Financial Wellbeing of Autistic Individuals

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Acknowledgements

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Summary

Autistic individuals are a significant minority in our society, impacting over 1 per cent of the population with numbers expected to grow substantially. Autism is characterized by a spectrum of neurodevelopmental differences and is a life-long diagnosis. The condition presents challenges to communication, social interactions and can be characterized by restrictive or repetitive behaviours. Autism is a complex condition and is often coupled with other health challenges such as anxiety or depression.

Despite extensive developments in treatment for autism which has improved wellbeing for autistic individuals, education and employment rates are still far lower than they should be and this leads to reduced participation in financial, social and consumer activities. It also means that autistic individuals and their carers are more likely to experience financial challenges and have limited access to opportunities for learning how to best manage their financial situations and improve their financial wellbeing.

Achieving financial wellbeing is important for everyone and it contributes to overall wellbeing and happiness. There is little known about the financial experiences, attitudes, behaviours and capabilities of autistic adults that affect their financial wellbeing.

This paper has two broad aims:

1. Explore the financial behaviours, attitudes and experiences of autistic individuals and their carers; and
2. Identify how financial education and financial institutions can support the strengths and abilities of these individuals to promote financial wellbeing.

The research was collaboratively undertaken by RMIT and the Cooperative Centre for Living with Autism (Autism CRC) and supported by ANZ. The study employed a co-design approach by including an autistic person in the research team. This ensured the topics, methods and results would be relevant and useful.

A qualitative study was conducted comprising five focus groups with a total of 16 adult autistic individuals and two focus groups with a total of 10 carers.

The key findings from the study are:

Defining financial wellbeing and independence

- The autistic participants viewed financial wellbeing as having an income; being free of financial stress; being comfortable; having extra money to spend; and having financial independence.
- Carers’ financial wellbeing was impacted by the stress and worry about the financial futures of those who depend on them for decision-making.

Challenges to financial wellbeing

- Financial hardship was commonly experienced by autistic individuals and their carers. Low levels of income and limited employment opportunities were the primary drivers of financial hardship. Carers of autistic people are grappling with financial challenges over and above those of other families due to high medical and living costs associated with autism.
• Autistic individuals are vulnerable to financial exploitation and scams.
• Co-occurring Obsessive Compulsive Disorder (OCD) often presents challenges to the financial and overall wellbeing of autistic individuals.
• Carers are concerned about the long-term financial futures of the person they care for. The financial support generally provided by carers included: giving financial guidance; acting as mediator between the person they care for and the bank; making some or all of the financial decisions for the person they care for; and providing partial or full financial support.
• Limited financial socialisation also plays a part in the lack of opportunity autistic people have to learn about and use money. The autistic participants expressed frustration at not knowing about general or everyday financial topics – such as paying rent, taxes or HECS.

Personal strategies and strengths for managing finances
• Some autistic individuals use simple strategies set up by their carers that allow them some autonomy in managing their day-to-day finances. These strategies can include clearly named accounts or ‘pots’ of money that are allocated for different expenses.
• Autistic individuals have many strengths because of their neurodiversity that were helpful in managing money. There is great potential for these strengths to be capitalised on if given the appropriate supports and opportunity.

Financial education topics of most value to autistic individuals and their carers
• Autistic participants were interested in learning about income and tax, how to make financial decisions and understanding debt. Other commonly rated topics were: avoiding scams, understanding mobile phone plans, choosing a bank account, understanding superannuation, knowing consumer rights, planning for the future and making an investment.
• The topics that carers were interested in depended largely on the needs of the person they cared for. Carers were interested in understanding income and tax, planning for the future, consumer rights, the National Disability Insurance Scheme (NDIS) plan and budget, knowing how to make financial decisions, using bank technology, Centrelink and benefits. Carers were also very interested in knowing how to create a model for independence, finding information about disability and other trusts, wills and contracts.

Learning financial skills: recommendations for financial education
• The autistic participants worried that they won’t be able to understand financial information when it is presented in the usual way because of their neurodiversity and its implications for information processing.
• Autistic participants said they preferred to learn by doing rather than just from a book.
• Many were anxious about the idea of assessments and were fearful of being ‘wrong’ or put in a situation where they could be criticised or ridiculed.
• Step-by-step, clear instruction was also preferred when learning new tasks or processes.
• Participants would like to see their own experiences and contexts reflected in case examples — a situation they can relate to.
• For workshop settings, recommendations included: small groups, quiet venue, shorter rather than longer in length, appropriately trained facilitators who understands the needs of autistic people.
Implications for financial institutions in supporting autistic individuals

- The autistic participants felt overwhelmed with the complex nature and volume of information they are confronted with when navigating banking tasks.
- Carers face barriers in trying to support the person they care for when they were not in all cases a signatory on the accounts.
- Autistic individuals commonly have high levels of sensory sensitivities causing many to experience distress in situations with bright lights, loud sounds, or crowds. Many participants avoid visiting a bank or other businesses because of this.
- Suggestions for banks included presenting banking processes in a clear, step-by-step manner.
- Bank staff could be made more aware of the needs of autistic people and how they can best be served. Overloading a person with lots of information and options frequently causes anxiety.

Conclusion

The autistic participants expressed a strong desire to learn more about money and viewed this as important for achieving or maintaining their independence.

Importantly, the study showed that the autistic individuals in fact possess strengths that are advantageous to managing money. With appropriate supports, these strengths can be capitalised on.

The neurodiversity that characterises autism presents a number of challenges in a world that is shaped for neurotypical people. Self-exclusion becomes the issue for some autistic individuals when the environment and social structures of work, consumption, and leisure are such that participation is unpleasant and stressful and invokes discrimination. Informed businesses that practise diversity can provide a greater range of approaches to task structure, service delivery and customer service that would suit an even wider range of individuals than just autistic people.
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1. Introduction

Autistic individuals\(^2\) are a significant minority in our society, impacting over 1 per cent of the population with numbers expected to grow substantially. The financial wellbeing of autistic individuals and their carers can be severely compromised due to the challenges associated with the condition caused by neurological differences. Autistic individuals face barriers to participating in education, employment and social activities which further reduces opportunity to develop financial capabilities, achieve financial goals and live a life that is aligned to their unique values, goals and meanings.

Financial wellbeing is an important subset of people’s overall wellbeing and capacity to live a comfortable life. It is generally thought of as being able to meet financial obligations, having enough money left over to enjoy life and the financial resilience to cope with unexpected expenses.\(^3\) The most important driver of financial wellbeing is income with other factors including capabilities, behaviours, psychological traits and attitudes.

We rely upon money for housing, eating, travelling, education, working, leisure, social acceptance and ongoing standards of living. It would be reasonable to expect that everyone should have the opportunity to learn how to use money. However, society’s expectations of people and money operate more like a map without a compass. Managing our financial lives can be complex and confusing and even more so for people that face barriers that come with disability and learning difficulties. For autistic individuals, the neurological differences characterising their condition, can make processing complex information extremely challenging.

Autistic people possess many valuable skills, abilities and strengths that are not readily recognised by society. They also face difficulties with socialisation and communication, and frequently exhibit restrictive or repetitive behaviours that present barriers to participation in everyday activities\(^4\). There is a great deal of mismatch between the financial, consumer worlds’ operational systems and how autistic individuals interact, communicate and learn. Identifying the unmet financial capability needs of autistic people is important for their inclusion and financial wellbeing.

