Speech Pathology Australia

Communication Access and Inclusion Terminology Report

Speech
Pathology

Acknowledgements

Note about language

Throughout this report the terms **'communication disability'**, **'communication difficulty'** and **'communication access'**, are used because these were the terms most commonly used by Speech Pathology Australia at the time of writing the report. It is acknowledged that there are a range of terms currently in use with regard to preferred terminology and this is discussed in the report.

Speech
Pathology
Australia

1/114 William Street
Melbourne, Victoria, Australia
(03) 9642 4899
www.speechpathologyaustralia.org.au

Contents

Executive summary

The communication rights of people with disability are stated explicitly in the United Nations Convention on the Rights of Persons with Disability (UNCRPD), under articles 2, 9 and 21.

However, there is inconsistency in:

a. terminology used to refer to people with disability who experience communication difficulties; and

b. the processes and environmental characteristics required to address these difficulties.

This makes it difficult to advocate for communication rights to be upheld in a consistent way.

The current project sought to explore terms currently being used throughout Australia, and to determine preferred terms. To achieve this aim, a two-phase research study was undertaken.

In the **first phase** of this study, the preferred terminology of Australians with communication disability and other key stakeholders (i.e. family members, advocates, educators, service providers and researchers) was investigated through eight focus groups. The findings of these focus groups informed the **second phase**, a national online survey.

The findings of the survey indicated across all stakeholder groups combined

The most acceptable term to refer to people with communication disability was:

'People with communication support needs'

The most acceptable term to refer to the processes and environments to support communication was:

'Inclusive communication'

Based on these findings it is recommended that Speech Pathology Australia (SPA) and speech pathologists use these terms when undertaking broad, national, awareness raising and advocacy activities.

Another key finding from the survey was that, despite acceptability overall, these terms were not the preferred terms for all stakeholder groups. Different individuals and stakeholder groups expressed differing views regarding preferred terminology.

Furthermore, there are contexts in which it is pertinent to use specific, non-preferred terms, for example, the use of 'communication disability' in the context of the National Disability Insurance Scheme.

Therefore, it is also recommended that Speech Pathology Australia and speech pathologists more widely, should consider the systems and contexts within which they are working, as well as individual and group preferences, when making decisions regarding terminology.

Background

The Communication Access and Inclusion Terminology Project represents the culmination of several related activities undertaken by Speech Pathology Australia to support the communicative rights of Australians. The foundational basis for these initiatives is the United Nations Convention on the Rights of Persons with Disability (2006).

First and foremost, communication rights and communication access in Australia must be considered with reference to Australia being a signatory to the United Nations Convention on the Rights of Persons with Disability (2006).

This project is also positioned within the context of SPA's vision, values and key objectives as detailed in SPA's *Strategic Plan 2020–2022*, and *Speech Pathology 2030: Making futures happen* (see Speech Pathology Australia, 2016, 2020a). Specifically, it is aligned with the key strategic pillar 'our impact', and the priority areas:

2.1 Increase recognition of the needs of people with communication and swallowing disorders

Strategies for 2020–2022…

2.1.2 Support development of National Standards for Communication Access through:

a. specific project to determine preferred terminology applied to the population of people experiencing barriers to communication, and the processes to address these barriers, across all relevant stakeholder groups in Australia, to ensure consistency, public understanding and acceptance.'

With a view to addressing communication rights in Australia, and consistent with SPA's vision, values and key objectives, the Communication Access Alliance was formed in 2017. The Communication Access Alliance aims to explore the possibility of developing Australian Standards for communication access with the ultimate aim of fostering communication accessible communities.

To further the work of the Communication Access Alliance, Speech Pathology Australia commissioned a literature review to determine the current legislative and policy context regarding communication access and to inform and guide the development of national communication access standards (see Speech Pathology Australia, 2018).

The main finding of the literature review was that, despite numerous activities to promote communication access, there remains a range of terms used to refer to people with communication difficulty and the processes implemented to address communication barriers, both nationally and internationally.

As such, a lack of clarity regarding preferred terminology among people with communication difficulties and other key stakeholders remains. This inconsistency is also evident in existing communication access standards and guidelines.

The first two recommendations of the literature review were to:

1. Determine preferred terms and definitions for the concept of communication access, for use in Australia.

2. Advocate for preferred terms to be used by governments, peak bodies, service providers, and other relevant agencies.

In response to this review, Speech Pathology Australia sponsored a study on the preferred terminology used to describe people with communication difficulties and the environmental processes required to address these difficulties, i.e. the Communication Access and Inclusion Terminology Project.

A reference group and research sub committee of the reference group were established to oversee the project. See Method section for full details on the role and composition of the reference group.

Research aim

The aim of the Communication Access and Inclusion Terminology Project was to identify and explore preferences relating to the terminology currently used in Australia to refer to people who experience communication barriers resulting from physical, neurological or sensory impairments, and the processes used to address these barriers. To address this aim, two phases of research were planned and carried out.

Approval to carry out each phase of this research was obtained on 3 August 2021 and 27 April 2022 from the University of Wollongong Human Research Ethics Committee (2021/058).

PHASE 1

To identify:

i. current terminology used regarding individuals (e.g., person with complex communication needs, person with communication disability, person with communication support needs)

ii. current terminology used regarding the process of addressing barriers to communication (e.g., communication access, inclusive communication, communication friendly)

iii. the acceptability of any terminology identified in the Communication Access Literature Review, currently in use nationally and internationally, not raised by the focus group.

PHASE 2

To determine the *preferability* of terms used to refer to people with communication difficulty and the processes and environments to address communication barriers, to facilitate shared understanding and consistency of use.

Method

Study design

The study was undertaken using a mixed methods approach (see Creswell, 2009) and was conducted in two sequential phases. The first phase utilised qualitative methodology to identify the range of terms used to refer to people who experience communication difficulty and the processes and environments that minimise these difficulties.

The second phase used quantitative methodology to gauge broad community preferability for the different terms identified in phase 1. Focus groups were employed to bring together people with communication disability arising from various etiologies to support understanding of the breadth and diversity of the people for whom the terms apply, and help generate robust discussion.

An online survey was employed in the second phase of the study because of its potential to reach broadly into the relevant communities, and determine consensus preferred terms.

A reference group was established to guide the study and support participant recruitment. A research sub-committee was also established to assist with the ethics application, data collection, analysis and reporting.

Reference group

The reference group ensured key stakeholders, including people with disability, were involved in all stages of the research. The reference group comprised:

i.   members of the Communication Access Alliance;

ii. speech pathologists from at least four different states or territories with experience working with people with a range of different communication disabilities and age groups;

iii. people from at least four different states or territories with lived experience of communication disability, including at least one person who uses augmentative and alternative communication (AAC) to communicate; and

iv. advocates representing people living with:

- life-long communication disability: e.g., intellectual disability, Deaf, blind, autism spectrum disorder, cerebral palsy, childhood apraxia of speech, or developmental language disorder;

- acquired non progressive communication disability: e.g., aphasia or acquired apraxia of speech; and

- acquired progressive communication disability: e.g., resulting from Parkinson's disease, or dementia.

Some reference group members represented two or three of the above stakeholder groups, e.g., one reference group member represents groups i, ii and iv. The reference group also supported recruitment of participants for the focus groups and surveys, promoting the focus groups and online survey through their individual networks.

PHASE 1
Focus groups

The aims of the focus groups were to:

i. identify terminology currently used to refer to individuals (e.g., person with complex communication needs, person with communication support needs) and processes (e.g., communication access, inclusive communication)

ii. gain feedback on terminology identified in the Communication Access Literature Review, currently in use nationally and internationally, but not raised by the focus group.

People with communication disability, their family members, speech pathologists, educators, other service providers and communication disability advocates were invited to participate in one of eight online focus groups.

