generally, young people felt a distinct lack of care and safety when engaging with the health system during and beyond the pandemic. Although they do acknowledge that healthcare workers were over capacity and care demands were exponentially high during the peak of the pandemic.

1. Young people felt there were a lack of safe spaces for them during the pandemic. Disclosing personal issues during telehealth appointments was difficult due to the lack of privacy in their homes.
2. Support people often were not allowed to accompany young people when receiving care/treatment during the pandemic. This became a significant deterrent for young people to seeking healthcare, and was especially hard for minors.
3. COVID-19 advice and support was limited for young people as it was mostly directed towards adults and elderly people. Additionally, information and websites were difficult to navigate and understand.
4. Most resources were for crisis services. This resulted in young people feel they were/are a burden to the health care system when they weren't yet at crisis point, but were still in genuine need of healthcare services.
 - Young people were acutely aware of the strain on the healthcare system in the wake of the pandemic, and expressed feelings of being 'undeserving' of what care is available, that 'others may need it more'.

“Doctor at vaccine place asked me to **prove** my chronic illness while closing the distance between us and **towering over me**. Luckily my dad was there and told him to get back.”

“(I) Was **not able to access a hospital** setting as **my health care was not considered a priority**”

ACCESSIBILITY

Post pandemic young people have noticed the significant changes to the logistics of accessing health services.

1. Services are still over-capacity, with many services having longer wait times than prior to or during the pandemic, there are fewer regional doctors, Medicare processes are slower, and many practitioners still rely on telehealth to keep up with demand.
2. Generally, telehealth was not the preferred access route for young people, but is still being relied on by many providers.
 - Issues such as long wait times, delayed and unpredictable call times, privacy issues, lack of rapport were identified, making telehealth highly undesirable for many young people
 - It was evident that preference for telehealth or face-to-face care was very individual, and therefore should be treated as such
3. Specialist access is reaching a point of inaccessibility. Significant to this is GP wait times for referrals (and repeat referrals) on top of the wait times for the specialist.
4. Young people feel that treatment is prioritized over prevention, leaving young people feeling like a burden to the healthcare system and practitioners.



"Doctors and healthcare professionals are overburdened, **reducing consultancy time and quality**"



"Almost all health services I tried to access, especially public, were **at their limit** and then some."



"**Hated telehealth, waiting** for a call **for hours** depending on the doctor"



"Waiting lists appear even longer, and you are **acutely aware how many people are missing out**"

COMMUNICATION & TECHNOLOGY

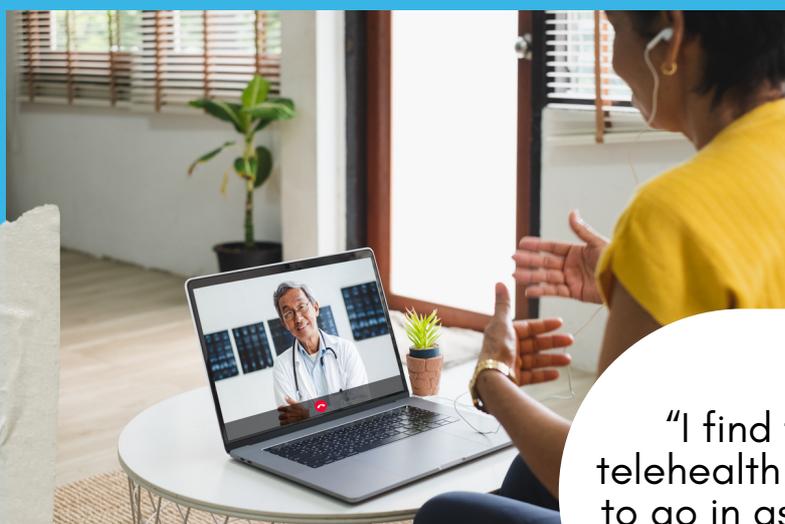


“Some practitioners seem to continue **only doing telehealth** – even if you don’t want this”

The pandemic has seen an increase in remote, online consultation and communication between consumers and health providers. For some it was helpful and offered easier access, but for others it was less than desirable. That being said, young people expressed that having both face-to-face and online options are helpful and useful. However, the logistics of this need to be improved.