The importance of developing financial capabilities has expanded considerably over the last decade\(^5\). While there is increasing research on improving the financial capabilities for individuals in many contexts there has not been much, if any, attention given to understanding the financial lives of autistic people.

There is little known about the financial experiences, attitudes, behaviours and capabilities of autistic adults. We do not know what barriers they face in their financial lives or how neurodiversity affects their financial wellbeing. We also do not know how the financial services sector can best support autistic individuals to promote their financial inclusion. What are the strengths and gaps in autistic individuals’ financial knowledge and skills? How can financial education be best delivered to ensure that autistic people have the confidence and abilities to participate safely and effectively in the financial world?

This paper will:
1. Explore the financial behaviours, attitudes and experiences of autistic people and their carers; and
2. Identify how financial education and financial institutions can support the strengths and abilities of autistic individuals to promote financial wellbeing.
2. Background

Over the last 20 years, the number of people diagnosed with autism has increased 25-fold.⁶ Autism is a neurodevelopmental condition that impacts more than 1 per cent of Australians and is more likely to affect males than females.⁷ Autism is a life-long condition that influences how individuals perceive, process and express their experiences of the world.

Autism moreover occurs on a spectrum, which implies gradations in neurodiversity and hence behaviour. Some autistic individuals experience severe speech impairment and developmental delays, while others have average or above average IQs. There are clusters of difficulties, of varying degrees, in the areas of social-communication. Characteristics also include restricted and repetitive patterns of activities, narrow interests, and sensory sensitivities.⁸

Autistic people commonly have difficulty in reading facial expressions and body language, problems adapting to change, a need for routine and predictability, being very sensitive to noise, smells, movement, visual stimuli, and feeling highly stressed in busy, chaotic environments. Research also suggests that these individuals have low levels of self-efficacy resulting from social-communication challenges⁹ or encountering discrimination. This can have detrimental impacts on their employment and education outcomes.

In addition, autistic individuals are often diagnosed with conditions that affect their mental health and exacerbate the challenges and barriers to participating in everyday life. Common co-occurring (co-morbid) diagnoses include anxiety, depression and obsessive compulsive disorders.

The more commonly discussed neurodiverse characteristics of autism usually pertain to its limitations and deficits. However, there are many strengths and abilities associated with autism such as high attention to and strong memory for detail, enjoying repetitive tasks, and unusual abilities to detect patterns in complexity (systemising).¹⁰ These traits can be advantageous to financial management if individuals are provided with appropriate skill development and opportunity.

Auticon¹¹, a company that employs autistic people, has identified the following spectrum strengths that are valuable to business:

- Logical and analytical abilities
- Sustained concentration and perseverance even for repetitive tasks
- Loyalty, conscientious and sincerity
- Exceptional eye for detail, differences and errors
- Awareness for quality
- Strong interest in factual matters and technical expertise

Enterprising businesses like Auticon demonstrate that - properly harnessed and with support provided to manage traits that limit the opportunities for autistic people to learn about and use money - the economic and social advantages to these individuals, their families and society could be substantial.¹²
Impacts of autism on individuals and families

During the last twenty years, gradual but significant changes in society’s autism awareness and service provision have improved the overall wellbeing of autistic adults.\textsuperscript{13} However, there is still a significant volume of evidence that shows many autistic adolescents and adults continue to experience unsatisfactory outcomes for employment, friendships and living arrangements. A nation-wide study of American, autistic individuals and their guardians found that only 34.7 per cent of youth had a tertiary education qualification while 55.1 per cent had held paid employment within the first 6 years after finishing high school.\textsuperscript{14} Similarly, autistic individuals in Australia are far less likely to complete tertiary studies than those without autism or those with other disabilities.\textsuperscript{15} The workforce participation rate of autistic people (15 – 64 years) is 40.8 per cent compared to 83.2 per cent of those without autism or other disabilities.\textsuperscript{16}

In Australia, the annual economic cost associated with autism has been estimated to range between $8.1 billion and $11.2 billion. This cost is borne by autistic individuals, families, community, and government.\textsuperscript{17} A Western Australian study found the median family cost of autism was estimated to be $34,900 per annum,\textsuperscript{18} most of which was due to a loss of income in order to care for an autistic child. Numerous international studies disclose that parents of autistic children experience higher levels of stress and higher frequency of mental health conditions compared to parents of typically-developing children and parents of children with other disabilities.\textsuperscript{19}

Financial capabilities and behaviours of autistic individuals

To date, there is little published research examining the financial capabilities and behaviours of autistic individuals. Topics about finances are sometimes included in programs for young autistic people transitioning from school or university to work.\textsuperscript{20} Programs that are developed, usually at university or college level, are specifically aimed at increasing graduates’ employment outcomes. They can include managing money as a topic along with other life skills.\textsuperscript{21}

If autistic individuals are not given the opportunity to develop financial capabilities and the confidence to interact as consumers, they are less likely to be able to live independently. A recent US qualitative study\textsuperscript{22} examined the financial capabilities of autistic youth and found that the participants associated living independently with having the ability to manage their money. The young people expressed concern that they did not have adequate financial skills and saw this as a barrier to achieving independence. The participants in the American study wanted access to financial education and saw this as being important to achieving their financial goals.\textsuperscript{23}

Lower levels of education, limited employment outcomes and social interaction challenges have reduced the opportunity for young autistic people to learn life skills in general, including how to manage money.\textsuperscript{24} Participating in today’s society requires the development of financial skills, knowledge and confidence in carrying out every day financial transactions and also learning how to set longer-term goals that contribute to their wellbeing. Autistic individuals – in view of their growing incidence - should not be excluded from improving their capacity to earn income and self-determine their lives.
A growing body of research and business start-ups extol work-ready autistic individuals while identifying enablers, challenges and outcomes. Employment is critical to their independence, increasing self-efficacy, and enhancing social interaction. Such efforts should be wider-scale, accompanied by commercial and government strategies and governance frameworks to build financial capabilities and increasing opportunities for autistic people as contributors and consumers.

In exploring ways to enhance financial wellbeing for autistic people, it is appropriate to initially focus on how their unique traits and characteristics can be advantageous to money management habits and choices. It is also important to identify flags or issues that are potentially detrimental to these people’s financial wellbeing, such as problems conceptualising money. In what ways do they do this differently? What are the financial enablers, challenges and outcomes for autistic people? How can the differences be utilised or if necessary managed, to engender financial wellbeing? What types of financial information is most useful and how should this it be best presented to autistic individuals?
3. Research methodology

This project was conducted by RMIT and the Cooperative Research Centre for Living with Autism (Autism CRC) with support from ANZ. The research employed collaboration and co-design approaches so that research topics, methods and results were relevant and useful. Ours included an autistic researcher to ensure that the approach, materials and language used were appropriate and relevant to autistic participants.

Autistic individuals and carers were recruited for this study through Aspergers Victoria, the Equality and Diversity Department of La Trobe University, and through word of mouth in relevant networks. Interested individuals contacted the researchers and were provided with information about the study and a consent form.

We held five focus group sessions with a total of 16 autistic individuals and two groups with 10 carers in total. The sessions were held at RMIT University in Melbourne CBD and La Trobe University, Bundoora and participants could choose the location most convenient for them.

The focus groups with autistic individuals were deliberately kept to a small size with an average of about three participants in each group. Rooms for the focus group sessions were carefully selected, taking into account conditions often experienced by autistic individuals such as sensory hypersensitivity. We chose rooms that were quieter, with solid rather than glass walls to reduce noise levels and exposure to outside activity.

