



Australian
National
University



Listening Together

Do young people with disability and young carers feel heard?

By Laura Davy, Molly Saunders, Talon Cass-Dunbar, Simone Bartram, Megumi Kawada and Luci McClusky

Suggested citation

Davy, L., Saunders, M., Cass-Dunbar, T., Bartram, S., Kawada, M., and McClusky, L. 2025. *Listening Together: Do Young People with Disability and Young Carers Feel Heard?* Project Report. Canberra: Australian National University.

Acknowledgements

Cover artwork by Luci McClusky, with support from Balkinder Maan.

The project team would like to extend our sincere gratitude to all the young people who took part in our surveys. We also wish to thank the organisations who helped us to promote the survey and find participants.

This project was supported by an ANU Futures Scheme 2.0 grant from the Australian National University.

Contents

Introduction	4
Research approach	5
Survey sample: who took part?	7
What young people’s survey responses reveal	2
Listening matters to young people.....	2
Limited opportunities for co-design and advisory involvement.....	2
Services young people use the most	3
Listening and responsiveness: how services measure up	4
The feedback gap: many want to give feedback, but few get the chance ..	6
What young people told us in their own words	7
Young people have clear ideas about what good listening looks like	7
Why listening matters to young people	8
When organisations don’t listen, young people feel unheard and harmed..	9
Young people identify clear enablers and barriers to good listening	11
Young people work hard to be heard.....	13
Young people want better listening everywhere.....	14
Discussion	15
How services can listen better: recommendations from young people	16
Creating cultures of listening.....	16
Openness and respect in every interaction	18
Conclusion.....	20
References.....	21

Figures

Figure 1: Importance of listening (n = 46)	2
Figure 2: Participation in advisory and/or co-design groups (n = 43)	3
Figure 3: Average listening and responsiveness ratings across service types	5
Figure 4: Feedback gap – how many participants wanted to vs actually gave feedback to services.....	6

Tables

Table 1: Demographic characteristics of survey sample (n = 72)	7
Table 2: Survey participants’ most used and second most used services.....	4

Introduction

Young people with disability and young carers are often encouraged to “speak up” about their experiences to drive change. But research shows that many face significant barriers in school, health care, disability services and other systems (Moore & McArthur 2007; Winn & Hay 2009; Connolly 2022). National data also shows how closely the two groups overlap – for example, more than one-third of primary carers also have disability themselves (ABS 2022).

A recent pilot study with young carers in the ACT found that even when young people do speak up, they often feel unheard or misunderstood (Davy, Cuffe & Priergaard 2023). It often took them time and effort to explain their needs, and even then, services often did not take their perspectives seriously.

This project builds on that work by turning attention to the other side of communication: listening. Drawing on ideas from the “politics of listening” (Dreher 2009; Goggin 2009; Thill 2015), it asks: What does meaningful listening look like to young people with disability and young carers, and how can organisations and systems do it better?

This report presents the findings from two co-designed surveys developed by a team of six researchers with lived experience of disability and caring. The surveys invited young people to share their views on:

- what good listening looks like
- whether listening is important, and
- what enables – or prevents – good listening from happening in practice.



Research approach

This project set out to understand how young people with disability and young carers think about listening, and whether they feel listened to by the services and systems in their lives. While earlier research has shown that they often face barriers and discrimination (Moore & McArthur 2007; Winn and Hay 2009; Connolly 2022), there is little evidence about their perspectives on listening or experiences of *being heard*. This project helps fill that gap.

We were guided by three core research questions:

1. How do young people with disability and young carers understand listening, and how do they define what it means to be heard?
2. Do they feel that the organisations and institutions that impact their lives listen to them in the ways they want to be listened to?
3. How can these organisations and institutions strengthen their capacity to listen to young people's voices, experiences and perspectives?

To answer the research questions in a way that genuinely reflects young people's experiences, the project used a co-design approach. Co-design is a participatory method that shifts away from traditional research — where studies are often done *to* people — and instead creates more equal relationships between researchers and participants. It treats young people as experts in their own lives, and values their knowledge in shaping the research questions, design and methods (Antonini 2021).

This approach also helps rebalance power within the research process. By involving young people from the start, co-design makes space for their perspectives to guide decision-making and ensures the project stays grounded in lived experience. Co-design is increasingly used because it brings together different kinds of expertise to create stronger and more practical insights (Turner, Merle & Fatien Diochon 2011).

Through regular workshops and collaborative meetings, a team of four community co-researchers – Simone Bartram, Talon Cass-Dunbar, Megumi Kawada, and Luci McClusky – and two researchers from the Australian National University (ANU), Laura Davy and Molly Saunders – worked together to develop two national online surveys. The survey questions were designed to be accessible, inclusive, and easy to engage with.

- The long survey asked in-depth questions about what good listening looks like and how people and services could listen better.
- The short survey invited responses to a single open-ended question about listening, which participants could answer in a variety of ways, including through drawings, audio, video, written responses, or other creative formats.

Participants were eligible if they were between 15 and 29 years old, lived in Australia, and identified either as a person with disability and/or as a young carer supporting a person with disability, such as a family member or friend.

To ensure the findings reflected lived experience perspectives, all members of the co-design group were involved in analysing and interpreting the survey data. Some team members contributed to data coding and thematic analysis, while others shaped interpretation of the findings through group discussions and reflections. This research received ethics approval from the ANU Human Research Ethics Committee (Protocol H/2024/0988).



Survey sample: who took part?

72 eligible responses were received: 56 long survey responses and 16 short survey responses. More than 4 in 5 participants identified as having a disability. Nearly one in three identified as having caring responsibilities, and 9 participants (17% of the sample) identified as both a person with disability and a carer.