Their key concerns were:

1. Telehealth was not user friendly for young people seeking health care. It was difficult to check availability and payment methods.
2. Technology can be unreliable and consultations can be interrupted, but if this happens the appointment needs to be promptly rescheduled.
3. There is a lack of personal connection using telehealth and online services, ideally this would be established first in a face-to-face setting.
4. Websites are often hard to navigate, with few instructions, and are not made with the user in mind.



“I find the ability to use **both telehealth** and physically being able to go in as a **great thing** since that wasn’t an option before.”

COVID CONSIDERATIONS

FOR WORKING WITH YOUNG PEOPLE



Listen to Young People's Experiences

Young people have so far felt left out of the conversation regarding COVID-19. Therefore it is critical that we listen to and acknowledge their experiences, thoughts, ideas, and opinions on this topic. This may seem obvious, however, it is clear that this has not been achieved adequately thus far. An explicit focus is therefore necessary.

Intersectional Lens



As in all situations, a focus on intersecting identities and experiences is essential for optimal support and engagement. As the pandemic has had a particular impact on marginalised groups, an intersectional focus is integral to any COVID-19 focused work.



Stay Up to Date on Latest Information

It has been shown that young people value expert knowledge with regard to the pandemic. By being clear that we are staying up to date on the latest information and recommendations, we may afford young people some comfort in this area.

Validate Young People's Needs



As stated, young people have felt disregarded with regard to the impacts of the pandemic thus far. There is also a common sense of guilt for using health services due to the pressure on the system, as well as feeling as though others (particularly older people) need care more. It is important that we work to acknowledge and validate young people's needs, and focus on the need for more care for all, rather than who deserves or needs the limited care available.



Offer Resources

As part of being left out of the conversation, young people feel they have had little access to clear and simple information regarding COVID-19, vaccinations, isolation, lockdowns, masks, and so on. Now that more information is known about these topics, it is important to ensure they are easily understood and disseminated to young people.

More information on next steps will be outlined in Section IV.

SECTION III

WORKSHOP 3: BUILDING SOLUTIONS FOR YOUTH HEALTHCARE

"How Might We... change the way young people, their networks & health workers communicate..."

So That...young people are heard & have agency over their healthcare needs?"

"How Might We...reimagine youth consumer and health provider relationships..."

So That...young people feel safe, cared for, and confident in their health providers?"

"How Might We... increase ease of access to health services..."

So That... young people understand the services that are available to them and can afford to use them?"

How Might We... advocate for increased accessibility to health services for young people..."

So That... they have the help they need in the way they need when they need it?"

IMPROVING HEALTHCARE FOR YOUNG PEOPLE

Workshop 3 focused on gaining insight and ideas from the collaborators about what HCNSW and AWCH can do to address the issues identified in Sessions 1 & 2.

We asked young people to brainstorm ideas to address the themes that emerged from Workshops 1 & 2. We asked them to think as broadly as they could to gain as much insight as possible, and then narrowed our ideas down to achievable goals for AWCH & HCNSW, as well as more wide-ranging advocacy ideas.

The following four key focus areas emerged...



ADVOCACY & AUTONOMY EDUCATION

Advocacy organisations and healthcare services can better engage young people by recognising young people's ability to advocate for themselves. This can be achieved by:



- Ensuring that young people understand their ability to consent/not consent to health related activities (e.g. information disclosure or treatment), and any limitations to their capacity under healthcare ethics or law.
 - Creating clear and easily accessible resources for this information
- Informing young people about potential scenarios in which an adult might have to step in to decide on the best course of action.
- Encouraging young people to take control of their health care, and especially when something might be wrong.
- Advocating for the development of feedback structures that hold health professionals accountable to the care they provide young people.
- Advocating for a focus on partnership between healthcare providers and young people
 - Including emphasis on shared decision making, fostering a health literacy environment, and decision support resources.

Why is this needed?