Eight focus groups were planned to ensure a mix of stakeholder perspectives, and state based representation. It was also deemed that eight would be sufficient as Guest, Namey and McKenna (2017, p. 3) identified that "more than 80% of all themes were discoverable within two to three focus groups, and 90% were discoverable within three to six focus groups".

To help refine focus group eligibility, the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) was used and communication disability was defined broadly as any loss or reduction in any body structure or function that supports communication.

To further assist interpretation, the following definition from Speech Pathology Australia's *Professional Standards for Speech Pathologists in Australia* was referenced; "a range of factors may cause or result in an individual or community having communication and swallowing needs. These may include but not be limited to delay, disorder, disability, impairment or loss, inadequacy or incongruence of communication and swallowing for social, personal, community and vocational needs" (Speech Pathology Australia, 2020b, p. 6).

Together, these definitions ensured people with sensory impairments such as hearing or vision impairment, and people with life-long or acquired speech, language or cognitive communication impairments that impact communication were included in the focus groups.

Further inclusion criteria specific to service providers (speech pathologists, educators, and advocates) included:

• at least 5 years' experience working with people with communication disability and/or in the disability sector

• if a speech pathologist, current membership with Speech Pathology Australia.

Participants across all roles and experiences were purposefully sampled to ensure representation across four key criteria: perspective, age, state, and location. The following representation was achieved:

• perspective (person with disability, family member, or service provider)

• age group (under 18 by proxy, 19–65, or over 65)

• state (WA, NSW, QLD, VIC, TAS, or SA)

• location (metropolitan, regional, rural, or remote).

Focus group procedure

The focus groups were iterative in nature with information raised by participants in previous focus groups, shared with the next focus group. This helped to ensure as many different terms as possible were considered.

A facilitator and note taker were present at each focus group. The note taker did not participate in the focus group discussion. Each focus group was audio and video recorded with participant consent.

Notes taken during the group were reviewed against the recording immediately after the focus group, to ensure accuracy. The facilitator checked participants' understanding of the questions being asked and provided opportunities for each participant to contribute throughout the focus group.

Focus group data analysis

Focus group participants were offered the opportunity to review the focus group notes specific to their group, in their preferred format, to confirm the notes accurately reflected the discussion. Additional opportunity to provide comments or alternative views on the topic was provided. Sixteen focus group members (one to three from each focus group) responded to the request to review the focus group notes, and three provided additional comments or views.

Once additional comments had been added to the focus group notes, a conceptual content analysis was undertaken. The steps outlined by Columbia University Mailman School of Public Health (2022) were used to undertake the analysis. Details of how each step was addressed within this study is outlined.

Steps

1 **Decide the level of analysis**

Phrase length was determined as the level of analysis. Terms with different forms of the same word were grouped together e.g., communication access, communication accessible, and accessible communication.

2 **Decide how many concepts to code for**

An initial set of codes were determined from the literature review. Flexibility was allowed, to add categories through the coding process as new terms emerged.

3 **Decide whether to code for existence or frequency of a concept**

It was decided that coding of frequency would be applied i.e., the number of participants per focus group who indicated they preferred a particular term.

4 **Decide on how you will distinguish among concepts**

It was decided that only exact stated words were to be used when coding, although variations on the root word would be included e.g., respect, or respectful.

5 **Develop rules for coding texts**

Rules for coding were developed by the project consultant. Only words used by participants would be used in coding, that is, no inferences were to be made, i.e., if a participant described patient, attentive, and responsive interactions, this would not be inferred as respectful. Very similar terms were grouped together e.g., AAC user, person who uses AAC; non-speech, and non-verbal.

6 **Decide what to do with irrelevant information**

Terms specific to a narrower group, were noted in an 'extra' category, but not used for coding e.g., language and learning disorder, cerebral palsy, accent, and hard of hearing.

7 **Code the text**

Coding was undertaken manually by the project consultant, by reading through the notes and noting preference and non-preference of existing terms/codes or adding new codes as they arose.

8 **Analyse results**

Results were analysed and interpreted by the project consultant. It was decided that non-preferred terms would be reported, but only data regarding preferred terms would be used to inform development of the on-line survey. More specific terms used e.g., language disorder, were to be reported on, but not included in the data analysis.

Any term used to refer to people with communication difficulties which was preferred by six or more participants across four or more focus groups was included in the online survey distributed in the second phase of the study.

For terms used to describe the processes and environments implemented to address communication barriers, any term preferred by three participants or more across two focus groups or more were included in the survey.

There were six terms to refer to people with communication difficulty which were clearly more preferred than others, with the least popular of these preferred terms, being 'complex communication needs' that was preferred by six participants across four focus groups.

For terms to refer to processes and environments to optimise communication, fewer terms were popular across participants, so numbers of participants and focus groups was lower for this term to still ensure a range of terms was included in the online survey.

The preliminary analysis was shared with the four members of the research sub-committee (two of whom had been note takers for the focus groups), to check before the results were finalised. No changes were made.

Elo et al.'s (2014) *Checklist for Researchers Attempting to Improve the Trustworthiness of a Content Analysis*, was used to guide preparation, organisation, and reporting of the content analysis of the focus group data.

PHASE 2
Online Survey

An 11 item online survey was developed in SurveyMonkey (Momentive, 2022) adhering to guidelines outlined by Eysenbach (2004). Question formats included eight demographic tick box responses, one open ended, free text response, and two rating scales.

It was anticipated that for those requiring communication partner support to complete the survey, it would take no longer than 30 minutes. However, it would take considerably less time (10–15 minutes) for those who did not require support to complete the survey.

The online survey was open to participants between 25 July and 30 August 2022.

The online survey was disseminated through Speech Pathology Australia social media, and networks of the reference group including the Communication Access Alliance, and AGOSCI's (formerly Australian Group on Severe Communication Impairment) national conference and social media.

The survey was available online in plain language and Easy English versions. The plain language statement about the survey was also made available in Auslan (Australian Sign Language) and audio format.

Data analysis

The online survey data was downloaded and collated into an Excel database. Data was screened for duplicate responses, valid responses for each question, and complete questionnaires for each participant.

Partially completed surveys were included where participants completed responses to questions 10 and 11, where they ranked terms in order of preference.

For question 9 only ('Please list below any terms you use to refer to yourself or others who have communication difficulties?') a conceptual content analysis was undertaken following the same steps used to analyse the focus group data.

To determine most acceptable terminology across all stakeholder groups, responses were weighted according to their ranking i.e., all terms selected as first preference were allocated six points, terms selected as second preference were allocated five points, and so on until the final preference was allocated one point.

A total score for each term was achieved by multiplying the score of each preference by the number of participants who ranked it thus. This process was undertaken for each term that referred to people with communication disability and each that referred to the processes/environments to address communication barriers.

A descriptive analysis (frequency counts) of the survey data was also undertaken to identify preferred terminology across and between stakeholder groups. As distinct from most acceptable terminology, most preferred refers to the terms which were ranked first by the most participants.

Most acceptable terms were calculated using all of the data from questions 10 and 11 asking participants to rank terms in order of preference, and so provides the best indication of which terms are acceptable across stakeholders, given some terms are particularly unacceptable to some.

Therefore, the most acceptable terms can equally be considered the least unacceptable. This is in contrast to the most preferred terms which were determined by looking only at the term which received the most number 1 rankings, and does not take into account non-preferred terms. See Appendix 1 for data specific to different stakeholder groups.

The *Checklist for Reporting Results of Internet E-Surveys (CHERRIES)* (Eysenbach, 2004) was used to guide steps taken to optimise validity of the survey results.

Results

Phase 1: Focus groups

Eight focus groups were run between 5–27 August 2021. Five focus groups comprised people with communication disability or their family members and three comprised professionals, acknowledging some people who attended the focus groups for people with communication disability are also professionals. Each focus group had four to six participants and ran for 1–1.5 hrs. A total of 41 participants contributed to the focus groups.