All focus group sessions ran for 1 to 2 hours. All participants were offered a $50 Coles-Myer voucher as a token of appreciation for participating in this research.

Before the focus group discussion commenced, all participants were asked to complete an anonymous questionnaire requesting demographic and diagnostic information and an indication of the type of financial knowledge and skills they were interested in knowing more about. Carers completed an additional questionnaire to measure stress, anxiety and depression levels.  

The focus group sessions’ with the autistic individuals included discussion about general feelings about financial wellbeing and money; confidence in using money; challenges faced; and the type of financial decisions for which they are already responsible. We asked about existing supports to help with managing their money, how participants learned about money and the financial topics they wanted to know more about.

The sessions with carers included a discussion about financial wellbeing; their financial responsibilities for the person they care for; challenges faced; their strategies for managing money; and knowledge of supports available to them.
4. Research participants

Three pairs of carers and autistic individuals participated in our study. The 16 autistic individuals participating in the study were aged between 17 and 67 years with an average age of 30. Nine participants were male and seven were female.

The 10 carers participating in the study were aged between 42 and 69, with the average age being 54. There were three male and seven female carers.

Autistic individuals

The autistic individuals each self-reported a diagnosis of autism, with the majority identifying as having Aspergers Syndrome (9).\(^1\)

The majority of individuals reported at least one co-occurring mental health condition (see Table 1). Most of the autistic individuals indicated they also experience anxiety (\(n=12\)), depression (\(n=9\)), and obsessive compulsive disorder (\(n=5\)). Most of the participants had at least two co-occurring conditions.

**Table 1. Autism diagnoses and other mental health conditions**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-reported diagnoses</strong></td>
<td></td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>3</td>
</tr>
<tr>
<td>Aspergers Syndrome</td>
<td>9</td>
</tr>
<tr>
<td>High Functioning Autism</td>
<td>4</td>
</tr>
<tr>
<td><strong>Co-morbid conditions</strong></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>12</td>
</tr>
<tr>
<td>Depression</td>
<td>9</td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder</td>
<td>5</td>
</tr>
<tr>
<td>Speech/Language impairment</td>
<td>2</td>
</tr>
<tr>
<td>Sensory Processing Disorder</td>
<td>2</td>
</tr>
<tr>
<td>Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder</td>
<td>2</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>1</td>
</tr>
<tr>
<td>Post-Traumatic Stress Disorder</td>
<td>1</td>
</tr>
<tr>
<td><strong>Number of co-morbid conditions</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>One</td>
<td>2</td>
</tr>
<tr>
<td>Two</td>
<td>7</td>
</tr>
<tr>
<td>Three</td>
<td>3</td>
</tr>
<tr>
<td>Four</td>
<td>2</td>
</tr>
</tbody>
</table>

\(^1\)Methods and classifications of ASD have changed over time and diagnoses such as Aspergers are now included in the one spectrum.
All autistic individuals spoke English at home and most were born in Australia, with three exceptions (China, New Zealand, and Serbia). One individual identified as Aboriginal.

The highest levels of education attained were: some high school (n=1), all of high school (n=6), TAFE/Diploma course (n=3), undergraduate degree (n=3), and postgraduate degree (n=3). Four participants were in a relationship. Most participants were working part-time (n=7) or studying (n=7).

Most individuals were either extremely satisfied (n=4) or somewhat satisfied (n=9) with the level of support they have received from family and friends. In contrast, less than half of individuals (n=7) were satisfied with the level of support they have received from community support agencies. When participants were asked which area they need more support in, more than half indicated employment support/work skill development (n=9) and money management/financial literacy support (n=8). Other support needs indicated by participants were mental and general health (n=6), dating and friendship (n=4), school/learning (n=3), life skills (n=3), social and communication skills (n=2), support for older people (n=1), and emotion regulation (n=1).

Carers of autistic individuals

Only one carer had an autism diagnosis. The carers all spoke English at home and were born in Australia, with the exception of one parent who was born in Malaysia.

Most carers had completed an undergraduate (n=3) or postgraduate (n=5) degree, and two had completed a TAFE/diploma course. Half of the carers were working full-time, three worked part-time, one was looking for work, and another had started a business. None of the carers were studying at the time of attending the focus group sessions.

The majority of carers had at least one dependent living with them and more than half (n=6) had a partner (one autistic partner). Carer information is detailed in Table 2.

Carer stress levels in this study were identified through carers’ self-reported responses on The Hospital Anxiety and Depression Scale (HADS). The HADS is a norm-referenced questionnaire used to detect states of anxiety and depression. It contains 14 items, with 7 items forming the Anxiety subscale (HADS-A) and 7 items forming the Depression subscale (HADS-D). Scores for each subscale range from 0 to 21, and scores are categorised as: normal 0-7, mild 8-10, moderate 11-14, and severe 15-21. Just over half of the carers in our study had normal levels of anxiety and depressive symptoms. However, one carer had mild anxiety and normal depression, two carers experienced moderate anxiety and normal depression, and one carer reported severe anxiety and severe depression.
Table 2. Characteristics of the individual being cared for

<table>
<thead>
<tr>
<th></th>
<th>Frequency (unless otherwise specified)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender (female / male)</strong></td>
<td>2 / 8</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>Average = 28; Range: 12 - 57</td>
</tr>
<tr>
<td><strong>Carer relationship</strong></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>6</td>
</tr>
<tr>
<td>Father</td>
<td>3</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
</tr>
<tr>
<td><strong>Self-reported diagnoses</strong></td>
<td></td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>6</td>
</tr>
<tr>
<td>Autistic Disorder</td>
<td>2</td>
</tr>
<tr>
<td>Aspergers Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>High Functioning Autism</td>
<td>1</td>
</tr>
<tr>
<td><strong>Co-morbid conditions</strong></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>8</td>
</tr>
<tr>
<td>Depression</td>
<td>3</td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder (OCD)</td>
<td>2</td>
</tr>
<tr>
<td>Speech/Language impairment</td>
<td>5</td>
</tr>
<tr>
<td>Sensory Processing Disorder</td>
<td>4</td>
</tr>
<tr>
<td>Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder</td>
<td>2</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>6</td>
</tr>
<tr>
<td>Prosopalgia</td>
<td>1</td>
</tr>
</tbody>
</table>

More than half of the carers were either extremely (n=3) or somewhat (n=3) satisfied with the level of support they receive from family and friends. Two carers were either somewhat or extremely dissatisfied. When it comes to the level of support received from community support agencies, four carers were somewhat satisfied and three were either somewhat (n=2) dissatisfied or extremely dissatisfied (n=1).
5. Defining financial wellbeing and independence

Autistic individuals (herein termed “individuals”) were asked what financial wellbeing meant to them. The responses included ‘not being in financial stress or struggling’, ‘being comfortable and having extra money to spend’, and ‘financial independence’. The descriptions of financial wellbeing provided by the participants reflected the research definitions currently used.\textsuperscript{30} It is generally agreed that financial wellbeing is “being able to meet current commitments and needs comfortably, and have the financial resilience to maintain this in the future”.\textsuperscript{31}

\textbf{Individual\textsuperscript{2}:} I guess financial wellbeing to me, it’s sort of like, having a stable income, just being able to manage money, being able to make sure you don’t overspend. You’re managing it well. You have some put aside in case of emergency...making sure that you’re financially prepared for the day-to-day and anything that may come up in between.

