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# Improving Access and Support for Consumers with Cognitive Disabilities

A Guide for Retailers

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## PROJECT PARTNERS



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# INTRODUCTION

It is important that all consumers can access the goods and services that are necessary for participation in modern life. To do this, they need to make choices about the products and services that will be best for them, including essential or basic services like energy, water and telecommunications. These choices and decisions are usually made before the consumer enters into a contract, in the ‘pre-sale’ or ‘pre-contract’ process. Standard pre-sales and pre-contractual processes, as well as processes for getting assistance or dealing with problems with a service, are not currently tailored to the requirements of all consumers, including many consumers with cognitive disabilities.

This document offers guidance to retailers to make their processes and communications more helpful and accessible to consumers with cognitive disabilities, who may have difficulties with learning, concentrating on, processing, remembering, or communicating information, and/or with decision-making.<sup>1</sup> This might include, for example, some people with intellectual disability, Acquired Brain Injury, or dementia, and some mental health service users. Unsuitable information, communication difficulties, stigma, discrimination and social isolation may mean people with cognitive disabilities cannot access the services they want and need. They may not have access to the kinds of support for making decisions that other consumers take for granted. Salespeople and other staff might have legitimate concerns about invading a consumer’s privacy or being discriminatory if they ask disability-related questions or suggest extra assistance or support. Consumers with cognitive disabilities may also encounter barriers to resolving problems with their product after the contract is made, such as problems in paying their bills or what to do if the product doesn’t work.

Service providers must work towards improving access to suitable and appropriate services for all consumers, including consumers with disabilities. This not only avoids unfair or discriminatory conduct, but also helps ensure that all people can live in the community and choose how they organise and run their lives. Improving access in this way requires thinking carefully about the processes used by an organisation at the pre-sale and pre-contractual point, and during the life of a contract.

This resource was developed in 2018 by a research team at the University of Melbourne, supported by the Melbourne Social Equity Institute, with funding provided by seven members of the Thriving Communities Partnership (Telstra, Yarra Valley Water, City West Water, South East Water, EnergyAustralia, Origin and AGL). It presents detailed, practical guidance for organisations, hardship/vulnerability teams and frontline staff to alter their pre-contractual and problem-solving processes to improve access to services and assistance for consumers with cognitive disabilities.

The guidance materials are based on existing research, detailed legal analysis, and the findings from two focus groups with nine people with cognitive disabilities conducted in September 2018. Expert advice was also supplied by a project advisory board, comprising representatives from the seven partner organisations, the Consumer Action Law Centre, the Energy and Water Ombudsman Victoria, Voice at the Table and the University of Melbourne.

The guidance focuses on three mechanisms for improving accessibility and support:

1. Identifying consumers' access and support requirements in a **non-discriminatory** manner, meaning creating processes that do not lead to a denial of service or other unfavourable outcome on the basis of a person's disability or impairment.
2. Improving the **accessibility** of communication and assistance within organisations by improving access to specialist problem-solving teams, enhancing the capacity of staff to meet diverse communication needs, and introducing processes for slowing down and taking the pressure off consumers.
3. Recognising and facilitating **supported decision-making**. Supported decision making occurs where a person chooses to use informal support from a trusted person or group of people, or formal support mechanisms such as a legally-appointed advocate, when they are making a decision. Service providers can facilitate supported decision-making by ensuring that supporters are recognised and included in processes at the consumer's request, and providing accessible and timely information.

Some service providers are already required by law to follow certain procedures and disclose certain information in contracting with consumers. The guidance offered here is consistent with those requirements and can be incorporated into service providers' existing systems.

# KEY PRINCIPLES FOR IMPROVING PROCESSES AND OUTCOMES

## Introduction

This section outlines the key principles underpinning better access to pre-contractual and problem-solving processes for consumers with cognitive disabilities. These three interrelated principles – non-discrimination, accessibility and supported decision-making – arise from the human rights enshrined in the *United Nations Convention on the Rights of Persons with Disabilities* as well as Australia’s domestic law and policy.

## Non-discriminatory processes and access to services

Pre-contractual and problem-solving processes must not be discriminatory towards consumers with cognitive disabilities. Non-discriminatory processes are processes that are designed in such a way that all consumers are treated equally favourably regardless of actual or perceived impairment or disability.<sup>2</sup>

Article 5 of the *United Nations Convention on the Rights of Persons with Disabilities* prohibits ‘all discrimination on the basis of disability’.<sup>3</sup> Disability discrimination occurs when a person is treated less favourably than they otherwise would be because they have, or are presumed to have, a disability or impairment. This includes both treatment that is explicitly discriminatory and treatment that has the effect of discriminating.<sup>4</sup>

In Australia, the *Disability Discrimination Act 1992*, which is a Commonwealth statute, establishes that discrimination on the basis of disability is unlawful in many areas of life, including accommodation, employment and the provision of goods and services.<sup>5</sup> Discrimination can be either ‘direct’ or ‘indirect’.<sup>6</sup> Direct discrimination occurs when a person with a disability is treated ‘less favourably’ in the same circumstances than someone who does not have the same disability.<sup>7</sup> Indirect discrimination occurs when a discriminator requires compliance with a condition with which a person with a disability is not able to comply, and so suffers a disadvantage.<sup>8</sup> For example, a post office that requires people to show a driver’s licence before they can collect an item would be indirectly discriminating, because people who are ineligible for a driver’s licence due to low vision, or for other impairment- or disability-related reasons, could not comply.<sup>9</sup> It is not unlawful to discriminate in the provision of goods and services if avoiding discrimination would cause ‘unjustifiable hardship’ for the service provider.<sup>10</sup>



Requests for information about a person's disability, or requests for information only made to people with disabilities, are unlawful if they are collected for a discriminatory reason.<sup>11</sup> It is also discrimination to deny a person with a disability a 'reasonable accommodation' or 'reasonable adjustment', including an adjustment that would allow them to comply with a requirement or condition.<sup>12</sup> Reasonable accommodations may include providing accessible information, modifying equipment and facilities, and enabling access to support.<sup>13</sup>

An act that constitutes discrimination will not be unlawful if it is part of a 'special measure'. A 'special measure' is an act that is intended to improve equality of opportunity for people with disabilities, including in accessing goods and services.<sup>14</sup>

It is important to note that each state and territory also has its own discrimination laws. While most of the state law is similar in content to the *Disability Discrimination Act*, there are some inconsistencies. For example, in some states discrimination occurs when a person with a disability is treated 'less favourably' than others, whereas in other states it is when a person with a disability is treated 'unfavourably'.<sup>15</sup> For this reason, it is important to be familiar with specific state legislation.

## The risk of discrimination in relation to decision-making

Practices and processes that draw a line between people who are capable, and people who are not capable, of making one or more decisions on the basis of disability or impairment are discriminatory. Such processes usually rely on generalisations and erroneous beliefs about the decision-making abilities and 'mental capacity' of people with cognitive disabilities. Assessments of a person's decision-making ability are also frequently based on a false assumption that it is possible to 'accurately assess the inner-workings of the human mind' and draw a meaningful line between capacity and incapacity to make decisions.<sup>16</sup> In reality, some people with cognitive disabilities may have trouble with consumer decision-making, while others may not. Some people may have trouble with some types of decisions, but not others.

Focusing on a person's actual or perceived impairment or disability has many negative consequences. It perpetuates the stigma often associated with cognitive disabilities, reinforcing the idea that people with cognitive disabilities are inherently less able to make choices and have control over their own lives. It also shifts attention away from the many social barriers to participation in consumer processes by people with cognitive disabilities, such as inaccessibility, lack of support, and discrimination itself.

Non-discriminatory processes will avoid intrusive and unnecessary inquiries about a person's impairment or disability, and instead focus on identifying and removing the barriers to a consumer's understanding or decision-making. These processes will also preserve consumers' privacy and facilitate access to supported decision-making which, as outlined in more detail below, is a practical way to assist people with cognitive disabilities to make decisions on the basis of their preferences.

## Accessibility and non-discrimination

Equality and non-discrimination also require businesses and individuals to ensure accessibility of products and services, information, technology, and the built environment.<sup>17</sup> Accessibility of information is particularly important for the enjoyment of legal capacity (discussed in detail in the next section), as it allows people with disabilities to make informed decisions when choosing and contracting for services.<sup>18</sup>

The duty to provide accessibility is an ‘ex ante’ duty, meaning that accessibility must be provided for people with disabilities regardless of whether someone has requested access.<sup>19</sup> The duty to provide reasonable accommodation is an ‘ex nunc’ duty, meaning it applies when it is requested by an individual.<sup>20</sup>

Non-discriminatory processes will prioritise accessibility for all, including consumers with cognitive disabilities. They will create opportunities throughout the pre-contractual and problem-solving process for consumers to flag accessibility issues, and ensure that personnel, materials and other resources are available to address them.

