



# Consumer Transactions: Equitable Support Models for Individuals with Decision-making Impairments

A pilot study supported by the Melbourne Social Equity Institute and the Melbourne Law School Major Collaborative Fund Project

## Summary Report

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## 1. Purpose and Aims

The purpose of this pilot study was to explore the challenges that individuals with mental and intellectual impairments<sup>1</sup> encounter when they engage in consumer transactions. The research team set out to gauge the viability of Supported Decision Making models for consumers. A specific focus was on transactions occurring in the finance, telecommunications, insurance, and utilities industries. The primary objective of the study was to establish which support models for individuals with mental and intellectual impairments may assist them to engage in consumer transactions.

The pilot study aimed to:

1. Identify the support needs of individuals with mental and intellectual impairments regarding consumer transactions; and
2. Identify support models to address those needs.

The key research questions underpinning the study were:

1. What supports are needed to ensure more equitable engagement in consumer transactions than is currently the case for individuals with mental and intellectual impairments?
2. How can these supports be implemented in practice?

The findings from this project, centred in Victoria, will be used to develop an application for major external funding for an Australia-wide project. Both this pilot project and the eventual larger project will help address Australia's obligations under international human rights law, particularly under the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

## 2. Impact

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<sup>1</sup> Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which opened for signature 30 March 2007, 2515 UNTS 3 and entered into force 3 May 2008 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”. The research team acknowledges that language in this field is important and contested. For the purposes of this report, the term “persons with mental and intellectual impairments” is used to reflect the language of the CRPD and “persons with decision-making impairments” is used when referring to the specific group of people that experiences barriers to decision-making.

The potential benefits of the pilot-study include:

- A better understanding of the needs of individuals with mental and intellectual impairments in relation to consumer transactions, which is an under-researched area.
- Providing individuals with mental and intellectual impairments the opportunity to influence service reform.
- Helping to establish support models which will enable more equitable engagement in consumer transactions for individuals with mental and intellectual impairments, allowing people with disabilities to be fully included as economic actors.
- Aiding consumers with mental and intellectual impairments to understand contractual obligations and associated risks.
- Encouraging service providers to ensure their transactions are socially responsible and cost-effective. This will help businesses with the costly issue of consumers with mental and intellectual impairments entering into unsuitable contracts which they cannot fulfil.
- Building expertise and tools for wider industry participation in supporting people with disabilities. This may include providing a training package or framework to service providers.
- Informing the implementation of models of equitable support which could potentially transform the consumer experience of individuals with mental and intellectual impairments, on a larger scale.

### **3. Method**

- Qualitative methodology; and
- Participatory research

#### **3.1 Ethics**

Ethics approval was obtained from the University of Melbourne, Mind Australia, and Scope Australia.

#### **3.2 Participants**

Two groups of participants were involved in this study:

1. Individuals with mental and intellectual impairments and;
2. Service providers, such as members of:
  - a) Disability service providers;
  - b) Community legal centres;
  - c) Companies (Telcos, banks, insurance agencies etc.)

#### Group 1 – Individuals with mental and intellectual impairments

The inclusion criteria for participation in Group 1 were that the individual be over 18 years of age, residing in Victoria, and have experience engaging in consumer transactions.

In order to recruit individuals with mental and intellectual impairments to the study, a recruitment flyer was developed in collaboration with the project partners, Mind Australia and Scope Australia. The flyer was then provided to the service providers to distribute to their clients.

Initially it was intended for focus groups to be conducted. However, due to difficulties recruiting participants the research team decided to pursue individual interviews instead given the time-limited nature of the pilot study.

Nine individuals<sup>2</sup> participated in a semi-structured interview with the researcher at the location of one of the partner community based service providers. The participants ranged in age from 38–58 years of age. The mental and intellectual impairments experienced by the participants included diagnoses of Asperger's Syndrome, Depression, Schizoaffective disorder, and Dissociative Identity Disorder.

The interviews were based on two broad questions – (i) what challenges do you experience when engaging in consumer transactions? and (ii) what supports would be helpful? The interviews were conversational in nature and the researcher adopted a flexible approach, exploring different lines of inquiry across the interviews given the diversity of the participants and their experiences of consumer transactions.