The aim was for each focus group to consist of eight to ten participants (as recommended by Krueger and Casey (2014), however due to challenges with recruitment and non-attendance, focus groups ranged from four to six participants.

It was observed that due to most focus group participants having communication difficulties (including both receptive and expressive communication disability) more time was required for discussions. The number of participants was therefore optimal to ensure all participants had sufficient time to contribute. See **Table 1** for a summary of demographic data of focus group participants.

Table 1. Demographic characteristics of focus group participants

Demographic characteristic	Number of participants n=41 (%)
Gender	
Male	10 (24%)
Female	31 (76%)
Age	
18–65	38 (93%)
65+	2 (5%)
Prefer not to say	1 (2%)
State	
VIC	18 (44%)
NSW	7 (17%)
QLD	6 (15%)
WA	3 (7%)
SA	5 (12%)
TAS	2 (5%)
ACT	0 (0%)
NT	0 (0%)

Region	
Metro	37 (86%)
Regional	4 (9%)
Rural	1 (2.5%)
Remote	1 (2.5%)
Role	
Person with disability	23 (37%)
Speech pathologist	11 (17%)
Researcher	6 (10%)
Advocate	10 (16%)
Educator	6 (10%)
Service provider (other)	3 (5%)
Parent	3 (5%)
Cause of communication disability	
Physical	18 (26%)
Cognitive	18 (26%)
Sensory	14 (20%)
Neurological	19 (28%)
Age groups worked with	
0–18 yrs	13 (24%)
19–65 yrs	18 (33%)
65+ yrs	9 (16%)
No response	15 (27%)

Note: For region, role, cause of disability and age groups worked with, participants could select multiple options. Therefore, the total exceeds number of participants.

Tables 2a and 2b present the data from the content analysis of the focus groups. They show the number of participants in each focus group that indicated clear preferences for specific terms. Some focus group participants indicated preferences for more than one term.

The tables show the variety of terms discussed including those not preferred by sufficient focus group participants to be included in the survey.

See table 2a for focus group data regarding terms to refer to people with communication difficulty.

Table 2a. Focus group content analysis: terms to refer to people with communication difficulty

Terminology	FG1 P	FG2 VIC	FG3 P	FG4 NSW	FG5 QLD	FG6 SA	FG7 P	FG8 WA/ TAS	Total number of participants	Total number of focus groups
Communication disability	1	1	2	0	0	0	3	2	11	5
Communication difficulty	2	0	0	1	0	1	1	1	6	5
Communication impairment	1	1	0	1	0	0	0	0	3	3
Communication access needs	3	5	1	0	0	1	0	0	10	4
Communication support needs	1	1	0	1	0	0	1	2	6	5
Complex communication needs	1	0	1	3	0	0	1	1	6	4
Uses AAC	1	1	0	0	1	0	0	1	4	4
Communication diverse	0	0	0	3	4	3	0	4	14	4
Non-speech/ non-verbal	0	0	0	1	0	1	0	0	2	2
Additional communication needs	1	0	0	0	0	0	0	0	1	1
Non-traditional communicator	0	0	0	0	0	0	0	1	1	1
Speech difficulty/ problem	0	0	0	1	0	0	0	2	3	2
Communication difference	0	0	1	1	0	2	0	0	4	3

During the focus groups, numerous terms were raised that referred to smaller, more discrete subgroups of people with communication difficulty e.g., Language and learning disorder, behaviors of concern, cerebral palsy, functional neurological disorder, speech impaired, non-verbal, non-speech, and cerebral palsy accent. These terms were not included in the matrix as they were considered insufficiently inclusive of the broad group of people with communication difficulty.

Specific words that focus group participants identified as non-preferred included 'disability', 'user', 'support', 'needs', 'special/specialist', and 'alternative'.

See table 2b for focus group data regarding terms to refer to processes to address communication barriers.

Table 2b. Focus group content analysis: terms to refer to environments and processes

Terminology	FG1 P	FG2 VIC	FG3 P	FG4 NSW	FG5 QLD	FG6 SA	FG7 P	FG8 WA/ TAS	Total number of participants	Total number of focus groups
Communication access	3	4	1	1	0	6	4	1	20	7
Communication supportive	1	0	0	0	0	0	0	0	0	1
Inclusive communication	0	0	0	1	1	0	0	3	5	3
Communication participation	1	0	0	0	0	0	0	0	1	1
Equal/Equitable communication +ve	1	0	0	0	1	1	0	0	3	3
Communication solutions	0	1	0	0	0	0	0	0	1	1
Communication friendly	0	0	1	0	0	0	0	2	3	2
Respectful communication	1	0	3	1	1	0	0	1	7	4
Communication awareness	0	0	0	0	1	0	0	0	1	1

Results

Phase 2: Online survey

Two hundred and forty people commenced the survey, with 162 questionnaires included in the data analysis. One hundred and forty six individuals (90%) completed all of the survey questions, and 16 individuals (10%) completed at least the demographic questions regarding role and some other demographic information as well as ranking at least some of the terms.

10 of the 16 participants who had only partially completed the ranking process were people with disability, whose perspectives can be more difficult to gain, so even partially completed surveys were considered valuable. At least 153 participants ranked every term.

See Table 3. for demographic characteristics of survey participants.

Table 3. Demographic characteristics of online survey participants

Demographic characteristic	Number of participants n= 162 (%)
Gender	
Male	12 (7%)
Female	147 (91%)
Unknown	3 (2%)
Age	
18–29	30 (19%)
30–49	79 (49%)
50–64	41 (25%)
65+	10 (6%)
Unknown	2 (1%)
State	
VIC	42 (26%)
NSW	39 (24%)
QLD	27 (17%)
WA	9 (6%)
SA	4 (2%)
TAS	39 (24%)
ACT	1 (0.5%)
NT	0 (0%)
Unknown	1 (0.5%)

Region	
Metro	119 (73%)
Regional	27 (17%)
Rural	13 (8%)
Remote	0 (0%)
No response	3 (2%)
Role	
Person with disability	32 (15%)
Family member	25 (12%)
Educator	12 (6%)
Service provider	113 (54%)
Advocate	23 (11%)
Other	5 (2%)

146 complete + 16 partial
Note: For role, participants could select multiple options. Therefore, the total exceeds number of participants.
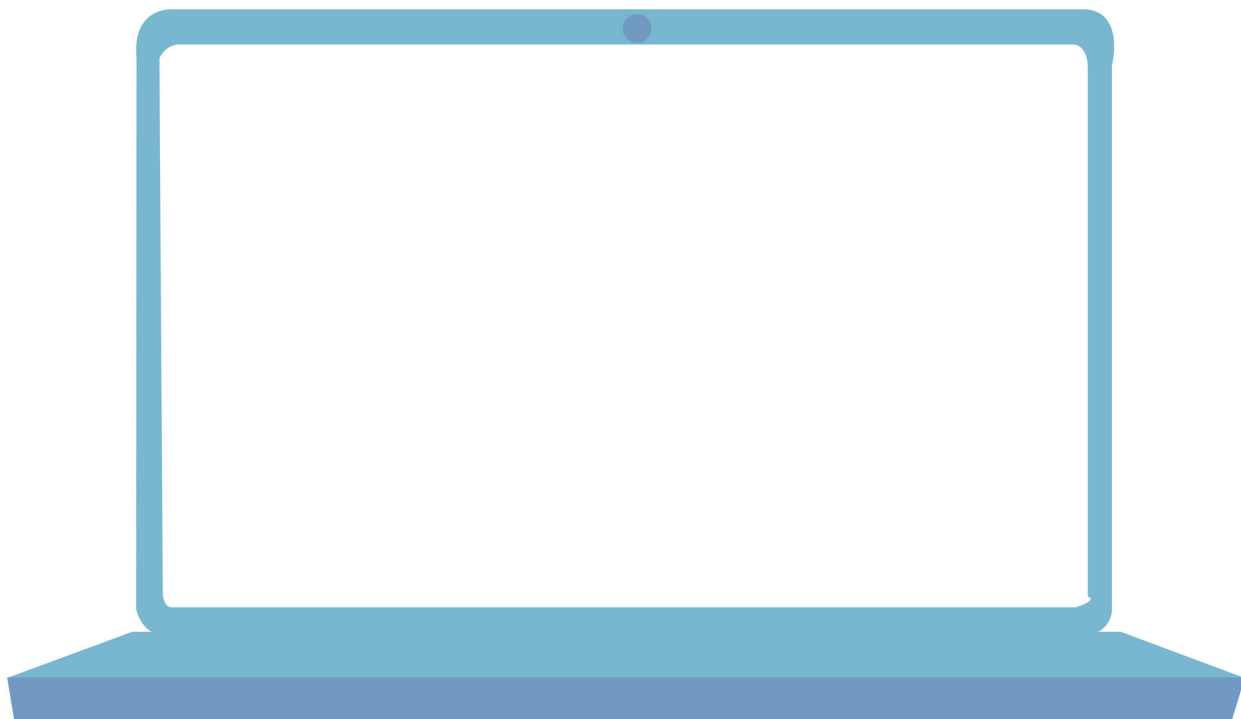
One hundred and fifty four participants responded to Question 9, **'Please list below any terms you use to refer to yourself or others who have communication difficulties?'** and more than 90 different terms were suggested. Terms which five people or more suggested are included in Table 4.