## Supported decision-making

Another element of accessible and inclusive processes is the recognition and facilitation of supported decision-making. Supported decision-making refers to a process where support is provided to a person to express their preferences and make a decision.<sup>21</sup> While decision-making skills may vary from person to person, all people have the right to make their own decisions and be recognised as legal actors.<sup>22</sup>

The right of all people, including all people with disabilities, to the enjoyment of legal capacity and to the support necessary to exercise that capacity, is enshrined in the *United Nations Convention on the Rights of Persons with Disabilities*.<sup>23</sup> The term ‘legal capacity’ refers to a person’s legal standing and ability to act within the framework of the legal system.<sup>24</sup>

The concept of supported decision-making arose as a response to the assumption that some people – especially people with cognitive disabilities – *do not* have the legal capacity to make their own decisions, especially legal decisions. This was due to the misconception, outlined above, that a person’s lack of ‘mental capacity’ (decision-making skills) justifies the denial of their ‘legal capacity’.<sup>25</sup> This misconception means that many people were – and continue to be – deprived of legal capacity because they have been diagnosed with a disability or impairment, or because they are deemed to lack the necessary mental capacity to make decisions. In these circumstances, a ‘substitute’ decision-maker, such as a guardian, decides on the person’s behalf. This removes the person’s decision-making power, giving priority to another individual’s assessment of the person’s ‘best interests’ rather than the person’s own will and preferences.



Supported decision-making is based on principles of ‘self-determination’, ‘accessibility’, and ‘will and preferences’.<sup>26</sup> In the context of decision-making, self-determination means that people with disabilities not only have a right to make their own decisions, but also to decide if they would like support to make those decisions. Accessibility recognises that access to support should not be restricted by a person’s finances, mode of communication or type of disability. The focus on will and preferences means that the purpose of support is to recognise and follow a person’s self-determined preferences, and not impose the supporter’s own views.

Supported decision-making has many benefits. It helps promote people’s rights and dignity, facilitates social and economic participation, and ensures that people’s voices are heard and respected.<sup>27</sup> More practically, supported decision-making can help people develop their decision-making skills and make decisions that accord with their needs and financial circumstances. People who have the support they require to make decisions are more likely to be happy and satisfied with their choices and to feel that they have control and agency in their lives.<sup>28</sup> Better decision-making experiences also have the potential to reduce consumer dissatisfaction and problems relating to financial hardship.

# GUIDELINES FOR MAKING FAIR AND EQUITABLE SUPPORT PROCESSES

## Introduction

This section presents a series of guidelines for frontline staff, hardship and vulnerability teams, and/or management to implement the principles outlined above and improve pre-contractual and problem-solving processes for consumers with cognitive disabilities. The guidelines are divided into three themes: identifying consumers' support and accessibility needs in a non-discriminatory manner; making space for supported decision-making; and supporting consumers through clear communication and assistance.

## Guideline A: Identifying accessibility and support needs in a non-discriminatory manner

Service providers should amend their processes to make inquiries about accessibility and support a standard practice and ensure that accessibility of information, communications and services is integrated as a matter of core business. Implementing the following guidelines can ensure that processes for identifying and referring people who would benefit from accessibility or support measures are non-discriminatory. This includes ensuring that privacy is protected, providing information in accessible formats, and offering products and services to meet a range of requirements.

### **1. ASK EVERYONE THE SAME THING**

- It may not be obvious that someone has a cognitive disability. Many people face challenges accessing consumer information and making decisions, especially for expensive transactions or complicated service offerings. Consequently, a range of consumers are likely to benefit from general questions about accessibility and support.

**2. ASK GENERAL QUESTIONS**

- You don't need to ask about a person's disability or impairment directly.
- Instead, you should ask general questions to find out what support, assistance and accessibility measures the consumer wants or needs. For example:
- 'Do you want to take some time and talk to someone you trust?'
- 'Is there someone (like a family member or worker) you would like to help you understand the information/pick a service/communicate with the retailer/manage your bill?'
- 'Is there anything I can do to help you access this information, service, product or conversation?'
- 'We have some written information and/or audio-visual information that makes this easier to understand. Would you like to see it?'

**3. EXPLAIN THE REASON FOR ASKING – AND ONLY USE THE ANSWER FOR THAT REASON**

- Some consumers might be worried about their privacy, or they might be concerned that they will be denied access to the service if they answer your questions or disclose their disability or access requirements.
- DO explain that you are asking the questions so that you can help the person get the right service for them, help solve their problem, etc.
- DO NOT deny someone a service on the basis of the answer they give. Everyone has a right to make their own decisions, even if those decisions seem risky or sub-optimal to you or any other person.

**4. ASK FOLLOW-UP QUESTIONS WHERE APPROPRIATE**

- Some consumers might appear in a way that raises concerns about their need for support. This might include appearing disoriented and confused, being unable to have a coherent conversation, appearing unable to remember or understand information, appearing unable to concentrate, or being accompanied by a carer or other person who speaks over the consumer.<sup>29</sup>
- DO ask follow up questions in this situation.
- DO use the communication strategies set out below (see guideline C3).

## **5. ENSURE THE PERSON'S PRIVACY IS PROTECTED**

- If a consumer tells you about their particular impairment or disability diagnosis, ask if it is okay before you share that information with colleagues, and what parts of that information are okay to share (for instance, that they have a mental health issue, but not the specifics of the diagnosis).
- If a consumer is referred to another department or service, ensure their privacy is protected.
- DO explain the reason for the referral to the other department or service – for example, that the person is having difficulty understanding the contract, is worried about whether they can afford the service, or would like to access additional information for certain products and services.
- DO NOT disclose private information unless you have the consumer's permission.
- Do not record private or irrelevant information about consumers on their files.
- DO clearly note a person's requests for Easy English descriptions, inclusion of a nominated support person or support service in conversations, or other requirements.

## **6. DO NOT ASSUME THAT EVERYONE HAS THE SAME ACCESS TO RESOURCES**

- Many people do not have access to the internet, and many websites and apps are not accessible to people with disabilities, including people with cognitive disabilities.
- DO make paper bills available to consumers who prefer them, free of charge.
- DO NOT assume that everyone has access to the internet, or can use apps or online portals to manage their accounts, monitor their usage, pay their bills, or interact with your organisation.
- DO NOT assume that direct debit payments will suit all consumers.
- DO ask the consumer relevant questions about their access to necessary resources. For example, if consumers are required to pay bills or manage their accounts online, it is important to ask, 'do you have a smartphone?', 'do you have access to the internet?', 'do you pay your bills online?', 'can I assist you with how to use our app?' and so on.

## **7. PROVIDE INFORMATION (INCLUDING WEBSITES) IN EASY-TO-READ, ACCESSIBLE FORMATS**

- All sales, contract and service information should be provided in easy-to-read formats, such as Easy English.<sup>30</sup> Easy-to-read documents deliver information with simple words and short sentences. Pictures and photographs are often used to reinforce the meaning of short sentences.<sup>31</sup>
- DO refer to guidance such as Scope Australia's guidelines on producing Easy English documents and the Melbourne Social Equity Institute's toolkit of resources for telecommunications suppliers to improve the accessibility of their information and ensure that consumers have access to assistance and support.<sup>32</sup> It is also crucial to consult with paid experts (people with cognitive disabilities) to provide drafting advice and test the accessibility of documents.
- It may not be possible to simplify complex or legally-mandated documents such as Critical Information Summaries. In these circumstances, it is still useful to prepare an easy-to-read summary of the information, which can then be read alongside the full version with the assistance of a supporter.
- DO make bills easier to read.
- If you issue separate bills for different services, consider using different colours or other distinctive features to make it easier for consumers to differentiate between them. Different colours should be pronounced (not subtle). Use different colours for final notices, but consider avoiding colours like red that might cause more stress or panic. Also avoid colours that are difficult for people with atypical colour perception ('colour-blindness').
- DO use images on bills, for example to indicate which number to call if a consumer is having trouble paying.
- DO make sure the phone number for the 'hardship' or support team, and other important numbers, are not hidden. Use large, bold font. Avoid using abbreviations like 'Acc No.'
- DO make it easy for people to get in touch, especially in times of crisis. For example, placing the support team phone number in large font on the back of a final notice envelope could make it easier for consumers to seek assistance during a difficult time.
- DO send friendly text messages to let consumers know there is a bill to pay. For example, send a first message when the bill has been sent, and a follow-up message after the due date (if necessary).

## **8. MAKE SURE YOUR BUSINESS IS ACCESSIBLE IN OTHER WAYS**

- DO remember that some people have multiple impairments or disabilities. This means physical environments, information and communication must be accessible to all. This requires, for example, documents that can be read by a screen-reader, wheelchair accessible buildings, and availability of sign language interpretation.
- DO NOT rely on automated phone systems as they are not accessible to people who use alternative or non-verbal forms of communication. Always ensure that an alternative to an automated system is available and easily accessible. Remember that some people's communication needs and preferences will be best served in-person.
- Information delivered in audio or video format may be clearer and more accessible for some people.
- DO make key information available in video format, with narration and captions included. The World Wide Web Consortium (W3C) Working Group provides detailed guidance on making accessible videos.<sup>33</sup>
- In the online environment, it is also important to make webpages uncluttered, avoid long sentences and paragraphs, and provide image descriptions.<sup>34</sup> The W3C Web Accessibility Initiative provides more detailed information on how to make web content accessible for persons with cognitive disability.<sup>35</sup>

## **9. OFFER A RANGE OF PRODUCTS THAT WOULD SUIT DIFFERENT NEEDS AND ACCESSIBILITY REQUIREMENTS**

- Products and services should be suitable and accessible to all consumers. This may require, for instance, having basic or 'vanilla' products that are straightforward and easy-to-use.
- DO assess the accessibility of your products and services for all, including consumers with cognitive disabilities.
- DO consult people with cognitive disabilities, and their representative organisations, on the design or adaptation of products or services.
- DO give consumers information about any concessions that they might be entitled to.