#### Group 2 – Service providers

A range of service providers were sought for this pilot study, including disability support services, community legal centres, and industry. To recruit service providers a method of purposive (targeted) sampling was used, in which the research team purposively invited particular service providers to participate due to their relationship to the issue under examination. Given the strong industry focus of this research project, assistance was provided by the Business Development Manager, Melbourne Law School, which involved meeting with various companies to explain the project and negotiate the conditions of participation.

Semi-structured interviews were conducted with ten participants:

- 2 Consumer advocates
- 3 Community lawyers
- 4 bank representatives

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<sup>2</sup> Due to the limited sample size the results of this pilot-study are not highly generalisable.

- 1 insurance industry representative

The interviews were conducted at the participant's workplace or the University of Melbourne. The questions asked of service providers were: (i) what challenges do consumers with mental and intellectual impairments face when transacting? (ii) what current policies and practices exist to respond to vulnerable consumers, including those with mental and intellectual impairments? (iii) what could be improved? (iv) would a supported decision making model be viable in practice?

### **3.3 Data analysis**

The interview data was analysed using NVivo (qualitative analysis) software. A general inductive approach was taken to the analysis of qualitative data to develop a thematic framework. As findings emerged from the qualitative data they were checked by the research team to ensure they spoke to the research context and questions. This enabled higher level themes to appear and to be contextualised by their supporting sub-themes. The qualitative analysis process was conducted by the researchers, one of whom conducted the interviews. Use of multiple researchers enabled cross-checking of coding and themes to ensure that analyses were credible.

## **4. Findings**

The findings of the pilot-study are arranged into two sections:

1. Challenges and;
2. Supports.

### **4.1 Challenges**

**Five** main themes were identified with regards to the challenges that consumers with mental and intellectual impairments face when engaging in consumer transactions:

#### *4.1.1 The impact of mental and intellectual impairments*

When asked what the main challenges were when engaging in consumer transactions most participants spoke about the relationship between their consumer behaviour and their mental and intellectual impairment:

*I guess I got myself into trouble partly because of this almost obsessive compulsive thing. And I was getting messages if you like to say that it's 'okay, it's all good, you're doing the right thing, you need this stuff' etcetera, and in reality I didn't.*

*(Consumer)*

Consumers explained that fluctuations in their mental health had an impact on the decisions they made as consumers. For example, when they were unwell they might buy products they did not necessarily need (e.g. one participant had multiple phones, tablets etc.) and were at risk of signing contracts they did not fully understand.

The emotional impact of engaging in unfair or unsuitable consumer transactions was also deemed to be greater for consumers with mental and intellectual impairments:

*I think it resonates with me more because the emotional impact is often greater. But also it sits within a cluster of a whole bunch of problems so that the social, financial, emotional impact is amplified. ... it's not just the Harvey Norman contract they're battling. They might be battling with their housing security, struggling with money anyway, might have a credit card – a debt collector chasing them for something else. And so the emotional impact is worse.*

(Solicitor)

#### 4.1.2 Financial hardship and access to suitable products

Financial hardship was a dominant theme which imposed challenges to transacting equitably for the consumers in this study. A key challenge that the participants encountered was a lack of access to suitable (typically meaning affordable) products in the marketplace. The consumer advocacy organisations strongly believed that within the marketplace there is a significant lack of suitable products available to vulnerable consumers:

*There's already a lot of poorly designed, poorly distributed products. So they're not designed to give consumers what they're really wanting or needing or expecting and they're not sold in a way that allows consumers to fully understand the bargain they're entering into. And there I'm thinking about, say, pay-day loans, consumer leases, there's a whole host of education products being sold door-to-door, solar panels being sold door-to-door on finance. There's a very long list. I think that those products affect consumers generally but I expect that someone experiencing an ABI [acquired brain injury] is more susceptible to entering into those products.*

(Consumer advocate)

Participants spoke of disclosing their financial situation to the companies they were transacting with, yet still being offered products that they felt were not suitable or appropriate for them:

