



AutismCRC

Money matters

Understanding the financial wellbeing
of autistic people

FINAL REPORT

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Autism CRC

Autism CRC is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to autistic people, there is no one term that suits all people. In our published material and other work, when speaking of adults we use identity-first language ('autistic person'), which reflects the belief that being autistic is a core part of a person's identity.

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1. Executive summary

Financial wellbeing is an important component of people's overall wellbeing, reflecting the capacity to live a comfortable and fulfilling life. Despite many autistic people having a desire to work, the majority are not employed full-time or are under-employed and have low levels of income. Such circumstances present serious constraints to achieving financial wellbeing. It means many autistic people are stressed and are not able to meet everyday expenses and bills or have enough money left over to enjoy life and not worry.

Although there is a growing literature on the financial wellbeing of non-autistic people, the financial wellbeing of autistic people and the factors that affect it has not attracted the same attention. This study sought to address this gap. We achieved this in two ways. First, in Phase 1, we conducted a large-scale survey with 191 Australian autistic adults to examine their objective financial wellbeing, including income and savings levels and their subjective sense of their financial wellbeing. We also wanted to understand the predictors of autistic adults' subjective financial wellbeing. Second, in Phase 2, we identified people who had rated themselves as having particularly high or low financial wellbeing to be interviewed in order to understand in greater depth the subjective experiences of financial wellbeing among autistic people. Twenty-one people generously agreed to be interviewed, including 12 people with high financial wellbeing and nine with low financial wellbeing.

Our Phase 1 survey-based results revealed that autistic people's sense of financial wellbeing is determined both by how much income they have at their disposal and the ways in which they are able to use that income, just like those in the general population. The more that people were able to save and the less that they had to borrow for everyday expenses, the greater their sense of financial wellbeing. Yet, meeting basic expenses and having the ability to save in this way were worryingly out of reach for many of our participants, whose income was simply not enough to support this. Our participants' financial wellbeing, on average, was lower than those in the general population.

Our Phase 2 interview-based results showed further the toll that low financial wellbeing can have on people's mental health and wellbeing. The absence of a reliable income meant that our interviewees did not feel they had enough to cover day-to-day expenses and a savings safety net for the unexpected. They felt this ultimately limited their life opportunities. These difficulties came despite the fact that many were extremely disciplined in their accounting and budgeting strategies, and that people worked hard to find financial security.

This research is, of course, just a beginning. Future studies are needed to investigate further the ways in which autistic people could secure more reliable incomes and identify what is needed to help support autistic people to do all they can to achieve financial resilience in often demanding and unpredictable personal and societal circumstances.

There are five key recommendations from this research. We suggest that sustained efforts be made to:

1. Support autistic people with getting and sustaining consistent, meaningful and accessible employment, including support with career planning at different stages of their lives.
2. Ensure that government financial supports are more generous, more easily accessible, and more predictable for autistic people and their families.
3. Work alongside autistic people to design and deliver easy-to-access financial literacy education for autistic young people and adults.
4. Provide greater support and guidance from financial institutions, particularly with regard to financial planning (including superannuation) and in navigating the processes and institutions which might be able to support financial wellbeing even in difficult circumstances.
5. Increase and ease of access to adult diagnostic and post-diagnostic services so that they are more accessible and affordable, potentially assisting with enabling autistic people to access the services and supports that they need for life and financial wellbeing.

2. Introduction

2.1 Background

Financial wellbeing plays a crucial role in most people's quality of life (Netemeyer et al., 2017). Research to date has demonstrated that perceived or subjective financial wellbeing is comprised of three main components: being able to meet financial obligations, having enough money left over to enjoy life and having the financial resilience to cope with unexpected expenses (Kempson et al., 2017). The most important drivers of subjective financial wellbeing are adequate income and financial behaviours such as active saving and not borrowing for everyday expenses (Australia and New Zealand (ANZ) Banking Group, 2018). Other factors include certain psychological traits such as locus of control, impulsivity and confidence in money management skills, and healthy financial attitudes are also believed to be important. Objective measures of financial wellbeing relate to people's financial circumstances such as income and saving levels (Comerton-Forde et al., 2018). Objective financial wellbeing, such as income, is associated with employment status in the general population (Stronks et al., 1997). Poor financial wellbeing has been linked to financial hardship, poor health, relationship instability and high levels of stress and anxiety.

All of this knowledge, however, comes from research with the general population. We know strikingly little, however, about the financial status of autistic people and, what we do know, is rather bleak. In Australia, almost two-thirds of autistic people are unemployed (Australian Bureau of Statistics, 2019), which means that they are likely to rely on a disability support pension (AUD\$24,552 per annum) or unemployment benefits (AUD\$14,708 per annum) as their primary source of income. These rates are 3.5 and 6 times lower than the average full-time earnings (AUD\$89,123 per annum), respectively, and are aligned with or sit significantly under the Australian poverty line (AUD\$23,764 per annum; Davidson et al., 2020). Studies from other countries corroborate this view, indicating that being financially disadvantaged is a pervasive issue among autistic people (Roux et al., 2015; Zwicker et al., 2017).

Despite this knowledge, we know virtually nothing about what financial wellbeing means to autistic people and whether the most important predictors of subjective financial wellbeing – that is, the income at one's disposal and the way that that income is used – are the same for autistic people as they are for those in the general population.

Two recent studies have made some efforts to address this gap in the literature. First, in 2017, ANZ funded a project conducted by researchers to examine the financial lives of individuals with a disability in Australia. The research also reviewed the financial capability outcomes for people with disability who had participated in ANZ's flagship financial education program called MoneyMinded (Russell et al., 2017a). For people with disability, the greatest barriers to subjective financial wellbeing were low levels of income and employment. Poor digital inclusion contributed to difficulties for people with disability in meeting banking needs, achieving independence and self-managed NDIS needs. Two recommendations were made by the researchers. First, facilitators suggested the usability of MoneyMinded should be improved, in the context of the needs of people with disability people. Second, facilitators also expressed the need for targeted training to equip them with the knowledge, skills, and confidence to better support people with disability.

