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Reinventing the Future of Financial Technologies with Autistic Adults

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Autistic adults are amongst the groups most likely to experience financial hardship, yet little is known about their money management practices or their use of financial technologies. Incorporating the perspectives from the Neurodiversity Movement and Crip Technoscience, my research aims to uncover how financial technologies are meeting the needs and preferences of autistic people and identify factors that may exacerbate financial exclusion. In this process, I aim to learn from the autistic community. The goal of my research is to facilitate a participatory design process in which autistic adults share and develop alternative approaches to financial technology that centre on the diverse voices, experiences and expertise of autistic people.

CCS Concepts: • **Human-centered computing** → **Accessibility technologies**.

Additional Key Words and Phrases: Financial technology (fintech), banking, moneywork, accessibility, neurodiversity, autism

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1 Introduction

Autistic adults are among the groups that are most likely to experience poor financial well-being and hardship due to unemployment, under-employment, and the lack of appropriate financial support [9, 11]. According to Autistica's Employment Plan [16], autistic adults have one of the lowest employment rates of disabled people in the UK, with less than a third being in employment in 2021 [20]. In addition, living with autism comes with additional costs related to things such as healthcare, therapy, special education and (informal) care [34]. Despite this, very little is known about the financial practices of autistic people [31], and even less about their use of financial technologies. Incorporating the perspectives from the Neurodiversity Movement and Crip Technoscience, **my research aims to uncover how financial technologies are meeting the needs and preferences of autistic people** and identify factors that may exacerbate financial exclusion. In this process, I aim to learn from the autistic community. The goal of my research is to facilitate a participatory design process in which autistic adults share and develop alternative approaches to financial technology that centre on the diverse voices, experiences and expertise of autistic people.

2 Background and Motivation

2.1 Autism and Financial Wellbeing

To date, there has been very little to no research on the use of financial technologies by autistic people. Research on autism and finance often focuses on 'the financial burden' of families with autistic children [8, 27]. Ghanouni *et al.* conducted qualitative research on independent living among autistic adults and parents of autistic adults in Canada

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[21]. They identified financial management as a core element for living independently and indicated that autistic adults might find managing and planning their finances challenging [21]. Their participants indicated they “cannot cope with things like finances” [21], p.6, without diving deeper into the reasons. Pellicano *et al.* conducted a qualitative study of the financial wellbeing experiences of a small sample of autistic adults in Australia [31]. Their analysis produced four themes around the financial wellbeing of autistic adults: 1) the importance of sufficient and stable income; 2) the role of social dynamics in financial wellbeing; 3) difficulties with financial planning; and 4) a desire to stay in control and avoid risk. [31]. These themes provide a good starting point for understanding which factors are important to autistic adults regarding financial wellbeing. However, the themes identified by Pellicano *et al.* (2023) tell us little about the lived experiences, money management practices or the use of financial technologies among autistic adults.

2.2 Financial Practices among autistic adults

Cheak-Zamora *et al.* studied the financial management skills among autistic youth [13]. They identified a “lack of skills in managing their finances and expressed the need for further education” [13], p. 1314. Cheak-Zamora *et al.* also reference a report from 2005 [43] looking at the use of financial tools among youth with special healthcare needs in the U.S., which indicates a low uptake of checking accounts and credit cards. These studies approach autism with a deficit-based view that seeks to educate autistic people rather than looking at how the tools and technologies could be changed to better fit the autistic experience. However, they also highlight that we currently do not have a full picture of the ways in which autistic adults manage their finances and how they utilise financial technologies to do so.

2.3 The Challenges for Autistic Adults in Moneywork

The literature points towards aspects that might shape the unique challenges of managing finances as an autistic adult in the current financial landscape. Moneywork is defined as the labour necessary to manage one’s family finances, including physical and social interactions involved in making payment transactions, money management practices, banking habits, and household finances [4]. This section draws on existing literature on related issues in moneywork that may not wholly reflect the autistic experience but provide themes that inform my research.

1) Statistically low income As discussed above, autistic adults are statistically likely to experience financial hardship due to under- and unemployment, many having to rely on state benefits or their families. The challenges of managing money on a low income have been researched in other contexts [14, 41, 42]. This prior research shows that people are resourceful. Contrary to popular belief, they have sophisticated systems to manage their money and often develop their own approaches to work around financial systems that are unsuitable for their needs.

2) Executive function: One of the challenges autistic people often face is struggles with executive functions [18, 23]. Also, Ghanouni *et al.* found in their study on independent living in autistic adults that issues with functional capabilities are a common theme [21]. These functions consist of skills such as planning, impulse control, and initiating action [23]. Dealing with finances often requires goal-oriented, long-term planning, budgeting and monitoring of one’s finances, which are connected to those executive functions. This might explain some of the money-related challenges autistic adults face.

3) Co-occurring issues: It is estimated that around 70% of autistic people have cooccurring issues [35]. Lai *et al.* conducted a meta-analysis on co-occurring mental health diagnoses in autistic people [25]. They found that the overall prevalence is 28% for ADHD, 20% for anxiety disorders, 12% for disruptive, impulse-control disorders, 11% for depressive disorders, and 5% for bipolar disorders [25]. Some of these issues may cause additional challenges regarding financial management. The links between financial problems and ADHD have been more thoroughly explored [12]. Mental

105 health conditions, such as anxiety or depression, come with their own challenges [25]. Barros Pena *et al.* explored how
106 financial problems caused by the fluctuating nature of mental health issues could be addressed using technology [4].