*They actually did sign me up because I did explain to them that I had financial difficulties and I'm still paying stuff off with other companies. So I did say all of that, I was very upfront. And the guy seemed to think that I would have no trouble with the credit check. So I did get the feeling though that not enough importance was placed on that.*

(Consumer)

Participants expressed a desire for companies to err on the side of caution when lending, for example by undertaking rigorous financial checks:

*... Less emphasis on 'yes I've just ticked the box and got my commission or signed up another person'. So I think the whole way it's been structured by these companies ... if it's part of their remit if you like, if it's part of their culture. And not only that, if it's actually written into their training and so forth that this is what you're meant to do when you encounter this situation.*

(Consumer)

#### 4.1.2.1 Importance of cooling off periods

Given the often fluctuating nature of the impact of mental illness, participants explained how they might be driven to transact when they are unwell, purchasing products that are unsuitable for them; when they stabilise they regret the transaction and are left with the financial burden and associated stress. Cooling-off periods are one mechanism that may assist consumers to determine whether a product is suitable for them. However, cooling off periods can only be effective if the individual is aware of their rights:

*When you speak to vulnerable people, people with disability, they often don't take much notice of, or don't understand the effect of cooling off rights, don't know how to exercise them, don't feel confident in exercising them. And at any rate they think they've got a good deal, so they're just waiting for the 10 days to lapse so they can take delivery of what they signed up to buy.*

(Consumer advocate)

Some participants suggested a concept similar to a 'cooling-off period' to assist them to manage their transactions better - a period of reflection, perhaps encouraged by the company or facilitated by a supporter, which is enforced before they actually decide to transact, rather than occurring after they have initiated the transaction. For such a mechanism to be imposed, disclosure of one's disability, and flagging of such on the customers file, would be essential.

#### 4.1.2.2 Disclosure of disability

In order to access suitable products, disclosure of one's disability was identified by companies and advocates as essential. If the consumer engages in a transaction for a product which is not suited to their financial circumstances then retrospectively there are limited options for redress, especially if the individual did not disclose their circumstances to the company. However the societal stigma that prevails around mental illness, and disability more generally, creates barriers to the forthright disclosure on behalf of the consumer:

*We can all talk about respecting people with disability and people with mental health issues, but not everybody walks into a branch or into a telco shopfront with a sign on their forehead or a sign on their chest, whatever it is, saying. 'I identify as having a mental health issue. Can you please treat me with respect?' And that exists for so many people in society. You can't necessarily walk in somewhere and have someone know that you speak English as a second language. None of wear signs on our forehead or our chests, to be honest.*

(Consumer)

*Identifying customers and their accessibility needs is sometimes a challenge because also customers don't necessarily open with that or even admit or acknowledge that they have a disability. That's probably where we find a lot of challenges, and we find that internally with our people as well. Some people not necessarily identifying themselves with having a disability.*

(Bank representative)

Some forms of mental or intellectual impairment are particularly difficult to identify if the consumer does not openly disclose – typically companies were notified by the consumer's carer or family and the contract was terminated. With many companies shifting away from face-to-face service provision to the digital space, knowledge of the customers' needs will become increasingly more difficult.

When a consumer does voluntarily disclose that they have a disability it is vital that staff respond appropriately:

*Have you got a disability? I said yes, I don't have to specify what type of disability ... This person, who is a lawyer with about 30,000 letters after his names, wants to know if I can read or write! Well I've just read his freaking form in two seconds flat, got most of it right ... and he wants to know if I can read or write? I wonder what kind of idiot this clown is, and that's social stigma... the point was that if I'm in front of him reading out the thing and I've actually written down what the answers are, it's quite obvious that I could read or write, well I'd like to think that it would be.*

(Consumer)

Adequate training for front-line staff is important to informing appropriate responses to consumers with mental and intellectual impairments.