See Table 4 for results of content analysis of Q.9. responses.

Table 4. Conceptual content analysis results of responses to survey Q.9

Term	Number of survey participants
Terms inclusive of whole group	
Communication disability	25
Communication difficulty	41
Communication impairment	14
Communication support needs	5
Complex communication needs	36
Communication difference	5
Multimodal communicator	5
Communication challenges	7
Communication disorder	6
Terms referring to sub-groups	
Person who uses AAC	13
Language and learning disorder	6
Speech impaired	6
Non-verbal	18
Non-speech	9
Cognitive trouble/impairment	5
Aphasic/with aphasia/dysphasia	17
Dysarthric/dysarthria	6
Stutter	6
Deaf/Hard of Hearing/Auslan user/hearing loss	14
Autistic	6

Two terms which were popular enough with focus group participants to be included in the online survey ranking activity, **'communication access needs'** and **'diverse communication'**, were only mentioned by one and two respondents respectively.

Also, some terms identified in the focus groups, did not appear in responses to Q.9. e.g., non-traditional communicator and cerebral palsy accent, indicating that while over 90 different terms were given by survey respondents, this list is likely far from exhaustive.

The data from Q.10 and Q.11 which asked participants to rank terms in order of preference, were analysed in two ways:

1. most acceptable terms; and

2. most preferred terms.

Most acceptable terms (including data across all preferences)

First the most acceptable terms across stakeholder groups were determined. Given the focus group data suggested that some terms are unpopular or unacceptable to some individuals and groups, it was decided that determining the terms which were the most acceptable to the respondents would best represent the varied stakeholder perspectives.

These results were calculated by multiplying the first preference responses by 6 for Q.10 (as there were six terms), second preference by 5, third preference by 4 and so on.

The same was done for Q.11 with the first preference responses being multiplied by 5 as there were five terms for this question. The sum of these calculations for each term was used to determine the most acceptable term for each question.

The most acceptable term to refer to people with communication difficulty across all stakeholder groups was **'people with communication support needs'**, and the most acceptable term to refer to the processes and environments to support communication was **'inclusive communication'**.

See Tables 5 and 6, and Figures 1 and 2 for results regarding most acceptable terms.

Table 5. Most acceptable term to refer to people with communication disability

Term	1st (x6)	2nd (x5)	3rd x4	4th x3	5th x2	6th x1	TOTAL
Diverse communication	150 n=25	70 n=14	56 n=14	51 n=17	52 n=26	63 n=63	442
Complex communication needs	198 n=33	130 n=26	128 n=32	75 n=25	54 n=27	18 n=18	603
Communication support needs	126 n=21	175 n=35	192 n=48	108 n=36	36 n=18	3 n=3	640
Communication disability	156 n=26	80 1=16	108 n=27	54 n=18	54 n=27	45 n=45	497
Communication difficulty	228 n=38	145 n=29	72 n=18	84 n=28	58 n=58	16 n=16	603
Communication access needs	114 n=19	200 n=40	76 n=19	102 n=24	62 n=31	15 n=15	569

Figure 1. Most acceptable term to refer to people with communication disability
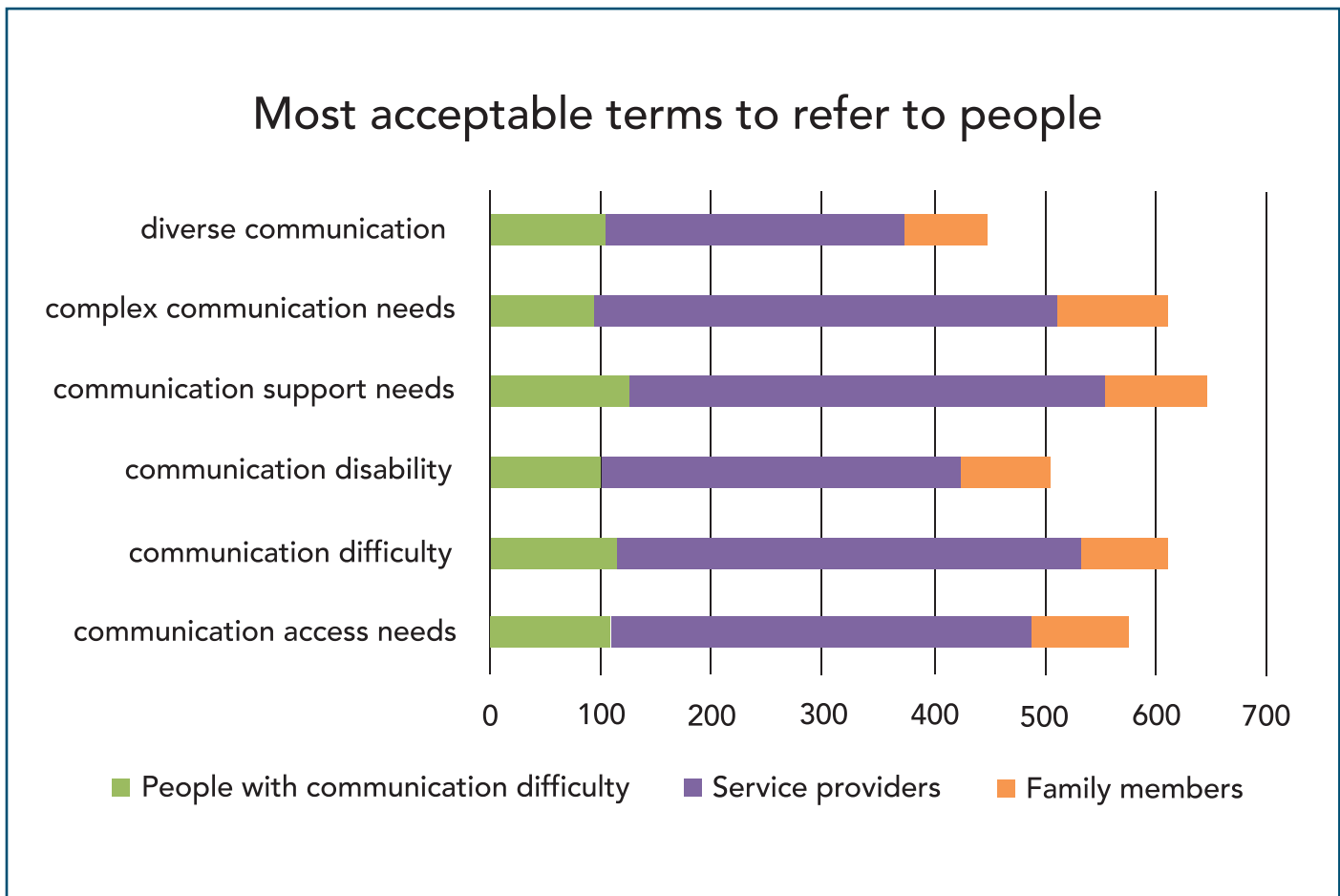
Table 6. Most acceptable terms to refer to processes and environments