The surveys primarily captured the perceptions and experiences of younger people, with the largest age group being those aged 15-18 years (34.72%), followed by 19-21- and 22-24-year-olds (both 22.22%). The majority of survey participants identified as women (58%), and around 14% identified outside binary gender categories. Just under one-third of participants identified as culturally and linguistically diverse. Two participants identified as Aboriginal or Torres Strait Islander.

Table 1: Demographic characteristics of survey sample (n = 72)

Demographic Characteristics	n	%		
Age				
15-18 years	25	34.7		
19-21 years	16	22.2		
22-24 years	16	22.2		
25+ years	15	20.8		
Gender				
Woman	42	58.3		
Man	16	22.2		
Non-binary/other	10	13.9		
Prefer not to say	4	5.6		
Disability status				
Person with disability	58	80.6		
No disability	14	19.4		
			Carer status	
			Carer	23 32
			No care role	45 62.5
			Did not answer	4 5.5
			Cultural and linguistic diversity	
			Culturally and linguistically diverse	16 30.0
			Not culturally and linguistically diverse	38 70.0
			Did not answer	18 25.0
			Aboriginal or Torres Strait Islander	
			Yes	2 2.8
			No	52 72.2
			Did not answer	18 25.0

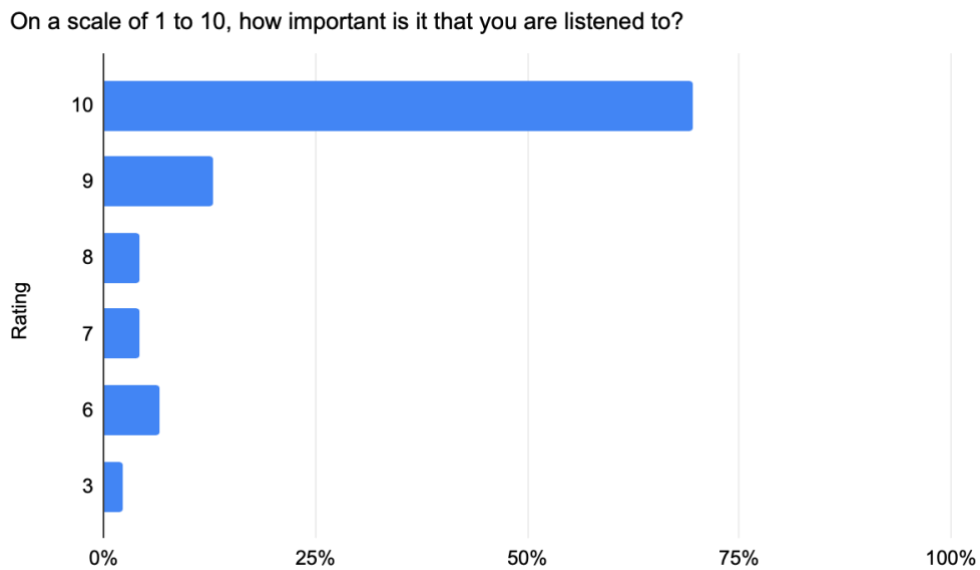
Of the 48 participants who identified as having a disability and provided further information on their experiences of disability, most listed multiple disability types. Mental health conditions (27 participants) and autism spectrum disorder (26 participants) were the most frequent. After that, medical illness (14 participants), intellectual and/or learning disability (11 participants), and mobility or physical disability (9 participants) were the most frequent. Of the 16 participants who identified as a carer and provided further information on their caring role, 9 (over half) currently live with the person they care for. Many participants mentioned caring for more than one person, with siblings (5 participants) and parents (4 participants) the most common care recipients.

What young people's survey responses reveal

Listening matters to young people

Participants placed extremely high importance on being listened to in their everyday lives. On average, they rated it 9.2 out of 10, and more than two-thirds (70%) gave it the maximum score of 10. This shows that listening is not just something young people expect from services, but a fundamental value in their relationships with peers, family, and the wider community.

Figure 1: Importance of listening (n = 46)

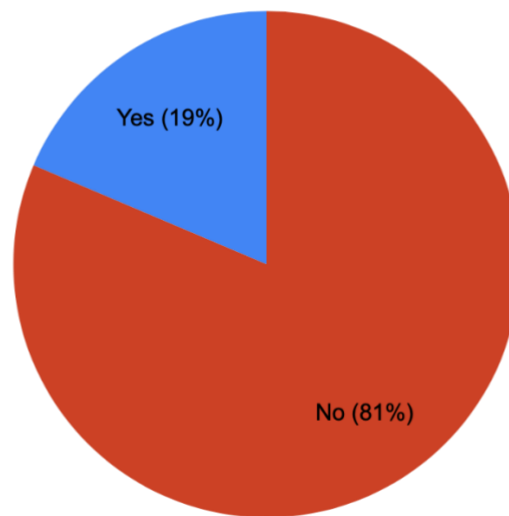


Limited opportunities for co-design and advisory involvement

Despite the high importance placed on listening, few participants reported having had opportunities to contribute their views in more formal ways. Almost four in five said they had never been included in advisory or co-design groups with service providers or organisations. This highlights a significant gap between the value young people place on being heard and the limited avenues available for their voices to shape decision-making.

Figure 2: Participation in advisory and/or co-design groups (n = 43)

Have you ever participated in a co-design or advisory group?



Services young people use the most

The survey asked participants two questions about their service use: first, which service they used the most, and then which service they used the second most. They were then asked to rate these services across a series of measures.