\textbf{Individual:} It means to be financially comfortable so I can afford things - that I don’t have to worry about that I can’t afford certain things and also to be employed as well.

\textbf{Individual:} For me, not having to worry that I might not have enough money to buy the things I have to have. My bills, my rent, my food. I’m a student, I live off Centrelink income. There is no way that’s going to turn into a home loan. So as long as I can get through my degree, tide myself over until a point when I am making a reasonable salary. From there, that’s when my priorities change because at that point I don’t have to worry about, “do I buy the expensive bread? Do I buy the home brand?” It’s “how many loaves of the nice bread do I buy this time?”

Striving for and maintaining financial independence was a common desire for participants. They also affirmed the important role that managing money effectively plays in achieving that goal.

\textsuperscript{2} Extracts from the focus groups use the following conventions:

- Words omitted to shorten quote: ...
- Explanatory information added by authors: [text]
- Multiple speakers: Individual 1, Individual 2 etc.
Individual 1: My mum’s not going to be around forever ... I do need to support myself. If I don’t have any money, how am I going to keep a roof over my head and have enough food and all that sort of thing? So, to me it’s important ... I feel like there’s obviously more things I should know about money, like how to manage it independently and wisely and make the right decisions.

Individual 2: I don’t live with my family. I live alone. I have to pay for everything myself. So I work. Three nights a week, I take on extra shifts ... I just buy all the cheap stuff. I freeze my bread so it lasts longer. So I just have toast.

“Another participant recognised that her strength in practical thinking can help her to achieve independence.

Individual: I’m a very practical thinker. I want to learn ... I want to be as independent as possible so I want to learn all that stuff and understand it.

A number of individuals expressed concern about their ability to achieve financial independence.

Individual: I think about what will happen when I get a full-time job and how I’ll be financially independent and what that will mean for me. I mean, when I’m financially independent, my dad’s probably not going to want to give me money ... Makes me feel a little bit concerned, but also happy because I’ll have financial independence.
6. Challenges to financial wellbeing

Throughout the focus group sessions, the individuals and carers talked about a range of financial challenges to their wellbeing and abilities to managing money. Not all of the challenges are internally generated; some challenges are externally-driven and not in the individual’s control. However, this makes awareness and knowing how to deal with environmental factors that affect financial decisions even more important.

Individual: Money and me don’t get along. I think money’s like the big elephant in the room. I know it’s there, but I don’t often talk about it. I live fairly hand-to-mouth, really ... I rent a room off [my carer] to live. It’s been quite a bit of latitude, but she’s always my safety net. She’ll sort of let me know when I’ve gone too far or backslid, let me know before I go too far most times, but I’ll sneak one past her occasionally ... I’ve been homeless. I’ve lived on the streets ... My dog’s put a big dent in the funds, but [my carer] doesn’t mind that. Yeah, I think money and me, we just agree to disagree.

Individual: I suck at budgeting ... I missed an entire month of rent ... I’m grateful my family pay, almost probably about 80% of my rent, because I got kicked out of home. I’m in a tiny little one bedroom thing, but I pay a percentage of my rent. And if I’m not on time, my family will pester me. And I felt so bad. And then I forget that I have bills coming up.

Individual: I think a lot about this [financial wellbeing] which is why I was interested in the study. It’s basically knowing how to manage my money properly, which I’m not terrible at but I could be better, and understanding financial kind of terminology. Because I can’t sometimes, get my head around it. I’m actually pretty smart but I just can’t get around certain things. For some reason, that part of my brain isn’t functional.

Financial hardship

Financial struggles and hardship was another challenge raised by both carers and individuals. The financial vulnerability and risk of poverty for people who are under-employed, or who have ongoing medical costs due to disability or long-term health conditions is well documented. For carers, the economic cost of having an autistic child is substantial, creating long-term financial impact on families. A mother described her difficulties:

Carer: Challenges at the moment are with my son’s emotional regulation issues. He can no longer attend school full time...so we can’t both work. My husband is only working two days a week - it’s all his job allows for ... there’s the issue of me also being autistic and I burnt out a couple of years ago ... And, I can only work casually now and that’s difficult in itself. So, the lack of income combined with the lack of being able to go out and seek a job that’s actually going to pay bills more, has been a huge part of it.
An individual also spoke about the financial difficulties experienced by his family.

**Individual:** Money's always been a big thing for our family because of the fact that my mum is single and my dad doesn't financially support us, and neither does my sister's dad. Mum's sort of fending on her own and she has to juggle looking after us, trying to find a job, and it's just ... every penny counts. Every penny counts with our family.

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**Exploitation and scams**

Autistic people are often known to have high levels of sincerity and trust in others. These are admirable traits and are considered to be strengths. But when coupled with difficulties in reading emotions in other people, these traits can leave them vulnerable to being exploited and scammed.

One mature-aged individual discussed the life-changing experiences of losing his house and a financial scam that led to him moving back with his parents and developing mental health issues.

**Individual:** I've lost confidence in managing money ... Throughout school and throughout uni, my parents were really managing my money for me. I didn't really have a part-time job or anything. I was just racking up big school fees and uni fees for my parents to pay. I only really started working after I graduated. That's when I really started making money, my own money. The first thing I did, I paid back my parents for the uni fees, so I was left with not much money in the first few years of work. I suppose in an attempt to be financially independent, around the age of 27 I had to move away from home for work purposes and I was faced with rent and bills when I left for the first time.

After a few years, I thought I was confident in managing my own money. Then after I'd been renting a place for a few years, the landlord offered to sell the unit to me. After that point, that big decision, things went downhill for me with my money management ... I didn't do my homework. I didn't really know what homework to do, what questions to ask, who to get advice from. I rushed into that decision and probably paid a bit more than I should have. I could have bargained for a lower price. That was one major decision I probably should have thought about more carefully.

Then after that, just to compound things, I was approached by a tradesman who turned out to be a conman. Basically, I lost all my life savings... That set the downward spiral for me from the age of 32 and then I had to quit my job because I was just having a mental breakdown. I could not keep up with the mortgage payments because of the financial ruin that I'd brought upon myself and my family and I had to move back into my parents' home when I was about 33/34. Then I was out of the workforce for two years because of my mental breakdown.
A few other individuals had experienced financial scams, including sharing account details with others, and signing up to monthly purchases for products such as food delivery boxes, without realising the ramifications of on-going payments:

Individual 1: If you’re on the autism spectrum, you’ve got the same problems as everybody else, the scammers. [We’re] not immune to scammers as well. You sign up for something, but you keep on getting it. That should be banned. That’s got nothing to do with autism … We’re just more vulnerable to it than most. There should be more regulation to help people with scams [and deal] with people trying to scam them.

Individual 2: Really, we are more susceptible because we’re more naïve in a lot of things. We can’t believe that somebody’s out to get me, someone’s out to steal from me. We can’t comprehend the notion that someone would lie to me, steal from me.

Compulsive behaviour

Obsessive Compulsive Disorder (OCD) is a common co-morbid condition experienced by autistic people. While compulsive behaviour is also experienced by neurotypical people, causing just as many problems when it comes to spending, for people with diagnosed OCD, the symptoms and outcomes can be more extreme.

During the focus group sessions, the challenge of compulsive spending was raised many times:

Individual: I haven’t developed that skill to restrain how much I actually spend. Sometimes I’ll go to check my bank account and it’s like, "Dammit, I don’t have enough money to pay for food for the next few days". It’s like that. It’s just like there’s always food in the house, but if I want to go out with a mate, that type of thing.