Term	1st x 5	2nd x 4	3rd x 3	4th x 2	5th x 1	TOTAL
Respectful communication	85 n=17	60 n=15	81 n=27	86 n=43	52 n=52	364
Inclusive communication	275 n=55	172 n=43	99 n=33	34 n=17	5 n=5	585
Equal communication	35 n=7	24 n=6	51 n=17	90 n=45	78 n=78	278
Communication friendly (environments)	130 n=26	172 n=43	135 n=45	62 n=31	9 n=9	508
Communication access	245 n=49	184 n=46	93 n=31	36 n=18	10 n=10	568

Figure 2. Most acceptable terms to refer to processes and environments
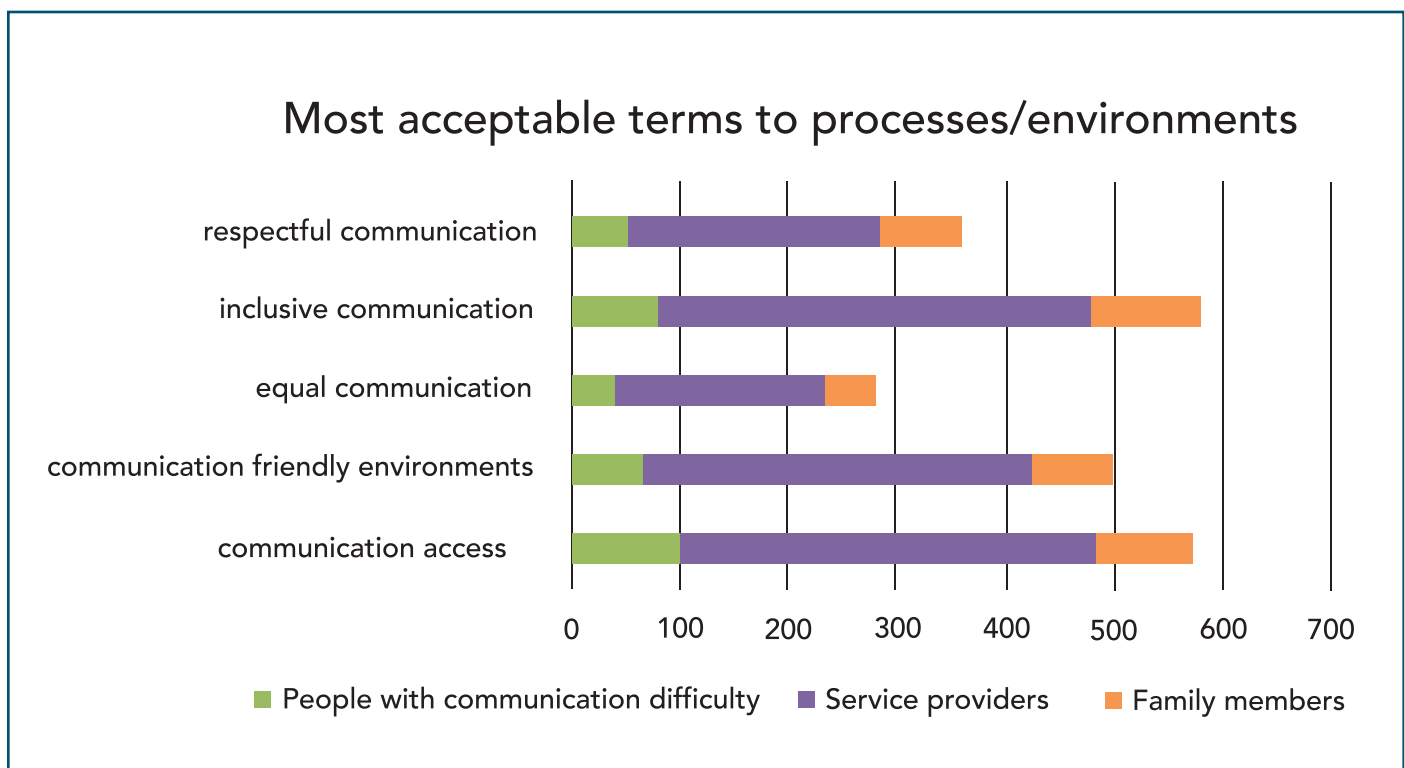
Further raw data and analysis of the most acceptable terms across different stakeholder groups can be found in Appendix 1.

Most preferred term (only first preference data)

The data from questions 10 and 11 were also analysed with regard to most preferred term. That is, the term selected as first preference by the most respondents.

The terms 'communication difficulty' and 'inclusive communication' received the highest number of first preference votes with 38 (23%) and 55 (34%) respectively.

See Table's 7 and 8, and Figure's 3 and 4 for data regarding most preferred terms.

Table 7. Most preferred term to refer to people with communication difficulty

Term	1st	2nd	3rd	4th	5th	6th
Diverse communication	25	14	14	17	26	63
Complex communication needs	33	26	32	25	27	18
Communication support needs	21	35	48	36	18	3
Communication disability	26	16	27	18	27	45
Communication difficulty	38	29	18	28	29	16
Communication access needs	19	40	19	34	31	15

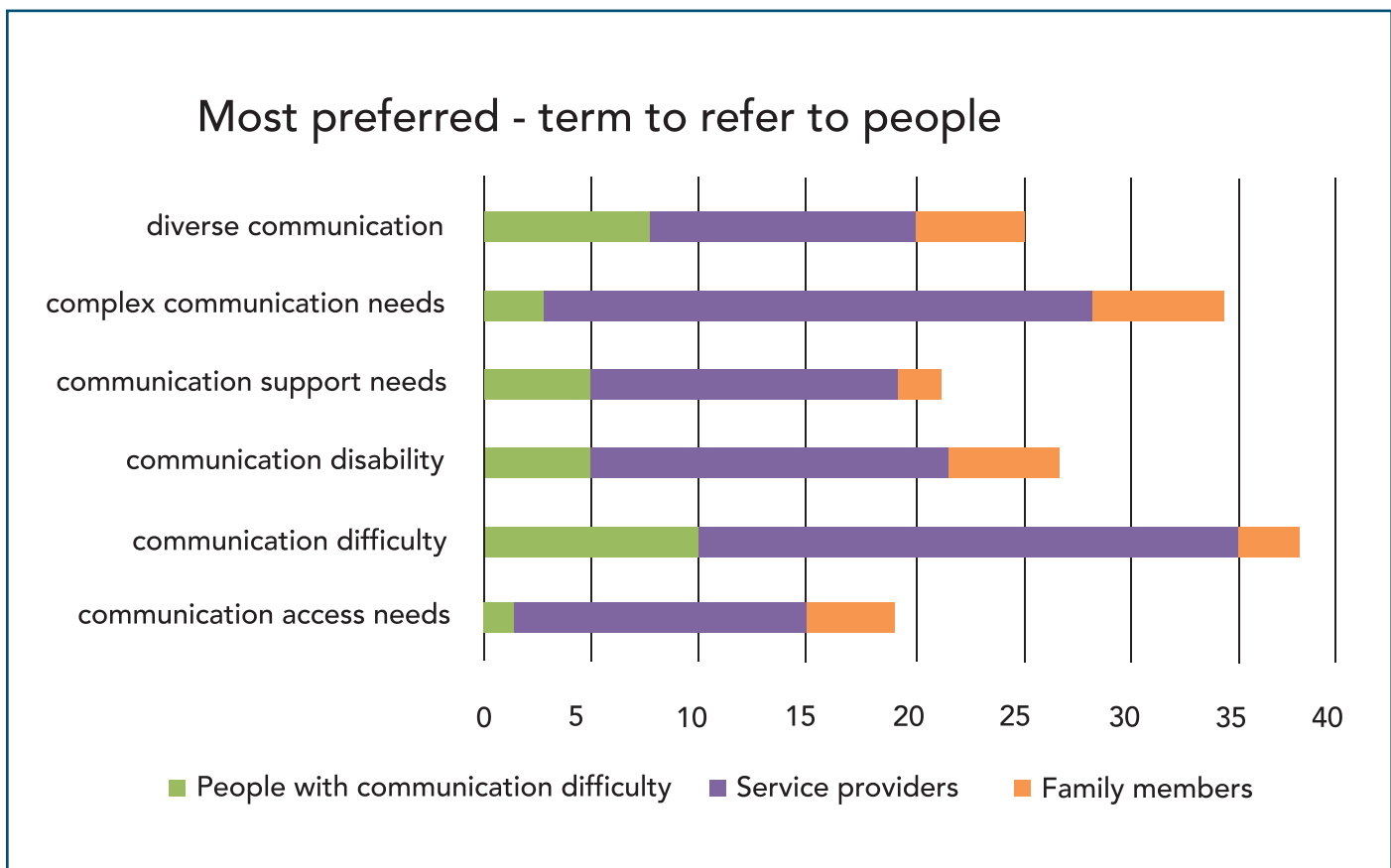**Figure 3. Most preferred term to refer to people with communication difficulty**