Two-thirds of participants named general practitioners (GPs), psychologists or counsellors, or disability support workers as their primary service.

Psychologists and counsellors were the most frequently nominated overall, followed closely by GPs and disability support workers.

When asked about the service they used second most, however, the pattern shifted. GPs emerged as the top response, while some services that were less prominent in the “most used” category, such as recreational groups, NDIS plan managers, and nurses, appeared more often as second choices. Around one in ten participants chose not to answer the question about second most used services.

Table 2: Survey participants' most used and second most used services

Service	Most used (number of participants)	Second most used (number of participants)
Psychologist or counsellor	13	6
General Practitioner (GP)	12	13
Disability support worker/s	12	2
Specialist medical doctor	4	3
Financial help (e.g. Centrelink)	4	1
Psychiatrist	2	5
Transport services	2	
Education and learning support services	2	6
Telephone support services (e.g. Lifeline)	1	1
Carer Gateway	1	1
Child protection services	1	
Employment services	1	2
Peer support group/s	1	
NDIS plan manager	0	2
Recreational services (e.g. theatre groups)	0	2
Nurse/s	0	1
Pastoral or religious support	0	1
Respite care services	0	1
Total responses	56	47

Listening and responsiveness: how services measure up

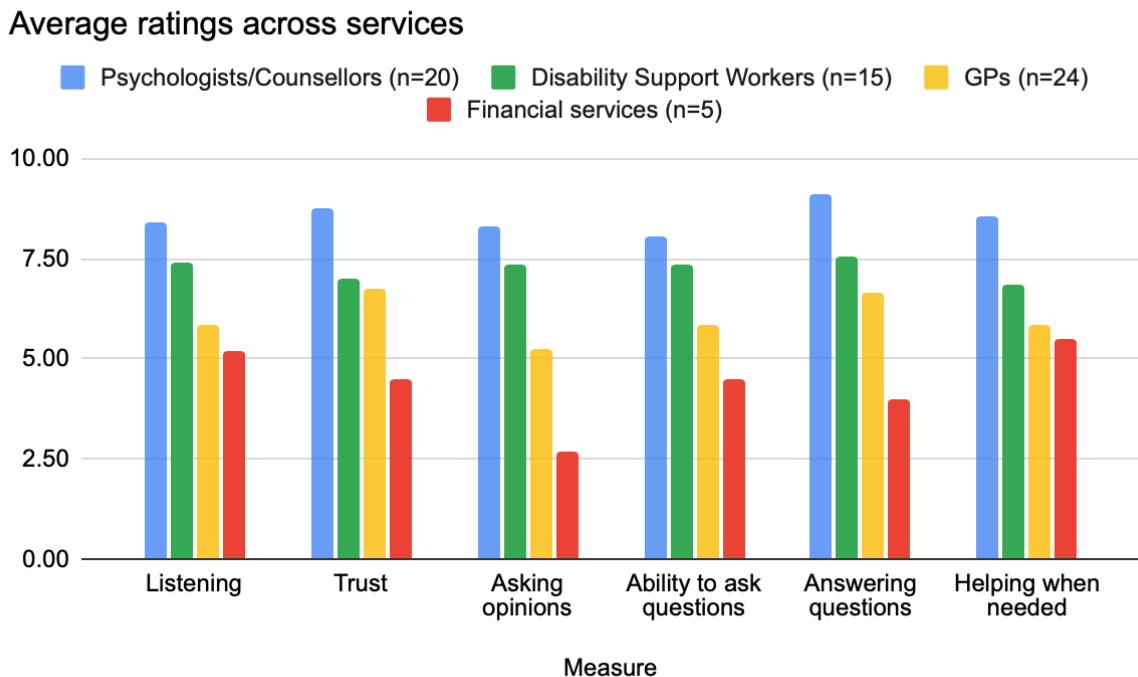
Having established which services young people use most often, the survey then asked participants to rate these services on a series of measures related to listening and responsiveness. We focus here on psychologists and counsellors, disability support workers, GPs, and financial help services (such as Centrelink), as these were both among the most frequently used and, in the case of financial help, particularly significant for the many young people who rely on them.

Psychologists and counsellors received the strongest ratings across the board. On average, participants gave them a listening score of 8.4 out of 10 and a trust score of 8.8. Disability support workers were rated moderately high, with an average listening score of 7.4. While not as strong as psychologists, these results still suggest young people generally feel supported by disability workers in day-to-day interactions.

In contrast, GPs were rated more modestly, with an average listening score of 5.9 and trust at 6.8. This suggests that while they are a central point of contact, young people do not always feel heard or supported in these interactions. Financial services such as Centrelink received the lowest ratings

of all, with average scores of 5.2 for listening, 2.7 for asking about your opinion, and 4.5 for trust. These figures highlight a clear gap between what young people value and what they experience when accessing financial support, and reflect participant views that these services often fail to listen or respond to their needs.

Figure 3: Average listening and responsiveness ratings across service types



These ratings reflect not only individual experiences but also the degree of personalisation embedded within different service models. Psychologists, for example, typically meet clients one-on-one, and listening and trust are central to therapeutic practice, which helps explain their consistently high scores. By contrast, financial help services such as Centrelink do not provide tailored, personalised support and are often experienced as punitive by recipients, which is reflected in their much lower ratings.