**10. AVOID THE LANGUAGE OF 'VULNERABILITY'**

- Terms like 'vulnerability' and 'disadvantage' are often used to identify and describe consumers who are at higher than usual 'risk of detriment' due to personal factors, such as age, disability, low literacy, or family status.<sup>36</sup> It can also refer to temporary circumstances such as unemployment, illness, being impacted by family violence, or being impacted by a natural disaster.
- This language may be unhelpful for people with disabilities because it places the focus on an individual's deficits, implying that there is something inherently different and disadvantaged about them.
- DO shift the focus away from individual impairments and onto the social and structural changes that can be made to improve access for all. These changes include the recognition of supported decision-making and implementation of universal accessibility discussed in these guidelines. This can also be thought of as a 'rights-based' or facilitative approach.
- For example, rename your vulnerability or hardship team 'the universal access team' or the 'customer support team'; refer to 'customers with disabilities' or 'supported customers' rather than 'vulnerable customers'.

## Guideline B: Making space for supported decision-making

Processes should also make space for supported decision-making. This means treating supported decision-making as the norm (while accepting a consumer's right to make their own decisions), having clear processes for listing and including supporters in pre-contractual and problem-solving discussions, and making sure staff are aware of key supported decision-making principles, such as the consumer's right to choose their own supporter and to proceed on the basis of the consumer's will and preferences.

**1. ASK ABOUT SUPPORT (BUT DON'T REQUIRE IT)**

- DO ask all consumers if they would like some time to think or talk with someone they trust before making a decision (see guideline A2 above for further suggestions).
- DO remember that people have a right to take risks and make mistakes.<sup>37</sup>
- DO remember that some people will not have a person in their life to provide support; in that case, taking extra time to assist the person and providing accessible information, and referring them to support or advocacy groups (see the list in Attachment A) can be particularly helpful.
- DO NOT refuse to serve someone if they decline to use support.
- DO remember that everyone can be supported – while supported decision-making has tended to focus on people with disabilities, any and all consumers might find these processes useful.<sup>38</sup>

**2. DO NOT MAKE ASSUMPTIONS – WITH ONE EXCEPTION**

- DO assume that every consumer has the ‘knowledge, experience, ability and willingness to lead his or her own life’.<sup>39</sup>
- DO NOT make any other assumptions about them.<sup>40</sup>

**3. ENSURE PEOPLE ARE CHOOSING THEIR OWN SUPPORT**

- Supported decision-making can only take place where the person is supported by a person or people of their choice.<sup>41</sup>
- DO NOT impose support where it is unwanted (even if the supporter is the person’s family member, friend or carer) – this is not supported decision-making.<sup>42</sup>
- DO be aware of the possibility of undue influence, for example, where there are ‘signs of fear, aggression, threat, deception or manipulation’.<sup>43</sup> These are also signs of financial abuse.
- If you think that a consumer is being manipulated by a support person, escalate the issue to your supervisor or other senior member of staff. Make sure staff have access to a range of information for people who may be experiencing financial abuse, such as the Federal Government’s MoneySmart guide, and elder abuse helplines, available at: <https://www.moneysmart.gov.au/life-events-and-you/families/financial-abuse>.

**4. ALLOW CONSUMERS TO LIST A SUPPORT PERSON ON THEIR ACCOUNT**

- It is important for consumers to have the option of listing a family member, friend, guardian or support worker on their account, so that someone else can make inquiries or pay bills on the consumer’s behalf.
- DO make this option available at any time (and through mail, phone or website contact), not just at sign-up.

**5. ENSURE THAT GUARDIANSHIP AND OTHER FORMS OF SUBSTITUTE DECISION-MAKING ARE ONLY USED AS A LAST RESORT**

- Some consumers might have a legally appointed substitute decision-maker, such as a trustee, guardian or power of attorney.
- DO remember that substitute decision-making should only be used as a last resort. It is often possible and appropriate to prioritise the will and preferences of the person even where a substitute decision-maker is involved.<sup>44</sup>
- DO seek advice and guidance from the relevant State or Territory body, such as Offices of the Public Advocate/Guardian or State/Public Trustee.<sup>45</sup>

# Guideline C: Supporting consumers through clear communication and assistance

Improving the capacity of staff to communicate with consumers and provide assistance in a clear and helpful manner can further facilitate consumers' decision-making and their ability to solve problems.

## **1. ENSURE THERE IS A DEDICATED PERSON OR TEAM IN CHARGE OF ASSISTING CONSUMERS WHO REQUIRE OR REQUEST EXTRA SUPPORT**

- DO ensure that a dedicated person or team with experience and autonomy is available to support consumers with cognitive disabilities and others who require or request support.
- There should be a clear and straightforward pathway for all staff to refer consumers to this person or team for issues and complaints, and staff should be made aware of this pathway.
- This support will likely reach more consumers through an outreach program such as participating in a 'bring your bills' day. These initiatives are more likely to be successful when they draw on good relationships in the community, when it is clear to attendees that the service is free of charge, and when organised in collaboration with a trusted organisation such as an Ombudsman, community legal centre, financial counselling service or other advocacy group. Attachment A includes a list of community and advocacy organisations who currently work with and for the disability community.
- DO ensure that all staff (not just those in the support team) receive training on supported decision-making and the rights of all consumers, including those with cognitive disabilities, to access services and enter contracts.

## **2. SLOW DOWN THE CONVERSATION AND THE PROCESS**

- For many people, communicating with salespeople or other retail staff can be intimidating or difficult. Large volumes of information, especially if the information is technical, can be daunting. This information may be unclear and inaccessible for consumers.
- One way to address this is to slow down the sales process and other interactions.
- DO adjust your communication to suit the person and the situation. (See guideline C3, below, for more information about accessible communication styles.)
- DO take the time to listen and understand.<sup>46</sup> For example, when consumers clearly state the amount of money they can afford to pay each week, do not ignore that information.

- DO ensure that you are not pressuring the person to make a particular decision.<sup>47</sup> Remind the person that they have options, and they do not have to decide right now.
- DO clearly explain any cooling-off periods that apply to the product or service.
- DO suggest sources of additional information, such as video guides, easy-to-read product information, or easy-to-read consumer guides published by the ACCC, CAV and other organisations.<sup>48</sup> (See guideline A7, above, for more information about accessible document formats.)

### **3. ADJUST YOUR COMMUNICATION TO SUIT THE PERSON AND THE SITUATION**

- Clear, concise and respectful communication is important for all consumers.<sup>49</sup> Personal and professional experience will mean staff already have many skills in this regard.
- In situations where you have concerns about a consumer's understanding, you should always try to enhance their understanding before you question or challenge their ability to make a decision.<sup>50</sup> Adjusting your communication is one way to do this.
- DO address the consumer directly, even if a supporter, family member, carer, interpreter or other person is present.<sup>51</sup>
- If appropriate, ask the consumer how they prefer to communicate with you.<sup>52</sup> Keep in mind that some communication barriers would be best addressed through the use of an interpreter.
- DO recognise multiple modes of communication. For example, some people might use a communication board or electronic device.<sup>53</sup>
- DO always try to enhance a person's understanding before you question or challenge their capacity to make a decision.<sup>54</sup>
- DO be patient and considerate when dealing with all consumers, especially when they are under stress or experiencing a crisis. Pressure, aggression, or lack of empathy can worsen people's circumstances, cause further stress, and make it less likely that they will engage with you.