Second, a separate component of the MoneyMinded project was completed in 2017, in partnership with Autism CRC, which focused on understanding the subjective financial wellbeing of autistic people specifically ($n = 16$) via focus groups (see Russell et al., 2017b). Most participants' understanding of subjective financial wellbeing aligned with the definition provided by Kempson et al. (2017). However, financial hardships were commonly experienced by these autistic people. Consistent with findings from the MoneyMinded impact report (Russell et al., 2017a) and the financial wellbeing survey of adults in Australia (ANZ Banking Group, 2018), the primary drivers of financial hardship in autistic people were limited employment opportunities and low levels of income.

Russell et al.'s (2017a) study provided a critical first step to understanding the financial wellbeing of autistic people. Nevertheless, the dearth of research on this topic meant that further research was necessary, using both quantitative and qualitative methodological approaches, in order to elucidate the subjective financial wellbeing levels for autistic people living in Australia, and their predictors.

2.2 Project aims

This project sought to:

1. Identify the objective and subjective levels of financial wellbeing of a large sample of autistic adults living in Australia;
2. Compare these financial wellbeing levels of autistic adults to those of the Australian general population;

3. Determine the predictors of autistic adults' subjective financial wellbeing; and
4. Understand in-depth the subjective experiences of financial wellbeing from the perspectives of autistic adults with self-reported high or low financial wellbeing.

3. Research design and methods

This study followed a two-phase explanatory sequential mixed-methods design (participant selection model; Creswell, 2006). Phase 1 began with the collection and analysis of quantitative data, an online survey with Australian autistic adults to address Aims 1 – 3. This first phase was followed by the subsequent collection and analysis of qualitative data (Phase 2) to address Aim 4. Critically, Phase 2 participants were purposively selected based on the quantitative (financial wellbeing) data they provided in Phase 1. The methods and results from each of these Phases are described in turn below (see Figure 1).

Figure 1: Schematic of study procedure



This study also adopted participatory methods in which an autistic researcher was involved in the design and implementation of the study, including conducting all Phase 2 interviews, and in the ongoing analysis and interpretation of the findings. Her involvement ensured that the study was respectful and supportive of our autistic participants, especially those with particularly low financial wellbeing.

Ethical approval for both Phases was obtained from Macquarie University's Human Research Ethics Committee (Reference number: 52019572512775). All participants gave informed consent prior to taking part in this project.

3.1 Participants

Phase 1

To be eligible for Phase 1 of our study, participants needed to have a clinical diagnosis of autism or self-identify as autistic, be aged 18 years or above, and live in Australia. We used a convenience sampling (snowballing) approach to recruit participants. Specifically, we contacted various organisations including state-based autism support organisations such as Autism WA and AMAZE, university partners of Autism CRC, as well as the researchers' extensive networks. A campaign with a video and flyer was circulated via Macquarie University and Autism CRC's social media, which then generated additional participants through Australian self-advocacy groups, clinician and researcher networks and online forums. Individuals interested in the study were directed to the online survey (powered by Qualtrics). Although there were no direct benefits to taking part in this part of the project for participants, the researchers donated \$5 to a charity (either Australian Red Cross, Beyond Blue, or Australian Wildlife Conservancy) for every participant who completed the online survey.

Two-hundred and seventy people responded to the survey. Seventy-nine responses were excluded due to partial survey completion ($n = 77$) or inconsistent diagnostic information ($n = 2$). The final sample consisted of 191 autistic adults aged 18 to 83 years ($M_{age} = 39.28$, $SD_{age} = 11.74$), including 147 (77%) who identified as a woman, 27 (14%) as a man and 12 (6%) as non-binary/other (3% did not disclose gender).

Participants reported their predominant ethnic background as White European (87%). At the time of survey completion, 151 participants (79%) reported living with others, including a spouse or partner (45%), children (34%), parent(s) (15%), friends or housemates (7%), other relatives (5%), while the remaining 40 (21%) lived alone. Two adults selected "other", one who lived in university accommodation and another who lived alone with daily support from ex-partner. One quarter of participants lived with more than one group of people (e.g., with both spouse or partner and children).

More than half (57%) of participants had obtained a university degree (undergraduate or postgraduate degree), while 62 (32%) had completed a certificate or trade course. Almost a third (31%) of participants reported that they were currently studying, and more than half (53%) were employed (including self-employment).

Most reported having received multiple diagnoses of mental and/or physical conditions, with 86% and 84% of people having at least one mental and physical condition, respectively. Most notably, almost three quarters of participants reported co-occurring diagnoses of depression ($n = 142$; 74%) or anxiety ($n = 139$; 73%). Eighty-five participants had children (45%), of which 69 (81%) had at least one autistic child.

Phase 2

For the subsequent qualitative component of this study (Phase 2), participants who had received particularly low (0 – 50) or high (50 – 100) subjective financial wellbeing scores in the Phase 1 online survey, and who had expressed interest in taking part in a follow-up study, were invited to participate in a semi-structured interview to discuss their financial experiences in depth.

Twenty-one autistic adults took part in Phase 2. There were 12 participants (nine women, three men) in the 'high financial wellbeing' group ($M = 86.32$, $SD = 6.14$, range = 71.42 – 95.83), aged between 28 and 69 years and nine participants (five women, four men) in the 'low financial wellbeing' group ($M = 19.18$, $SD = 14.81$, range = 3.78 – 47.22), aged between 24 and 56 years. Across the groups, all participants identified as White, with the exception of one person in the high financial wellbeing group who identified as South-East Asian. Two participants in the low financial wellbeing group self-identified as autistic, while the remaining 19 participants had received independent clinical diagnosis of autism, most later in life ($n = 16$; 84%, average age = 33 years). Diagnoses of co-occurring conditions were common to both groups, especially anxiety and depression.