At the same time, these raw scores do not capture the full complexity of young people’s experiences. As one participant described, it took many years of feeling unheard before finally finding a psychologist who listened and understood them. This participant gave their current psychologist/counsellor a rating of 10 for every measure, but provided additional information about their prior experiences via the audio comment function of the survey:

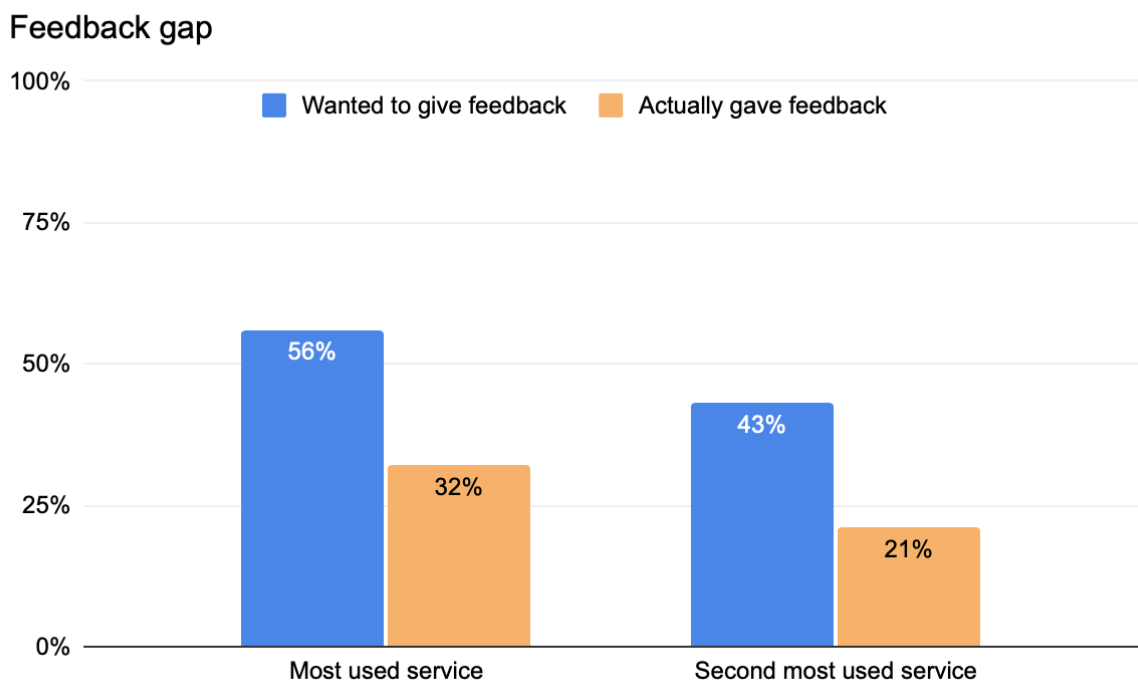
Um, OK, definitely 10. Like, my counselor is bloody amazing. [...] I've been seeing therapists since I was 13, so many different therapists, I feel like none of them have listened to me, and I feel like, when I got my autism diagnosis, I really wanted to talk about autism because I didn't even understand what autism was, and I just wanted to understand like how it affects my life and like just try to understand myself better. And they always just dismissed me... But the one I have now, definitely does, she's amazing (P53L).

This, like the qualitative findings from the survey presented in the next section of this report, shows that behind every rating there is often a longer story about the struggle for a young person to be heard.

The feedback gap: many want to give feedback, but few get the chance

The survey revealed a consistent gap between young people’s desire to give feedback and their actual opportunities to do so. For their most used service, over half of participants (56%) reported that they had wanted to provide feedback, yet only about a third (32%) had actually done so. A similar pattern appeared for their second most used service: 43% wanted to give feedback, but just 21% had followed through. These findings suggest that even for the services young people rely on most, mechanisms for giving feedback are not working as well as they could, and services may be missing valuable opportunities to learn from young people’s experiences.

Figure 4: Feedback gap – how many participants wanted to vs actually gave feedback to services



What young people told us in their own words

Young people have clear ideas about what good listening looks like

Survey participants had very clear ideas about what good listening involves. They described both the attitudes that help build trust, and the behaviours that show genuine interest and attention.

Attitudes and approaches that build trust

Many young people thought that good listening starts with **care**. One person described it as “actually caring about my feelings” (P41L), whilst another emphasised that genuine care involves “wanting to actually help someone in need, not just doing it to be paid” (P48L). Care was demonstrated through being respectful, non-judgemental, and providing a safe and open space to talk.

Participants also emphasised the importance of **believing what young people say**, showing **empathy**, and **validating their feelings**.

Many young people also explained that good listening requires a commitment to **actively trying to understand** the speaker. This goes beyond hearing words. It involves “paying attention” (P9L; P1L), and noticing “what is not being said, what is being felt and what is being expressed through tone, expression and body language” (P8L). For some, this meant being willing “to learn” (P42L) and engaging in perspective-taking:

In order to understand what someone else’s point of view (is), you have to put your own biases and views aside, even if you do not agree with them, it is still something you have to respect and listen to (P52L).

Through these responses, young people highlighted that good listening requires caring, non-judgmental attitudes and a real commitment to understanding their point of view.

Behaviours and actions that show genuine listening

Young people had different views on the specific actions and behaviours that demonstrate good listening. For example, several participants said that eye contact was important, while others pointed out that eye contact could be difficult for some people with disability. This highlights that **listening is situational**, and needs to be responsive to the person and context:

Good listening is very situational in my eyes, sometimes good listening is just sitting there not responding and allowing someone to just talk. Other times it needs to be more active, actually taking it in, responding, giving advice, showing that you truly understand (and) are retaining the information. It depends on the circumstances and of the individual who is talking to you. Even consideration of what their needs are and what they would want in reference to the situation displays good listening (P6S).

