JFA Purple Orange / Julia Farr Group

Language Survey Report

2023-2024

Feedback from the South Australian disability community &
Purple Orange audience on:
Language used to describe & discuss disability

Purple Orange

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Language Matters

The language we use to describe and discuss disability has a significant impact. It can change the way that members of the disability community feel; for better or worse. Language also influences attitudes and understandings of disability among non-disabled people.

At the time of our conception (2006) under the current 'Purple Orange' identity, a disability language consultant was engaged: who recommended '*people living with disability*' as the best option for language choices.

In the *almost* twenty years since, the disability movement has made great progress- as has the thinking around clear, safe and respectful language choices.

In order to make sure that we are respectful of the preferences of the community we represent, we did a call out for feedback (in 2023) on individual language choices and received 182 responses.

Contributors included:
- Julia Farr Group employees
- Board members
- Peer network members
- Our broader community- engaged through our newsletter and social media.

This covered a mix of people who work in the sector (but do not claim identity), people in the immediate circle of someone in the disability community (through family or close personal connection), as well as people who identify as a member of the disability community.

Who Responded?

*"What is your relationship to
JFA Purple Orange?"*

1. Full time / Part time employee - 30 responses

2. Casual Employee - 17 responses

3. Board member - 3 responses

4. Peer Network member - 17 responses

5. Member of the broader community - 115 responses
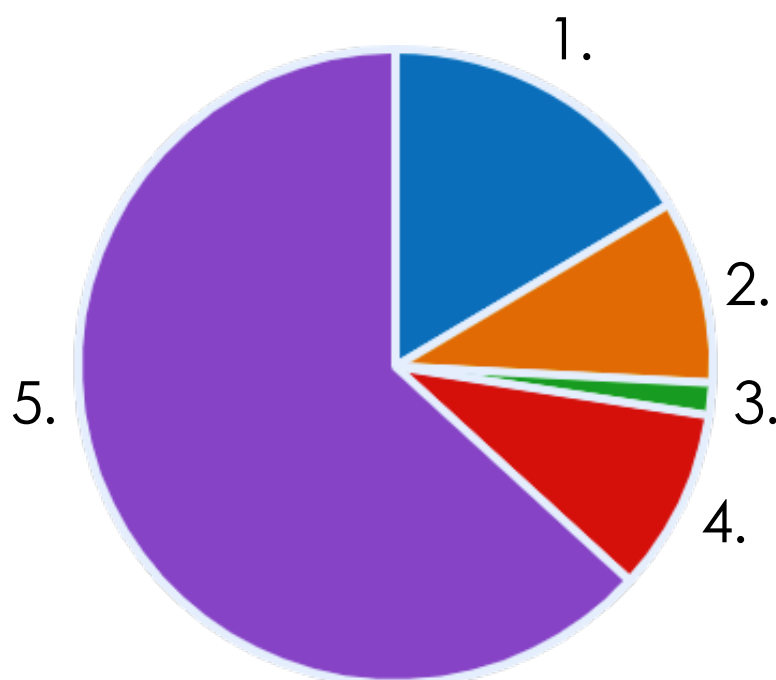
How do you identify?

"What is your relationship to disability?"

This question was an open text box, allowing people to be specific, and intentionally choose an individual description that best suited them, therefore answers are not as easily defined.

Of the individual responses:
121 identified in some way as belonging to the disability community. **(67%)**
The remaining 61 split between identifying as a 'family member', or 'someone who does not have a personal connection- but works in the sector'. **(33%)**

Some examples of responses are:

"I work in the field and have family members with disability."

"I am neurodivergent, but do not identify as living with a disability."

"I identify as living with disability and chronic illness and I'm a family member of people living with disability."

"I identify as experiencing variable disability."

"I experience disability, work in the sector, and am a family member/supporter of."

"I identify as living with a disability & work in the field of disability."

"I am disabled."

"I work in diversity and inclusion and do not have disability."

31%

of respondents who are a member of the disability community prefer **Person-First language**

27%

of respondents who are a member of the disability community prefer **Identity-First language**

What language do you prefer for yourself?