3.2 Procedure

Phase 1

Recruitment for the study began on February 3rd, 2020. When the first lockdown occurred in Australia due to the COVID-19 pandemic in April 2020, 41 adults had taken part but recruitment was halted given the possibility that the government restrictions impacted people's financial experiences and wellbeing. We re-opened the survey on February 25th, 2021 and closed it on May 31st, 2021. An additional 229 participants had completed the survey at this time, during which there were no government restrictions related to COVID-19 and the vast majority of Australian citizens had not undergone lockdown since November 2020. To check whether time of survey completion (pre- vs post-COVID-19) affected the results, we conducted the relevant statistical tests

on the objective and subjective financial wellbeing measures. There were no significant group differences on any measure (p s > .09); therefore, all participants were included in subsequent analyses.

The online survey included questions about participants' demographic information. The following measures also formed part of the survey.

Autistic traits. Autistic traits were measured using the 28-item AQ-Short (Hoekstra et al., 2011), an abbreviated version of the full 50-item questionnaire (Baron-Cohen et al., 2001). Each item is rated on a 4-point Likert scale ranging from *definitely agree* to *definitely disagree*. Sample items include "I find social situations easy" and "I am fascinated by numbers".

Objective financial wellbeing. To capture participants' current financial situation and objective financial wellbeing, we asked participants about their main source of income, total annual income before tax, total amount of savings and investments, home loan amount, and other loan amount.

Subjective financial wellbeing. We measured participants' subjective financial wellbeing using the financial wellbeing measure designed by ANZ Banking Group (ANZ Banking Group, 2018). This measure consists of 11 questions that encompasses three components of subjective financial wellbeing (Kempson et al., 2017), including 1) the ability to meet financial commitments such as loan payments and bills (three items, e.g., "How often do you run short of money for food or other regular expenses?"); 2) the extent to which people feel comfortable about their current and future financial situation, and allow them to enjoy life (four items, e.g., "How often do you have any money left over, after you've paid for food and other regular expenses?"); and 3) financial resilience for the future and ability to cope with unexpected future expenses or fall in income (four items, e.g., "Just say you had to pay an unexpected expense tomorrow, that is the same amount as your household's monthly income. How much could you pay from the money you currently have, from cash or in a bank savings account?"). Total subjective financial wellbeing scores ranged between 0 and 100. Higher scores indicate better financial wellbeing.

The ANZ Roy Morgan Financial Wellbeing Indicator^a can produce equivalent subjective financial wellbeing scores as the ANZ financial wellbeing measure for the general Australian population.

^a Further information about the indicator can be found at www.bluenotes.anz.com/financialwellbeing

This indicator was used to compare the subjective financial wellbeing of our autistic adults with the general Australian population. To facilitate comparison with ANZ Roy Morgan Financial Wellbeing Indicator, we classified participants' total subjective financial wellbeing score into the following four categories: 1) no worries (scores >80); 2) doing OK (scores between 51 and 80); 3) getting by (scores between 31 and 50); and 4) struggling (scores <=30).

Active saving. Saving behaviours were measured using two main questions designed by ANZ (ANZ Banking Group, 2018). The first question asked participants: How often do you save money so that you could cover major unexpected expenses or a reduction in income? This question was rated on a 5-point Likert scale ranging from *Always* to *Never*. The second question consisted of three items and asked participants to indicate how well these statements are true for them: 1) I try to save money to have for emergency use in the future; 2) I try to save some money regularly even if it is only a small amount; and 3) I always make sure I have money saved for bad times. Items were rated on a 5-point Likert scale ranging from *Extremely true* to *Not true at all*. Participants could report 'don't know' for any of these items. Total active saving scores ranged between 0 and 100, with higher scores indicating higher active saving behaviours.

Not borrowing for everyday expenses. Borrowing behaviours for expenses were measured through three questions designed by ANZ (Australia and New Zealand Banking Group, 2018). Questions were: 1) How often do you have to borrow money or go into debt to buy food or to pay daily expenses, because you don't have enough money?; 2) How often do you have to borrow money to pay off debts?; and 3) How often do you tend to overdraw or go into negative balance (where your account is below \$0) on your everyday transaction account? The first two items were rated on a 5-point Likert scale ranging from *Always* to *Never*. The third item was rated on a 5-point Likert scale ranging from *This happens to me most months* to *This has never happened to me*. Participants could report 'don't know' for any of these items. For the third item, participants could also report 'Not applicable'. Total not borrowing scores ranged between 0 and 100, with higher scores indicate reduced borrowing for everyday expenses.

Confidence in money management skills. We measured confidence in money management using three questions designed by ANZ (Australia and New Zealand Banking Group, 2018). Participants were asked to rate how confident they were about their ability in the following aspects of their budgeting: 1) managing money day to day; 2) planning for financial future; and 3) making decisions about financial products and services. Items are rated on a 5-point Likert scale ranging from *Very confident* to *Not confident at all*. Participants could report 'don't know' for any of these

items. Total confidence skills ranged between 0 and 100, with higher scores indicate higher confidence.

Phase 2

An autistic researcher conducted all semi-structured interviews between 24th April and 17th June 2021. Individual interviews took place predominantly via Zoom, with two being completed via email, as per the interviewees' communication preferences. During each interview, we asked participants a series of open-ended questions about their financial wellbeing (including their current and past financial experiences), its perceived impact on other aspects of their life, and their perspectives on how their financial wellbeing could be supported. Primary interview questions were provided to participants ahead of the interview to accommodate processing differences.

Interviews varied in length, between 27 and 108 mins ($Md = 64.2$). All Zoom interviews were recorded with participants' prior permission and transcribed verbatim by a transcription service. Transcripts were then returned to each participant for review, to ensure accuracy and to remove any details, should they wish. All participants were compensated for their time with a AUD\$50 gift voucher.

3.3 Data analysis

Phase 1

Descriptive analyses were used to report the objective and subjective financial wellbeing of the autistic sample. Below, first, we compare participants on demographics, health, and financial wellbeing by their income categories: 1) Low: those with income under \$25,000; 2) Medium: those with income between \$25,000 and \$74,999; and 3) High: those with income \$75,000 and above. Next, we used multiple hierarchical regression to identify the statistical predictors of subjective financial wellbeing. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Missing items were addressed through excluding cases listwise during analyses. SPSS Statistics version 21 for Mac was used for all statistical analyses.