Despite some variations, most young people identified a set of common, concrete actions that show attentiveness and interest in the speaker and make them feel heard. These included:

- Asking respectful questions; not jumping to conclusions or being afraid to engage and say the wrong thing
- Providing appropriate responses, including non-verbal cues such as nodding and ‘mhms’ and repeating what the person has said
- Looking at and facing the speaker
- Not interrupting the speaker
- Not using devices, such as phones, or fidgeting whilst someone is speaking
- Writing down and recording what the person is saying, where appropriate
- Providing time for the speaker to explain themselves and process new information
- Relating anecdotally or emotionally, where appropriate, to what the person is saying
- Providing genuine and truthful responses, and not going off a script
- Providing appropriate follow-up to what has been said. For example, one young person wrote about the importance of providing plans that reflect the conversations had, whilst another said providing help, when requested, is important:
- When I say that I have auditory processing disorder and can’t hear well, actually taking action to improve communication (e.g. slowing down, using visuals, writing words).

Why listening matters to young people

In the survey, young people described three main reasons why listening is important: it supports dignity and autonomy, strengthens relationships and belonging, and helps services meet their real needs.

Listening supports autonomy, dignity and respect

Many young people said that listening is important because it “shows respect and respect signals a sense of dignity, value (and) interest...” (P8L). For many, listening was simply “common decency” (P4L, P53L), whilst others framed it as a fundamental “right to be listened to” (P51L). Participants also emphasised that being listened to was important because it recognises them as people who “deserve autonomy and consideration, (just like) literally everyone else” (P10L).

These comments highlight that listening matters because it affirms young people’s worth and values their contributions:

Everyone wants to feel heard, particularly if you are ignored based on the way you are for most of your life (P45L).

Listening builds community, connection and belonging

Young people also described listening as essential for building relationships and fostering inclusion and belonging in communities. This was clearly highlighted by a young person who wrote:

Feeling listened to is important to be me because it means that others care about my needs and wants. It demonstrates commitment to a relationship and helps create a sense of belonging contributing to mental and emotional wellbeing (P18L).

Many participants echoed this, saying that being heard helps them to feel less alone. One person described how good listening practices make them feel like they have “a support system” (P40L). Another spoke about the importance of signs of attentiveness that signal care, connection and belonging:

I like it when people remember my name, my favourite colour, or some obscure game or show I was talking about the other day. It makes me feel like I’m more social than I actually am... (P54L).

These responses show listening helps young people feel valued within their relationships and communities.

Listening helps services to meet young people’s real needs

The third reason participants thought listening was important is that it enables people to understand their circumstances and meet their needs:

It’s validating to hear others listen to your needs as they understand you and your circumstances more (P46L).

This includes emotional needs, medical needs and disability support needs. As one participant explained, talking and being listened to helps them “to cope with what is going on around them” (P48L). Another said listening is crucial “so that (their) symptoms are properly investigated and (they) can receive proper medical treatment” (P33L).

Across these comments, young people showed how good listening is essential to receiving adequate support. Without it, their needs are often overlooked, misunderstood, or unmet.

When organisations don’t listen, young people feel unheard and harmed

Young people’s listening experiences

A small number of survey participants described positive experiences of being heard. For example, one young person stated, “there are some amazing (disability support) workers!” (P50L) However, the majority described feeling ignored or dismissed in many of their interactions with services and organisations. As one participant put it, “no one really listens” (P1L). Another said people “don’t care enough to listen” (P53L).

Many young people highlighted persistent issues with **medical professionals**, particularly general practitioners and specialist doctors. They described

situations where their symptoms, experiences of pain and expertise over their own body were dismissed. As one participant shared, “I’ve had a lot of negative experience of being dismissed (by medical professionals)” (P21L). Although some young people said they had **psychologists and counsellors** who listened well, most noted they had to see multiple practitioners before finding someone who understood them.

Young people also felt particularly unheard within the **education system**. One participant described their education supports as “the worst” (P42L). Another described stark discrepancies in their experiences between different education providers:

I have had different experiences from different providers. School was excellent (8/10). The university I went to for bachelors (4 years) was also excellent (9/10). However the university I attend for Masters is only okay and I have felt disadvantaged this year (5/10) (P26L).

These comments show that across health, education and other service systems, young people often felt organisation often did not listen to them, either consistently, or at all.

The harms of not listening

Across the survey, young people described the serious impacts of not being listened to on their lives. Many spoke about feeling dismissed or misjudged, which in some cases led to a decline in mental health and even suicidal thoughts. For example, one young person said, “I can start panicking if I am not listened to” (P20L). Another described how an “unempathetic and uncaring” response from their therapist sent them “into shock” and made them contemplate suicide (P7L).

Young people also shared how poor listening can lead to inadequate medical care, misdiagnosis, and worsening health conditions. As one participant explained:

I have also faced doctors not believing my pain and symptoms, resulting in them assuming it was due to drug dependencies or mental illness or a factitious disorder (P33L).

They described how her chronic pain and weight loss were misdiagnosed:

...one of the GP's at the clinic mimicked sticking fingers down his throat to make himself throw up to insist I had Bulimia.... (I was) later diagnosed with stage 5 endometriosis (P33L).

After repeated experiences of not being heard, many survey participants experienced a growing reluctance to speak up at all. One said, “sometimes I feel that my GP thinks I make things up or that every symptom is just anxiety. This makes me upset, and I’ve started going to the GP less” (P26L).

This withdrawal extremely concerning, because it signals how poor listening practices can further silence young people’s voices, which in turn exacerbates the risk that they receive inadequate and inappropriate support. As one

participant put this: “It is important because I find I cannot be given adequate help if I am not listened to...” (P56L).