Individual: If I’m really obsessed about something. Like I might be obsessed with getting this video game or … Not so much these days, but in the past, I might think, “Oh, this is great, I want that game. I really want that game. I need it. Oh, my God”, and I can’t stop thinking about it. “It’s the best game in the world. I’ll buy it. Yeah. I need it immediately.” And it’s like I’m addicted to drugs or something. And then I get it and I probably could have waited until I had a bit more money.

Conversely, one autistic individual spoke about compulsive saving to the extent they would not buy food or other necessities.

Individual: I know it’s good in the way that I save money… but I found that actually for a while I couldn’t bring myself to spend money on food. I thought, “I had some snacks, they would keep me going” … I’m good at saving money, but I’m not sure if you’d call that good. Maybe, maybe not, - I don’t know.
Problems conceptualising money

A smaller number of individuals discussed their difficulties with grasping the concept of money. Having difficulties conceptualising ideas is considered to be a common barrier for individuals. It is important to note that the sixteen individuals who participated in the focus groups are of varying cognitive capacity, and therefore their abilities to conceptualise and understand money will also vary.

Following are two examples of how autism can affect individuals’ abilities to understand financial concepts.

Individual 1: I have trouble comprehending past $1000. After that, it’s just too much information. So processing all this information is quite ... It’s kind of like your brain shuts down. It just goes blank. Whereas if you get step-by-step structure, then it’s easier to process. You go, that’s step one. Go through step one. Then after that you go to step two and process that. So it’s slower and kind of more direct way to learn all those things.

Individual 2: It’s like there’s a wall in my mind where the neurons can’t get through or something, in terms of understanding. Like I understand it best, more than I used to, in terms of money, spending, like basic kind of money with cash, but things like forms... and superannuation and how debts work, and benefits, and all the stuff. That’s confusing to me, and it’s not that I try to avoid it, I try to understand it, but it can be difficult and I remember it took me ages to understand currency, differences in currency.

Other challenging situations cited were:

- Bad financial habits passed on from parents
- Compulsive tracking of bank account details or personal loans
- No knowledge on how to get paid for contractual work
- Being too trusting
- Fined by bank for late fees without realising the reason
- Missed payments leading to penalty fees
- Feelings of financial inadequacy due to peer pressure
- Coin sensory sensitivity led to giving away of coins
- Credit card tap and pay feature led to going over budget
- Accidentally setting up a bank account with fees
Carers’ difficulties in helping with banking

As most of the individuals were dependent on the support and advice of their parents or carers, it was important for carers to be able to access the individuals’ bank accounts. However, there are of course privacy and protection guidelines that banks must adhere to and many of these are to protect the account holder. Financial abuse and exploitation is a concern among vulnerable groups. While these safeguards are critical to safe banking for most people, they do create difficulties in the situations faced by carers in trying to support the banking needs of the person they care for.

Carer: When we set up that model [of bank accounts], [the bank] didn’t ask that question [around privacy]. But when I have a blow-up once every seven months, like [my daughter] lost her PayPal account, had a dispute with the account...and there’s about a thousand dollars of disputed charges. But I can't talk to [the bank directly]. So I spoke to the [bank] manager. And then, I ask them, will you please get [my daughter’s] permission to talk to me. Because, I just haven’t got time to get down and fill out the paperwork to get power of attorney.

Carers’ levels of financial responsibility

With the exception of a few individuals who have been able to achieve independent living, most individuals - both young and older - were largely financially dependent on their carers. The range of financial supports provided from carers to individuals included:

- Providing financial advice
- Acting as a mediator between the individuals and banks
- Making some or all financial decisions on behalf of dependents
- Offering partial or full financial support

A carer discusses her charge’s financial support needs:

Carer: Perhaps it’s different for me because I’m a carer and a friend, and the person that I care for is 57 years old. When we first met, he was in quite bad financial difficulties because he had not been diagnosed with autism at that stage. He has only been diagnosed in the last seven or eight years. So it took quite a while to fix up all his finances and now it’s really me that keeps an eye on it all.

I see him as still working towards his independence. He gets his pension - I let him do what he wants with that money and I pay all the bills and keep everything going. He contributes and that’s what I ask [of] him. What do you feel comfortable in paying? But he is no good at saving... His idea of saving is, “wait an hour and I'll go back”. He wants it when he wants it. We have to negotiate because we don't have a lot of money.

In regards to the fact that I may pass away before him, we have organised all the power of attorneys - medical, financial, everything at this stage - it’s one of my family members who will do that. But we have a back-up plan where we have a solicitor and an accountant who he knows will help keep an eye on him as well, because he won’t manage at all... He doesn't go out and spend a lot of money, but he just doesn't have the concept about when it runs out.
Due to the extent of the financial guardian support provided by carers, worries and concerns were raised around the financial wellbeing and independence of the person they care for when the carers pass away.

**Carer 1:** I think long-term for our kids who can never be financially independent when we’re gone - it is a worry about who is actually going to take over like everything, all their care. But financially as well. I personally don’t want to put it in the hands of some government body because...it’s quite restrictive from my understanding. But also, they don’t have our kids’ best interests, it’s just a bit of paper really. If we don’t have extended family who may be there to help...that becomes really problematic. Who do you actually get to look after the finances plus everything else as well? So, it becomes really tricky and worriesome for most of us.

A young participant was also aware of his mother’s concern for his long-term financial independence.

**Individual:** I think a lot about my future because I live with just my mum and I’m just a single child. My mum and I rent and even with the two of us, we struggle financially, but we still pay the bills and buy the food and pay for water and gas and electricity. We still manage, but my mum worries a lot about what’s going to happen to me when I’m older or once I finish school and stuff. I haven’t even found a job that I want to do yet.

**Limited financial socialisation**

The most important vehicles for financial socialisation are family, school and work. The majority of the individuals in our study said that most of their understanding about money came from their parents. While this is true for most young people, for those who aren’t autistic, the home is just one avenue for learning. Financial socialisation usually includes other opportunities – school, learning through doing, and the workplace. These contexts are often not available to autistic people to the same extent as they are for those without autism.

Individuals in our study reported that the topics they mostly learned from their parents included bank accounts, credit cards, loans, rent, wants and needs, and saving.

**Individual:** Rent was something that was introduced through my parents. They explained that, because I heard the term “rent” and was like, “What’s renting?” And they’d go, “Oh, you can pay to just live in a house, but you don’t own the house.”

Although parents provided some financial education, there were still learning gaps, described by one individual who had received financial teaching from both her parents and her bank.
**Individual:** It's mainly my parents that really informed me, and then when I went to the banks, my bank in particular, explained to me what the process was, what I actually do. I have absolutely no knowledge at all when it comes to taxes... or HECS... my school [didn't] actually explain very well what HECS meant, and so when I got to uni, I was a bit lost. I was supposed to pay this $250 thing.

Other approaches to financial education included self-learning through the internet and personal experiences, speaking with friends or other people.

Some individuals in our study did remember some key lessons about money they learned in school.

**Individual:** I think the earliest concepts, when it comes to school in terms of education, was needs and wants. That's probably the first thing that I've learned: needs and wants. That completely went out the window, though...

**Individual:** First, I was learning about money at primary school... we all had the plastic money and stuff and we used to practise with it... The teacher would make up scenarios... Like if something costs $5.00, then you'd have to give them the amount of change to make it back up to $5.00 again.

