



What young people said

Self-care



About this paper

This paper is a summary of the thoughts and reflections of young people with disability who attended the 2023 National Youth Disability Summit (the Summit) on the topic of self-care.

The 2023 Summit was the third of its kind, run by Children and Young People with Disability Australia (CYDA). It was a two-day hybrid event, with participants from all over Australia, taking part online or in person at Burgmann College in Canberra. It was attended by 60 young people with disability between the ages of 12 and 25.

The Summit was co-designed by CYDA's Youth Council, made up of 12 young people with disability. The Youth Council chose the topics for discussion, the speakers, the location, and the activities of the Summit.

The three discussion topics chosen by the Youth Council for the 2023 Summit were:

- **diagnosis**
- **inclusive education**
- **self-care**

This paper is one of three, summarising what young people said at the Summit about each of the three topics.



Contents

Summary	3
What young people said	5
On self-care and disability:	5
On self-care and rejecting ableist standards:	6
On the commercialisation of self-care:	6
Self-care as a radical act:	7
On judgement of disabled people for practicing self-care:	7
On collective care and community:	8
On lack of access to common forms of self-care:	8
On self-care as work for disabled people	9
On self-care as an investment in yourself	9
Thanks and acknowledgement:	10
Acknowledgement of Country:	10





Summary

Young people spoke about different definitions of self-care. They talked about the industry and commercialisation of self-care, and how it can be viewed as a luxury or an indulgence. They spoke about the idea of self-care as something people engage in to recharge and increase personal productivity. They spoke about the gendered nature of societal ideas about self-care, and how self-care can be viewed as selfish or lazy and invoke feelings of guilt.

In contrast, they also described self-care as the practical things that all people need to do to take care of themselves, like getting enough rest, eating, drinking water, showering, running errands and having enough income to meet your basic needs. They spoke about how this can look different for disabled people than it does for non-disabled people and can sometimes be hard work. For example, organising support workers, engaging in advocacy, and dealing with government agencies to have your basic needs met.

They described how disabled people doing things to meet their own basic needs can be judged as a luxury or indulgence by people who don't understand the needs of disabled people.

Young people spoke about the importance of doing things you love, seeking out joy, and finding things that feed you spiritually, in addition to meeting your basic needs. This might mean hobbies, music, reading, dressing up, sports, or other fun activities. They spoke of this as a radical act for young disabled people in a society that does not expect or support disabled people to have complex emotional and spiritual lives. They referred to unmasking and embracing disability identity as acts of self-care.

They also spoke about the pressure on young people with disability to neglect their own self-care for the sake of conforming to non-disabled standards and fitting in.

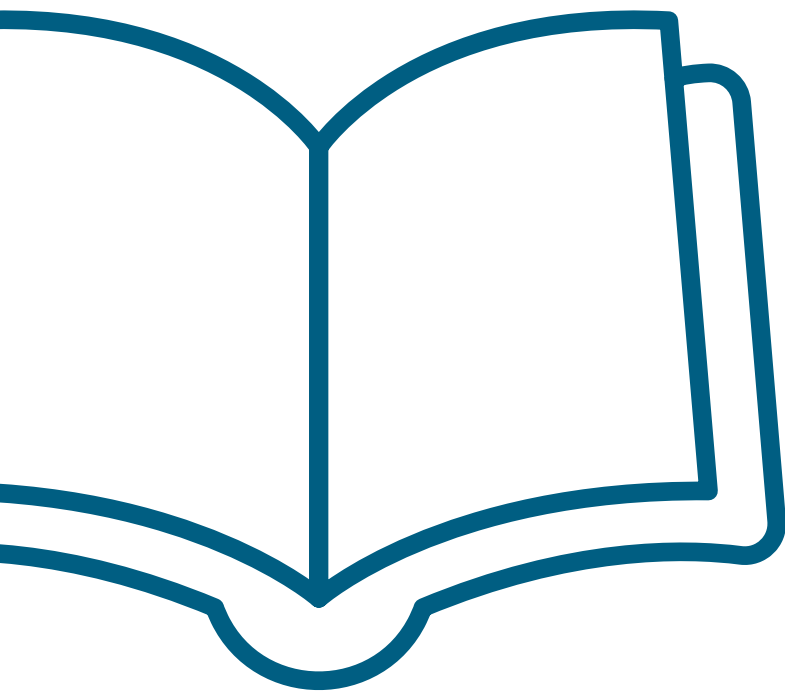
Some young people spoke about their lack of access to things that are generally recommended to non-disabled people as self-care, like exercise or retail therapy, due to the physical or financial limitations associated with disability.



Summary

Young people talked about the journey of discovering what self-care means for them and having to figure it out independently rather than being taught or supported to practice self-care in their own way. They spoke about feeling disappointment when commonly recommended methods of self-care didn't work for them.