This question, directed specifically for those who **identify as having a disability / being a member of the disability community**, asked what language their preference is when talking about **themselves specifically**.

The question gave five options:

- Person-first "I am a person with disability"
- Identity-First "I am a disabled person"
- Euphemism such as "I live with disability"
- A combination of above
- Other

The 'other' option included a text box with an open field where respondents could provide a unique response.

Answers in this field included:

"I am neurodivergent."

"Combo mostly of- person experiencing disability and disabled person."

"Depends on the context, but generally prefer identity first."

"I prefer not to use the term 'disabled' or 'disability' in relation to myself."

"I have a disabiltiy."

1. 🔵	Person-First	37
2. 🟠	Identity-First	33
3. 🟢	Euphemism	11
4. 🔴	A combination	19
5. 🟣	Other	21

What language do you prefer for your community?

This question, directed specifically for those who **identify as having a disability / being a member of the disability community**, asked what language they prefer to use when talking about **the disability community.**

The question gave the same five options:

- Person-first "people with disability"
- Identity-First "disabled people"
- Euphemism such as "people living with disability"
- A combination of above
- Other

The 'other' option had responses including:

"Identity first - neurodivergent people"

"People with different abilities."

"Disabled people, people with disability, but not "people living with disability."

"People who experience disability (we aren't disabled, we experience disability)."

"I like identity first language when it is disabled people talking, but I feel that when people without disability are talking about us, they should use people with disability Also helps me identify authentic disability leadership."

1. ●	Person-First	36
2. ●	Identity-First	23
3. ●	Euphemism	24
4. ●	A combination	24
5. ●	Other	13

What language do allies prefer?

This question, directed only at those who consider themselves an **ally of the disability community,** asked what language they feel most comfortable using when talking about the **disability community**.

The question gave the same five options:

- Person-first "people with disability"
- Identity-first "disabled people"
- Euphemism such as "people living with disability"
- A combination of above
- Other

The 'other' option had responses including:

"Either people first or identity first, according to individual preference."

"I have no preference."

"Autistic, neurodiverse - for these particularly, it is brain wiring and "living with a disability" is offensive. I don't carry my brain in a handbag, it's my identity and what makes me amazing, but also have challenges."

"Not sure what term, but focus on disable/disability seems a negative approach. a term that identifies with "Ability" I feel is more appropriate.

#	Category	Count
1.	Person-First	35
2.	Identity-First	6
3.	Euphemism	31
4.	A combination	24
5.	Other	16

Should the JFA group be flexible with language?

Question six asked *"How would you feel about having **flexible options** in our language guide that we may use language **interchangeably** based on the **context** of the work or author preferences?"*

There were three response options:

- Positive - I Support people choosing their own language within reason
- Negative - I think we should stick to one answer
- Other

The 'other' option had responses including:

"I think the person or group you are working with self-identity should be most important."

"Language should be clear, precise and plain. this will allow maximum understanding across the community."

"I personally support people choosing - but government and organisations need guidance as this isn't clear."

"Label by its definition is a subjective bias."

"I support disabled people choosing their own language, but I'd rather the wider community uses identity-first especially for disabilities like autism. I'm autistic. I hate hearing "person with autism" most of all."

"Confusing and not helpful for the general community."
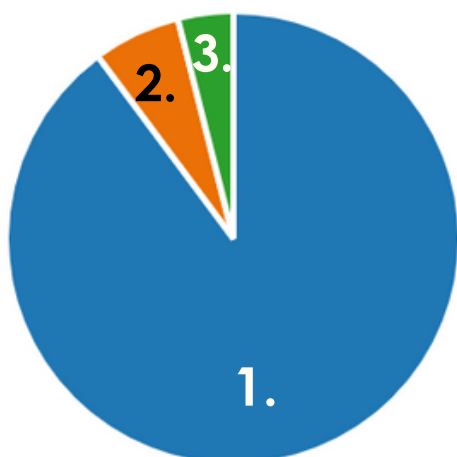
1. 🔵	Positive	159
2. 🟠	Negative	11
3. 🟢	Other	7

Anything else to share?