Overall, the survey participants made clear that not being listened to can have profound consequences. It can lead to significant mental and physical harms and a reduced trust in professionals and institutions, which further compromises young people’s safety within service systems.

Young people identify clear enablers and barriers to good listening

When talking about their experiences of being heard, young people identified many factors that helped organisations listen well, as well as many factors that made listening difficult. These insights highlight both the conditions that support good listening and the barriers that can silence young people’s voices.

What makes listening possible

Many survey participants spoke about the importance of accessible, safe and non-judgmental spaces, where they felt free to express themselves openly. As one young person explained:

In the context of organisations and services, good listening to me means providing a safe and open space to have my voice, my opinions and thoughts shared in a non-judgemental way (P14S).

Young people said these spaces work best when they are given **time to speak** (P16L), and when staff **communicate truthfully and respectfully** to build trust (P22L). They also emphasised the importance of staff adopting the attitudes and behaviours of good listening discussed earlier – respect, curiosity, patience and empathy.

Many young people also explained that good listening relies on **clear and accessible avenues for feedback**. Importantly, organisations need to show a genuine “willingness to hear and accept feedback” (P37L). The option to give anonymous as well as non-anonymous feedback was also key, because it helped some young people to “not feel threatened by the organisation for having issues with the service” (P55L).

Finally, some young people described how **shared lived experience** with staff, such as neurodivergence, made a big difference to their willingness to speak. Shared understanding can foster deeper connection and reduce young people’s fear of being misunderstood or judged (P53L). At the same time, shared lived experience does not remove the possibility of misunderstanding, nor does it remove the importance of listener’s self-awareness. Lived experience supports, but does not guarantee, good listening.

Together, these comments show that organisations can support good listening by promoting respectful interpersonal behaviours, ensuring safety and trust, and providing clear, accessible communication processes.

What prevents good listening

Young people identified several factors that prevent good listening. A key issue was **inaccessible communication processes**. Many felt ignored because service systems were clearly not designed with them in mind. As one person

explained, “folks with disability/ies are routinely ignored” because of “the vast inaccessibility of the world we live in” (P10L). **Confusing or inaccessible feedback channels** made some young people disengage from services altogether.

Stigma was another significant barrier, particularly for those facing multiple forms of disadvantage. One participant explained:

I don't have adequate identity documents due to abusive family environment, and this has made it hard to access any services that ask for ID. I have also found that the mental health sector and youth programs are very quick to ignore me and label me as mentally ill instead of listening to me (P56L).

Many young people also said they held back from speaking up because they feared being seen as difficult or losing access to essential services. This fear often stemmed from previous experiences of being judged or dismissed, combined with the reality that there are limited service options available. As one young person explained, they felt unable to give feedback “because it was the only specialist who I was able to be referred to” (P33L). Another avoided giving feedback because they did not “want to make the delays worse” (P6L).

For others, a **lack of trust** was the main barrier. When organisations felt uncaring, unresponsive or untrustworthy, young people often chose not to speak up. Participants described feeling unable to give feedback to their service because “I felt like it would be ignored/overlooked” (P52L), “I feel like they don't care enough to listen” (P53L) and, “i didn't think that it would be acknowledged” (P29L). These comments show how poor cultures of inclusion, care and respect within a service provider are a significant barrier to good listening.

Some young people also highlighted how **rigid bureaucratic rules** could stifle an organisation’s ability to meaningfully listen and respond to their needs. One young mother explained:

policies also have had a massive impact on me receiving services and asking them accessible. As a parent to a child who is disabled as well as being disabled myself it was incredibly difficult to find a service provider that would allow my son to be in the company car due to him being in a car seat. The initial provider wouldn't let any clients have their children in the car and this makes was made even more stressful by how the workers were not allowed to have my number and me having to take a seperate car (P5L).

Overall, young people told us poor listening often results from inaccessible and unsafe feedback systems, past negative experiences, bureaucratic inflexibility, and limited service options – all of which make it harder for them to speak and be heard.

Advocates make a difference

Advocates played an important role in many young people's efforts to be heard. Depending on the situation, advocacy could be an **enabler** or a **barrier** to good listening.

For many young carers, advocacy was about ensuring that the needs of their loved ones were clearly communicated and respected. As one participant explained, they wanted to be listened to better, "not for myself but for the person I care for. To be able to advocate for them and to ensure that their needs are communicated appropriately" (P50L).

Young people with disability also highlighted how advocates – friends, family members, support workers – can help bridge communication gaps, especially when the advocate knew them well. One person said they wanted people to "listen even if I repeat myself, (and)... to others who are advocating for me" (P22L). For these young people, advocates helped them to express feedback, clarify their needs and ensure their voices were taken seriously.

However, some participants also noted that advocacy needs to be approached carefully. In some cases, organisations may default to listening only to the advocate, overlooking the young person themselves. This risk highlights the importance of balancing advocacy with meaningful engagement with the voice, preferences and communication styles of young people with disability.

Young people work hard to be heard

Because of the barriers they faced, many young people spoke about the *work* they had to do to make themselves heard. They described the energy it takes to explain their needs, explain them again when those needs are forgotten, and challenge systems that are confusing or inaccessible. Several said this effort is draining, discouraging, and "can get quite frustrating" (P29L). Their experiences illustrate how being repeatedly ignored can add a significant emotional load to the act of trying to be heard.

Some described needing to be persistent – sometimes relentlessly so – when dealing with complex services systems. One young person explained what it was like trying to communicate to Centrelink:

Centrelink is routinely inaccessible and when accessed, confusing to report, confusing to find more information, and when called do not provide information I was seeking, even after being on hold for hours (P55L).