One aspect of the power imbalance between consumers and professionals, as well as young people and adults is knowledge. By having a stronger knowledge foundation, including legal rights pertaining to their bodies, privacy, and consent, the disproportionate power imbalance may be shifted. Young people would be better equipped to navigate the health system, as well as establish power for themselves, when working with health professionals who may overlook concerns young people express about their health needs. Essentially, young people seek to rely less on the credibility of adults or older people when it comes to their health needs and access.



CULTIVATING COMMUNITY

Creating and fostering an environment in which young people feel safe and seen will significantly strengthen relationships and ultimately help increase youth engagement.

To do this, organisations and services can:

- Develop peer-support groups for young people in the health system, as well as conduct further research into peer support work in health services, particularly mental health.
- Create collaborative feedback and reflection opportunities at regular intervals in a young person's engagement with a service so that there is open dialogue between staff and young people and the power imbalance is reduced.
- Provide co-design staff training/retraining regarding relationship building and care of young people, then use this training to ensure the services offered to young people have been designed with them.

Why is this needed?

Young people want to be proactive in their healthcare and their self-advocacy. Having collaborative relationships between healthcare workers, health advocates and young people will create stronger working relationships that will see a significant change in the health system that reflects the needs and goals identified by young people. This will transform the health system to suit the needs and wishes of young health consumers.

PRIORITISING YOUNG PEOPLE'S PRIORITIES

Affordability is a key priority for young people and needs to be a key priority for advocacy organisations wanting to work with young people.

- Young people expressed an urgency for an increase in government funded services that placed an emphasis on health prevention as opposed to crisis response.
- Young people see an opportunity for healthcare services to be less transitional and more geared towards providing a safe and less stressful experience for young people by eliminating any fee for service and out of pocket expenses.
- We heard the need for a more diverse range of bulk billing services and a increase in bulk billings sessions provided.
- A more streamlined approach to submitting Medicare claims and subsidies. Young people thought this responsibility could always be that of the service. The current process is difficult to navigate and overall disempowering.

Why is this needed?

Affordability is one of the largest barriers preventing young people from accessing the healthcare they need. Many young people are financially independent, however typically do not have the luxury of high-income. Many young people are in a complex time of their lives, juggling work, education, social life, family, and health. This is further complicated for young people living with disability or chronic illness. Healthcare is essential and young people want truly universal health access and more government funded health access to be advocated for.





PROVIDING OPTIONS & INFORMATION

The accessibility needs of young people heavily tie in with a better understanding of their self-agency and knowledge, as well as some logistical needs.

- Young people want education about how the health system works and what to expect so that they can better navigate it for themselves.
- Young people want simple and uncomplicated information that is easy to access so they may also better inform themselves.
- Young people want options when accessing healthcare. The pandemic shifted how health services work, and for some, telehealth and remote access is functional, but for others it is not.
- Young people want stronger, streamlined health networks, so that they can rely on their contacts within the system and be supported by the network they cultivate through their health needs.

Why is this needed?

Young people need flexible access to health services and have understanding of the health system and how they fit into that to better access and use the system. Essentially what young people want is options and information. For AWCH and HCNSW to engage better with young people, having options for how young people can access your services, as well as a variety of information, will go a long way to create stronger engagement with young people.



SECTION IV

NEXT STEPS: IMPROVING OUR WORK WITH YOUNG PEOPLE



Association for the Wellbeing
of Children in Healthcare



LESSONS LEARNED

At the end of Workshop 3, we asked our collaborators for direct feedback regarding the engagement processes used for the Walking the Talk project.

The main feedback we received was:

- Shorter, but more numerous, engagement sessions
- More structured activities and methods of collaboration and engagement
- More information available about what sessions will entail earlier in the project process

Demographics also show only one participant was Indigenous. This is an area we aim to address in future youth engagement.

We also asked collaborators to rate their experience (1 being worst, 10 being best) engaging with Walking the Talk:



Lastly, we asked collaborators what their favourite part of working on Walking the Talk was:



"Communicating with people my age who have gone through similar experiences."