Phase 2

We followed Braun and Clarke's (2006, 2019) method for reflexive thematic analysis, using an inductive (bottom-up) approach (i.e., without integrating the themes within any pre-existing coding

schemes or preconceptions of the researchers) to identify patterned meanings within the dataset. Our analysis was informed by two team members' experience and training in psychology, and a third by nursing and their positionality as an autistic advocate. The team liaised multiple times to review the themes and subthemes, focusing on semantic features of the data (staying close to participants' language), resolving discrepancies, and deciding on the final descriptions of themes and subthemes.

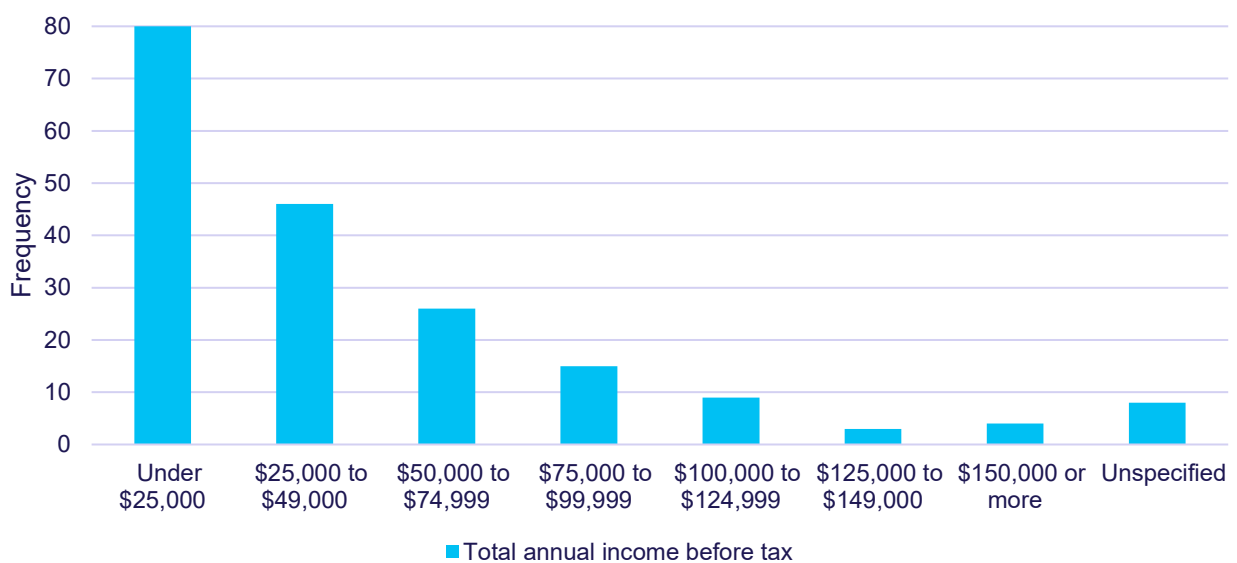
4. Findings

Phase 1

4.1 Financial wellbeing of autistic adults

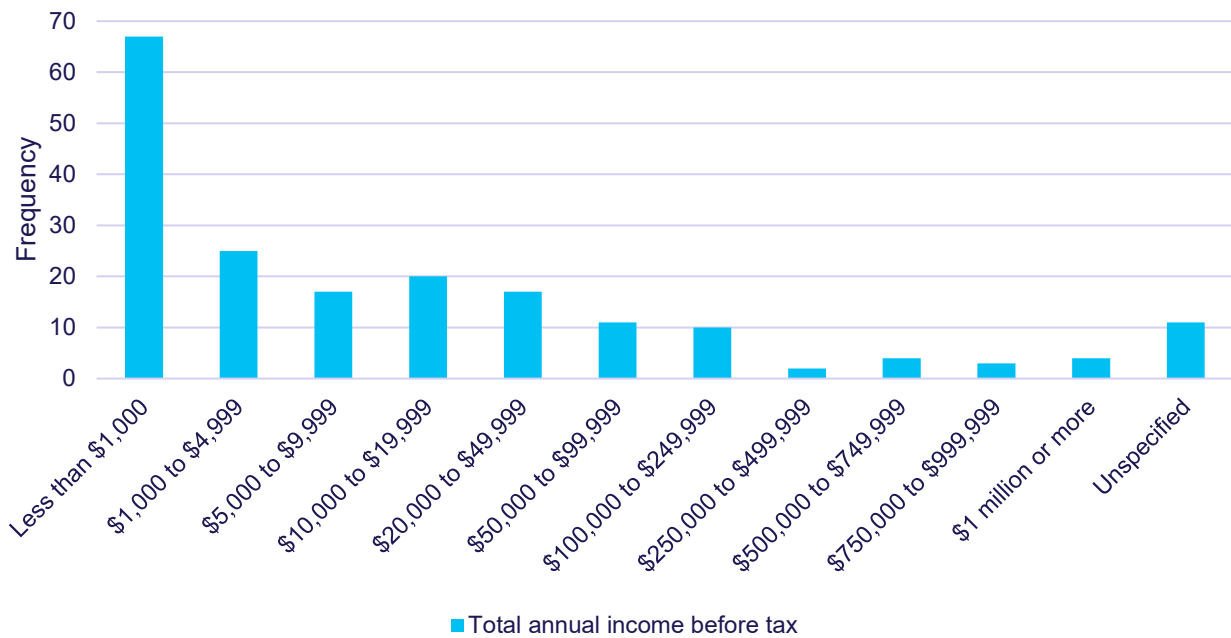
Income levels. A large proportion of our autistic adults (42%) had total annual income before tax below \$25,000. Only 21% of participants had income above \$75,000 (see Figure 1 for income levels). The main source of income for our autistic adult were wages or salary (38%), followed by government benefit or allowance (37%). These data contrast significantly with those from the general population: 63% of the general population report employee income as their main sources of income, followed by 23% on government benefit or allowance (Australian Bureau of Statistics, 2021a), with the average Australian employee annual income of \$66,576 (Australian Bureau of Statistics, 2021b).