Some participants in the pilot study felt that disclosing that they have a disability, but not the specific nature of it, would uphold their right to privacy and is something they felt comfortable doing. The risks associated with disclosing include that a consumer with a mental and intellectual impairment could be treated poorly, disqualified from accessing certain products, or cut-off from transacting altogether. Respect for privacy and mindfulness not to discriminate against consumers were central themes to the discussion of disclosure:

*We accommodate people the best we can, unfortunately we're not fully aware of some people's personal circumstances and we need to be extremely careful about that, we can't make accusations about someone's state of health; we've got to respect them and respect their privacy. And they're able to engage in products and services, if it's suitably available to them and suitably for their needs.*

(Bank representative)

Consumer advocates suggested that a flagging system would be useful to keep a record of the customer's disability status so that staff were aware and could respond to the consumer appropriately through diversion to separate processes. However, representatives from the banking sector were sceptical of this approach.

#### *4.1.3 Poor understanding of products*

A lack of understanding of products was identified as a barrier to equitable participation in consumer transactions for the participants in this study:

*Even me who appears to do their research still has no idea. And I still don't fully – because I'm more concentrating on the end goal, which is getting my thing at the end of the day, a lot of it is to do with not really being cognitively aware of what's actually happening. As we said it's hard enough...*

(Consumer)

It was apparent that most participants did not fully understand the products they had transacted for, including such things as loan terms, the accrual of interest, repayment schemes, and mobile phone plans and associated entitlements (e.g. data usage).

##### *4.1.3.1 Inaccessibility of product information*

A direct contributor to the inability of the consumers to understand products was the apparent inaccessibility of product information, such as terms and conditions, which outline the consumer's contractual obligations:

*how about stopping with the forms and let me speak to a person who will navigate through working something out, because all this trying to pigeonhole people, especially people with Asperger's into one category, into one nice pigeonhole, it's not going to work.*

(Consumer)

*That policy thing that takes like half an hour it felt like. My mind is starting flipping out, I've got a pretty short attention span, so I'm losing my shit after all this talking.*

(Consumer)

Consumer advocates expressed concern with the inaccessibility of contracts for consumers in general. Similarly a representative from the insurance industry stated they still had not made Disclosure Statements fully accessible and this is an ongoing challenge.

#### 4.1.4 Lack of confidence

Some consumers in the sample said they lacked the confidence to participate in transactions with big companies:

*I think the key challenge would be confidence that I would be dealt with properly, you know dealt with like any other person. Confidence that I won't get an immediate knock back. Even not knowing enough about my past to know whether I'm eligible to go and do something, that's really hard.*

(Consumer)

Having the confidence to say 'no' and decline an offer was also identified as a significant issue for some consumers, particularly in the context of door-to-door sales. This can be a common issue for some persons with an intellectual disability due to 'acquiescence bias'<sup>3</sup> whereby they are more likely to please those with whom they interact. This may also be a problem relating to elderly consumers:

*What we've found is that also part of the profile is these people withdrawing from society, they may have lost a partner, may not have family, be on their own, they're vulnerable and there's no support and effectively these people just go under the radar ... there's no support group, there's no family, the spouse may have died, they might have been married for 50 years, all of a sudden they're on their own ... So they've presented in a situation of isolation, of loneliness, they're in a state where these people who are vulnerable from others, because they want to earn the trust with people they befriend and that trust is abused.*

(Bank representative)

#### 4.1.5 Communication barriers

For individuals experiencing challenges with their mental health and cognition, communication with others may be difficult. Consumers with mental and intellectual impairments may experience difficulty expressing their desires and wishes, or in interpreting information that is communicated to them. To provide one example, a consumer in the study decided to change to pre-paid vouchers for her mobile phone service because communication was such a significant challenge:

*I did have a plan, and that got so complicated that I switched to vouchers. Then I could keep a handle on what was going on and I didn't have to deal with people in service really. I could just go and buy a chip, buy the voucher and it was much less painful. So, I've gone around things a different way and I don't do anything that I don't need to do, because it's too hard to deal with people.*

(Consumer)

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<sup>3</sup> Zak Toomey, 'Changing the FCRA Opt-Out into the FCRA Opt-In: A Proposal for Protecting Mentally Disabled Consumers from Manipulative Credit Card Marketing' (2009) 12 *Journal of Gender, Race & Justice* 621, 625 citing Celia B Fisher et al, 'Capacity of Persons with Mental Retardation to Consent to Participate in Randomized Clinical Trials' (2006) 163 *American Journal of Psychiatry* 1813, 1818.