"Being able to collaborate simultaneously with others through the slides but also doing so on my own!"

"Inclusivity and acceptance."



"The workshop was interactive and people could collaborate without verbal communication."



YOUTH ENGAGEMENT STRATEGY



Based on feedback and findings of this project, a Youth Engagement Strategy has been developed for AWCH and HCNSW to implement.

This includes:

- A Youth Engagement Guide for AWCH & HCNSW
- Next Steps including an outline of Commitments for AWCH & HCNSW, based on collaborators ideas identified in Section III,
 - Continued Collaboration
 - Development of Resources
 - Education and Training
 - Advocating for Change

These commitments will be upheld by both organisations in 2023 and beyond.

Lizzy Harnett
CEO of AWCH



Association for the Wellbeing
of Children in Healthcare

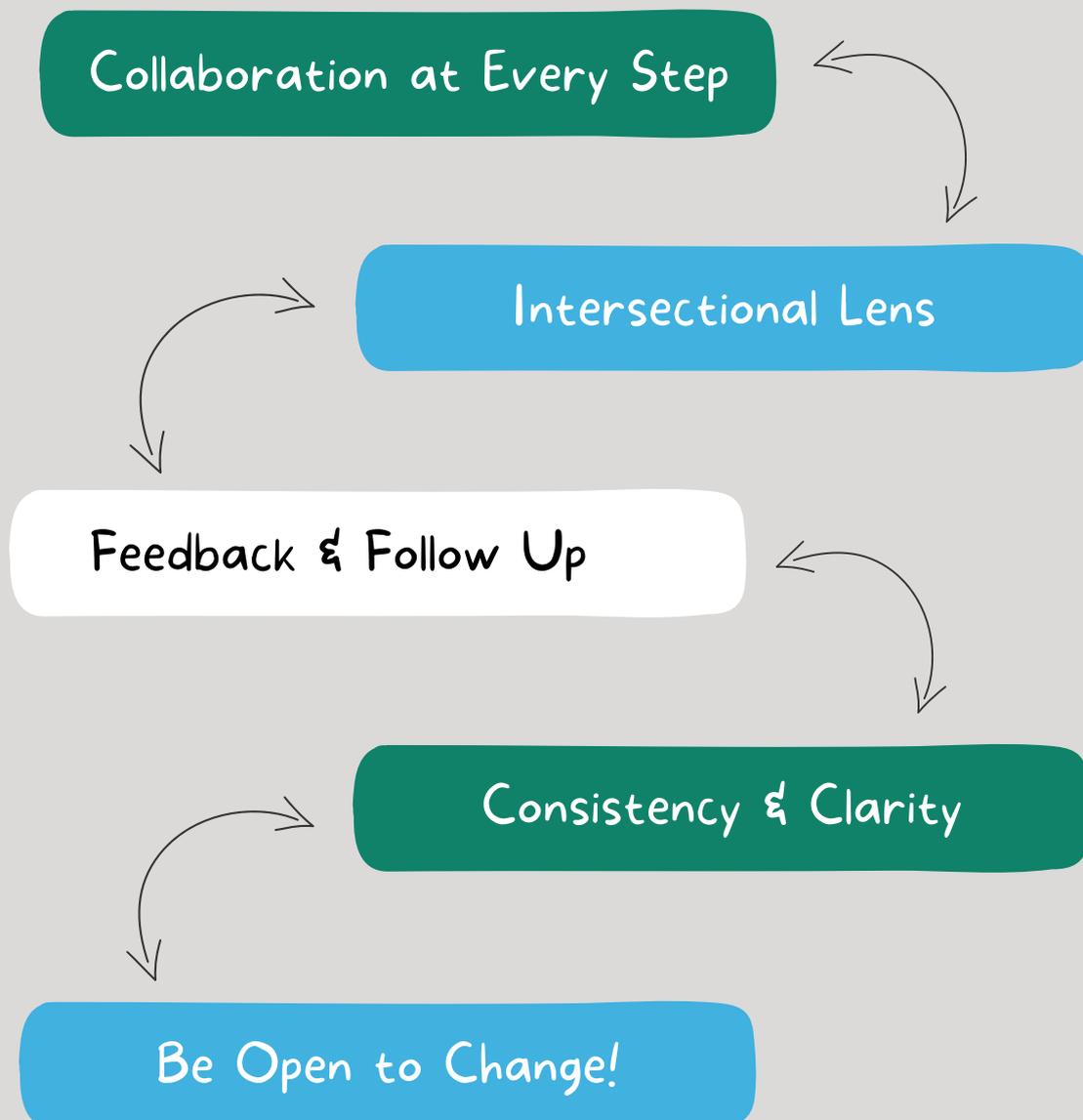
Anthony Brown
Executive Director of HCNSW