"This can include anything you'd like us to know or include in a language guide."

The final question was an open text box, allowing people to be open in their contribution. There was 81 responses. Answers included:

"It's critical that we take guidance from the disability community about the way we use language as an organisation. I think we should be flexible and responsive to people's preferences, but as someone who would be helping to share people's stories, I would also love to make sure I am requesting people's preferences in the most sensitive and respectful way. I'm specifically looking for advice around how we might phrase questions to people regarding their preferred language around their disability and their experience of disability."

"Create comfortability around pronouns too."

"Language will and does change over time in our community. Be flexible enough to meet changing needs of community over time."

"I think 'living with disability' and 'lived experience' are confusing as it is sometimes interpreted to include family members of people with disability. I've worked with carers and with people with disability and it's important to recognise they have different experiences and perspectives and it's not always appropriate to group them together."

"I think it is important to acknowledge language preferences of different disability groups as well as individual preferences and the wishes of the entire disability community. I am autistic and there is a strong push in my community for identity-first language but I am aware this is not the case in other communities who may prefer person-first language. I also really dislike the living with disability language - I live with my cats, not autism."

"I use disabled person usually, but person with disability when I'm around government or in formal environments to avoid the negative stuff that can result. Its also a way of illustrating that there is no one clear term, and that's okay!"

Continued:

"I feel very strongly about removing 'living' with and having the options of person or identity first only. we should follow PWDA guide on language like 'vulnerable' - remember that different groups also have different preferences - have this conversation about language on a 5 yearly basis minimum."

"The point is that it's not about being politically correct but about understanding the story behind identity."

"I am excited we are having this conversation! I'm a strong advocate for 'disabled person' as I think we have moved past needing person first, and also I am disabled by barriers in society. Although I support people using their own preference in conversation I think as an org we need to be consistent in our coms. There is already so much fear and doubt in the wider community about getting things wrong that having a clear message can be helpful in enabling conversations and learning without fear. I'd like our language guide to also include some text around asking about access needs and support so this can be consistent and we role model to other orgs how to do this."

"I think it's important to use language flexibly, but also to make the point to any groups e.g. clients of the inclusion training, that they should always check first because it's so subjective. Also, I think it's important to address the use of words like 'crip' - some people use it as an empowering term about themselves, but it's not always appropriate that friends or others use that word about the person."

"I use person living with disability when I choose to disclose. I would like the word disability to change to 'different abilities'. I think the word 'disability' will always carry a negative stigma."

"Inclusive language for disabilities is using terminology that does not alienate a person living with a disability and ensuring they have full accessibility to the services, society, and situational supports that empower them. The United Nations recommends using people-first language with the term 'persons with disabilities.' A useful style manual is provided by the Australian Government which can serve as a general guide for what terms not to use, as well as appropriate alternatives."

"Simple - nothing about us, without us!"
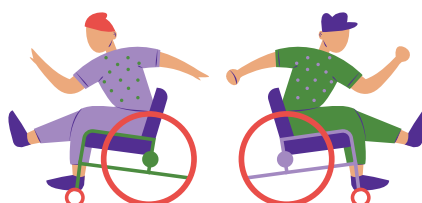
Continued:

"What we teach, being reflected in our own policies. Take your prompts from the community/person with whom you speak."

"Not everyone identifies in the same way - there can be two people with the same 'situation' and one will identify as 'proudly disabled' and the other will steadfastly refuse to be labelled as 'disabled', plus every position in-between. We need to keep space for this ambiguity in how we define who's 'in' and who's 'out' so as not to be exclusionary. This can be more prominent in intersectional communities, including First Nations and CALD communities. Sometimes we exclude people on this basis, as if they have less to offer purely based on how they label themselves, or their 'loudness' in how they identify, rather than the relevance and value of their experiences, voice, and input. Sometimes this comes from within the community where people only want those who loudly proclaim their disabled identity or neurodivergent identity to have a voice rather than focusing on the value of diverse contributions. In this way, there's a risk the disability pride movement dominates disability voices while there is an invisible quiet part of the community who are not heard. Ideally, we need to do more to encourage new voices rather than always going to the same voices. We also make assumptions about people - especially when we need to 'tick boxes' or achieve numbers within a cohort - requirements like these can encourage us to make assumptions or have inadvertently exclusionary practices to ensure we get the numbers unambiguously right, yet other times we speak about the importance of recognising 'invisible disability' and diversity in how people identify. So I think our language guide needs to clearly recognise there is ambiguity and diversity and we support and embrace this. We should measure our organisation's work as being genuinely representative of the disabled community (or a cohort within) at an overall level, rather than nit-picking and assuming at the level of individuals. Therefore, I support a more flexible approach to language and practice than we currently have."

