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NDIS Independent Review Panel c/- NDIS Review Secretariat Department of the Prime Minister and Cabinet PO Box 6500 Canberra ACT 2600. c/- contactus@ndisreview.gov.au

To the NDIS Independent Review Panel

This submission addresses one of the objectives stated in Part 1 of the Terms of Reference for the NDIS Review, to examine *the user journey, including awareness and access to the scheme, assessment, planning, review processes, and navigation of supports and key transition points.*

To provide a context for my comments the following information is provided, I am

- a speech pathologist with more than 35 years' experience working with people with multiple and complex communication needs, and in particular people with moderate and severe intellectual disability
- the internationally recognised expert in the development and writing of Easy English which is the creation of written information for people with low and/or limited literacy.

Furthermore

- I developed and wrote the initial and following Easy English Writing Style Guide (2006, 2008) and Images for Easy English (2007). These were the first written guidelines for Easy English. They were and continue to be based on evidence best practice. I have provided the Victorian Government with their guide, Easy English How to comply with the Victorian Government Accessible Communication Guidelines 2014. This guide is on their intranet
- Current best practice Easy English development has built on that initial work and is guided by the latest available research
- I have been developing and training Easy English for 18 years the longest of any practitioner in Australia, and
- I continue to advertise the only 2 day Easy English training in Australia to organisations in the development and use of Easy English, including current research and international perspectives. We receive registrations from all states and territories in Australia and from international participants.

Access Easy English, the business I run,

- is on the Federal Government DHS Procurement Panel for Easy English services And
- is the only provider of Federal Government Easy English training services
- has recently been accepted onto the newly created NDIS Accessible Communications
 Panel for Easy English services. Note: This panel has taken 3 years to become active
- is currently the only preferred provider of Easy English services to a number of state governments.

In 2022 my team were acknowledged both nationally and internationally for our work and our longterm commitment to and the current development of best practice and quality Easy English with the following awards. Note the National Award for the NDIS sector.

- International Zero Project Shortlist 2023
- International Global Award 2022
 Most Outstanding Communicator for people with Disability
- Australian National Enablement Award 2022
 Most Outstanding Communicator in the NDIS Sector
- APAC Insider Small Business Award 2022 Easy English training

Victorian Chamber of Commerce and Industry (VCCI) – COVIDSafe Business Community Award Finalist 2022. For our pro bono COVID19 content development.

I have recently returned from an invited presentation at the United Nations in Vienna, Austria on Easy English and universal access for all people with low literacy. Two further invited plenary conference papers are upcoming, being,

- KLAARA International Easy to Read Conference Plain Language, Easy English, Portugal, July 2023
- East Asia International Society of Augmentative and Alternative Communication (ISAAC) Conference. South Korea, January 2024.

Speech Pathology Australia, my professional association also recognise our Easy English work as leading the awareness, development and best practice of Easy English.

Recognising this, it is specifically named in their *Speech Pathology 2030 - making futures happen* report, which has informed the previous, current and will inform the next strategic plan of the association.

It includes Communication accessible communities (1) and Skilled and confident families and carers (5), which specifically includes Easy English as being part of positive and meaningful engagement for all families. ¹

The *Professional Standards for Speech Pathologists in Australia*² also identifies to 'Maintain high standards of communication, information sharing and record keeping' (1.5.) we use accurate, accessible communication to respond to the needs of individuals and communities in all circumstances, which includes 'informed consent' (1.1).

¹ Speech Pathology Australia. (2016). Speech Pathology 2030 - making futures happen. Melbourne. <u>https://www.speechpathologyaustralia.org.au/SPAweb/whats_on/Speech_Pathology_2030/SPAweb/</u> <u>What_s_On/SP2030/Speech_Pathology_2030.aspx?hkey=3fad1937-a20e-4411-8b46-369f61570456</u>

² Professional Standards for Speech Pathologists in Australia (2020) <u>https://www.speechpathologyaustralia.org.au/SPAweb/Resources_for_Speech_Pathologists/CBOS/P</u> <u>rofessional_Standards.aspx</u>

Our professional standards also recognise the importance of Article 19 of the Universal Declaration of Human Rights³ and Article 21 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).⁴ Both these Articles state individuals have the right to access information in the way they can understand, to take part and to make meaningful choices. It also states it needs to be at the same time as other content is available to the public, and the person who needs it can locate it.