Autistic participants were adamant that there should be more opportunity at school to learn about money and how to survive in a financial world. A few individuals felt very let-down that they didn’t learn about money earlier in life and wished that they had more lessons to do with money at school.

**Individual:** It's ridiculous in high school that they teach you all this rubbish you're never going to need and then they didn't teach you about taxes or managing money or, managing a household. It's ridiculous how little...practical life stuff is just not even touched by high school because algebra is more important.

An older individual shared his difficult life experiences resulting from an early lack of financial education.

**Individual:** To me, it's getting the right type of education to the individual right at the beginning, so that they can have a better grasp and not be like me, where I have come out of work... And I've got no super, nothing, and I'm having to live on a pension. I’ve got that much debt. I’m having to sell the house... But, it's getting to individuals early enough so they can get a grasp of the importance of money... and finding the balance with life. Because too often people just don't have the education or understanding how to use money as a tool.
7. Personal strategies and strengths for managing finances

Autistic participants spoke about a range of strategies they used for managing their money. A few used separate bank accounts for saving money. The parents of one individual helped her set up three bank accounts for different purposes – everyday transactions, living expenses and savings goals.

**Individual:** And I’ve got three accounts, a little account, a big account and a savings account ... So, the little account is my access account. That means that I can access that from an ATM. And the other two accounts, it means that I can have my budget across the three accounts. So I can have my daily living costs in my little account. Things like my rent and bills and petrol for my car come out of my big account. And then my savings account has things, like, if I need a new car, or if I want to go overseas.

Another individual uses his obsessive compulsive traits to his advantage in terms of financial management and daily living skills. This demonstrates the potential that autistic people have in building financial capabilities. Undertaking tasks such as budgeting can for most people seem repetitive and tedious, but many autistic individuals excel at these types of financial management tasks. Remembering patterns or numbers is also likely to be a skill.

**Individual:** Over the past eight years or so, I think I’ve really learned to optimise my autism to help with my finances. Like, I’ve figured that, “Okay, I get fixated on things.” Let’s kind of weaponise that, and let’s use my fixation and my obsession with numbers and tracking detail and stuff to manage money ... I guess I just notice all these things, like all the little rituals and things that I’ll do. I would try to walk to the shop and I was thinking, “Why am I trying to get to the shop and back without stepping on the cracks in the pavement?” It was like, if I want to set myself a challenge, why don’t I set myself a challenge of, “Hey, don’t spend more than $25 every time I go to do this.” ... Every day I have to go check in all the cupboards in the house. I was thinking, “Hey, why don’t I make the challenge that every day I have to pick up the rubbish on the floor every day, or do 10 push-ups a day or something? Why don’t I trick that compulsive part of my brain and make it compel me to do helpful things?”

Another individual spoke of his ability to memorise details for his money management strategies, but also how relatively minor irregularities cause him enormous anxiety.
Individual: I get really anal about exact amounts. If I borrow $23.97 from someone, I pay them back $23.97. And I expect the same of other people. You know, my desk is a mess. My clothes are a mess. But my bank accounts are pristine. Any time numbers are involved or there’s any form of mathematics involved, it has to be perfect.

So I’ve learned very quickly that because I use my debit card for things, if something comes out, it’s not automatically reflected in my bank balance. It says “EFTPOS debit of this amount” but it doesn’t tell me where it’s from. That takes a couple of days. I’ve learned to memorise exactly how much certain regular things are that I take out. So that at the end of every day, I look in my bank account ... And if something doesn’t match up, I start to freak out. I go nuts.

Autistic participants’ quest to learn was high. Realising that money is key to their independence, they are thirsty for knowledge and to learn how they can manage better. It was certainly clear, though, that they were not without existing strategies or habits already developed. It was also evident there were strengths that could be capitalised on, to help them achieve and maintain independence.

Individual: I’m a very practical thinker. I want to learn all the topics. I want to be as independent as possible so I want to learn all that stuff and understand it.

Individual: I’ve always been a saver. I always try and save as much as I can ’cause I love travelling. I like to spend money on big things, so I always have been a saver, I guess.

Individual: I think I’m good at managing money because I have good self-control, and I’m organised, and I don’t spend much money on many things as well.

Other financial management strategies used by individuals include avoidance of spending leaks, i.e. unplanned spending of small amounts, budgeting and sticking to routines, not using credit cards, and relying on parental guidance for money management.
8. Perceptions of the role of financial institutions in supporting autistic individuals

Carers and individuals shared many thoughts and experiences about how financial institutions can better support them. The majority felt that banks and other services do not cater well for their needs. The complex nature and volume of information that individuals are confronted with when trying to transact was often overwhelming and best left to their carers to organize. Carers however also faced barriers in trying to support the person they care for when they weren’t in all cases a signatory on the accounts.

One carer had positive experiences working with her bank to support her autistic child. She attributed this to one particular bank manager, who had knowledge of her child’s disability.

“It’s just too much information..... Whereas if you get step-by-step structure, then it’s easier to process. You go, ‘that’s step one. Go through step one’.”

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**Carer:** I went to open a bank account for my young man - who is a non-decision maker, I had a great bank manager and he knew someone that had a significant disability, which makes a difference doesn’t it. Because he understood exactly where I was coming from. And when [my son] turned 18, I’ve had no issues with the bank because... he's been identified as a non-decision maker and my husband and I are signatories on the account.

A few individuals expressed their distrust and negative opinions of banks and their perception of banks’ conflict of interest in providing financial education.

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**Individual:** It's probably a bit cynical, but I think banks teaching you financial skills is like the fox is teaching chickens life skills.

**Individual:** You go to your bank, but they've got a vested interest as well. Everyone seems to have a vested interest.

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A large number of carers raised the question of the banks’ role in supporting autistic individuals (or people with disabilities) and extended responsibilities that go beyond providing traditional bank products and services. These include staff having an understanding of challenges experienced by individuals, banks providing tailored services to individuals to minimise risks of fraud and over-spending, and banks allowing, with adequate safeguards, carers to assist in financial management of the person they care for.
Carer: What role does the bank have if you go to the [bank name], and they’re the ones that loan the money? What role do they play in ensuring it’s the right loan? So, you know, when they’re dealing with these people and their extra challenges, what role do they play? Does it need to be some sort of legislative ... some law that says they have certain extra protections because of their vulnerability?

Carer: We need to educate [banks that] we don’t all fit in the same box... You should be able to go in and there should be a line to say, “here I am, this is the line I fit into, and I’m going to have a great person I can speak to that’s going to help me”.

Carer: The bank can help them by, you know, putting in apps or putting in types of products that will send the money to the rent, send the money to here, send the money to there. But the problem is, like before, I said you know, you can have a square box that says, "I’m autistic." You tick it. The problem is when that person ticks it, they might get help but they’ll most likely be discriminated against. The bank will say, "Oh, he’s a risk. She’s a risk." “They’re a risk because of the autism.” So, what do we do?

“We don’t have filters to help us or awareness so we might get other people’s emotions as well that we’re processing without realising it. So we might have a meltdown at a branch and having staff understanding what’s going on and having a place like a sensory room at a branch could be very helpful.”

Autistic individuals often have sensory sensitivities, causing many to experience distress in situations with bright lights, loud sounds, or crowds. A participant commented that due to these sensory sensitivities, autistic people have different preferences for engaging with the banks and that individuals should be given a choice.

Additionally, staff could be made aware of the characteristics that autistic individuals may display and know how to reduce the anxiety and sensory overload for autistic customers.