Young people spoke about how society has individualised the idea of self-care when collective care can be more effective. They spoke the value of disability culture and community in relation to this.





What young people said

The following quotes have been de-identified to protect the privacy of young people who attended the Summit.

On self-care and disability:

'[R]est can be something that is not for the purpose of being more productive later, but for the purpose of caring for your body and caring for yourself. Which is just not what the culture says. Self-care is often tied to, how [can it] make you better, to [be] a better worker later. But for us, it's like, how do I, like, love myself now. So, I think we're pretty cool in that way.'

'[G]rief is a big part of acquiring or being born with a disability, and I think having space for some of that grief is really important. You don't want to sit in it. Obviously, you want to have gratitude, and being able to recognize, you know, the opportunities that you have, and have been given, and what what's going on in your life. But at the same time, you know, grieving is really important.'





What young people said

On self-care and rejecting ableist standards:

'[F]or me, like, self-care is about rejecting societal pressures, because measuring up to those is never going to work.'

'I realised that needing to be worthy enough, or needing to be productive enough, comes from that place of internalised ableism, and feeling like I need to be productive to be a valued member of society. And so, I feel like I've denied myself a lot of self-care ... to be productive enough to have worth.'

'It's been a constant process of reassuring ourselves that even though we're not being productive, it's still important.'

'Self-care for me means sort of taking a break from the idea of health as a moral choice ... You can't decide your way into being healthy.'

'[Self-care is] taking time out to look out for yourself and try to see it as; you're not being selfish. Because I know myself. I'm very caring of other people, more than myself.'



On the commercialisation of self-care:

'I feel like sometimes for non-disabled people, self-care can be a bit of like, a bit performative or a bit gimmicky. Like, "oh, I'm gonna buy my face mask", and "I'm gonna read the new book". Yeah, a lot of consumerism. A lot of it's like an industry. It's a price.'



What young people said

Self-care as a radical act:

'[T]here's lots of people who believe [disabled people] don't and should not be allowed to exist. So, the act of loving yourself, of caring for yourself, of seeking out joy, is very radical and resistive.'

'I think that people should be allowed to exist in whatever capacity they need to exist, whether that be taking up slightly more space or taking up slightly more resources.'



On judgement of disabled people for practicing self-care:

'If [non-disabled people] just saw someone laying down in their bed for twelve hours, they're gonna call that person "lazy", but for the disabled person, that is their version of self-care, because their body needs to recharge from all the stress that it's already putting on itself.'

'[T]hings that might look unnecessary, or luxurious, or even, like, lazy to an abled person might be like, the bare minimum that a disabled person needs to not be in a lot of pain, or completely overstimulated or exhausted.'

'[T]here's this ongoing fear that if disabled people get the supports that they need, it'll be like, subtracted from abled people, or they'll have to bear, like, the brunt of the costs or the workload, or they'll be working so hard, so that disabled people can, you know, have cheaper equipment and, you know, an adequate living wage, and stuff like that. But I really do not think that's the case. It's really not a matter of give and take. It's more support and more rights for everyone.'



What young people said

On collective care and community:

'I think that I, like, at least how I find it is practiced in my disabled communities, is very much about, we take care of ourselves by taking care of each other.'

'I think that self-care is actually really collective care.'

'[B]eing around other neurodivergent people is probably something I wish younger me knew about as, like, a form of self-care.'



On lack of access to common forms of self-care:

'I wish that I knew how to verbalise my self-care needs to my specialists when I was younger. Examples that were provided to me to undertake were not appropriate for me.'

'[P]eople talk about self-care being, like, getting out and exercising or going out and socialising, and some people just don't have the energy or the ability to do that.'



What young people said

On self-care as work for disabled people:

'When it comes to disabled people, usually our self-care is systematically treating symptoms, rather than purely just for enjoyment, or luxury or leisure.'

'[F]or some non-disabled people, their needs are met by society, so they don't have to fill those needs themselves. But if your basic needs, like connection, are not being met by society or by external sources, you then have to do those things which in an ideal world would already be provided for you.'

'[F]or us, it's predominantly medical based, [to] make sure that we can keep going, keep surviving, whereas able-bodied people use it as, kind of like, a holiday from life.'

'[U]sually, self-care is about, you know, what gives you energy. But for me, with a disability, self-care actually takes energy away from me.'

'[T]here are days where I would just like to go to Woolworths, do my grocery shopping, and come home easily.'

On self-care as an investment in yourself:



'Self-care is doing the hard thing to set you up better for later.'

'I like to think of self-care as, you're taking care of your current self, and then your future self.'

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Acknowledgement of Country:

Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed, and produced. We pay our respects to their Elders past and present and acknowledge that sovereignty was never ceded. This is, was, and always will be, Aboriginal land.