No part of the NDIS or any pathway connected to the NDIS does this

- effectively for the people who need access to written information when they have low literacy
- with any or clear processes
- in a timely manner
- in a way people can request what they need
- in a way people can locate i.e.in places other than the internet.

Australian literacy data

From the current adult literacy data, the Organisation on Economic Cooperation and Development (OECD) in partnership with country specific government research agencies, such as the Australian Bureau of Statistics in Australia, the *Programme for the International Assessment of Adult (16-65 years) Competencies (PIAAC)* states

- In Australia 44% of the adult Australian population do **not** have the literacy to manage a range of day-to-day readings skills. This does **not** include rural and remote Aboriginal and Torres Strait Islander people. **Nor** does it include people who live in institutions.
- when information is about numerical concepts, including time, money, estimates, budgets or the language of numbers such as *before* and *after*, the percent is now 53% of the adult Australian population who do **not** have the literacy to manage a range of day to day numerical literacy tasks.

³ United Nations (1948) Universal Declaration of Human Rights <u>https://www.un.org/en/about-us/universaldeclaration-of-human-rights</u>

⁴ United Nations. (2006). Convention on the Rights of Persons with Disabilities (UNCRPD). <u>https://www.un.org/development/desa/disabilities/convention-on-the-rightsof-persons-with-disabilities/convention-on-the-rights-ofpersons-with-disabilities-2.html</u>

- For both these scenarios when English is your second language it is 10% worse, i.e.
 54% for reading and 63% for numerical concepts.
- Low literacy is not just the domain of a few people with disability, or only people with intellectual disability. It is the hidden disability of far more people. Under stress or being anxious can also impact on one's literacy, as does age and illness.

Easy English and Easy Read

When I began Easy English development 18 years ago, I was initially commissioned to review Easy Read developed in the UK (and in other countries). At that time, it was identified that Easy Read was an important strategy, but was being written at a complex level that many people with low literacy could **not** and still can **not** read, understand and know what to do with. Hence the introduction of Easy English.

The guidelines I wrote in the mid 2000s are still the basis of Easy English writing. With the ongoing research they have evolved into guidance that is measurable and repeatable for people who create best practice Easy English. Therefore, the documents created for the public is evidence based, best practice Easy English and is most value to the people who need it. It is also critically, consistently developed.

In contrast, in 2005, research was published stating people with intellectual disability reported Easy Read was better than what they had used before (which was only complex or plain language content), but to **keep improving** on it.

To look back at content developed in Easy Read at that time (2003-2005) and compare it with currently developed content (2022- 2023), including what is commissioned and used by the NDIS clearly shows there has been no improvement in its development.

For some content it is far less readable and less functional for readers than 20 years ago. This is **not** OK.

Why do the NDIS continue to ignore best practice?

It is extremely frustrating that the NDIS are only commissioning and publishing content in Easy Read, which is **not** best practice for people with low literacy, nor is it as simple and easy to use as best practice Easy English.

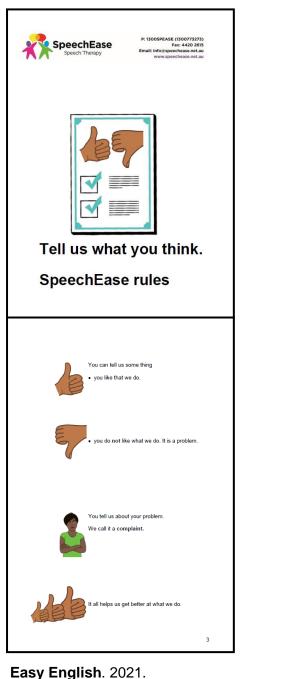
Accessing the NDIS or services for your NDIS plan should never be a reading test.

Attached is an example I created recently in Easy English, See Appendix 1, of the same content from one of the publicly available reports from the Disability Royal Commission that is in Easy Read, See Appendix 2. It is a clear illustration, of the significant differences in them.

Read also the analysis attached

- Appendix 3, Basterfield 2019 *What's in a name*, a summary of my research and international presentations on this topic.
- Appendix 4 is further detailed discussion in my recent submission to the NDIS CALD Strategic Development, pages 15-23.

Further example



How to make a complaint. 7 pages. Home page and page 3. Full copy can be provided. Developed by Access Easy English For an allied health service that provides services to NDIS participants and other

services to NDIS participants and other people in their community.



Easy Read. Date of development not included. (Currently on website) Complaints policy and how to make a complaint. 28 pages.

