

A young child with curly hair is holding a large green book in front of their face, with only their eyes and nose visible. The book is the central focus of the image.

CANBERRA HEALTH LITERACY NETWORK

**INVOLVING CHILDREN & YOUNG
PEOPLE IN DECISION MAKING**

LIZZY HARNETT

CEO - AWCH



Firstly I would like to acknowledge the traditional custodians of the land on which I work and live and pay my respects to Elders past, present & emerging.

I am speaking to you from Wallumedegal land today where the AWCH Office is located





ABOUT AWCH

- The Association for the Wellbeing of Children in Healthcare (AWCH) is a national NFP advocating for the needs of children, young people (C&YP) & their families within the healthcare system in Australia for almost 50 years.
- This is achieved by working in partnership with C&YP, their families, health professionals and the broader community, to:
 - promote and advocate for C&YP's rights in healthcare.
 - educate and raise awareness regarding the needs and rights of C&YP in the healthcare system
 - influence on policy development and provision & information and support for professionals, non-government and government organisations, consumers and the general community.
 - provide resources for health professionals about engaging with C&YP, models of care, position statements and policies relating to care of C&YP and information on supporting parents/carers, C&YP using the healthcare system.



ABOUT ME

- Lizzy Harnett
- CEO of the NFP Association for the Wellbeing of Children in Healthcare (AWCH) dedicated to rights of C&YP in healthcare.
- Health professional
- Health management, quality & safety & consumer engagement (Public, Private and MoH)



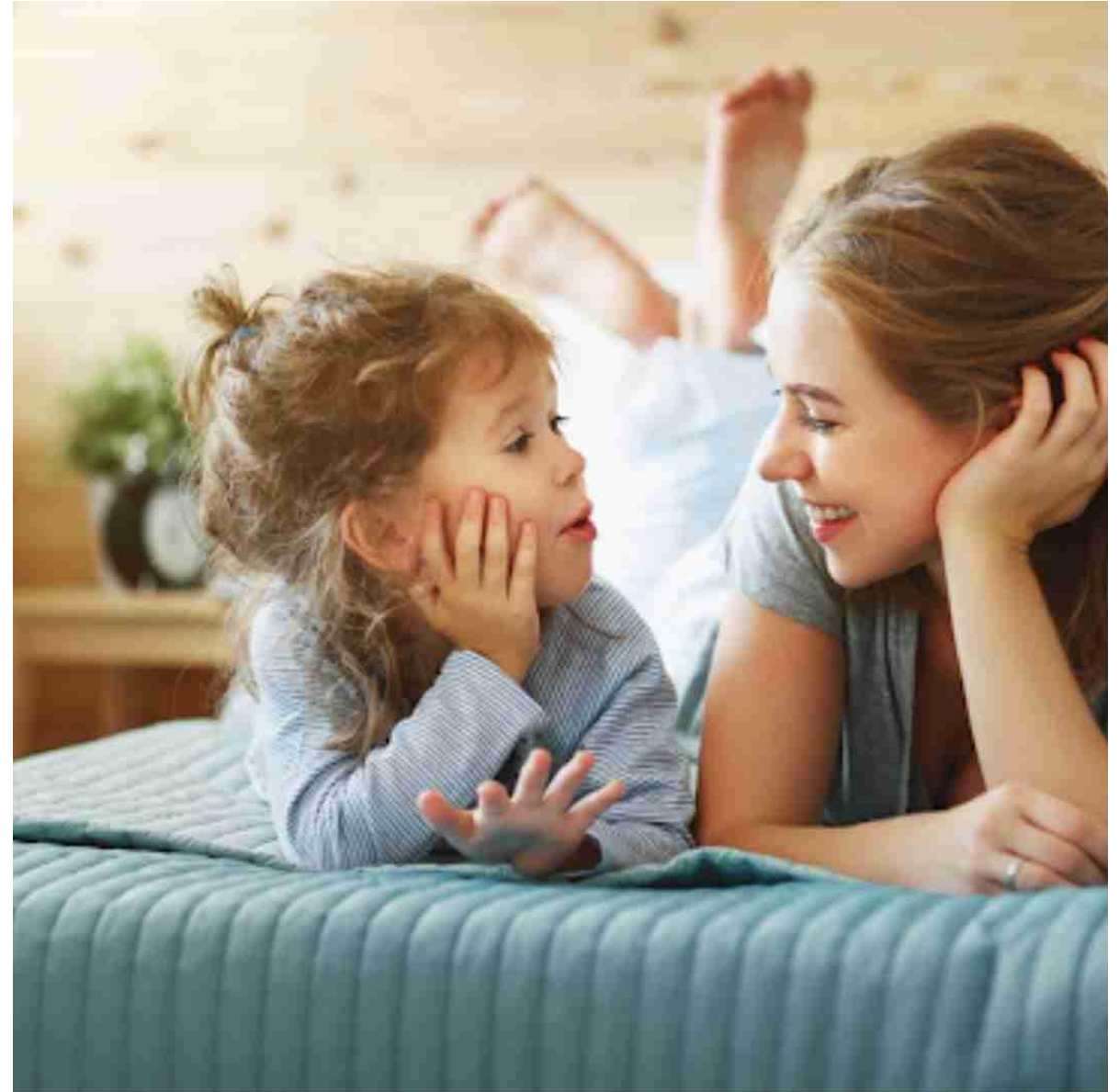
WHY?