Table 8. Most preferred term to refer to processes and environments

Term	1	2	3	4	5
Respectful communication	17	15	27	43	52
Inclusive communication	55	43	33	17	5
Equal communication	7	6	17	45	78
Communication friendly (environments)	26	43	45	31	9
Communication access	49	46	31	18	10

Figure 4. Most preferred term to refer to processes and environments

Figure 4. Most preferred term to refer to processes and environments
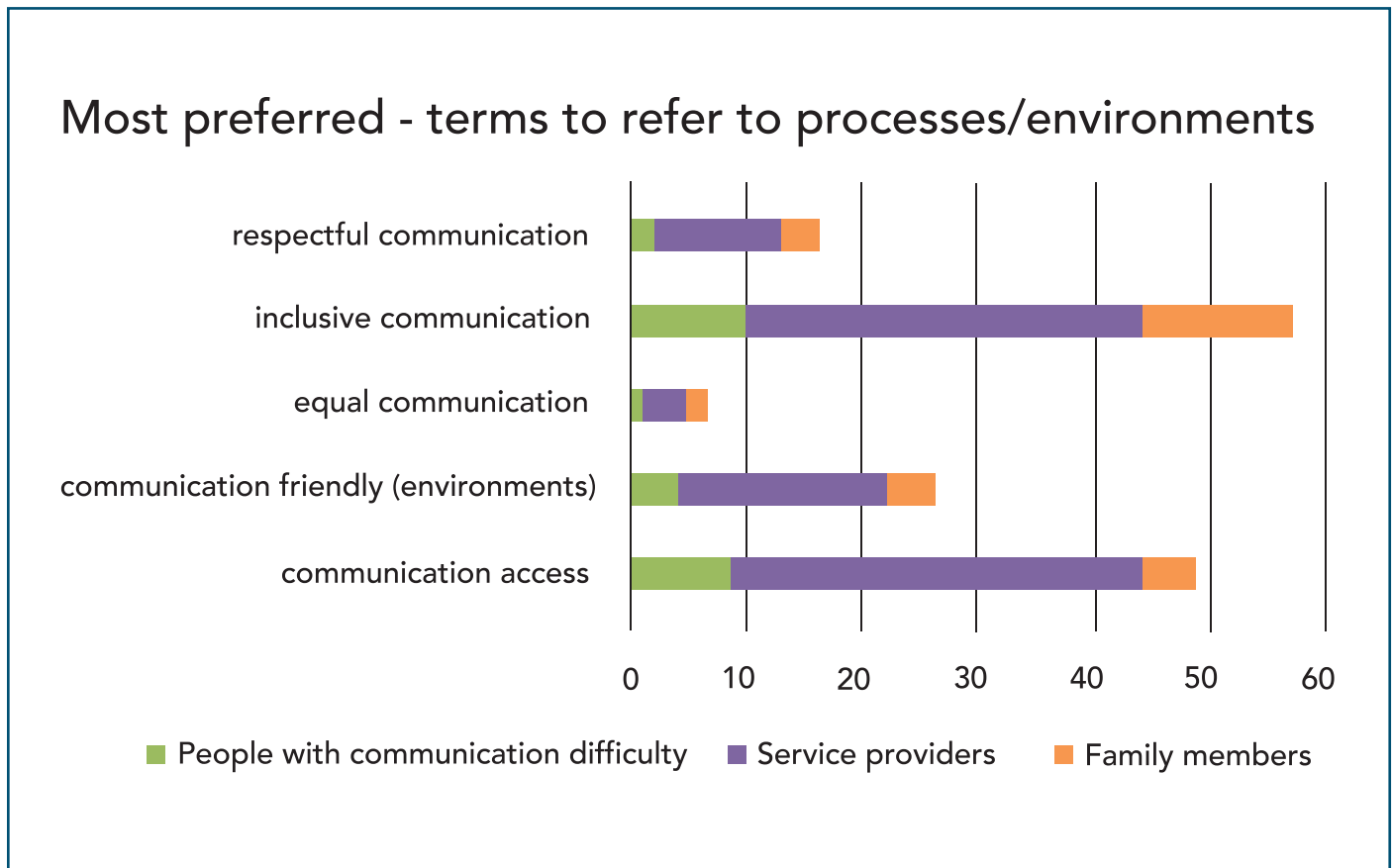
Further raw data and analysis on the most preferred terms across different stakeholder groups can be found in Appendix 1.

Discussion

Speech Pathology Australia (SPA) recognises that words are powerful and that they can affect the way people feel about themselves and how they are viewed by others. (Speech Pathology Australia, 2022).

For advocacy and awareness raising purposes, there is value in using consistent terminology so all stakeholders, including people with disability and their family members, service providers, advocates, researchers, policy makers and governments are clear about who and what is being referred to. In addition, "using common terminology and standards locally will make it easier to compare service evaluations, audits and research findings" (Money et al., 2016, p. 37).

This mixed methods study indicated that the preferred term to refer to people with communication difficulty, based on number of participants who ranked the term number 1 of the 6 options was **'communication difficulty'**.

When taking into account preferences across all terms, by weighting each term according to preference, the most acceptable term was found to be **'communication support needs'**.

The most preferred term based on number of participants who ranked the term number 1 and the most acceptable term taking into account all preferences to refer to processes and environments to optimise communication was **'inclusive communication'**.

This study highlights a number of converging issues which arise when exploring preferred terminology with regard to communication disability and processes for addressing communication barriers. This section will examine these issues including models of disability, meanings and definitions of terms, the heterogeneity of the population being referred to and contextual factors.

Models of disability and language

Language continually grows, adapts and evolves as new words emerge to better reflect societies and cultures. The development of new models of disability has contributed to the rejection of some terms, development of new terms, and shifts in the perception of some terms.

For example, the currently commonly accepted social model of disability **rejects** words and phrases like:

- suffers from...
- afflicted by...
- mute
- dumb.