Others spoke about the difficulty of identifying or expressing their needs in the first place. Their comments highlight how their communication styles were often not recognised, supported or understood. As one participant wrote:

I struggle to identify what i need let alone stand up for what i need. i believe i sometimes ask for help in a way that doesn't register as asking for help to others. it's disappointing when this happens. i can be really struggling and sort of trying to hint that i need help, im not sure its always obvious. its scary to ask for help, especially being late diagnosed and still having to figure where i need more support than others (P31L).

This participant, like many others, described having to adjust themselves to systems and people who did not recognise their communication needs, and who were not always trustworthy or safe. Their experiences highlight the emotional, cognitive and practical labour young people often undertake simply to be heard.

Young people want better listening everywhere

The young people expressed a desire to be listened to better across nearly every aspect of their lives. Most commonly, they wanted their feelings, challenges and personal interests to be acknowledged and taken seriously. One young person with disability emphasised the importance of being heard regarding “how I feel” (P1L). Others wanted people to listen to their “interests/obsessions” (P42L), their love life (P45L), their financial worries (P45L), and what it is like to live with “someone who has a disability, as someone with a disability” (P54L).

Many participants also wanted better listening from services and institutions. This included the healthcare system where, as discussed, young people often felt dismissed or invalidated, as well as the disability support system, including “NDIS plan managers [and] allied health professionals” (P28L).

Education and employment were also common areas of concern. One student noted the need for more empathy in the classroom, asking others to “be understanding of my struggles” (P17L). Another participant shared the emotional toll of being judged for taking time off due to disability, describing the pressure and guilt created by negative societal attitudes:

One of the biggest struggles I've faced with a disability in society (work/school) is that if people need to take time off that they are seen as lazy or pathetic... I feel like every time I need to take time off I am letting everyone down, after hearing people's comments about other people who need to take time off (P32L).

Finally, many young people wanted to feel more heard in their family and social relationships. As one person shared, “i wish he (my dad) would listen to me more” (P14L). Another said, “I would like to feel better listened to by my family” (P18L), while a third explained “I wish my friends and family listened to me more and reached out/took me seriously” (P35L).

Discussion

This discussion is based on the co-design group's workshop discussions of the survey findings and how they should be interpreted. While this project initially focused on institutional and service-based listening, the community co-researchers emphasised that many of the findings also resonate within informal relationships, including those with friends and family. This is particularly relevant, given that many survey respondents expressed a desire to be better listened to in their family and social relationships.

The co-design group also highlighted that listening is relational and imperfect. Everyone listens poorly sometimes; the key thing is to keep learning and growing. They noted that while giving young people time to open up and speak is important, there may also be times when a young person does not want to talk. Respecting this choice is itself a form of listening.

In this vein, the community co-researchers – like many survey respondents – emphasised that listening is a deeply interpretative and subjective phenomenon. There is no single or universal way to make sure someone feels heard. Context matters, and what might be experienced as attentive and supportive by one young person, may be perceived as disrespectful or dismissive by another. This underscores the importance of understanding what helps each young person feel heard. The following section translates this insight, alongside other findings, into recommendations for listening better to young people with disability and young carers.



How services can listen better: recommendations from young people

Grounded in the young people's survey responses, we have formulated several recommendations for how organisations and service systems can listen better to young people with disability and young carers. These range from organisation-wide recommendations to attitudinal and interpersonal recommendations that individual staff should adopt.

Creating cultures of listening

What service providers should do	Why this matters (what young people told us)
<p>1. Educate your staff and others:</p> <ul style="list-style-type: none"> Invest in regular anti-discrimination, disability and carer awareness training. Encourage parents, peers and the broader community to learn about disability and caring. 	<ul style="list-style-type: none"> Training helps staff understand the lived experiences of young people with disability and young carers, including the unique ways they may communicate and navigate everyday challenges. Training can also reduce stigma, which many identified as a major barrier to good listening. Community awareness helps remove the burden from young people to constantly explain themselves and can improve understanding and support in their everyday environments.
<p>2. Hire people with lived experience of disability and caring:</p> <ul style="list-style-type: none"> Recruit, support and promote people with lived experience across roles and levels. 	<ul style="list-style-type: none"> Employing people with lived experience can make services more accessible, relatable and responsive to young people's needs. It also helps build safety, trust and connection.
<p>3. Provide safe, accessible feedback mechanisms:</p> <ul style="list-style-type: none"> Clearly signal that feedback is welcomed. Offer both anonymous and non-anonymous options. 	<ul style="list-style-type: none"> Young people said it is essential to have safe ways to give feedback without fear of negative consequences. Accessible, well-designed processes enable young people to speak honestly and safely.

<p>4. Ensure follow through:</p> <ul style="list-style-type: none"> • Communicate back to young people about what has changed as a result of their input. 	<ul style="list-style-type: none"> • Many young people stressed the importance of follow-through: people acting on what they share. Follow-through matters in both formal feedback systems and everyday interactions and builds trust by showing that speaking up - and listening – leads to real change.
<p>5. Actively try to create equal and trusting relationships:</p> <ul style="list-style-type: none"> • Improve access to advocacy and support. • Make information free, accessible and easy to navigate. • Review policies and processes that may create unequal access or discourage young people from speaking up. 	<ul style="list-style-type: none"> • Reducing systemic inequality helps young people feel able to speak up. Young people said access barriers, cost, complexity and stigma can silence them. Creating more equitable systems makes listening possible.
<p>6. Support and recognise young people’s decisions:</p> <ul style="list-style-type: none"> • Embed a commitment to respecting young people’s choices across policies, programs and staff roles. • Create decision-making processes that prioritise young people’s preferences and prevent their voices from being overridden. 	<ul style="list-style-type: none"> • Listening includes respecting young people’s choices and ensuring their views are not overridden. Young people said this commitment should exist across all levels of an organisation.