Home page and page 7.

https://www.ndiscommission.gov.au/easyread

Commissioned by NDIS Quality and

Safeguards Commission.

For all NDIS participants & families.

Note: The example in Easy Read above, is from the NDIS Quality and Safety Commission website. There does not appear to be any *How to make a complaint* document on the NDIS website, except in so-called plain language. It only takes you to an email online form.

Research shows that Australian **Easy Read** is developed in the range of **grade 3 to grade 10** reading equivalence with an average of grade 5 reading equivalence. This does **not** equate to low literacy. It is also such a wide range of literacy skill requirements, that a person can not guarantee that this or the next fact sheet or report etc is something they will be able to read and understand. Mostly content that the NDIS have developed is about facts and reports and policies. In Easy Read it is more likely to be at the upper levels of reading equivalence.

It does not and should not be like this. Easy Read is **not** accessible to people with low literacy or the vast majority of people with intellectual disability. If it includes PhotoSymbols which are photos taken from the UK (firstly non-Australian demographics, and then places, services, and buildings that are not Australian) most readers can not identify with them. Other people who do not identify as having an intellectual disability will not engage with your Easy Read materials.

It is an enormous waste of money and resources.

Research consistently shows **Easy English** development ranges in reading equivalence from **grade 0 to grade 3**, with an average of grade 2 reading equivalence.

This is more likely to meet the needs of people with low literacy, including people with intellectual disability. The known reading equivalence average for people with intellectual disability who have read accessible written information, who identify they can read or know some written words is equivalent to a 7-year-old reading age, which is grade 2 reading equivalence.

People who need low literacy can see and describe the differences if not the specifics of the above analysis. They describe Easy English as having fewer words, shorter sentences, and use more words they know. They also talk about Easy English having more space on a page. This aids them in accessing the content. They often surprise themselves about how many words they can read and then understand when using Easy English.

Easy English has a maximum of **4 images on a page**, compared with Easy Read, which has an average of 6 images per page. Easy English also uses specific and clear images without extra superfluous content. People who have minimal literacy use the images to understand the content. They want to know what every line or different looking item means in the images. Every line in an image needs to be critically evaluated to determine if it needs to be there.

If an image is used across different topics, such as an image to represent sleep/bed at home it is similar but different enough to look different to represent 'sleep away from home.'

Easy English development uses universal design principles, making it accessible to anyone who has low literacy, irrespective of their diagnosis.

Easy Read often uses photos, usually PhotoSymbols from the UK, as mentioned above, or a set designed by that company, which no one else in Australia or internationally uses or only 1 set of images, which is only known to people who use communication boards.

Research from 2019 identified **Easy Read** writers assume that everyone can read and write to the same level of the people they work with, hence there is no consistency across organisations or between organisations in its development. There are no measurable and repeatable list of check points that writers can match with each other or across organisations. It is unreliable in how it is developed and the people they believe they are writing for. Many people will also say it is only for people with intellectual disability. Based on the photos you often see in most Easy Read development this would be a reasonable assumption. People who do not have an intellectual disability do not relate to the photos of people with intellectual disability, and do not to engage with it. This is supported by the research.

Easy Read developers report they use the same pool of consumers, often in groups to get feedback on their content development. These people become non typical users of easy-to-read information. They get used to the content, the style, the images and photos being used. This does require a level of motivation, cognitive skill and problem solving to interpret. That is **not typical** of most people with intellectual disability or people with acquired disabilities or mental health disability or other disabilities who need to access the NDIS.

Easy English principles ensure consumer reviews occur in 1:1 meetings, with new consumers who do not see themselves as readers. Our team link the topic being reviewed to www.accesseasyenglish.com.au admin@accesseasyenglish.com.au

the motivation or interest of the reader, and their life experience. For example, a document about how to choose a lawyer which discussed lawyers' fees, required people who (1) knew what a lawyer was and (2) would be likely to need to pay for these services and not be using legal aid.

A more typical reader most often has low confidence and self-esteem with their reading and understanding of information. Our Easy English consumer reviewers may only see 2 or 3 documents in a year. New consumers are always being recruited to review Easy English. This continues to improve Easy English development, and does not rely on 'what we have seen before.' It results in better content long term.