Another participant spoke of his difficulty with numeracy and how this impacted him when making a transaction:

*Part of it is that I'm dyslexic when I hear numbers; they have to be chunked together. For example, if the number was 1 3 5, and the operator calls back 1 3 5, I process it as 5 3 1, and the operator then gets frustrated because I'd call them back in reverse. It is not done intentionally, I don't process that information.*

(Consumer)

## **4.2 Supports**

When asked what supports participants with mental and intellectual impairments would find useful when engaging in consumer transactions **three** main themes emerged. Overall the supports required by the consumers in this study aligned with the Supported Decision Making model:

*Just having someone there so that if you have moments, because a lot of people get anxiety and then they can't talk. So if someone's there, they can kind of start off themselves and if they get into any trouble, the other person can say, 'Well what's she's actually aiming for here is' ... because it's really easy for anyone with any diagnosis to have anxiety or panic attacks really. So I think it would be great, it would make a huge difference.*

(Consumer)

*... one thing that I've noticed is if there's supports, then people can feel more comfortable, and they can access more things. And just the fact that some people are really in an unstable stage, whereas that can be maybe something they could say – 'Well okay, we'll just get you stabilised and then we'll revisit this in a couple of months and see if that's still what you want to do.' And then we'll support you in doing that.*

(Consumer)

*I mean actually having someone tell you what actually things mean on the bill is probably a really good idea.*

(Consumer)

### **4.2.1 Suggested approaches to providing support**

Support to assist consumers to gather information and weigh up the options that are available to them was a prominent suggestion. One approach was for the supporter to act as a conduit between the company and the supported person (the consumer):

*Maybe the organisations could have accredited or approved products. If there was a representative organisation that supported those people, playing that decision making role, with the people they assist, and then maybe that network might be a way of sharing safe appropriate products, or companies that have been given the stamp of approval for dealing sensitively with people with impaired cognition.*

(Consumer advocate)

*A good analogy might be the buyer's advocate, when you go buying a house, someone that does the bidding for you. It's that kind of idea, that you say look I want to go out in to the marketplace, I need a new phone, I need a new fridge. So you've got someone to say, well I know which businesses are going to do the right thing by you. It's about getting on the front foot and meeting needs, before the person goes out spontaneously to try and meet their own needs.*

(Solicitor)

Similarly, consumers felt that support which enabled them to better understand products, discuss their options, and then select products that are suitable to their needs would be helpful. The provision of such support must allow them to maintain their personal autonomy.

#### *4.2.1.1 Dedicated support teams*

The potential for diversion of consumers with mental and intellectual impairments to a dedicated department, similar to hardship teams which already exist within most companies, was also explored

*you ring this number and say you'd like supported assistance to work out what insurance you need, or you're making a claim but you need supported assistance, and they've already incorporated that into their workplace and their call centres, they go, 'Ok, we know that that goes to that special team,' and that special team are aware they're dealing with someone that needs extra care, so even from a selling point of view, they're saying – really fleshing out what they need and actually offering the right product.*

(Consumer advocate)

*If you identify these people, they go over here.' You now – the main sales force doesn't just get to go, 'Go for broke on them.'*

(Solicitor)

#### *4.2.1.2 Facilitators of supported decision making*

Consideration was given to who exactly would be responsible for providing support to the consumer. This included two approaches:

- companies having dedicated support teams within their staffing structure to provide support to consumers with mental and intellectual impairments; and

- community based disability services to provide support to the individual and act as conduit between the supported person and the marketplace.