- Children and young people, just like adults, have human rights.

One of these key rights is the right of all children & young people to express their views freely on all matters affecting them

- The main international human rights treaty on children's rights is the Convention on the Rights of the Child (CRC) which was developed in 1989 & Australia signed in 1990.

The CRC is the most widely ratified human rights treaty in the world.



CHILDREN & YOUNG PEOPLES RIGHTS

In 2010 (the 21st anniversary year of the United Nations Convention on the Rights of the Child)

AWCH partnered with Children's Healthcare Australasia (CHA) and a number of other stakeholders, to review the Convention, particularly as it related to children and young people in healthcare.

From this project the Charter on the Rights of Children and Young People in Healthcare Services in Australia was developed, including posters which you may have seen around the Hospital which were developed with C&YP.



WHY?

For children and young people:

- Ensures their right to express their voice, experiences, opinions & ideas about matters that affect them – C&YP are experts in their lives just as adults are
- When C&YP are involved in the design of services, programs & projects it means that services better meet their needs
- When well supported gives C&YP confidence to better participate in all areas that affect them: education, community, etc...

For organisations:

- It is critical in getting services that meet the needs of C&YP as only they know what works well and what needs improving
- It ensures that there is demonstrable respect and value for the needs and wants of C&YP
- If done well has a positive effect on the relationships between staff and C&YP



**“Children are one third of
our population and all of
our future.”**

Select Panel for the Promotion of Child
Health, 1981

HOW?

Top 10 tips engaging with C&YP

1. Treat children and young people with respect
2. Don't talk down to children and young people
3. Don't be a "try hard"
4. Don't make assumptions about what children and young people are capable of
5. Remember that children and young people are as diverse as any other population group
6. Tell children and young people how they will be involved and always provide feedback
7. Be open to new ideas, especially ones you may not have thought of
8. Give children and young people time and space to say what they mean
9. Give clear objectives and limits for decision making
10. Steer clear of professional jargon whenever possible

From The NSW Advocate for Children and Young People - [top-tips-for-children-and-young-peoples-participation.pdf](#)

BEDSIDE TO BOARDROOM

- These principles/rules are true whether you are involving C&YP in treatment decisions at the bedside or involving them in the plans for the development of a new paediatric service or the strategic plan for the healthcare facility in the Boardroom
- <https://www.acyp.nsw.gov.au/childrens-parliament-2017>
- <http://create.org.au/in-care-resources/>



AVOIDING TOKENISTIC ENGAGEMENT

- It is critical to ensure up front that C&YP know what is in their sphere of influence to avoid tokenism!
- Be mindful of involving C&YP as early as possible in the process!



IAP2 Spectrum of Public Participation

IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION					
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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Supporting the involvement of children and young people in decision making

- Ideas on how to facilitate the involvement of C&YP in decisions about their own care.
- What you can do at the immediate point of care - e.g. decisions about tests, and treatments, informed consent, deciding on a care plan, asking questions, having conversations with health professionals, providing feedback on their care.



Barriers to involvement

- Attitudes
- Misconceptions about resources required
- Lack of understanding about developmental stages
- Confidence of staff in how to facilitate the involvement of C&YP in decisions.
- Misconception about legalities and agency.
- Misconception as to the abilities of C&YP and the likely results of participation
- Formal and rigid consumer engagement structures in place
- Fear and anxiety



Diversity

- Involving trusted and skilled staff or community members & peers is important for all C&YP participation but is absolutely critical for culturally and linguistically diverse C&YP and families, Aboriginal and Torres Strait Islander C&YP and their families and a range of other groups of C&YP that may face a range of additional issues in dealing with the healthcare system







**"Pretty much all the honest truth telling there is in the world is
done by children."**

— Oliver Wendell Holmes, author and poet

Great resources

- NSW Advocate for Children and Young People
<https://www.acyp.nsw.gov.au/>
- AWCH C&YP Rights in Healthcare Factsheet
<https://awch.org.au/wp-content/uploads/2019/03/AWCH-CYP-Rights-Factsheet-V2.pdf>
- Charter of Children's and Young People's Rights in Healthcare Services in Australia
<https://awch.org.au/wp-content/uploads/2018/10/kids-rights-in-healthcare-australian-version-final-210911web.pdf>
- Video - Listen Up: Rights of Every Child in Healthcare
<https://www.health.nsw.gov.au/kidsfamilies/programs/Pages/child-rights-video.aspx>
- Video - Be in the Know: Rights of Young People in Healthcare
<https://www.health.nsw.gov.au/kidsfamilies/programs/Pages/young-people-rights-video.aspx>
- <https://organizingengagement.org/models/>
- https://cdn2.hubspot.net/hubfs/522228/campaigns/participation-resources/participation-guide/Engaging%20children%20and%20young%20people%20in%20your%20organisation.pdf?__hssc=63901360.2.1602644885100&__hstc=63901360.b707df39ee3ae8a2917cade19b05d07b.1602116992415.1602116992415.1602644885100.2&__hsfp=2057530925&hsCtaTracking=352fc5b2-8ec4-4848-b505-c827fae66826%7Cd0ec8cea-9135-4f1f-bde8-f64167bcc673

Involving C&YP in service design and review



THANK YOU

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