AWCH & HCNSW'S YOUTH ENGAGEMENT GUIDE: SNAPSHOT

During the Walking the Talk Workshops, we worked alongside the collaborators to draw out themes from the discussions that were taking place.

From this, we developed the five key necessities for youth engagement:



For the full Guide, see Appendix A!

NEXT STEPS: AWCH & HCNSW'S COMMITMENTS



The next steps for AWCH & HCNSW involve commitment to four key objectives.

These objectives are based on the ideas put forth by the Walking the Talk collaborators as outlined in Section IV: autonomy & advocacy education, cultivating community, prioritising young people's priorities, and providing options & information.

Continued Collaboration

1

AWCH & HCNSW commit to continuing our collaboration with young people through various methods of engagement and communication, including: social media, surveys, projects, education and training.

The Guide (see Appendix A) will be implemented by both organisations.

Development of Resources

2

AWCH & HCNSW commit to utilising the findings from Walking the Talk to develop various resources. These may be aimed at:

- Young people
- Healthcare professionals
- Organisations & staff

Resources may include:

- Fact sheets
- Guides/frameworks/toolkits
- Training manuals
- Interactive resources

Education & Training

3

AWCH & HCNSW commit to a focus on education and training specific to young people, youth healthcare, engagement and advocacy.

Focal points for this include:

- Healthcare rights + young people
- Advocacy skills including personal healthcare advocacy
- Group work, collaboration & engagement skills
- Healthcare system navigation

Advocating for Change

4

AWCH & HCNSW commit to advocating for system-wide change in order to improve youth healthcare and engagement by concentrating on:

- Overcoming systemic barriers to youth healthcare such as cost & accessibility.
- Tackling ageism/adultism in healthcare
- Inclusivity in healthcare
- Cultivating youth-friendly healthcare spaces



CONCLUSION

✦ **Young People's Experiences of Healthcare & Health Engagement**

Themes were:

- Ageism & Adultism
- Consumer/Provider Relationships
- Accessibility
- Inclusion, Community & Engagement
- Navigating the System
- Services Features
- Finances & Eligibility
- Stigma & Negative Perceptions

✦✦ **Building Solutions**

Ideas were:

- Advocacy & Autonomy Education
- Cultivating Community
- Prioritising Young People's Priorities
- Options & Information

The Walking the Talk Project 2022 has offered crucial insight into young people's experiences, opinions, and ideas about healthcare & health engagement.

✦✦ **Young People, Healthcare & Resilience in the Face of COVID-19**

Themes were:

- Fear, Isolation & Avoidance
- Lack of Safety & Care
- Accessibility
- Communication & Technology

✦ **Next Steps**

- Youth Engagement Guide
- Continued Collaboration
- Education & Training
- Development of Resources
- Advocacy for Change

Walking the Talk has created a foundation for meaningful youth engagement & collaboration, and for real change in the youth health and engagement landscapes.

This is the start of a more youth-focused future for AWCH & HCNSW!

ACKNOWLEDGEMENTS

Funding for the Walking the Talk project has been provided by the NSW Government through Multicultural NSW and the Australian Government through the Consumers Health Forum of Australia.

The Association for the Wellbeing of Children in Healthcare & Health Consumers NSW are funded by the New South Wales Ministry of Health.