Individual: I personally like a person to talk to. Other autistic people might prefer a computer to speak to if they’re tech-savvy, which younger generations definitely are. However, walking into a bank, there’s a lot of processing. If we need to stand in a line, then that’s a sensory thing where some people might stand too close to us. Every time we step forward to get a way, the person steps forward to get closer. There’s a lot of emotions. We don’t have filters to help us or awareness so we might get other people’s emotions as well that we’re processing without realising it. So we might have a meltdown at a branch and having staff understanding what’s going on and having a place like a sensory room at a branch could be very helpful.

Another focus group participant suggested that banks should be informed of autism diagnoses so that autistic people could receive appropriate support. For example, understanding that sensory hypersensitivity can cause problems in processing information will enable staff to know how to interact with and best help an autistic person. Overloading a person with lots of information and options frequently causes anxiety. Presenting a banking process in a clear, step-by-step manner will be helpful.
9. Financial education topics of most value to autistic individuals and their carers

We used the topics included in ANZ’s MoneyMinded financial education program as a basic guide to explore the interests of the participants. We asked participants to express their level of interest in the topics as presented in Table 3.

Table 3 shows financial topics that individuals were most interested in knowing about.

Most individuals were interested in learning more about income and tax, how to make financial decisions and understanding debt (band 1). The second band of topics included avoiding money scams, understanding mobile phone plans, choosing a bank account, understanding superannuation, knowing consumer rights, planning for the future and making an investment. In the third band, topics ranged from renting or buying a home, Centrelink and NDIS, credit cards, using banking technology, saving, budgeting and buying a car.

The fewest number of participants (though still about half) were interested in learning about pay day and online loans, saving up for something special and setting goals.
<table>
<thead>
<tr>
<th>Most commonly rated</th>
<th>Topic</th>
</tr>
</thead>
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| Band 1              | Understanding income tax  
|                     | How to make financial decisions  
|                     | Understanding debt  |
| Band 2              | How to avoid money scams  
|                     | Mobile phone plans  
|                     | How to choose a bank account  
|                     | How to plan for the future  
|                     | Know my rights when I buy things  
|                     | How to make an investment  
|                     | Understanding superannuation  |
| Band 3              | Renting or buying a home  
|                     | Centrelink and benefits  
|                     | NDIS and plan budget  
|                     | Credit cards  
|                     | Using banking technology  
|                     | How to save  
|                     | Doing a budget  
|                     | Buying a car  
|                     | How to plan my spending  
|                     | How to prioritise my spending  |
| Band 4              | Pay day and online loans  
|                     | Saving up for something special  
|                     | How to set money goals  |

For carers, their level of interest in topics depended largely on the needs of the person they cared for.

All carers in the focus groups were interested in understanding income and tax, planning for the future, consumer rights and the NDIS plan and budget. 9 out of 10 carers indicated interest in knowing how to make financial decisions, using bank technology, saving, investment, choosing a bank account, superannuation and Centrelink and benefits. Band 3 topics that interested carers included setting goals, planning spending, budgeting and knowing about money scams. Band 4 topics included credit cards, mobile phone plans, prioritising spending, debt and saving up for something special.

Less than half the 10 carers interviewed were interested in knowing more about payday or online loans, buying a car or renting and buying a home.
### Table 4 - Carers’ ranking of financial topics

<table>
<thead>
<tr>
<th>Most commonly rated</th>
<th>Financial topic</th>
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<tbody>
<tr>
<td>Band 1</td>
<td>Understanding income and tax</td>
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<td></td>
<td>How to plan for the future</td>
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<td></td>
<td>Know my rights when I buy things</td>
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<td></td>
<td>NDIS and plan budget</td>
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<tr>
<td>Band 2</td>
<td>How to make financial decisions</td>
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<td>Using banking technology</td>
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<td>How to save</td>
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<td>How to make an investment</td>
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<td></td>
<td>Understanding superannuation</td>
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<td></td>
<td>Centrelink and benefits</td>
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<tr>
<td>Band 3</td>
<td>How to set money goals</td>
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<td>How to plan spending</td>
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<td></td>
<td>Doing a budget</td>
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<td></td>
<td>How to avoid money scams</td>
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<tr>
<td>Band 4</td>
<td>Credit cards</td>
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<tr>
<td></td>
<td>Mobile phone plans</td>
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<td></td>
<td>How to prioritise spending</td>
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<td></td>
<td>Saving up for something special</td>
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<td></td>
<td>Understanding debt</td>
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<tr>
<td>Band 5</td>
<td>Pay day and online loans</td>
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<tr>
<td></td>
<td>Buying a car</td>
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<tr>
<td></td>
<td>Renting or buying a home</td>
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In addition, some individuals and carers identified other areas where they needed support, such as:

- Community support services funding
- The services banks offer
- Increasing passive income
- Minimising tax
- Where to go when everything goes “pear-shaped”

Carers specifically wanted to know where they can get support in the following areas so that they can ensure long-term care for their charge:

- Creating a model for independence
- Disability and other trusts
- Wills
- Consumer rights
- Contracts
10. Learning financial skills: Recommendations for financial education

Autistic participants gave examples of how they preferred to learn new skills. While there is a range of preferences, there seemed to be a predominance of wanting to learn by doing, rather than just from a book.

Individual 1: I prefer doing something. I’m not really good when you give me a book and I have to read it. That’s where I really fail. It’s better if I actually do it. Like an actual scenario on how you would go about doing it – not just get a book and “here you go”.

Autistic participants also suggested that having a “sounding-board” would be useful when learning new processes, ie. someone they could check in with to see if they were doing the task correctly.

Individual 2: If you want to have someone working with you and quizzing you maybe, and saying “So, how would you do that?” and then you go “Ah, maybe this and that” and again having that sounding-board thing. For me, anyway, that would be useful.

A few individuals talked about how assessment of any kind caused a lot of anxiety. Even if the assessment wasn’t paper based – like an exam, they were quite fearful of being in a situation where they could be criticised or ridiculed.

Individual 1: [I prefer] not being assessed on anything. Sometimes even not really talking about it... ‘cause that could be a bit hard with social anxiety.

Individual 2: I think being assessed, it’s almost like you’re being criticised. And being a person on the spectrum, you can get criticised a lot ‘cause we don’t do things that are deemed to be normal ... In my head it would be like, “oh, I’m an idiot,” you know. “They think I’m stupid or something.”

It was observed that in the focus group setting, autistic participants seemed quite relaxed and open to discussing their experiences and giving opinions on the topics. Small group workshops for financial education could work well if individuals were not made to feel at risk of being “wrong”.

A common recommendation was for a user-friendly workbook or app that meets the learning needs of young autistic people.
Autistic participants and carers made common recommendations for building financial capabilities through financial education:

- **Promote the importance of financial education:** All participant groups thought that the importance of learning about money was not promoted well enough in society. They felt it was something that everyone assumed that people knew about and found it frustrating that they didn’t know where to go to learn about various financial topics.

- **Teach financial education to children earlier:** This was the most common recommendation from all participant groups. While some carers and parents did what they could to help their children learn about money, they would have found a structured approach or a guide to be very useful. A user-friendly workbook or app that met the learning needs of young autistic people was a strong recommendation.

- **Financial education conducted by independent organisations:** The lack of trust in financial institutions was quite evident in our research. Participants recommended that independent organisations would be best placed and trusted to help people learn about money. However, participants did welcome banks’ investment in and funding of community efforts to help people learn about money.