# Tips for improving your communication and enhancing understanding

- ✓ ask the person about their communication preferences, and then attempt to communicate in their preferred way
- ✓ speak slowly, and generally slow down the pace of the conversation<sup>55</sup>
- ✓ speak in clear, short sentences<sup>56</sup>
- ✓ simplify, reorganise or rephrase information to clarify your meaning<sup>57</sup>
- ✓ break down complex information into small pieces<sup>58</sup>
- ✓ revisit or repeat key information<sup>59</sup>
- ✓ 'ask one question at a time'<sup>60</sup>
- ✓ avoid slang, jargon and technical terms<sup>61</sup>
- ✓ use the consumer's own words if useful<sup>62</sup>
- ✓ provide a real-life demonstration (e.g. demonstrate how the product works)<sup>63</sup>
- ✓ avoid abstract concepts (like time or money), or explain them clearly when you need to use them<sup>64</sup>
- ✓ go through written material together (see guideline A7, above, for more information on accessible written documents)<sup>65</sup>
- ✓ write down key points if the consumer says this will be useful<sup>66</sup>
- ✓ use photos, charts or diagrams if they are available<sup>67</sup>
- ✓ offer to take a break<sup>68</sup>
- ✓ move to an area with less noise or distractions<sup>69</sup>
- ✓ test understanding by asking questions, asking the person to repeat things in their own words, or other tactics described above; never simply ask 'do you understand?' – people might automatically say 'yes' to this question<sup>70</sup>
- ✓ don't ever pretend to understand if you don't; if you can't understand what the consumer tells you, ask them to repeat or say it in a different way, then (if appropriate) ask for someone to interpret<sup>71</sup>

**4. AVOID UNFAIRLY INFLUENCING THE CONSUMER**

- If calling a consumer on the telephone, ask them if they are in a good place to talk, and if they have the time to talk now.
- Avoid nodding or smiling to influence the consumer's choice.<sup>72</sup>
- Present all relevant and viable options and alternatives to the consumer.<sup>73</sup>
- Provide recommendations (if appropriate) but do not persuade.<sup>74</sup>
- Use clear, consistent parameters for comparison – for example, give the pros and cons of each option.<sup>75</sup>
- DO remember that the decision-maker is always in control.<sup>76</sup> Trying to convince the decision-maker to change their will and preferences takes away their control and defeats the purpose of supported decision-making.<sup>77</sup>
- If engaging in 'cross-selling,' take extra care to listen to the wants and decisions of the consumer. Make sure that you offer them a product that would suit them, and do not persist if they say no.
- Avoid sales techniques, such as door-to-door and unsolicited sales, that pressure consumers. They can cause harm to consumers and are more likely to have negative consequences for people with disabilities, elderly people, Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse backgrounds.<sup>78</sup>



# FOCUS GROUPS: TESTING AND IMPROVING THE GUIDELINES

## Introduction and background

### PURPOSE AND AIMS

The guidelines outlined above were initially formulated by reference to existing research (including a 2016 pilot study exploring the experiences and support requirements of consumers with cognitive disabilities),<sup>79</sup> legal analysis, and input from the project partners and advisory board. We then held focus groups in order to seek the opinions of people with cognitive disabilities about how to improve service providers' processes, and to explore whether people with cognitive disabilities thought the guidelines were appropriate and useful.

The aims of the focus groups were:

1. to create a forum for people with cognitive disabilities to identify necessary changes to processes and practices;
2. to enable an in-depth discussion and exploration of the forms of support for consumer transactions that we identified in the earlier pilot study; and
3. to focus on what the participants thought was needed to make their interactions with service providers easier and better.

The key research question was

*What processes and practices are necessary to enable service providers to identify and support consumers with cognitive disabilities to enter consumer transactions for their services?*

## METHOD

A participatory, human-rights based research methodology informed the design and conduct of the focus groups.<sup>80</sup> The focus groups were conducted with the purpose of advancing the rights of people with cognitive disabilities and were co-facilitated by a consumer researcher (a person with lived experience of mental health services). The focus group discussions were designed to be sufficiently open-ended to enable participants to raise issues that mattered to them – including issues that were not previously identified by the research team – and to advise the research team on the appropriateness and relevance of their prior work.

Two focus groups of between three and six people with cognitive disabilities were conducted in September 2018. The focus groups were facilitated by the project's Research Fellow, Dr Yvette Maker, and co-facilitator Ms Vrinda Edan who has extensive experience as a mental health consultant and consumer researcher.

The focus groups were structured around five scenarios based on examples of consumer issues reported by the partner organisations and advisory board members. Each scenario set out a problem or issue facing a hypothetical consumer, and a series of process changes (based on three or four of the guidelines outlined above) that could help address the problem or issue. Participants were asked to consider each element of the scenarios, to indicate if they liked or disliked each suggestion for process improvements, and to suggest other problems or ideas that were not addressed in the scenarios.

## The five scenarios

### SCENARIO 1: ALISON'S STORY

Alison uses the same company for gas and electricity. She got one bill for her electricity, and one for her gas. She was confused and paid the electricity bill twice. She meant to pay the gas bill. Alison got lots of letters in the mail telling her to pay her gas bill. She ignored the letters because she thought she had already paid. One of the letters was a final notice. Alison's gas service was cut off.

#### *Our ideas for Alison*

- Send electricity and gas bills that are different colours. This will make it easy for Alison and other consumers to tell the bills apart.
- Alison might find it useful to ring the company to ask for help. Make sure the support phone number is clearly marked on each bill.
- Think about having a 'bring your bills' day in Alison's local community. This is where people from the electricity and gas company can help people like Alison to understand their bills and ask questions.

- Use Easy English principles when designing bills or 'how to read your bill' guides. This will make them easy for everyone to understand. For example:
  - use short sentences that only have one idea;
  - avoid technical language or jargon;
  - put important information in large plain font; and
  - use lots of white space.

## SCENARIO 2: SUZIE'S STORY

Suzie works at a gas company. Suzie answers a customer service call from Ahmed. Ahmed says that he has received a very expensive gas bill. Suzie asks him lots of questions about the bill. She asks what his customer number is. She asks why he has been using so much gas. Ahmed doesn't seem to understand the questions.

### *Our ideas for Suzie and Ahmed*

- Suzie should slow down. She should speak in clear, short sentences. She should not use technical language or jargon.
- Suzie should ask Ahmed questions about how he has been using appliances like heaters or the stove. She could ask whether Ahmed has had something happen in his life that might explain his increased usage, such as:
  - being sick or going to hospital;
  - having new caring responsibilities; or
  - losing his job.
- Suzie should break all information into smaller pieces. For example, if there are three things that Ahmed needs to know, list them. Suzie could say, 'The first thing to know is...the second thing to know is... the third thing to know is...' etc. Go back to the important information by listing the three things again.
- Suzie should ask Ahmed if he usually gets help to make decisions. Tell Ahmed about the help that the company can give. For example:
  - put Ahmed's call through to the support team;
  - offer to call a person who will support him; and
  - tell Ahmed he can choose his own support if he wants it.
- Suzie should offer to give Ahmed information in another format. For example, offer to send him Easy English information about understanding his bill. An 'Easy English' section on the company's website that has information about how to get support or help with bills might be helpful.

### SCENARIO 3: ISHITA'S STORY

Ishita comes into a mobile phone shop with her support worker, Richard. Lee is working at the shop. Ishita tells Lee she wants a new mobile phone. Ishita tells Lee that she wants to buy an expensive mobile phone handset with lots of calls and data. Richard seems worried about how much it will cost.

#### *Our ideas for Ishita, Lee and Richard*

- Lee should make sure he talks to Ishita, because she is the customer. He should also include Richard in the conversation.
- Lee should focus on finding out what Ishita wants and needs. Lee could ask Ishita what she wants to use the phone for. For example, Lee could ask Ishita whether she would like to use the phone to:
  - make calls;
  - send messages;
  - watch TV or movies;
  - play games;
  - look at websites.
- Lee should listen out for what Ishita wants, and not what Richard thinks she needs.
- Lee should make sure he tells Ishita and Richard about lots of different products and prices. This will help Ishita make an informed choice, with Richard's support. For example, Lee should tell them about the expensive, cheap and mid-range products that are available.

### SCENARIO 4: REBECCA'S STORY

Rebecca has moved into a new house. She rings up to sign up for a new electricity plan. The salesperson on the phone tells Rebecca that she can manage her account, look at how much power she has used, and pay her bills using the new mobile phone app. Rebecca isn't sure she will be able to use the app.

#### *Our ideas for Rebecca*

- The salesperson should ask Rebecca questions one at a time. For example:
  - Do you have internet access?
  - Do you have a smartphone?
  - Do you use apps?

- The salesperson should ask Rebecca if she has had an account and bills in the past. Did she get bills in the mail? Or on the web? Ask if Rebecca has any problems or issues with that way of doing things. Give Rebecca useful information about the best option for her.
- Do not assume that Rebecca has access to the web. Tell Rebecca about the other ways she can manage her account. For example, she can call customer service and tell them her customer number.
- Ask Rebecca if there is anything else that would help, such as:
  - Getting information about her options in writing,
  - Getting a support person listed on her account who can also make inquiries or use the app.
- Show Rebecca how to use the app. Describe how to download it, open it and use all the features. This might take some time, so be patient.

### SCENARIO 5: JUAN'S STORY

Juan is in crisis and the bills are piling up. Mail keeps coming but he can't bring himself to open it. His water bill was due a few months ago, but he hasn't paid. The water company has tried to call him and sent him some letters. Juan does not answer the phone calls, and his water company is not sure he received the letters.

#### *Our ideas for Juan*

- Put the phone number on the back of the bill envelope. Put a note on the envelope that says, 'If you are worried about this bill or have any questions, please call us on 03 5550 3661'. This will make it easier for Juan to get in touch, even if he is not opening his mail.
- The phone number should go directly to people who have been trained to be friendly, supportive and focused on problem-solving. For example, the dedicated support or 'hardship' team.
- Send Juan a polite text message that gives him the contact number of the support team. For example, 'A friendly reminder from Water Company that your water bill is due. Call 903 5550 3661 if you need help paying this bill. Please ignore this message if you have already paid.'
- When Juan, or any other customer, opens a new account, invite them to pick a friend, family member or other supporter. A supporter is someone who is listed on your account. It should be someone you are happy to:
  - Call the company if you cannot call yourself,
  - Get calls or mail from the company about your account.