"I think it would also be helpful to include/update guidance on language for the blind, deaf, autistic, etc, communities plus intersectional communities (e.g. CALD, LGBTQIA+, etc)."

"I think it's good to allow people to self-identify (within reason), so your terminology should reflect that."

Continued:

"I personally think person or identity first is MUCH better than 'living with'. For me 'living with' makes it sound like this very personal burden, and all people with a disability have a socially mediated component. Because my disability is mostly due to social structure and stigma (Autism, ADHD, etc) I think this makes me particularly sensitive to this burden-oriented 'living with' language. I like 'disabled person' because I am in a constant state of being disabled by the structure of society. For me, 'person with a disability' sounds almost like, oh their a real person that has a disability, rather than, disabled people are real and worthy of everything. Having said all that, I would not get annoyed if someone used person first language to describe me in the same way I would if someone used euphemistic language."

"I prefer to find out how people self-identify and go with that. just like pronouns I think we need to be kind and understanding of each others' journey and what feels right to them. if I am not sure my default is person first."

"In my interactions with Purple Orange I have witnessed them respecting the preferred choices of the people they engage with which is brilliant."

"I feel strongly that people need to feel comfortable both in how they describe themselves and their experiences and how they are described/referred to. I think it would be great for JFA to establish a standard section at the beginning of any group session/meeting/public forum where a quick statement is made about what language will be used by JFA staff for the purpose of the meeting and inviting anyone present to set their own language preferences."

"Sometimes too much energy goes into euphemistic terms that try to soften or tiptoe around definitions of disability. I admire the Blind and Deaf communities who are comfortable using those clear, unabashed descriptors - "blind" and "deaf". I have disabilities. I am disabled. Nothing offensive or confronting about using those terms."

"I'm glad this is being reviewed and I really encourage flexibility around the approach because there's just no right or wrong answer any more. But I do encourage more use of identity first language because we should be presenting more pride around disability."

182

people who responded belonged to multiple groups, including JFA Group full time and part time staff, casual staff, board members, as well as employees of other local NGOs, and the disability community.

87%

of people who responded support the JFA group using language flexibly - within reason. This includes: not using slurs, and identifying reasons behind langugae choices.

56%

of people who consider themselves allies feel more comfortable using 'people with' or 'people living with' when they refer to the disability community.

81

respondents had more they wanted to contribute when offered the opportunity to share their feedback on language. Though responses differed, there was overwhelming support for the conversation to continue.

Summary and Next Steps

Generally, across all fields, those **with disability** had preferences **away** from inclusion of "living" in the phrase "people living with disability"
There was a fairly even split between identity-first and person-first language of "person / people with disability" and "disabled person / people"

The majority of **non-disabled** people prefer "living" to be included in the phrase "people living with disability". This is likely a reflection of the work that Purple Orange have done in the past to educate that this is the best / most appropriate language choice.

87% of respondents supported use of flexible language that aligned with an author (or a community's) preference. This would be accompanied by a 'note on terminology'

The open text field had varied answers, all of which showed a deep passion for multiple types of language choice. A majority applauded the existence of the survey, requesting regular reviews of things like language.

These results will be used to inform and develop an updated Language Guide that will be used by the Julia Farr group to describe and discuss disability in policy submissions and other work.

It will include an example 'note on terminology' and resolve other language questions on regularly used phrases and words.

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