- **Variety of teaching formats to aid people’s diverse learning styles:** A common recommendation for financial education programs is to ensure that a variety of learning styles are catered to. Even within groups of autistic individuals, there are differences and preferences in styles, presentation and format to achieve optimum learning.

- **Use real-life, relevant scenarios:** Both carers and autistic individuals suggested that examples used in training reflecting their lives, circumstances and financial situations would be helpful in relating to the content.

- **Step-by-step learning:** The particular learning needs of autistic people require reduced levels of complexity in the content and delivery and clear instructions given in a logical order. Once the order of process is learned, individuals generally will be able to recall the steps each time the task needs to be completed.

- **Group engagement and discussions:** While there are varying levels of comfort and discomfort with social situations and interactions among autistic individuals; small group formats for delivery of financial education have the potential to work well especially for young adults. There are some important considerations however that need to be given to group discussion formats, size of group, venue, timeframe and most importantly, a facilitator with appropriate training and understanding of autistic people.
11. Conclusion

Our research provides important insights into the unmet financial capability needs of autistic individuals, and those of their carers. There was clear concern about gaining or maintaining employment. Participants were unsure about topics such as tax, income and loans. They also didn’t know where to go to get information outside their family. Individuals worry that they won’t be able to understand the information when it is presented in the usual way because of their neurodiversity and its implications for information processing. There is however a strong desire among the participants for learning about money and being able to develop the financial skills to enable their independence.

The study showed that the autistic individuals in fact possess strengths that are advantageous to managing money. These strengths may include, depending on the individual, having attention to detail and strong memory of detail, and recognising patterns. Even tendencies for compulsive behaviour can be re-directed to be beneficial to financial management. There is potential for these strengths to be developed if the appropriate supports are provided.

Carers of autistic people are grappling with financial challenges over and above those of other families. They feel stress and worry about the financial futures of those who depend on them for decision-making. In the study, carers expressed confusion and uncertainty in knowing how to help the people they care for manage money both now and in the future. They also found it difficult maintaining a balance between helping the person they care for and wanting to encourage their independence.

Autistic individuals are a significant minority in our society and the rate of diagnoses is predicted to increase substantially. Over the last decade, developments and innovation in methods of diagnosis and early treatment have enhanced the wellbeing and outcomes for autistic individuals. Even so, the education and employment rates for these individuals are still far lower than what they should be and this leads to lower levels of participation in financial and consumer activities.

Importantly, employment and financial stability is critical to living independently – a commonly-held aspiration for autistic individuals and people with disability. Professor Simon Baron-Cohen from the Autism Research Centre, University of Cambridge believes that the human rights of autistic people are not being met11. Being excluded from public services, employment, education and being vulnerable to exploitation and abuse due to neurodevelopmental differences, breaches the United Nations Convention on the Rights of People with Disabilities (UNCRPD), to which Australia is a signatory. Australia’s National Disability Strategy (Commonwealth of Australia, 2011) explicitly calls on all sectors of Australian society to meet the UNCRPD obligations.

Owing possibly to their differences being “invisible”, autistic individuals in many cases are not at the forefront of efforts devoted to people with more visible challenges. By expanding our consideration and understanding of the challenges and barriers that are faced by autistic individuals, participation and inclusion in everyday life can be broadened.

The neurodiversity that characterises autism presents a number of challenges in a world that is shaped for neurotypical people. Self-exclusion becomes the issue for many autistic individuals when the environment and social structures of work, consumption, and leisure are such that participation is unpleasant and stressful and invokes discrimination. Informed businesses that practise diversity can provide a greater range of approaches to task structure, service delivery and customer service that would suit even a wider range of people than just autistic individuals.
There is enormous potential for businesses and financial institutions to benefit from meeting the specialised needs of autistic individuals. Simplifying product and service information not only assists these individuals, but also many other customers who struggle to deal with the complexity of banks’ offerings. Financial institutions could consider providing increased employment to autistic people and offering products and services that take into account their qualities and characteristics.

Companies such as Auticon in Europe are actually capitalising on the strengths of autistic people. For companies that offer similar approaches to their product offerings and services, this would also be advantageous to the company and the growing numbers of autistic individuals, their families and society in general.

For services that involve face-to-face interaction, for example bank branches, a number of fairly low-investment initiatives could help: staff training in cue utilisation (understanding the effect of stress on information-processing abilities and learning to “read” autistic people); personal, calm and unrushed interactions; clear and specific instructions without ambiguity and peaceful environments.

Having online, instructive and interactive learning capacities on websites could help people to independently access knowledge. ANZ’s MoneyMinded and in particular MoneyMinded Online is an example of a financial education program that could be further utilised to provide support to autistic individuals.

All these supports would also assist many other customers such as older people and people with different disabilities.

Incorporating co-design principles into product development from ideation to delivery is advocated by innovative organisations such as Auticon, and Autism CRC. It is but an incremental step for financial institutions to broaden and streamline their product and service offerings for an under-utilised but potentially valuable and valued segment of our society.
References


Auticon website (www.auticon.co.uk)


Endnotes

1 It is noted that identity-first language (e.g. autistic individuals) is often the preferred language of many people on the autism spectrum; therefore this terminology has been used in the document.
2 See endnote 1 above
3 Kempson, Finney & Poppe, 2017; Consumer Financial Protection Bureau, 2015
4 American Psychiatric Association, 2013; Randall et al., 2016
5 Kempson et al., 2017, op cit.
6 Autism CRC, 2016
7 ABS, 2015
9 Hatfield et al., 2017; Browning, Osborne and Reed, 2009
11 Auticon website (http://auticon.co.uk/)
12 Scott et al., 2017
13 Howlin, 2005; Levy & Perry, 2011
14 Shattuck et al., 2012
15 ABS, 2015, op cit.
16 ABS, 2015, ibid.
17 Synergies Economic Consulting, 2011
18 Horlin et al, 2014
19 Bouma & Schweitzzer, 1990; Bolton et al, 1998; Piven & Palmer, 1999; Abbeduto et al., 2004; DeLong, 2004; Mazefsky et al., 2008; Kuusikko-Gauffin et al., 2013; Totsika et al., 2011
20 Duncan, Ruble, Meinzen-Derr, Thomas & Stark, 2017
21 See Dipeolu, 2015; Duncan et al., 2017
22 Cheak-Zamora et al., 2017
23 Ibid, p.1314
24 Neary, Gilmore and Ashburner, 2015
26 Auticon in Europe is a good example.
27 Hedley et al., 2017
28 The questionnaire was a validated scale- The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).
29 HADS; Zigmond & Snaith, 1983
30 Kempson et al; CFPB, 2015, op cit.
31 Kempson et al., p. 16
32 Batavia & Beaulaurier, 2001; NDS, 2011
33 Auticon (www.auticon.co.uk)
34 Hatfield et al., 2017
35 Grohmann, Kouwenberg and Menkhoff, 2015
36 Kim and Chatterjee, 2013
37 Grohmann et al., 2015
38 Study authors’ emphasis.
39 Crane et al., 2009; Rogers & Ozonoff, 2005; Talay-Ongan & Wood, 2010
40 MoneyMinded is a financial education program developed by ANZ in 2003. Delivered by community organisations across Australia and the Asia Pacific, the program aims to increase the financial skills, knowledge and confidence of vulnerable groups within the community. For more information about MoneyMinded, visit www.anz.com/moneyminded