Suggesting instead:

- **person with...**
- **person who…**

In terms of new words, 'neurodiversity is a term that was coined by Australian sociologist Judy Singer in the late 1990s to describe 'the limitless variability of human cognition' (People with Disability Australia, 2021). And with regard to shifting perspectives of people towards terms, the identity model (or affirmation model) of disability shares the social model's understanding that the experience of disability is socially constructed, but differs to the extent that it asserts disability as a positive identity' (Disabled World, 2023).

Growing advocacy for the use of identity first language is reflected in Speech Pathology Australia's recently released practice guide *Working with autistic people* which states:

"There are different views regarding the terms used to talk about autism. The main point of difference is between people who prefer 'identity first' language (e.g., autistic person) and those who prefer 'person first' language (e.g., person with autism, person on the autism spectrum). Recently, the Autism CRC draft *National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia* was published (Trembath et al., 2022). As part of the process for developing the Autism CRC draft guideline, the Guideline Development Group conducted an online community survey to learn the preferences and acceptability of various terms among all key stakeholders. The findings indicated a strong preference for identity-first language among autistic people and high levels of acceptance for identity-first language across all stakeholder groups. Accordingly, identity-first language was adopted in the draft guideline. Given the complementary nature of the Autism CRC draft national guideline to the revised Speech Pathology Australia position statement and practice guide, identity-first language has also been adopted in the Speech Pathology Australia documents. Where 'Autism Spectrum Disorder' or 'ASD' is used, it is in reference to the diagnostic criteria." (Speech Pathology Australia, 2022b).

Note: The National Guideline for supporting the learning, participation and wellbeing of autistic children and their families in Australia developed by the Autism CRC has now been finalised and can be found at **https://www.autismcrc.com.au/access/supporting-children**

Use of terms and language reflecting identity creates challenges when looking to determine preferred terms of a group unified only by their proximity to speech pathology practice. While it was made explicit that the aim of this project was to determine terms for Speech Pathology Australia and speech pathologists to use in awareness raising and advocacy activities, it is clear from the findings of the present study that many prefer terms which reflect their individual situation rather than terms inclusive of the broader group of people with communication difficulty.

This study attempted to ascertain a single most preferred term to refer to:

  a. people with communication difficulty

 b. processes and environments that minimise communication barriers.

Findings revealed that no one term was universally preferred by all study participants. However, the most acceptable terms preferred by the most participants, could be determined. These terms were 'people with communication support needs' and 'inclusive communication'.

With regard to a preferred term to refer to people with communication difficulty, in this study the term **'communication difficulty'**, was the most stated term when asked how people refer to themselves or others with communication difficulty, and most respondents selected this term as their first preference. But it was not ranked highest by participants overall when all preferences were taken into consideration.

'Diverse communication' was more popular with people with communication disability and family members than with service providers, possibly reflecting the move away from medical and impairment models of disability and towards the identity model of disability.

The word **'diverse'** is used to positively reflect identity of a range of marginalised groups e.g., culturally and linguistically diverse, gender diverse, neurodiverse, reflecting both difference and variety; a characteristic of people with communication disability.

With regard to terms for processes or environments to address communication barriers, 'inclusive communication' was both the most acceptable term overall and the most preferred when only first preferences were considered.
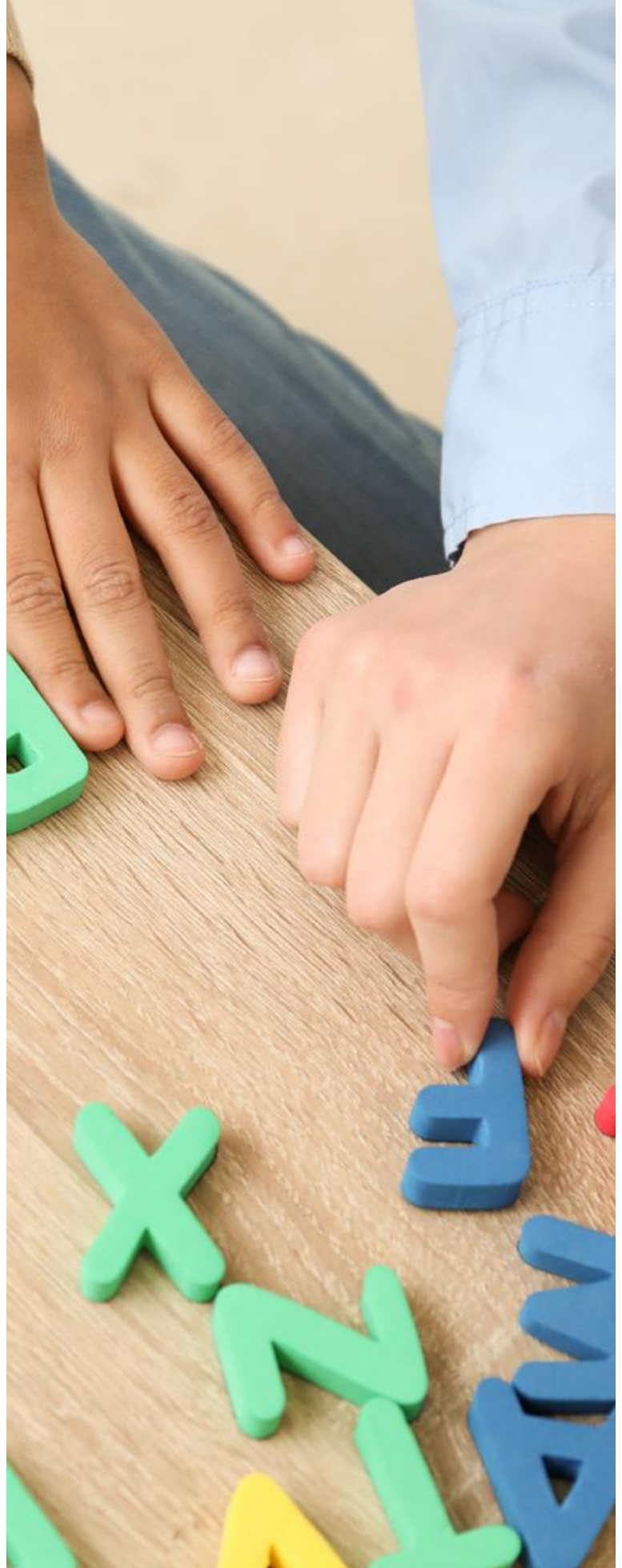
Models of disability and language

A key problem which arises when exploring terminology relating to communication disability is that there are terms with different meanings, being used synonymously. As stated in the results section, stakeholders currently add a range of words to the word 'communication' to indicate a 'communication disability' e.g., 'challenge', 'concern', 'disorder', 'problem', or 'need'. Yet all these terms have different meanings, connotations, and implications.

In outlining the role of a speech pathologist, Speech Pathology Australia's (2020b) Professional Standards state "a range of factors may cause or result in an individual or community having communication and swallowing needs.

These may include but not be limited to delay, disorder, disability, impairment or loss, inadequacy or incongruence of communication and swallowing for social, personal, community and vocational needs" (Speech Pathology Australia, 2020b).

In this instance the term 'communication needs' is used highlighting the challenge in finding a term which is broad and inclusive enough to represent the diverse group that speech pathologists work with.

With regard to a term for processes and environments to address communication barriers, the most preferred term was **'inclusive communication'**.

The Royal College of Speech and Language Therapists (RCSLT) in the United Kingdom have adopted the term 'Inclusive Communication' with a view to genuine inclusion of people with communication disability. (See, Royal College of Speech and Language Therapists, 2023).

Definitions and guidelines for inclusive communication and other terms were developed over a 3 year project, which included broad member consultation by the RCSLT (See Money et al., 2016).

It is recommended that Speech Pathology Australia adopt the description of inclusive communication outlined by the RCSLT:

"Inclusive communication is an approach to communication which enables as many people as possible to be included in that interaction.