As Easy English is simpler for the end user, it will take longer to create than Easy Read. One Australian Easy Read developer, usually commissioned by the NDIS and other federal government departments, describes on their website that Easy Read is plain language with pictures. This is **false**. Nowhere in the world does anyone describe Easy Read as such. Plain language experts do not recognise Easy Read as being anything like plain language.

Department heads and decision makers need to be more aware of these crucial differences and commission what people need.

Digital Inclusion

None of this discussion addresses the enormous issue of digital inclusion for people with low literacy. Digital inclusion is the

- affordability of digital tools such as internet and hardware relative to your income,
- your access to them and
- the extent you can use those digital tools.

So, why is that important?

Firstly, the computer and use of the internet is based in literacy. Knowing that at least 44% of the adult Australian population do **not** have the literacy to manage a range of day to day reading tasks, this added element of using the internet makes this even more challenging for many people.

You need to be able to know about the keyboard, and location of letters on the keyboard, to be able to spell or at least copy letters into the address menu when searching the internet. When you land on a website there are significant skills required to navigate and locate what you may be looking for. It is common to have no phone number readily available on provider or services websites, (or not available at all) instead a chat box or email is the primary means to access that service, which relies on literacy once again. This is discriminatory.

It may appear to professionals who use computers daily, that computer access, use of them and the internet is well developed through all our communities. The data below demonstrates this is certainly **not** the case.

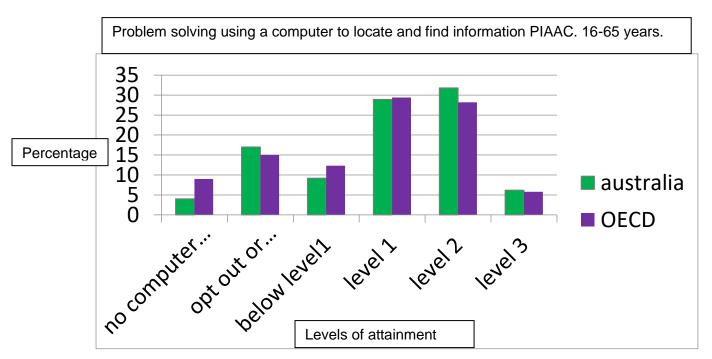
The NDIS policies and processes must address this in how information is disseminated and provided to the community and in particular communities where English is a second language, as there are added challenges and difficulties.

One in five households do **not** have access to computers. Where are these households likely to be? Low socio-economic groups, institutions and disability group homes and other congregate care environments such as forensic units.

Clinical experience has also highlighted that many support staff do not have access to the internet in their own home.

In the work I do with clients providing Speech Pathology services in community residential units (group homes) it is rare to see a computer available to clients there.

During the pandemic, state governments recognised this considerable need for families. They issued laptops and dongles to many families for remote learning. However, being given a laptop and dongle does not equate to having digital literacy.



This graph indicates only two in five people where English is their first language (Level 2 and 3) are able to use the internet at a level of competency to find and locate information, to then use it to work out what they need to do.

This is not sufficient for the many vulnerable people who are meant to be able to access and use the NDIS, and in particular people with English as a second language.

To have low literacy there needs to be an immediate entrance to information that the person can read and use. It is not possible for the person to travel through multiple levels of navigation to locate content.

But this is what the NDIS does expect. The person will have given up. Best practice indicates only one level of navigation, at most, is when you will achieve **some** equity for **some** people in access via the internet.

Studies in 2020⁵ and 2021⁶ weighted aspects such as access, affordability (in relation to income) and digital ability to find what you need, to do what you want on the technology. It is called the Australian Digital Inclusion Index (ADII)

The average ADII in the report at March 2020 was 63 (out of 100). A score of less than 53 (out of 100) was considered to be a low index. In 2021, the average score out of 100 was 67, during the pandemic. However, analysis showed it was the people who already had good internet use who increased their skills. Those who had low or poor digital inclusion scores did not improve at all.

Below is a summary of their March 2020 findings, which was collected in the first year of the pandemic.

- People who were offline more than 2.5 million people;
- People with a mobile only limits data availability 4 million people.

These are more likely to be people who are marginalised and be a significant part of vulnerable communities. There is a likelihood to be more people using pay per use internet access, and availability to the internet is related to cash/income available rather than using an annual subscription service. This is also a more costly way to access the internet than a subscription.

This is the list of groups with a low Digital Inclusion Index.

- House hold income Q5 (under \$35k) and household income Q4 (\$35K- \$60K)
- Aged 65 +
- Less than secondary education
- Disability
- Not in labour force (ADII score 54.3)
- Indigenous Australians (ADII score 55.1).