Openness and respect in every interaction

What individual staff should do	Why this matters (what young people told us)
<p>1. Believe young peoples lived experiences:</p> <ul style="list-style-type: none"> • Take young people seriously when they explain what’s happening in their lives. 	<ul style="list-style-type: none"> • Young people said it is essential to be taken seriously when they share what is happening in their lives. Being doubted or dismissed can cause emotional and physical harm. Believing someone includes validating their feelings and not telling them how they “should” feel or react to their experiences.
<p>2. Be empathetic and non-judgmental:</p> <ul style="list-style-type: none"> • Use a calm, compassionate tone and show genuine care. • Avoid blaming, shaming or reacting negatively when young people share difficult experiences. 	<ul style="list-style-type: none"> • A compassionate, non-judgmental attitude helps young people feel heard and safe. This emotional safety builds trust, which is the foundation of good listening.
<p>3. Educate yourself, and ask respectful questions when needed:</p> <ul style="list-style-type: none"> • Educate yourself as best you can, and if you still don’t know, then ask. • Respect people’s boundaries: ask questions that are appropriate to the context and to the relationship you have with this person. • Check your understanding by summarising what you’ve heard and inviting correction. 	<ul style="list-style-type: none"> • Young people said services often make assumptions about their lives. • Educating yourself reduces the onus on young people to teach you about their experiences. • Asking respectful questions shows genuine interest and helps ensure young people’s needs and perspectives are understood.

<p>4. Give young people time and space to speak:</p> <ul style="list-style-type: none"> • Allow extra time for conversations when needed; avoid rushing or interrupting. 	<ul style="list-style-type: none"> • Some survey participants said that they need more time to find the right words or express their experiences. Patience creates a safer, more inclusive environment where they can speak without pressure.
<p>5. Ask young people what good listening looks like to them</p> <ul style="list-style-type: none"> • Do what they tell you, and show that you're listening, both verbally and non-verbally. 	<ul style="list-style-type: none"> • Listening is more than hearing. Young people often highlighted the importance of body language and behaviour: not interrupting, facing the young person, avoiding distractions (like phones), and showing presence and respect. • Young people also said that good listening is subjective, so it's important to check in with them about what makes them feel heard.



Conclusion

This report examined what listening means to young people with disability and young carers, and how organisations and services can listen more effectively. Through a co-designed and accessible research process, 72 young people shared powerful insights into why being heard matters, the consequences of being ignored, and the everyday labour they put into making themselves understood.

Young people described a clear picture of what good listening looks like: it involves care, respect and understanding, supported by safe, open and inclusive environments. They emphasised the emotional, social and practical importance of being listened to, linking it to autonomy, community inclusion and access to adequate, and at times, life-saving support.

However, many young people also reported feeling consistently unheard by the systems and services they rely on, including education, employment and disability services. This lack of listening leads to tangible harms: misdiagnosis, mental distress, social isolation and the withdrawal from services altogether.

Because of the many challenges they experienced to being heard, young people expressed a strong desire to be listened to more deeply across all aspects of their lives. Their lived expertise is the basis of the recommendations presented in this report: practical actions for organisations and service providers to strengthen their listening practices, including through education, safe and accessible feedback mechanisms, meaningful follow through, and empathetic staff who give young people the time and space to speak.



References

- Antonini, M. (2021). An Overview of Co-Design: Advantages, Challenges and Perspectives of Users' Involvement in the Design Process. *Journal of Design Thinking*, 2(1), <https://doi.org/10.22059/jdt.2020.272513.1018>.
- Australian Bureau of Statistics. (2022). *Disability, Ageing and Carers, Australia: Summary of Findings*, Australian Bureau of Statistics, <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#cite-window1>.
- Davy, L., Cuffe, H., & Priergaard, J. (2023). *'I kind of had to step up, you know?' Insights from an ACT-based pilot project on young people and care during the COVID-19 pandemic*. Canberra: Australian National University.
- Dreher, T. (2009). Listening across difference: Media and multiculturalism beyond the politics of voice. *Continuum*, 23(4), 445–458. <https://doi.org/10.1080/10304310903015712Goggin2009>.
- Connolly, H. (2022). *From Checkbox to Commitment: what children and young people with disability said about identity, inclusion and independence*. Commissioner for Children and Young People, South Australia.
- Moore, T., & McArthur, M. (2007). We're all in it together: supporting young carers and their families in Australia. *Health & social care in the community*, 15(6), 561–568. <https://doi.org/10.1111/j.1365-2524.2007.00719.x>.
- Thill, C. (2015). Listening for policy change: how the voices of disabled people shaped Australia's National Disability Insurance Scheme. *Disability & Society*, 30(1), 15–28. <https://doi.org/10.1080/09687599.2014.987220>.
- Turner, F., Merle, A., & Fatien Diochon, P. (2011). *How to Assess and Increase the Value of a CoDesign Experience: A Synthesis of the Extant Literature*. [Paper Presentation] Mass Customization, Personalization, and Co-Creation: Bridging Mass Customization and Open Innovation, San Francisco, United States.
- Winn, S., & Hay, I. (2009). Transition from school for youths with a disability: issues and challenges. *Disability & Society*, 24(1), 103–115. <https://doi.org/10.1080/09687590802535725>.