Figure 1: Income levels



Almost half of the participants (48%) had total savings and investments amount below \$1,000 (see Figure 2).

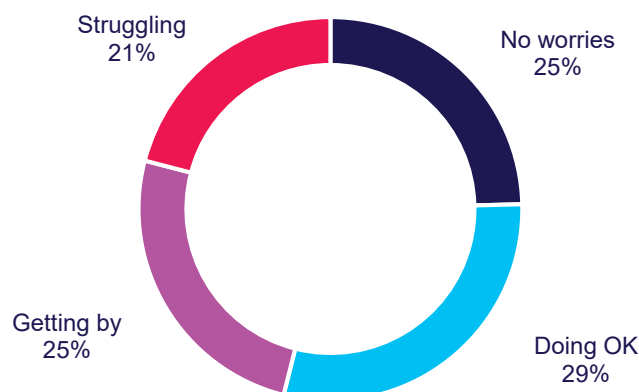
Figure 2: Levels of savings and investments



In terms of loans, most autistic adults had no home loan (64%) or other loan (59%).

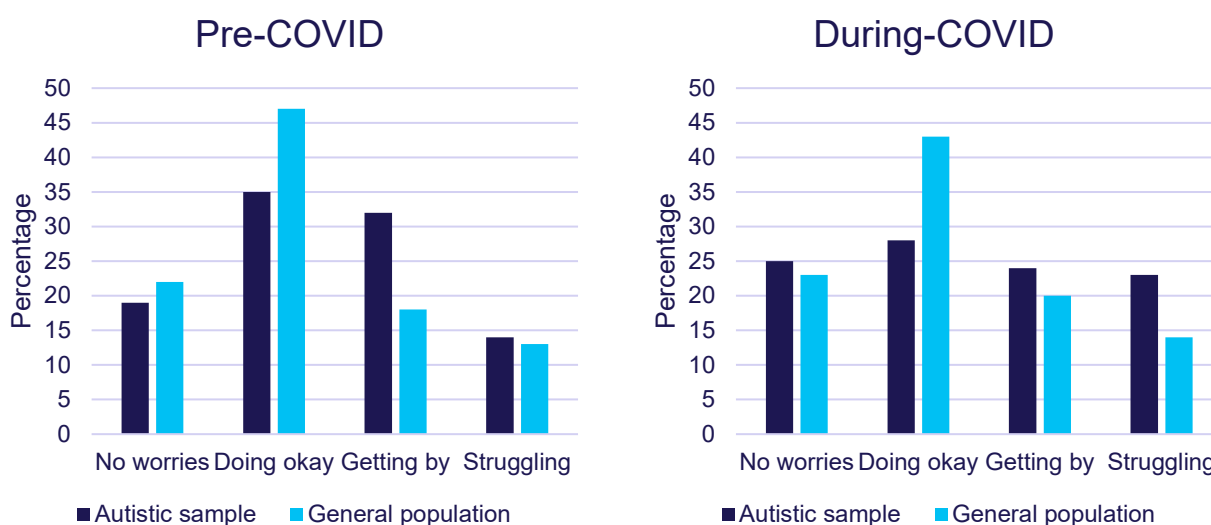
Financial wellbeing. The average subjective financial wellbeing scores out of 100 for our sample of adults was 52 (see Figure 3 for breakdown of scores by categories).

Figure 3: Subjective financial wellbeing categories



Using the ANZ Roy Morgan Financial Wellbeing Indicator, two separate comparisons for pre-COVID-19 (responses collected in early 2020) and during-COVID-19 (responses collected in 2021) were conducted to account for the financial impact of the pandemic. The average subjective financial wellbeing scores of our autistic sample pre- and during-COVID were 51 and 53 respectively. The scores of the general Australian population were 61 and 59 (see Figure 4 for comparisons). Therefore, overall, the subjective financial wellbeing of the Australian general population was better than our sample of autistic adults.

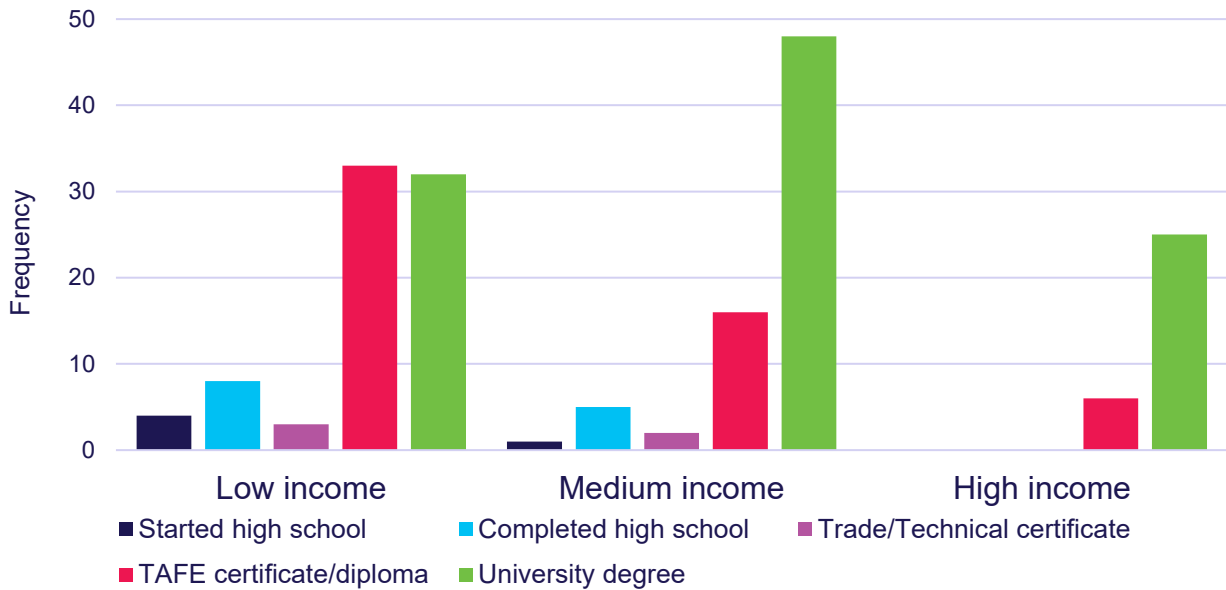
Figure 4: Comparisons of subjective financial wellbeing categories pre- and during-COVID