## **PARTICIPANTS**

The inclusion criteria for participating in the focus groups were that each participant was aged 18 or over, lived in Victoria, and self-identified as experiencing ‘challenges with cognition (e.g. concentrating, learning and remembering) and/or your mental health’.

Participants were recruited using purposive sampling with assistance from Mind Australia (Mind) (a not-for-profit community mental health support service). Mind was selected because it is a leading organisation that provides support to persons with cognitive and psychosocial disabilities, with close ties to the University of Melbourne. An Information Flyer was provided to Mind and distributed to its services in Victoria.

This recruitment process did not initially yield enough participants. To generate further interest, the research team posted an electronic version of the information flyer on the social media pages of the Melbourne Social Equity Institute (including Facebook and Twitter).

Nine people participated in two focus groups at the Melbourne Social Equity Institute’s offices in Carlton. The participants ranged in age from 33 to 63. Seven participants were female and two were male. Participants reported that they had been diagnosed with one or more conditions or disabilities including Acquired Brain Injury, intellectual disability, learning difficulties, Bipolar Disorder, Depression, and Tourette Syndrome.

## **DATA ANALYSIS**

The focus groups were recorded and transcribed by a professional transcription service. The research team used the NVivo qualitative analysis software to organise and code the data according to its content and themes. The analysis was conducted by the team member who conducted the focus groups. Cross-checking of coding and themes was conducted by another team member to ensure the analysis was credible.

The analysis took the form of a content analysis, meaning ‘a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns’.<sup>81</sup> A combination of conventional content analysis and directed content analysis was used, whereby data was read multiple times, and codes were derived from the data without preconceived notions of what would arise (conventional content analysis) and from the scenarios and areas of interest previously identified in the study (directed content analysis). A general inductive approach was taken when writing up the analysis, which involved summarising the data and drawing clear links between the summary findings and the aims and objectives of the project.<sup>82</sup> Once preliminary results from the focus groups were summarised, they were checked for accuracy by requesting members of the focus groups to review them.



## ETHICAL CONSIDERATIONS

Ethics approval was obtained from the University of Melbourne. A range of ethical considerations were taken, some of which were designed specifically to ensure that the communication and support requirements of people with cognitive disabilities were met.

People with cognitive disabilities are often considered to be ‘difficult’ to engage as research participants.<sup>83</sup> This has traditionally limited their involvement in research. However, it is crucial that the experiences of people with cognitive disabilities are heard and included, especially on matters that directly affect their lives.<sup>84</sup>

Currently, there are no universal guidelines or practices for ensuring a guarantee of informed consent with participants with cognitive disabilities, who may traditionally have been considered unable to provide informed consent. The research team was mindful that a prospective participant’s individual ability to provide consent might vary depending on the nature of the individual’s disability or impairment and any medication or treatment they may be receiving.

However, people with disabilities are experts regarding their own abilities and, as the *United Nations Convention on the Rights of Persons with Disabilities* affirms, researchers must presume that participants who express interest in participating in research have legal capacity. Some potential participants, however, may require extra supports to ensure full and informed consent and participation. The associated risks were managed as follows:

- The project materials provided to participants were accessible, to facilitate informed consent.
- Participants were encouraged to draw on support for decision-making when reading the project materials and deciding whether to participate by, for example, discussing it with a trusted family member, friend, or support worker.
- The Research Fellow responsible for recruitment spoke directly with each prospective participant who expressed an interest in the research in order to provide all essential information so that the person could make a decision as to whether or not to participate.
- This process included a discussion of any possibility that the individual’s ability to consent may vary throughout the project, and the participant’s wishes about what should happen in such a circumstance.
- The Consent Form and Plain Language Statement were read aloud and discussed with participants verbally as they arrived at the venue, regardless of whether they had already signed it.
- Participants were reassured that they would be de-identified in the data and in all reports and other publications arising from the focus groups. This was made clear in the Plain Language Statement and Consent Form and was verbally discussed with participants prior to each focus group. The participants were also informed that their personal information (such as name, address and telephone number) would be kept confidential.

One focus group participant opted to attend the focus group with a support worker. The facilitators checked that this participant, and the other participants, were happy to have the support worker present prior to commencing the focus group.

## Findings

The focus group participants reported that they had a range of problems when dealing with utilities and telecommunications providers. Many of the issues raised were about access – for instance, feeling ‘pushed’ into using online bills, and the need for plain language and useful images on bills and other documents. Others were about perceived inappropriate or unhelpful behaviour from providers, including pressure-selling and cold-calling (discussed further below).

Support for making decisions and dealing with providers was clearly important for most, if not all, participants. Participants referred to a wide range of supporters, including parents, siblings, friends, lawyers, paid support workers, support coordinators, peer support workers and guardians.

The participants were generally supportive of the suggestions for how providers could improve their processes. Some of the guidelines were more popular than others – for instance, participants were strongly supportive of the suggestions for making bills easier to read, and for listing a useful support number on the back of the envelope for bills or overdue notices. The focus group participants were less worried about their supporters ignoring their wishes and saw them as useful (if not essential) mediators in their interactions with providers.

In the following sections, the research findings are presented in detail. The first section outlines the participants’ feedback on the focus group scenarios, including ideas that they liked, ideas that they were less enthusiastic about, and new ideas they offered. The second section discusses other issues and complaints about current processes that the participants raised. Some of these were outside the scope of the current study but warrant further investigation.

### **FEEDBACK ON THE GUIDELINES AND SCENARIOS**

Each of the five scenarios presented to the focus groups incorporated three or four of the ‘guidelines for making fair and equitable support processes’ outlined earlier in the report. The focus group participants were positive about the recommendations for ensuring that accessibility and support needs are identified in a non-discriminatory manner, making space for supported decision-making, and supporting consumers through clear communication and assistance. One participant emphasised that the costs that companies incur when making their processes more accessible should not be passed onto individual consumers.

## A. Identifying accessibility and support needs in a non-discriminatory manner

*'I feel demeaned and not respected when I ring up'*

The participants agreed that discrimination was a concern for them. They highlighted the problems that people with cognitive disabilities can face when they are dealing with providers. In some instances, disclosing one's disability can help the other person understand the consumer's circumstances and respond appropriately. In other instances, disclosure can lead to (or at least create a legitimate fear of) being labelled and discriminated against.

As one participant explained,

'I feel demeaned and not respected when I ring up and the company treats me like in a stereotypical way a person with a mental illness... Then sometimes on my history, [it says this customer] is angry. Well, [she is] angry and frustrated and entitled to be, but because she has a mental illness and it's identified, that's part of her symptomology. So we can disregard that and treat her as a difficult customer and whatever, you know, flag on her final whatever.'

This reinforced the importance of asking neutral questions to all consumers about their support requirements and their usual decision-making process (see guidelines A1, A2 and B1, above). Participants were supportive of the idea of asking a general question to all consumers, although some indicated that this might seem like an inappropriate or invasive question if the reason for asking it was not also explained (see guideline A3). On this basis, the guidelines were revised to de-emphasise the 'help' and 'support' component and instead be more general and conversational – for example, 'do you want to take some time to think or talk to someone you trust?' – and to emphasise that the staff member must explain the intention of the question, namely, to help the person make the right decision rather than to deny them access (see guidelines A2, B1). Depending on the answer, follow-up questions about contacting another person or providing information in other formats can then be asked (see guideline A4).

These findings also point to the importance of training staff so that they better understand the reasons that consumers might behave in unexpected ways, and the communication needs of consumers with cognitive disabilities. This will equip them to interact in a way that is not dismissive or disempowering but is focused on assisting the consumer and solving their problems. Training should also emphasise the need to protect consumers' privacy, to ensure that any disclosure is not misused and that consumers are not simply labelled as difficult or combative, which can have long-term effects on their ability to deal with the provider (see guideline A5).

*Avoiding 'this push to everything online'*

Another matter that participants felt strongly about was the practice of many providers shifting consumers to online bill payment. One participant said:

'I think to push everyone by these companies, all of them, into using the internet to pay their bills is an outrage... I find it difficult and I struggle with it cognitively and I can't sometimes [tell] which way is up. This is extremely distressing for me, because in other ways I'm very competent... [T]hese kind of things disclose my areas of – where I don't manage so well and that I actively struggle with.'

Participants agreed with our suggestions that providers should ask consumers if they had access to the web, to a smartphone, and to apps, and that providers should not assume that consumers have access or want to use the web to manage their accounts or pay their bills (see guideline A6). Some participants said they were comfortable using apps. One participant observed that ‘people do have trouble reading screens’. Others said they preferred paper bills and stressed that these should be available. As one person explained, ‘I prefer my bills on paper in my letterbox. I can deal with that.’ This suggestion was added to guideline A6.