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APPENDIX A:

AWCH & HCNSW'S YOUTH ENGAGEMENT GUIDE



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AWCH & HCNSW'S

YOUTH ENGAGEMENT GUIDE



Association for the Wellbeing
of Children in Healthcare

2022



Acknowledgements

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The Association for the Wellbeing of Children in Healthcare & Health Consumers NSW are funded by the New South Wales Ministry of Health.

Special thanks to the young people who collaborated on the Walking the Talk project: Margherita Dall'Occo-Vaccaro, Ishvar Barani, Zoe Cushing, Zac Chu, Ethan Neish, Fulin Yan, Dominique Rose, Brielle Wenham, William Honon, Annelise Ryan, Felicity Palmer, Aristidis Tsoulakos, Devin Lam, Rebecca Yu, Aakriti Chhetri, Natalie Merchant, and Dion Stravroulakis.

Without you, Walking the Talk wouldn't exist!

Suggested Citation

Spongberg-Ross, I. (2022). Youth Engagement Guide. The Association for the Wellbeing of Children in Healthcare, Australia. <https://awch.org.au/wp-content/uploads/2023/01/Youth-Engagement-Guide.pdf>

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We acknowledge the Traditional Custodians of the land on which we all meet and work throughout Australia.

We recognise their continuing connection to land, water, and community and pay respects to Elders past, present and emerging.

We acknowledge that sovereignty was never ceded.

This always was and always will be Aboriginal Land.



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OVERVIEW

This Guide is a part of the Walking the Talk project, a collaboration between the Association for the Wellbeing of Children in Healthcare, Health Consumers NSW, and young people.

Findings from the project offer a foundation for improved youth engagement among organisations and services. This Guide collates these findings and synthesises them into practical, effective guidelines for optimal youth engagement.

In Workshop 3 of the Walking the Talk project, we also asked the collaborators to provide feedback regarding engagement processes and experiences.

We asked:

- "What values do you hold when working in a collaborative space?"
- "How do young people want to be involved in designing and implementing a youth engagement strategy that aims to move the dial on meaningful youth engagement?"

Five Key **Necessities** for Youth Engagement

From the findings we developed five key necessities for youth engagement:

- Collaboration at Every Step
- Intersectional Lens
- Feedback & Follow Up
- Consistency & Clarity
- Be Open to Change!

The five necessities are outlined below, with practical examples offered, and supporting quotes from collaborators included.



Collaboration at Every Step

Young people want to, and should be, involved in every step of the way during engagement with organisations, services, and systems. By centring a collaborative approach from the beginning of the engagement process, the inherent power imbalance present in consumer/professional and young person/adult dynamics may be addressed.

"Genuine partnership & active participation, as opposed to tokenism."

How to?

- Using methods of engagement that optimise collaboration, e.g. if engaging online, shared documents allow all involved to edit in real time making sharing ideas equal and simple.
- Surveying large groups of young people to gain diverse insight
- Treating young people equally to those engaging with them e.g. remunerating young people for all work, giving equal time to ideas and discussions
- Recruit young people as early as possible, ask how they want to be engaged with, and include them in the design and development of engagement. This allows for the most positive experience for all, as well as the most effective outcomes!

"Remuneration for our time."

"Real partnership."

"Young people involved in every step of the process."

"Active participation and engagement."

"Shared decision making."

*Intersectionality is a framework for understanding **how aspects of a person's social and political identities combine to create different modes of discrimination and privilege.**

Intersectional Lens



An intersectional* lens is integral to effective and meaningful youth engagement. Including diverse groups is critical to engagement, thus recognising the intersections of various identities and the impact of intersecting oppression is also essential. Further, by including age in this analysis we can conceptualise the impact of age and adult power more effectively.

How to?

- Acknowledging intersecting identities and the impacts of such on all areas of life including engagement.
- Offering interpreter services including AUSLAN
- Ensuring engagement is accessible, including: physical, visual, audio, and sensory.
- Keeping individuality at the fore; no one person can represent an entire group, and the core of intersectionality acknowledges the individual experiences of intersecting identities and experiences.

"Value everyone's opinion."

"Inclusion of lots of different young people, not always the same voices."