4.2 Group comparisons across income levels

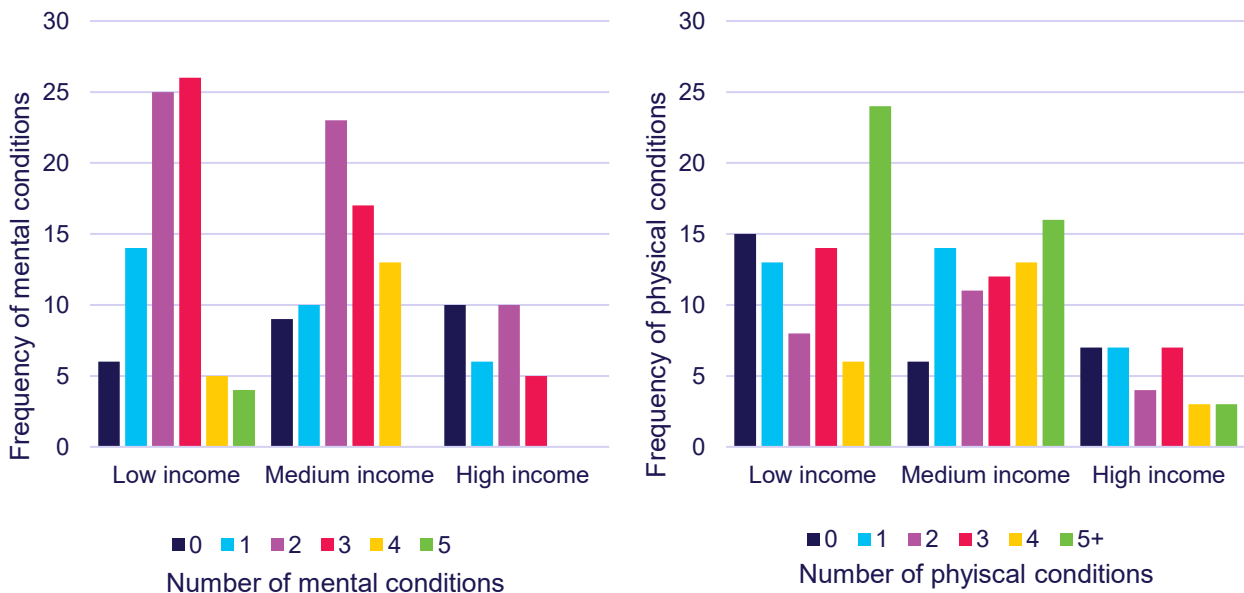
We further compared participants on demographics, health, and financial wellbeing by their income categories (low, medium, and high). Although adults with high income were slightly older than those with low or medium, this difference was not significant. There were also no differences in income categories across adults with various gender identities. There was, however, a significant link between income and education: adults with high income were better educated than adults with low or medium income, with minimum education level of TAFE certificate of diploma (see Figure 5).

Figure 5: Comparisons of highest levels of education by income categories



Furthermore, autistic adults with high income tended to have lower number of mental and physical health conditions than adults with low or medium income. Only the group difference on number of mental health conditions, however, was significant (see Figure 6).

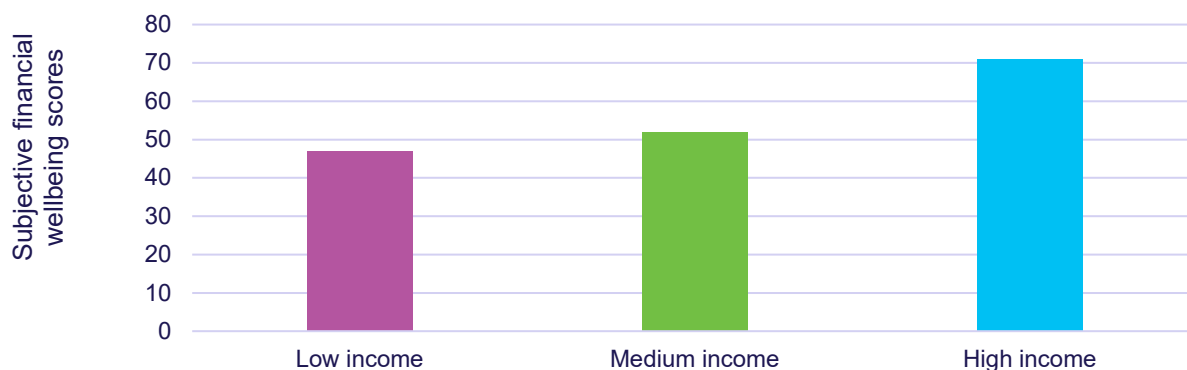
Figure 6: Comparisons of number of mental (left) and physical (right) conditions by income categories



Critically, there was a significant link between income and participants' financial wellbeing scores: where the lowest income earners had the lowest subjective financial wellbeing (average score: 47),

and the highest income earners had the higher subjective financial wellbeing (average score: 71) (see Figure 7).