Some participants also said they preferred going into a shop rather than calling on the phone or shopping online when they wanted to sign up for something new. Choosing a new product was described as ‘pretty overwhelming’, and more helpful service was often available in-store. One participant also mentioned the importance of personal service, and salespeople who take the initiative to find and offer an appropriate product:

‘That’s why I ended up going to [store] and... at the desk, [the salesperson] just took one look at me, “hang on miss, I’ll be back in a minute” and brought me this telephone, which was even on sale, which is even better. “I think you’d probably be able to figure this one out.” He was dead right.’

Another participant said that they liked to shop at one location because it had quiet spaces where you could talk to someone:

‘I go to the shop, it is – you actually go into – even though it’s open, some areas are open, you can actually go in and you can actually talk to someone face to face regardless because you can still hear them when you talk to them, only because you’re talking to the person and the noises are out on the outside.’

Guideline A8 was amended to include these recommendations.

*‘Don’t denigrate it, you just have to say plain language’*

We asked the focus group participants about the importance of easy-to-read, accessible information (see guideline A7, above). They were particularly emphatic that providers should make better use of images, especially on bills.

‘What I was saying about pictures is that some people might not [be able to]... read or write, pictures is just one way of showing what they can and can’t do, something like a phone, pay a phone bill, that shows you...’

Participants suggested using pictures to show which number to call if they were having trouble paying a bill, and which number to call for other problems. These suggestions were added to guideline A7.

The participants said that all bills should be in plain language or Easy English, including useful images and large font for important numbers. One participant also noted the importance of considering the accessibility requirements of people with multiple disabilities, such as people with vision impairment, when designing bills.

We showed the participants examples of different coloured gas and electricity bills which were provided by AGL. Most of the text and formatting was the same on each

bill, but some important information (amount due and due date) was set against a different coloured background – orange for gas and blue for electricity. The participants said the different colours would ‘help me to pay for the bills that have got to be paid’ and meant the bills ‘would definitely be easier to read’. Some participants thought the colour differences could be more pronounced, such as having the document header in a different colour. One participant noted that colours that are difficult for people with atypical colour perception (‘colour-blindness’) should not be used. We added these suggestions to guideline A7.

*‘It’s an unbelievable amount of information’*

The focus group participants also agreed that providers should offer information in multiple formats, particularly written information that the consumer can take away with them and read before making a decision.

‘I have a processing disorder, so I don’t process things as fast as other people, which is part of my Tourette’s, a neurological condition. Look, I understand all this, but... just say I read something, I have to read it, like, three times.’

Participants agreed that consumers should be told about the range of options available to them when they are shopping for a new product, including the expensive, cheap and mid-range choices that are available (see guideline A9). One participant noted that this often means there is a lot of detailed, complex information to consider. This reinforced the importance of giving people the time, information and support to make a decision.

## **B. Making space for supported decision-making**

*‘Not to assume, just to ask’*

The focus group participants agreed that all consumers should be asked the same questions about support, but these questions should be subtle, and it should not be assumed that someone needed help (guideline B1). One participant noted that a universal system – where everyone is asked the same things – could reduce stigma against people with disabilities.

Participants agreed that a support person could be helpful for lots of reasons – to ‘get a better deal’, ‘look over [the contract] with me and make sure it’s right’, ‘explain things that you might not have quite grasped’, be ‘on the ball about your needs and aspirations and what you want out of that purchase’ and help with technology like apps and websites.

We discussed several options for contacting a support person, including the provider offering to call a support person if the consumer asks, or offering to call back when the consumer and support person are together.

*‘If I had a support person on there, it would be great’*

Participants stressed the importance of having the option to list a family member, friend, guardian or support worker on the consumer’s account, so someone else could make inquiries or pay bills on the consumer’s behalf. Participants said this would be

especially helpful if the consumer is in hospital, is uncomfortable speaking on the phone themselves, or otherwise needs support to manage their affairs. Participants said this would be ‘very useful’ and should be a ‘standard thing’. One participant suggested that consumers should have the option to add a support person at any time, not just during sign-up. New guideline B4 was added to address this.

*‘The issue about who’s recognised to assist people by these companies also matters’*

Some participants also expressed their concern that their support relationships were not respected or taken seriously. This demonstrates the importance of educating and training staff about supported decision-making and indicates that a standard process for listing supporters on consumers’ accounts could make things easier for many.

A standard, mainstreamed process for listing supports could also avoid confusion and ensure that substitute decision-making is not presumed or encouraged (see guideline B5). For example, one focus group participant said she had trouble inquiring about her own account after appointing an account nominee; a system underpinned by supported decision-making principles would enable multiple points of contact and focus on facilitating support rather than denying access. The wide variety of supporters identified by the participants showed that providers must adopt a flexible and responsive approach when identifying and including supporters. Education and training on supported decision-making could assist here.

*Listing a support person: ‘Maybe people should be able to choose’*

The participants were generally not concerned about being taken advantage of or pressured by a support person, although some agreed that it could be helpful for consumers to be able to put limits on the authority of a person listed on their account (see guideline B3). For example, several participants said they would not want their support person to be able to open or close an account.

Participants suggested several processes to do this effectively. One was a two-stage process, where the company confirms with the consumer before implementing a major change requested by the supporter. Another was to give the option of listing a person who should be contacted if the consumer cannot be contacted:

‘Specifically, if I cannot be contacted, please contact my guardian or support worker or [other nominated person].’

We also asked some participants about the best way for salespeople to interact with a consumer who was accompanied by a support person while shopping. We suggested that the salesperson could ask the consumer whether they want the support person to be included in the conversation (see guideline B3). Some participants thought this was ‘probably best’, although others did not have a strong view.

We asked the participants if it was important for the salesperson to focus on what the consumer – not the supporter – wants. We were interested in their views on the risk of undue pressure or a support person ignoring their preferences. The participants did not express a strong view on this, apparently because they assumed that consumers would be supported by someone they trusted and with whom they had a good relationship. They emphasised that the salesperson should not stop the supporter from helping the consumer by, for example, pointing out a problematic contract term.



Some participants also suggested that the most important thing was for the consumer and support person to have a ‘common understanding’ before they went shopping. In other words, the consumer should be at the centre of the situation, with all other parties working to find the solution they want:

‘It seems to me reasonably that if you’re going to make a significant purchase and you’re in a vulnerable situation that you might talk with your support worker about your phone before you go. I think that’s important, so the support worker has an understanding of what it is that you want very clearly, so that when you go to the shop you – your support worker, if your memory and concentration and decision-making is... isn’t always good, so that your support worker, who presumably you trust, to support you in decision-making... can actually hear the conversation and explain things that you might not have quite grasped or ask things that you might have left out, suggest things to you or at least have a discussion with you about – especially if you don’t have a trusted family member or friend or someone who’s handling that for you, then – or that you choose for that not to be the case, then your support worker is on the ball about your needs and your aspirations and what you want out of that purchase.’

### **C. Supporting consumers through clear communication and assistance**

*A dedicated team: ‘Yeah, I hate when it goes “1, 2, 3, 4”’*

We asked participants if companies should have a phone number that they can call to get help with understanding a bill, paying a bill, or other questions (guideline C1). The number would go directly to a team of people who have been trained to be friendly, supportive, and focused on solving problems. The participants thought this was a good idea, especially because it would mean they could skip the ‘press 1, press 2’ menu.

This number could be advertised, for example, on the consumer’s bill and on the back of envelopes. The participants were very enthusiastic about the suggestion to put the phone number on the back of the envelope, describing it as ‘amazing’ and ‘really good’.

*‘A simple thing... ends up in hours of frustration and stress’*

Continuity of service and an awareness of consumers’ circumstances and requirements was considered to be important by some participants. Such arrangements could also minimise the stress and frustration that consumers feel if they have to spend long periods on the phone trying to get through to someone who can help.

*‘Actually sit down with... someone and go through it all’*

We asked the participants whether they thought slowing down processes could be helpful. For instance, if a consumer agrees that they want to use an app or the website to manage their account, we asked if it would be useful for the salesperson to slowly explain and describe the app to the consumer. Participants agreed that this could be useful, especially for people who had a disability that affects their understanding or concentration.

Some participants said that getting information in writing following a phone call could be ‘very useful’. Others said that having time to go away, read information (possibly with a support person) and think about your options was helpful before making decisions (guideline C2):

‘unless there is some urgent need why she needs a phone right now, on this particular day, is to get all the information and actually sit down with a support worker and – or someone and go through it all and then make some decision about what’s appropriate.’

One participant indicated that slowing down and giving consumers time to review all relevant information was important to avoid being misled into thinking that ‘this is really good, whereas in fact there are other things that might not suit you’. It was suggested that stopping ‘the whole pushing thing’ would improve confidence in the company:

‘[M]aybe they’re not doing anything that’s illegal, but it’s sort of – it’s on the line of ethical behaviour’

We also discussed whether text message reminders could be helpful if a person was in crisis and the company could not contact them (guideline C3). Participants suggested two text messages: a reminder before the bill was due, and another message if the bill was overdue. They did note that this would not be useful for some consumers, such as people who do not check their phones or people who are in hospital. One participant reinforced the importance of contacting a support person or other account nominee in these situations. In other words, providers should assume that there is a good reason for the consumer’s lack of contact and involve the support person to ensure that the account does not get disconnected or other problems can be resolved.