Integrating informal supports into the above models was also identified as important:

*The ability to either have or not have someone come with you as a support. So if I want my carer, or if I've got a good friend that I want to bring along with me to these sessions so they're in the loop as well and then we can talk about it afterwards. Sometimes I have trouble and I do, I need someone else to be almost my secretary to be able to talk it out as well.*

(Consumer)

Granted the complexity of the large business involved in the study, introducing a supported decision making model into their existing structures was perceived as exceedingly complex and costly:

*Well we're a major bank. We're exceedingly complicated. We've been around for 175 years. We've got hundreds of products, thousands of processes and literally 20 or 30,000 front line staff in Australia alone. So nothing's easy, which is why it's important to start with the right points in the process, and the people that are designing our front line processes or our systems. And again, there's multitude of systems and some of them work differently in different channels and some of them work differently in different sectors of customers, so a retail customer or commercial customer, if you're a deposit customer or a home loan customer. Its different systems, with different purposes.*

(Bank representative)

If community agencies are to be responsible for providing dedicated support to consumers with mental and intellectual impairments, then it is important that the supporters are appropriately trained to understand consumer rights.

#### 4.2.2 Accessing support

When participants turned their attention to the viability of the Supported Decision-Making model in practice, questions arose surrounding how such a model would be accessed by those in need of support:

*It needs to be practical. So these changes need to be seen as essential. I think that there's a long, long way to go for that to be part of the mentality with large commercial entities, but some of the support services need to be essential. Some of them already are, however they're not advertised. So advertising is huge...*

(Consumer)

For the individual to access a dedicated supported decision making system they would likely be required to disclose their disability. If the support was provided by community based disability and mental health service providers, then stigma related to disclosing may be lessened.

To counteract the stigma associated with disclosing, one consumer advocate proposed that the term 'supported person' could be used by companies to identify consumers who require additional support when making a transaction. Rather than relying on the individual to self-disclose directly to staff every time they make a transaction, a card could be issued to those who require additional support.

#### 4.2.3 Cultural change and staff training

Moving to a human rights-based approach to disability is a process of transition, which requires awareness raising and training across the community. This may include the development of resources to assist individuals to better understand the experience of persons with disabilities, for example training programs and resource toolkits. Participants were therefore asked to provide feedback on the topic of staff training:

*I think there should be a little bit of training around the difference between, when people have a mental illness they often have an acute phase or phases. And that's not the whole person and I think there could be a little bit of training around that sort of thing. You know that, hey yeah, a person can be sick, but that's not been their whole story.*

(Consumer)

*I suppose the difficulty for us is that the staff aren't professionally trained to assist with that. I'm not trying to wash that aside, but people who are specialists in this area are going to be social workers or people from the medical profession, at that relationship to understand those key identifiers. With our front-line staff, a lot are trained to assist, but to look even further, I don't know whether we'd be suitably trained or qualified to make that judgement, because we don't want to discriminate our customer or anything like that.*

(Bank representative)

The high turnover rate of front-line staff was perceived as a potential barrier to the effectiveness of a training program:

*What I would say is that that stuff's quite hard, because it's not sustainable. You know, our front line staff get hit with dozens of changes every week. Their attention span is so much that staff turnover is high and constant, particularly in the front line roles. Think about call centres and branches. It's high turnover of staff. So anything we do needs to be really sustainable. So, the things that I've been trying to do and focus on is how to we build into product design, how to we build into process, technology, systems, because that lasts forever.*

(Bank representative)

Both industry representatives and consumers suggested that cultural shifts more broadly across the company would be beneficial.

Commission based incentive schemes were identified as a barrier to the equitable treatment of consumers with mental and intellectual impairments:

*I think obviously where there's commission based selling, then front-line staff aren't going to want to see those issues. They're just going to want to see their transaction go through.*

(Consumer advocate)

Instead of focusing on front-line staff, one representative from the finance industry suggested that the target of training and education be directed to high level staff, such as those “that actually define the processes that the front line staff have to follow. Front line training’s good for awareness, but at the end of the day, the front line staff have to do what they’re told as far as process goes”.

## **5. Summary and conclusions**

The research team plans to conduct consultations with consumers, industry, and community based service providers to inform the development of a model of support in 2017.

Findings from this pilot-study indicate that in developing the support model the following issues should be considered:

- who is best placed to provide the support required;
- the role of informal supports (e.g. carers, family);
- ensuring that the support model is highly accessible to ‘vulnerable’, and sometimes isolated, consumers;
- potentially limiting the scope of the model and focusing on a specific area of industry given the complexity of each sector;
- considering the delicate balance between protection of consumers and empowerment.