Australian Digital Inclusion Index <u>https://h3e6r2c4.rocketcdn.me/wp-</u> content/uploads/2021/10/ADII_2021_Summary-report_V1.pdf

⁵ Australian Communications and Media Authority (2020) Measuring Australia's Digital Divide. Australian Digital Inclusion Index 2020. <u>https://digitalinclusionindex.org.au/wp-content/uploads/2020/10/TLS_ADII_Report-</u> <u>2020_WebU.pdf</u>

⁶ Australian Communications and Media Authority (2021) Measuring Australia's Digital Divide.

The October 2021 data did not include anyone from the Northern Territory. It showed that people with high and very high digital inclusion improved. However, those with low and very low digital inclusion stayed the same, The digital inclusion gap is now wider.

There needs to be a print and mailout budget for the vast numbers of people who need to access the NDIS and are unable to due to their digital literacy skills.

Printed content needs to be available in Easy English, and also plain language for some people.

Further submissions

I am attaching several reports previously submitted regarding accessible information for people with intellectual disabilities and other people with low literacy, for your review sent to

- the NDIS,
- the NDIS Quality and Safety Commission
- Disability Royal Commission.

They are

- Appendix 4 NDIS CALD Strategic Development 2023
- Appendix 5 Federal Government Style Guide on Easy Read (2021)
- Appendix 6 Disability Royal Commission re COVID-19 (2020)
- Appendix 7 Disability Royal Commission re Accessibility (2019)
- Appendix 8 EBP Accessible Information analysis NDIS Commission (2019)
- Appendix 9 Stuart Robert MP regarding NDIS (2019)
- Appendix 10 National Disability Strategy 2010-2020 re delivery of outcomes (2017).

I have only ever received a response from my submission to the NDIS CALD Strategic Development (2023) and the Disability Royal Commission re Accessibility (2019).

The 2023 response was from the Prime Minister and Cabinet Office asking to forward the submission to your team. The response to the 2019 Accessibility submissions was to ask me to provide some guidance to the organisation who had been contracted to write the Disability Royal Commission reports.

The Disability Royal Commission hadn't started at that point. As it had never been an open tender for work, and I was not being recompensed for any consultation, I declined. However, the Disability Royal Commission do not appear to have reviewed whether the contractor was fit for purpose and able to provide the service that people with low literacy needed to better understand and participate in the Disability Royal Commission.

Summary of submission

Knowing that 44% of the adult Australian population do **not** have the literacy to manage a range of day to day reading tasks, resourcing needs to be given over to the development of current evidence based best practise Easy English. It has an average reading equivalence level of grade 2.

As discussed in this submission, the NDIS, the NDIS Quality and Safety Commission and related federal government departments and agencies continue to release information in Easy Read; this is not good enough. It is clearly not what the audience needs. It is on average at a reading equivalence level of grade 5. However, much of it requires much higher, more developed literacy skills. The images selected in the Australian Easy Read are specifically of people with intellectual disability. Many other people in the general community who value easy to read content are not going to engage with Easy Read, as they do not see themselves represented in the images.

The NDIS must provide printed copies of content. It should not be left to a small request on a website page that is difficult to locate to request this. And once again this relies on internet access to do this.

It is a reality that the internet and websites are in our community. The NDIS website needs to be redesigned so those who may have some limited digital literacy skills, may be able find the Easy English. It is possible to rethink the navigation and complexity of websites to make them user friendly to this community.

The NDIS needs to commission current evidence based best practice and effective Easy English accessible information for all our community.

Recommendations

- 1. The NDIS must
 - a) review what it is commissioning in accessible written content for people with low literacy, usually called Easy Read.
 - b) consult with experts about quality best practice Easy English, and plan for the NDIS to be the leading provider of quality best practice Easy English.
 Currently it is not.
 - c) develop policies that outline specific requirements and content needed for people with low literacy in all aspects of the NDIS
 - d) develop policies on where printed NDIS information is available and flyers to advertise this availability with phone numbers to request it. It needs to be available in all LACs and all NDIS offices.
 - e) develop policies for the NDIS and its agencies to have simple to navigate websites (one level of navigation) that include content in Easy English.

I would be pleased to discuss these issues with the Chair and Committee.

Cally Bastettetof

Thanks, Cathy

Cathy Basterfield

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