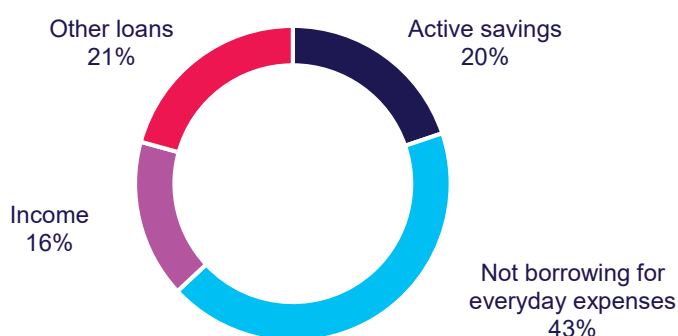
Figure 7: Comparison of average subjective financial wellbeing scores by income categories



4.3 Factors that predict subjective financial wellbeing

When the participant demographics and financial behaviours and confidence in money management skills were factored in, we found that active saving, not borrowing for everyday expenses, income, and other loan amount predicted a significant amount of variance in subjective financial wellbeing scores (see Figure 8). Autistic participants' financial behaviours (active savings and not borrowing for everyday expenses) alone (63%) were the most important factor that influence subjective financial wellbeing.

Figure 8: Factors that contribute to subjective financial wellbeing^b



^b The influence of each factor is represented by the percentage shown next to it (obtained by summing the standardised regression coefficients and rescaling each one to a percentage; the percentage figures thus represent the shares of the explained influence of these 4 factors on financial wellbeing).

Phase 2

4.4 Interview findings

Phase 2 of the study sought to understand autistic people's views and experiences of financial wellbeing in greater depth, from those who self-reported high or low financial wellbeing. These groups were selected specifically to understand financial wellbeing, its barriers and enablers, from a diverse range of perspectives.

Preliminary analysis of the transcripts has revealed an extraordinarily rich set of reflections from our participants. Our analysis is ongoing but has so far focused on what financial wellbeing meant to people and their own subjective experiences of financial wellbeing.

People across both low and high financial wellbeing groups, described how financial wellbeing had several components for them. First and foremost, they spoke of how it meant **having enough to make ends meet** – “having enough money to live on”, “to pay your bills, buy food” – “basic living expenses” – and “to just survive and exist”. As one person explained:

“Financial wellbeing means that I have enough money to pay for the house that we live in... having enough money to pay my bills and pay them on time – to be able to turn things on like heat or cooling depending on the weather and not have to worry about, how am I going to pay this bill?”

Our participants also described how financial wellbeing was more than just having “money to pay day-to-day bills” – that there should also be “a little leftover”, **a safety net for the unexpected**. This provided “the security of knowing that you're not going to find yourself in a crisis unexpectedly, and that you can meet that crisis, like a sick pet, a sick kid, a car malfunction, without it completely destroying your life”.

They also highlighted the importance of having “a little bit to put into savings on a regular basis”, **to build up “security in your future”**. They wanted to ensure a sense of certainty with their finances – “just not that it's fine today and tomorrow it's terrible” – to “have a proper plan for the future money-wise”, including the ability or desire “to help out with adult children or grandchildren if they needed us to”.

Our participants were also clear that **financial wellbeing is about “having choices”**. It means “being able to afford to do what you need to do and some of what you *want* to do” – “having a little leftover to have fun, without having to check salaries/income each week to make sure that’s enough”. One person summed this up:

“Financial wellbeing means living a life knowing that you will have money to pay day-to-day bills, security in your future and the ability to put money aside for the nicer things in life such as saving for a holiday.”

Finally, our participants also emphasised the subjective nature of financial wellbeing – specifically, of **“not having to worry about it”**. The absence of “any sense of strain, anxiety or tension” was critical. They also reported that they wanted to feel “comfortable money-wise”, “in control of my budget, finances, that sort of thing”, and “having a sense of confidence that you are going to be okay financially in the future”.

“Financial wellbeing is a type of financial ability to do things you need to do and being able to support yourself while you’re doing those things, and not to stress about whether you have the money to do them or not.”

Having access to “a steady stream of income” – either through employment or through government support – made a critical difference to our participants’ sense of financial wellbeing. It allowed them to have enough money to cover their expenses and it removed some of the uncertainty by allowing them to put some money aside, to have a buffer and build some financial resilience for the future. Yet, a reliable income was simply not a reality for most of our participants. Despite “wanting to work” and feeling that they have “insights that neurotypical people don’t” and “something to contribute”, many described difficult employment histories. They recounted problems finding jobs – and even when they were able to find jobs, “not being able to keep them for very long” because they “didn’t function well in that kind of environment”, “my brain finds it hard to do boring stuff, I need the challenge” or that they “struggle to get through the working week – just pure exhaustion”.

“Throughout my entire life, I’ve struggled to hold down a job.”

Consequently, many, including participants across both the low and high financial wellbeing groups, described work difficulties such as “having a breakdown at work”, being “in big burnout”

and being “just absolutely mega-broken”. As one participant described: “everything just went crazy, it fell apart – and I got fired and went into hospital”.

For those participants on government benefits and allowances, **many struggled to get the benefits they ought to have access to** because they had difficulties completing the requisite forms (particularly for the National Disability Insurance Scheme) or meeting the relevant requirements (for JobSeeker). One person said, “I just had so many problems with the Centrelink system in trying to be honest and do the right things, and still being harassed and having to jump through ridiculous hoops, that I just said to them, ‘I’m taking myself off because I can’t maintain this, dealing with you’. It was ridiculous”.

“I don’t like relying on government benefits because they can be taken away at any point.”

Many people, especially those in the low financial wellbeing group, simply did not earn enough income to achieve optimal financial wellbeing. They found it difficult to save any money and when they were able to put some money aside, “then something will happen... and it physically hurts to watch your money drain away just because you can’t keep adding to it, but you need to keep spending it to survive”. Participants described the “constant battle to have enough money to pay for things” – not being able to “afford to go to the doctor because doctor didn’t bulk bill”, having “periods of homelessness”, and having “the food needs covered but not have anything left for clothing or do anything recreational at all”.

These challenges were in spite of the fact that they reported attitudes and behaviours that suggested that they were managing their finances well. For participants across both low and high financial wellbeing groups were “very conservative around money and risk”, were highly disciplined and “overcautious” about budgeting. Some stated they were “terrified of debt” and therefore “don’t have credit cards”, instead describing an “inclination to hoard as much money as I possibly can, just from the experiences of having nothing”.