*‘It can be frustrating saying the exact same thing more than once’*

We asked the participants about some strategies for communicating more clearly, like breaking down complex ideas into small parts and asking one question at a time. Participants agreed that this could be useful. They were also supportive of the suggestion that staff should speak in short, clear sentences without technical language or jargon (which was described as ‘a no-no’). Participants said it was important not to ask too many questions. Being asked the same question repeatedly was frustrating and could feel like an interrogation.

Some participants noted that companies should also be aware of potential language barriers – for instance, they should offer an interpretation service for consumers who want or need to communicate in another spoken language or sign language. We amended guideline C3 to make this suggestion clearer.

*‘You’ve got to figure it out, how to get the people’*

The participants were also supportive of the idea of a ‘bring your bills’ day, where people from electricity, gas, water and telecommunications companies can help their consumers understand their bills and ask questions. They emphasised the importance of spreading the word and finding the right contact points in the community. The participants had several suggestions for making this useful and effective, including making sure lots of companies come, making sure it is free of charge, and advertising it in prominent neighbourhood places:

‘especially in more country areas, don’t forget the churches, because it might be only be a lot of grandmas that go there, but they’ve got the children and grandchildren, so you’d be surprised at how if they see something like that, they’ll tell everybody you’re going sort of thing.’

## OTHER BARRIERS AND CAUSES FOR COMPLAINT

*‘Because I can’t read, write or spell, they thought they could get me’*

Many participants expressed frustration, irritation or disappointment with some aspects of service providers’ conduct and processes that were not addressed in our scenarios. Telephone interactions were the biggest source of difficulty, with many participants indicating a real fear that someone was trying to trick or scam them. Several participants said that cold calls from utilities and telecommunications companies could be confusing and/or misleading. They said it can be difficult to tell who is calling and were suspicious that callers were being intentionally vague or untruthful.

‘Actually, with a mild intellectual disability you can get tricked quite easily, especially when you’re not well, that once I changed over to a wrong company because they said that was part of who I was with, they actually said they were part of the company I was with there, sort of blah, blah, blah, then I realised I was changing over and by the time I realised, I was in the wrong.’

This was a regular and pervasive experience for participants and their families, and they felt hassled and pressured:

‘But they kept trying to force me to say yes. So I ended up giving in, I said yes and then the next minute my sister turned up and when I told her what happened, she goes, “no you shouldn’t have done that”.’

Participants said these calls sometimes had negative consequences, like switching to a ‘better offer’ that had a greater cost, or getting locked into a new contract without realising:

‘Sometimes they make it they’re trying to do a better offer, but it’s actually more expensive than – or it turns out to be more expensive.’

Some participants said they had learned to just hang up on unsolicited callers, because this was the best way to deal with them. One participant also said it was important to avoid giving out personal information, like a phone number.

*‘Try and get someone who has some understanding and empathy’*

Participants also said they had difficulties when they called a provider, for example, to make an inquiry or solve a problem. Some participants reported communication difficulties if the person they spoke to had a strong accent. One participant was critical of the process of getting through to someone who could assist them:

‘I have to ring up and go through this whole rigmarole with them, explain to them that I’ve got a mental health condition. Go through and try and get someone who has some understanding and empathy for this situation, get – insist that I speak to higher and higher levels of people and team leaders, spend hours on the – has this happened to you? Hours on the phone...’

These interactions were unnecessarily stressful:

‘what is really sometimes a simple inquiry or a simple thing to change ends up in hours of frustration and stress over the phone, which for a person with mental health condition is a killer.’

The participant argued that providers should be held accountable for these impacts:

I just think it’s wrong that people are not accountable for their behaviour; that recordings aren’t listened to. When I’ve said when I ring up sometimes, you listen to the recordings of me over the – you listen to them. You listen to what’s going on. I don’t care. I’ve got no privacy anyway.’

More meaningful targets and monitoring processes could go some way towards addressing this; we added this suggestion to our general recommendations for organisational change, set out below.

Participants in both focus groups expressed frustration that providers do not understand cognitive disabilities like intellectual disability and Acquired Brain Injury. Participants said providers need to get better at listening to people with cognitive disabilities. They also suggested that employing someone with skills in this area would be useful.

## Conclusions

The participants in the focus groups discussed a range of problems and difficulties they encountered when dealing with service providers. Some of these were sources of serious concern, inconvenience and stress in their lives, especially where they affected their ability to communicate effectively and get useful assistance. Support for decision-making and for communicating with providers were important to many of the participants.

The participants offered a great deal of useful feedback on our recommendations for improved processes. They emphasised the importance of clear bills (including good use of images and colour), a flexible and responsive approach to listing and contacting supporters where needed, sensitivity to and awareness of people with cognitive disabilities, and positive communication that is easy to access and does not make the consumer feel pressured, confused or misled.

# IMPLEMENTING THE GUIDELINES ACROSS YOUR ORGANISATION

The recommendations in this document offer detailed, practical suggestions for improving pre-contractual and problem-solving processes to benefit consumers with cognitive disabilities. While many of the changes are minor and will be straightforward to implement, they do require awareness and action at every level of the organisation. This was highlighted in the focus groups, with participants observing that providers exhibited little awareness of disability and expressing concerns that real change would not happen if it was not formalised in governance structures and obligations.

Implementing the recommended changes across your organisation will necessitate attention to the following dimensions:

## **a. Structures that enable supported decision-making**

- Ensure there is a dedicated, well-resourced support team.
- Ensure all consumer information is available in accessible formats.
- Create a process for support that includes timely triage, multiple points of contact, and easy access to a real person over the phone.

## **b. Training**

- Staff across your organisation are likely to benefit from disability rights training. Such training can increase their awareness of disability rights issues and their obligations in regard to ensuring the rights of consumers with disabilities are respected. It can also help staff to develop their communication skills, Easy English drafting, and other measures for improving access.
- Training should be designed and led by people with disabilities.

## **c. Leadership**

- The commitment of leadership is crucial to the implementation of a rights-based approach to engaging consumers with cognitive disabilities.
- Leadership can provide ongoing support, guidance and supervision, and should facilitate regular updates to policies and procedures that support good practice and demonstrate organisational commitment.

**d. Community education and awareness-raising**

- Complement changes to your internal processes with consumer engagement initiatives to make consumers aware of the services and support that are available.
- For example, participate in a ‘bring your bills’ day, where consumers can come to a community event to get a better understanding of their bill, and to make good decisions (see guideline C1, above).
- These events can also build trust between companies and consumers.
- Alternatively, your organisation could provide small funding grants to community organisations to conduct their own education and awareness-raising events. See Attachment A for a list of advocacy organisations, service providers, and other organisations who may be interested in these initiatives.

# ATTACHMENT A: LIST OF RELEVANT ORGANISATIONS

## ADVOCACY ORGANISATIONS

### **AUSTRALIAN FEDERATION OF DISABILITY ORGANISATIONS (AFDO)**

Ross House, Level 2, 247 Flinders Lane  
Melbourne, VIC 3000  
(03) 9662 3324 or 1800 219 969  
[office@afdo.org.au](mailto:office@afdo.org.au)  
<http://www.afdo.org.au>

### **INCLUSION AUSTRALIA**

Level 2, 418A Elizabeth Street  
Surry Hills, NSW 2010  
<https://www.inclusionaustralia.org.au>

### **PEOPLE WITH DISABILITY AUSTRALIA (PWDA)**

Tower 1, Level 10, 1 Lawson Square  
Redfern, NSW 2016  
(02) 9370 3100 or 1800 422 015  
[pwd@pwd.org.au](mailto:pwd@pwd.org.au)  
<http://www.pwd.org.au>

### **REINFORCE**

Ross House, Level 2, 247 Flinders Lane  
Melbourne, VIC 3000  
(03) 9650 7855  
[reinforce@rosshouse.org.au](mailto:reinforce@rosshouse.org.au)  
<http://reinforce.org.au>

### **SELF ADVOCACY RESOURCE UNIT (SARU)**

Ross House, 247 Flinders Lane  
Melbourne, VIC 3000  
(03) 9636 6856



saru@rosshouse.org.au  
<http://www.saru.net.au/>

### **VALID (VICTORIA ADVOCACY LEAGUE FOR INDIVIDUALS WITH DISABILITY)**

235 Napier Street  
Fitzroy, VIC 3065  
(03) 9416 4003  
<https://www.valid.org.au>

### **VICTORIAN MENTAL ILLNESS AWARENESS COUNCIL (VMIAC)**

Building 1, 22 Aintree Street  
Brunswick East, VIC 3-57  
(03) 9380 3900  
<https://www.vmiac.org.au>

### **WOMEN WITH DISABILITIES VICTORIA**

Level 9, 255 Bourke Street  
Melbourne, VIC 3000  
(03) 9286 7800  
<http://wdv.org.au>