"Nothing about us without us!"

"Inclusion & acceptance."

"Discretion, privacy and safety."

"Respect for everyone's stories and experiences."



Feedback & Follow Up

Providing an effective method of feedback for young people is essential to ensure they are afforded dignity and power in the engagement process. Not only allowing for feedback, but taking feedback on (even if it challenges the organisation/service/system), and providing follow up on any changes made as a result of feedback.

Similarly, follow up post-engagement is important to young people, including results, changes, impact, and future opportunities for engagement.



How to?

- Feedback surveys with open-ended questions to allow for specific feedback
- Communicating to young people that all feedback is welcome and will be considered
- Providing regular (e.g. fortnightly) updates on the project/process they are involved in
- Streamlining feedback and follow up processes to be clear and simple



Consistency & Clarity



"Transparency about results of our involvement and feedback."

Consistency is important to effective youth engagement. Young people value consistency with regard to communication, updates, and planned activities. Clarity of what is expected of them is helpful for young people who often have many commitments including school, TAFE or university. Similarly, honesty and transparency from organisations, particularly regarding outcomes, is important to young people.

How to?

- Remaining consistent with communication, e.g. scheduling regular updates, a newsletter, or social media, and sticking to it!
- Offering all information clear and up front including remuneration processes and amount, what is expected of all involved, what engagement is likely to result in, and so on.
- Being honest if outcomes or proposed changes are not achieved as expected. Young people would prefer honesty and transparency about disappointing outcomes, rather than receiving no updates or being misled about outcomes.

"Honesty, and clear, consistent communication."



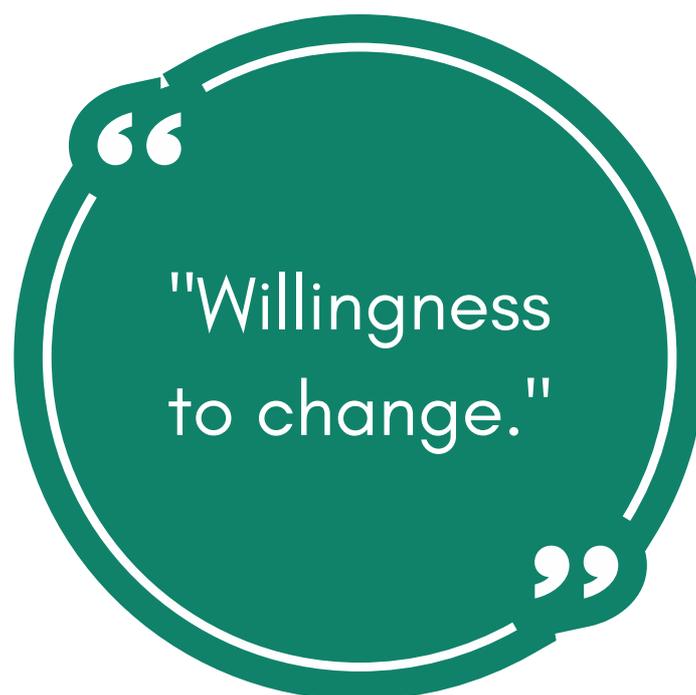
Be Open to Change!

One of the most imperative aspects to engagement is being open to change. A common experience for young people is participating in an engagement process, sharing ideas and thoughts, only to see no change as a result of their work. It is critical that organisations are genuinely open to taking on young people's ideas and feedback.



How to?

- Being clear with young people that their engagement and feedback will be reflected upon and taken into consideration even if it is contrary to current organisational processes and knowledge (**and meaning it!**)
- Following up with young people about the impact of their engagement, any changes made (**or not made**), and so on.
- Creating and fostering an open, inquisitive environment for young people to share their experiences, opinions, and ideas. Being explicit about the safety and welcoming nature of the engagement space is important to ensure young people feel comfortable.



THE WALKING THE TALK MODEL FOR YOUTH ENGAGEMENT



Each of the five necessities are equally important and should be consistently upheld throughout the entirety of the engagement process.

ACKNOWLEDGEMENTS

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