This approach:

– recognises that all human beings use many ways of understanding and expressing themselves

– encourages, supports and enables people to use whatever ways of understanding and expressing themselves which they find easiest.

It does not relate only to a specific activity for a particular group. It is an overarching approach which is relevant to:

– everyone and in all situations, not just people with communication support needs

– all communication at individual, organisation and population levels

– all modes of communication— face-to-face, telephone, written, and online. (Royal College of Speech Language Therapists, 2023).

Heterogeneity of people with communication disability

The different perspectives, motivations, capacities and different sub-group agendas, combined with the challenge of finding a comprehensive and meaningful term for diverse audiences, makes determining **'a single preferred term'** for the majority, extremely challenging and potentially unachievable.

Determining a preferred term which is inclusive of everyone with a communication disability is problematic for several reasons. Communication disability varies considerably in nature and severity.

For example, someone with a profound intellectual disability will communicate differently to someone with a mild intellectual disability and someone who is Deaf will use different communication methods and strategies to someone who has a moderate hearing loss.

Also, some people with communication disability report their communication difficulties to be context dependent.

For example, a person who is Deaf does not experience communication barriers when interacting with other Deaf Auslan users, but may when interacting with a person who does not know Auslan.

For these reasons, people with communication disability may perceive they have little in common with another person whose communication disability results from a different cause.

Some people with communication disability and those who work with them will use terms which are specific to their situation. For example, when asked what terms they currently use, 17 said aphasia, 14 said AAC user, and 14 said Deaf or Hard of hearing.

These terms, while relevant to subgroups of the larger group, are not inclusive of all people with communication disability. Rather, they are strongly linked to identity and identification with the sub-group, but not the larger group.

Numerous terms are contentious with some stakeholders preferring them, while others opposing them e.g., 'needs', 'support' and 'impairment'. People with Disability Australia argue that the word 'needs' is not consistent with the social model or rights-based model of disability and that people with disability have rights not needs (People with Disability Australia, 2021).

However, it can also be asserted that while all people with communication disability have rights, their individual access and inclusion needs will differ. For example, a person who is Deaf may need an Auslan interpreter for access, while a person with an intellectual disability may need simplified language and images to support their access.

The unifying factor for this group is proximity to speech pathology practice, which reflects the aim of the project, to determine terms for use in advocacy and awareness raising by Speech Pathology Australia and speech pathologists.

Current policy and legislative frameworks

Regardless of perception or preference of members and key stakeholders, Speech Pathology Australia operates within both National and International policy and human rights contexts. Therefore, they need to be mindful of the language and terminology used within these contexts.

The World Health Organisation and United Nations in particular use specific terminology with regard to communication disability, rights and access.

The UNCRPD—Article 2, definitions, states—"'Communication' includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology."

The UNCRPD—Purpose—states "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

Within Australia, the rights of people with communication disability are upheld by the Disability Discrimination Act (DDA), and services are funded by the National Disability Insurance Scheme (NDIS), so when Speech Pathology Australia or speech pathologists generally, are undertaking work relating to matters governed by legislation regarding the DDA or NDIS, use of the term **'disability'** would be recommended.

As a general principle, making decisions regarding terminology use should be systems and context sensitive.
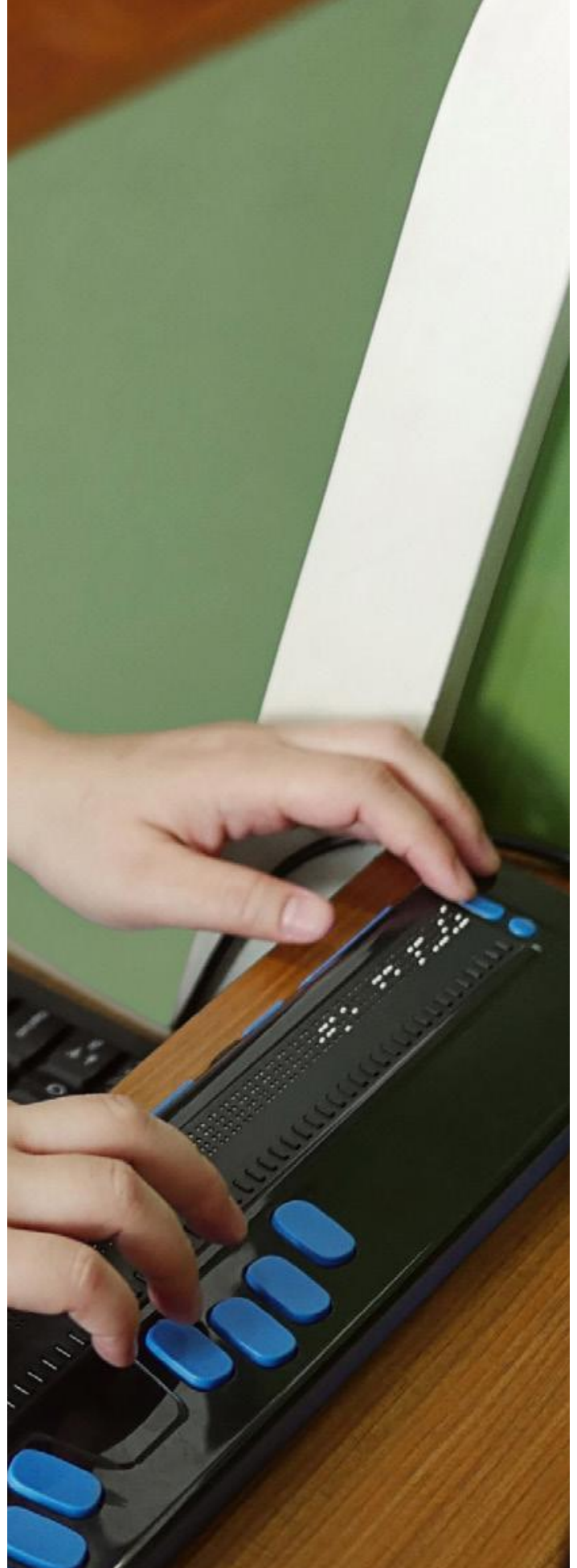
Study limitations

The focus groups had no participants from the Australian Capital Territory or Northern Territory, and there was only one participant from the Australian Capital Territory and none from the Northern Territory that participated in the online survey, so some regional differences may have been missed.

There was also very limited representation of Aboriginal and Torres Strait Islander peoples in the study, and further research is warranted to determine preferences of these groups.

The number of completed surveys was low and may not be representative of a national population, so findings should be considered with caution.

It is also very difficult to discuss terminology without using some specific terms and the term 'communication difficulty' was the most used term in the plain language statement and survey, which may have influenced participants' responses.

Conclusion and recommendations

There are many terms currently used to refer to people with communication disability. Some are broad and inclusive, and others are specific to type of disorder or cause of communication disability. Most vary in their meanings and implications.

This study found the most acceptable term to refer to people with communication disability across all stakeholder groups to be 'people with communication support needs', and the most acceptable term to refer to the processes and environments to support communication and minimise barriers was 'inclusive communication'.

With regard to a most preferred term, there was no single term which was obviously preferred across all stakeholder groups to refer to either people or processes. Though a group of terms appear to be more preferred than others and some differences between stakeholder groups preferences are apparent.

Based on the findings of this project it is recommended that the terms 'people with communication support needs' and 'inclusive communication' be used by Speech Pathology Australia and speech pathologists when collectively referring to a range of different people and contexts in support of advocating for the communication rights of all Australians.

However, individual and group preferences for different terminology will need to be used when referring to individual people and groups. Similarly, Speech Pathology Australia and speech pathologists generally should also consider systems and contexts when making decisions regarding use of terminology.

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Speech Pathology Australia

**Communication Access and
Inclusion Terminology Report**