### **YOUTH DISABILITY ADVOCACY SERVICE**

Level 3, 180 Flinders Street  
Melbourne, VIC 3000  
(03) 9267 3709  
[ydas@yacvic.org.au](mailto:ydas@yacvic.org.au)  
<https://www.yacvic.org.au/ydas>

## **GOVERNMENT**

### **NATIONAL DISABILITY INSURANCE AGENCY (NDIA)**

1800 800 110  
<https://www.ndis.gov.au/about-us>

### **OFFICE OF THE PUBLIC ADVOCATE**

Level 1, 204 Lygon Street  
Carlton, VIC 3053  
1300 309 337  
<http://www.publicadvocate.vic.gov.au>

# LEGAL SERVICES

## **CONSUMER ACTION LAW CENTRE (CALC)**

Level 6, 179 Queen Street  
Melbourne, VIC 3000  
(03) 9670 5088  
<https://consumeraction.org.au>

## **DISABILITY DISCRIMINATION LEGAL SERVICE**

Ross House, Level 2, 247 Flinders Lane  
Melbourne, VIC 3000  
(03) 9654 8644  
[info@ddls.org.au](mailto:info@ddls.org.au)  
<http://www.ddls.org.au>

## **FEDERATION OF COMMUNITY LEGAL CENTRES**

Level 3, 225 Bourke Street  
Melbourne, VIC 3000  
(03) 9652 1500  
[administration@fclc.org.au](mailto:administration@fclc.org.au)  
<https://www.fclc.org.au>

## **FLEMINGTON KENSINGTON COMMUNITY LEGAL CENTRE**

22 Bellair Street  
Kensington, VIC 3031  
(03) 9376 4355  
[fklegal@fkclc.org.au](mailto:fklegal@fkclc.org.au)

## **VILLAMANTA DISABILITY RIGHTS LEGAL SERVICE**

Deakin University, Waurin Ponds Campus  
Building IB, Level 3, 75 Pigdons Road  
Waurin Ponds, VIC 3216  
(03) 5227 3338  
[legal@villamanta.org.au](mailto:legal@villamanta.org.au)  
<http://www.villamanta.org.au>

## **WESTJUSTICE**

Level 1, 72 Buckley Street  
Footscray, VIC 3011 (also in Werribee and Sunshine)  
(03) 9749 7720 (Footscray and Werribee)  
(03) 9091 8237 (Sunshine)  
[admin@westjustice.org.au](mailto:admin@westjustice.org.au)  
<http://www.westjustice.org.au>

## ENDNOTES

1. The research team acknowledges that language in this field is important and contested. When referring to impairment and disability in this report, we use the meaning established in Art 1 of the *United Nations Convention on the Rights of Persons with Disabilities* (see n 3). It states that '[p]ersons 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'.
2. *Disability Discrimination Act 1992* (Cth) s 5.
3. *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) ('CRPD') art 5.
4. *Ibid* art 2.
5. *Disability Discrimination Act 1992* (Cth) ss 5, 15, 24 and 25.
6. *Ibid* ss 5 and 6.
7. *Ibid* s 5.
8. *Ibid* s 6.
9. *Equal Opportunity Act 2010* (Vic) s 9.
10. *Disability Discrimination Act 1992* (Cth) s 29A.
11. *Ibid* s 30.
12. CRPD arts 2 and 5(3); *Disability Discrimination Act 1992* (Cth) ss 5 and 6.
13. Committee on the Rights of Persons with Disabilities, *General Comment No. 6 (2018) on Equality and Non-Discrimination*, 19<sup>th</sup> sess, UN Doc CRPD/C/GC/6 (26 April 2018), para 23.
14. *Disability Discrimination Act 1992* (Cth) s 45; Australian Human Rights Commission, *Special Measures* (2018) <<https://www.humanrights.gov.au/quick-guide/12099>>.
15. For 'less favourably' see *Anti-Discrimination Act 1977* (NSW) s 49B, *Anti-Discrimination Act 1991* (Qld) s 10, *Anti-Discrimination Act 1998* (Tas) s 14 and *Equal Opportunity Act 1984* (WA) s 66A, and for 'unfavourably' see *Discrimination Act 1991* (ACT) s 8, *Equal Opportunity Act 1984* (SA) s 66 and *Equal Opportunity Act 2010* (Vic) s 8.
16. Committee on the Rights of Persons with Disabilities, *General Comment No. 1 (2014) Article 12: Equal Recognition Before the Law*, 11<sup>th</sup> sess, UN Doc CRPD/C/GC/1 (19 May 2014) ('General Comment No. 1') para 15.
17. Committee on the Rights of Persons with Disabilities, *General Comment No. 2 (2014) Article 9: Accessibility*, 11<sup>th</sup> sess, UN Doc CRPD/C/GC/2 (22 May 2014) ('General Comment No. 2') para 13.
18. *General Comment No. 1*, UN Doc CRPD/C/GC/1, para 17.
19. *General Comment No. 2*, UN Doc CRPD/C/GC/2, para 25.
20. *Ibid* para 26.
21. This can be informal (such as family members and friends) or formal (such as independent advocates and advance statements). See Eilionoir Flynn and Anna Arstein-Kerslake 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10(1) *International Journal of Law in Context* 81-104, 84.

22. *General Comment No. 1*, UN Doc CRPD/C/GC/1.
23. *CRPD* art 12.
24. Bernadette McSherry and Kay Wilson, 'The Concept of Capacity in Australian Mental Health Law Reform: Going in the Wrong Direction?' (2015) 40 *International Journal of Law and Psychiatry* 60-69, 62.
25. *Ibid* para 12.
26. *General Comment No. 1*, UN Doc CRPD/C/GC/1, para 29; BIZCHUT, *Supported Decision-Making Service for People with Disabilities: Service Model* (BIZCHUT, The Israel Human Rights Centre for People with Disabilities, 2016) 12.
27. Mental Welfare Commission for Scotland, *Good Practice Guide: Supported Decision Making* (November 2016) <[https://www.mwcscot.org.uk/media/348023/mwc\\_sdm\\_draft\\_gp\\_guide\\_10\\_\\_post\\_board\\_\\_jw\\_final.pdf](https://www.mwcscot.org.uk/media/348023/mwc_sdm_draft_gp_guide_10__post_board__jw_final.pdf)>.
28. Margaret Wallace, *Evaluation of the Supported Decision Making Project* (Report, Office of the Public Advocate South Australia, 2012).
29. Financial Counselling Australia, 'About Capacity and Decision-making' (Factsheet, nd).
30. *Ibid*; Mental Welfare Commission for Scotland, above n 27, 15 and 27.
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34. Australian Network on Disability, *A Beginner's Guide to Accessible Content* (2018) <<https://www.and.org.au/pages/a-beginners-guide-to-accessible-content.html>>.
35. W3C Working Group, *Media Accessibility User Requirements: W3C Working Group Note 03* (3 December 2015) World Wide Web Consortium (W3C) <<https://www.w3.org/WAI/intro/people-use-web/diversity#cognitive>>; see also Maker et al, above n 32.
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37. Mental Welfare Commission for Scotland, above n 27, 18-20.
38. Yotam Tolub, *Alternatives to Guardianship in Financial Affairs* (BIZCHUT, The Israel Human Rights Center for People with Disabilities 2016) 18.

39. Ibid, 77.
40. Financial Counselling Australia, above n 29.
41. Mental Welfare Commission for Scotland, above n 27, 17.
42. Ibid.
43. *General Comment No. 1*, UN Doc CRPD/C/GC/1, para 22.
44. Financial Counselling Australia, above n 29.
45. Ibid.
46. Kokanovic et al, *Fact Sheet 3: Practices to Improve Supported Decision-Making in Mental Health Services*, Health Direct <<http://media.healthdirect.org.au/publications/Fact-Sheet-3-Practices-to-Improve-Supported-Decision-Making-in-Mental-Health-Services.pdf>>.
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48. See for example, Consumer Affairs Victoria, *Easy English Factsheets* (4 October 2017) <<https://www.consumer.vic.gov.au/resources-and-tools/consumers-with-a-disability/easy-english-factsheets>>; Australian Competition and Consumer Commission, *Your Rights When You Buy Something* (11 July 2016) <<https://www.accc.gov.au/publications/your-rights-when-you-buy-something>>.
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57. Gooding et al, above n 49, 16; BIZCHUT, above n 26, 20.
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61. Financial Counselling Australia, above n 29; Gooding et al, above n 49, 16.
62. Financial Counselling Australia, above n 29.
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67. Financial Counselling Australia, above n 29; BIZCHUT, above n 26, 20.
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69. Scope, above n 47; Financial Counselling Australia, above n 29.
70. Gooding et al, above n 49, 18.
71. Ibid 17.
72. Intellectual Disability Rights Service, *Fact Sheet: Consumer Protection and People with Intellectual Disability* (May 2014).
73. Mental Welfare Commission for Scotland, above n 27, 17.
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75. BIZCHUT, above n 26, 21.
76. ADACAS Advocacy, *Support My Decision* (2018) <<http://www.support-my-decision.org.au/>>; Office of the Public Advocate, above n 65, 18.
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