Nevertheless, **the stress of financial insecurity was often too much to bear**. It made doing everyday things like going to the supermarket, cooking and doing domestic chores, a real challenge. They described “being so overwhelmed that I don’t remember to pay bills or to call Centrelink”. It also “limits what I can do”. Not being able to get a car and a license meant that one participant “couldn’t do things in other areas, which meant that I was sort of suffering socially”. One participant, who was also a parent, explained further: “not being able to provide my kids with not

just basic things, like clothes, but on a weekend if they're with me, to be able to say, 'oh, let's jump in the car and drive to such and such a place. It's been really difficult to just have that freedom to offer new experiences to them". It also made it impossible to plan financially for the future: "I'm just preparing for the next disaster, basically". As one participant put it:

"It's just a constant layer of strain... most people will think of poverty as living in a caravan or a tent or on the street or something. But there's this other kind of strata, I think. I've looked at where the poverty line is and I've always been below it. I've never had more than \$3,000 in my bank account ever. It's always just coming in and going out, and you're always behind. So, all of this, I guess, is accumulative over a lifetime. It's one layer of strain on top of anything else that happens, like family breakdowns and relationship problems and all the rest of it."

5. Limitations

There are two important limitations to our study.

First, our participants were predominantly of white ethnic background and were more likely to identify as female. It is therefore possible that a selection bias may have existed, particularly toward those who are willing to consent and then feel able to convey their experiences via a survey or through an in-depth interview.

Second, only one of our participants reported an intellectual disability and it is likely that our recruitment methods may have led to a bias towards people who used traditional forms of communication and were not accessing more specialised supports. We acknowledge that, although this project is one of the first to focus on the financial wellbeing of autistic people, one critical next step is to examine the financial wellbeing of autistic people in under-served groups, including those with intellectual disability, those who use non-traditional forms of communication, those from culturally and linguistically diverse backgrounds and/or those who require high levels of care and support.

6. Implications for research and practice

This study reveals how much money does matter in autistic people's lives. In line with results from general population samples, our Phase 1 results demonstrated that autistic people's sense of financial wellbeing is determined both by how much income they have at their disposal and the ways in which they are able to use that income. Supports and capabilities beyond income itself explained a good deal of autistic adults' financial wellbeing scores. The more that people were able to save and the less that they had to borrow for everyday expenses, the greater their financial wellbeing. These quantitative findings were corroborated by our qualitative, Phase 2 findings. Overall, our interviewees felt that financial wellbeing meant having enough money to make ends meet, to save for unexpected future expenses in the future, and not to have to worry about unpredictable demands, and they felt that these were often beyond reach.

We also discovered that our participants' financial wellbeing was lower than those in the general population. These findings are not surprising in the context of their financial circumstances. Almost half of participants revealed that their annual income was less than AUD\$25,000 – with many being below the Australian poverty line. Lower incomes can create significant challenges meeting basic expenses and limits people's ability to save. The link between income and financial wellbeing scores suggest that lower income autistic people are likely consistently to feel less secure and less able to plan for the longer term compared to those with higher income.

Our Phase 2 qualitative findings also further demonstrated the toll that low financial wellbeing can take on people's mental health. Precarious employment and government support meant that they did not have a stable income to cover day-to-day expenses and a safety net for the unexpected. This meant that people were often limited in the choices that they could make about how they go about their lives. And that they were also forced to make impossible choices, like whether to pay to eat or pay the rent. This was despite the fact that many were extremely disciplined in their accounting and budgeting strategies, and that people wanted to have financial security.

All of these points provide us with a clear sense of the crucial next steps in research and practice. We need to know more about the ways in which autistic people could secure more reliable incomes, and the ways in which autistic people can be supported as they seek to maintain financial sustainability in often demanding and unpredictable personal and societal circumstances.

7. Key recommendations

Five key recommendations emerge from this work. They are:

1. **Support with getting and sustaining employment** – consistent, meaningful employment is a good in and of itself, but is also a vital means of ensuring financial wellbeing and peace of mind. Autistic people need and deserve better and more accessible opportunities to participate in the labour market, secure good work and then sustain themselves in meaningful employment. There have been some important pilot projects in Australian and internationally focused on this question, but more research is needed on how employers and others can more adequately assist autistic people in this regard, including opportunities for career counselling at different life stages.
2. **Government supports need to be more generous, accessible, and more predictable** – employment will not be a route to financial wellbeing for all autistic people, just as it is not for many non-autistic people. It is vital therefore that more is done to ensure that government supports for those unable to access reliable employment are supported financially at an adequate level and that the process of applying for and accessing these funds is straightforwardly manageable for autistic people and their families.
3. **Finance education early in life** – participants in our research reported that they felt as if there was little opportunity for them to access formal advice, support and education on financial management, especially early in adult life. Being outside of higher education and/or employment, many autistic people also miss out on the informal teaching in financial management that is available for other young adults. Civil society organisations, advocacy groups and government service agencies, should respond to this absence by providing easy-to-access co-produced financial education for autistic adults in the future.

“I do feel there was no one teaching me how finances work, especially around that end of high school, into my first job, into uni, into my first real, post-uni job. That big transition moment in my life, I didn’t feel there was anyone in terms of finance and career and forward-planning.”

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4. **Support and guidance from financial institutions** – it has become apparent throughout this research that autistic people could benefit greatly from additional help with financial planning, especially long-term planning (including superannuation), and in navigating the processes and institutions which support financial wellbeing. It would be welcome, therefore, if leading financial institutions, including retail banks, could offer bespoke support and obligation-free advice for autistic people so that they could achieve greater financial independence for themselves and their families.

 5. **More accessible and affordable adult diagnostic and post-diagnostic services** – many people expressed that they might have set about life very differently had they known that they were autistic earlier – that they might have been able to navigate crucial life choices differently had they been able to access services and supports (including the NDIS) with a diagnosis. We recommend, therefore, that further efforts continue to be made to protect, enhance, and increase existing, affordable diagnostic services for adults, as well as the provision of post-diagnostic support.

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Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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