107 **4) Digitisation of Money:** Despite autistic people’s general preference for digital or online services [12], the
108 digitisation of the financial sector comes with a range of accessibility issues [1, 19, 40]. In addition, Barros Pena *et al.*
109 explored the problem derived from digitising personal finance [5]. Between other issues, they identify the removal of
110 friction by user interfaces that, for example, make borrowing easy but hide high interest rates [5]. Especially young
111 autistic adults are vulnerable to predatory behaviour, such as payday lending [13, 38]. Another aspect is what Barros
112 Pena *et al.* call the ‘individualisation of finance’, the assumption that finances are managed by one account holder solely
113 responsible for any financial decision [5]. The reality is that moneywork is highly interwoven with networks of care
114 [1, 26, 31], but financial technologies are not built for those use cases [5]. Pellicano *et al.* identified that family dynamics
115 can have a strong, positive influence on autistic people’s financial wellbeing [31]. This shows the need for technology
116 that considers social dynamics and support structures.
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121 **3 Research Objectives**

122 The overall goal of my PhD research, is to investigate how adverse consequences of digitising finances can be addressed
123 by engaging in a participatory design process with autistic adults. The following research questions will be addressed:
124 RQ1: How appropriate are existing digital financial technologies to the money management needs and preferences of
125 autistic adults? RQ2: What challenges do autistic adults experience with money management in general and financial
126 technologies in particular, and what coping strategies have they developed to manage them? RQ3: How could financial
127 technologies be different if designed from autistic perspectives? RQ4: What can we learn about the design of existing
128 financial technologies by studying and critically assessing them from autistic perspectives and practices?
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135 **4 Research Approach**

136 **4.1 Neurodiversity and Autism**

137 My research approach is underpinned by a social approach to disability, as discussed by Shakespeare [36]. As opposed to
138 the medical view of disability as an individualised issue of personal limitation, in the social model, disability is seen as an
139 issue of social exclusion and oppression [36]. The Neurodiversity paradigm builds on similar grounds. It acknowledges
140 that a large proportion of people have ways of thinking and perceiving the world that can be described as neurotypical.
141 People with notable differences in how they perceive and make sense of the world are, therefore, neurodivergent [44].
142 Autism was historically seen as a ‘syndrome’, a medical condition present from birth and characterised by difficulties in
143 relating to and communicating with other people, as well as a ‘desire for sameness’ [24]. This narrow view changed when
144 Wing argued that autism is better defined as a spectrum of related conditions [45]. Belek extends this view and defines
145 Autism as a collection of traits (sensitivities, preferences, tendencies, strengths), a mix of biological and societal factors,
146 that occur in different variations across people [6]. However, the reality is that Autism is still discussed in pathologising,
147 deficit-based ways [44] and because of that often framed as a ‘social communication disorder’ [29]. Damian Milton has
148 contributed to changing that perception by redefining the issue as the ‘double empathy problem’, emphasising that it is
149 a breakdown in mutual understanding. Allistic or neurotypical people struggle to understand autistic people as much
150 as the other way around [29]. Therefore, all should share the burden of resolving the communication challenges.
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4.2 Participatory Design and Crip-Technoscience

Participatory design is a suitable approach to reject the deficit-based view of Autism in technology design. Participatory design is a process of mutual learning between researchers/designers and the communities they are working with [10, 37]. The aim is to empower not just individuals but the wider community they are part of by reimagining their futures through the design of (digital) technologies [10]. Crip-Technoscience [22] or Neuroqueer-Technoscience [33] are concepts I will draw on that take this model even further. Crip-Technoscience centres on disabled people as knowers and makers. As Hamraie and Fritsch explain: “Crip technoscience emphasizes that disabled people are not mere consumers of, or objects for, assimilationist technologies, but instead have agential, politicized, and transformative relationships to technoscience.” [22], p. 16.

5 Contributions to Date

5.1 First Study

Participatory Design begins by understanding people’s current, lived practice before imagining future alternatives [10]. The first two research questions (RQ1 and RQ2) are being addressed in an initial study to generate a picture of the problem space. The goal of this study is to gain insights into autistic adult’s experiences with ‘moneywork’. The study seeks to answer the following research questions that broadly align with themes defined by Pellicano *et al.* in their research on autistic adult’s experience of financial wellbeing [31]: **How are autistic adults managing their money?** EVERYDAY FINANCES: How do autistic adults manage their everyday finances? RELATIONSHIPS: How do autistic adults manage their money in social contexts, and which financial relationships are essential? FUTURE PLANS: How do autistic adults think about and plan their financial future? TECHNOLOGIES: In what ways do autistic adults use and appropriate systems and financial technologies to better suit their needs?

Using these questions as a guide, I am exploring how autistic adults manage their money in the current financial practices and technology landscape. The aim is to uncover hidden connections, underserved areas, and the challenges that autistic adults face and to give a first indication of the community’s priorities.

5.2 Participant Recruitment

For this study, participants are autistic adults over 18 years of age with an autism diagnosis and residency in the UK. They have no learning disabilities, are able to communicate verbally, and are comfortable interacting with researchers through a video call. Participants also have some degree of financial independence, i.e. they make decisions about their own money, which may come from any source (e.g. employment, state benefits, or provided by family). According to an open letter by Pellicano *et al.* there have been some cases of fraudulent participants who posed as autistic for financial gain, which is why the decision was made to require an official diagnosis [30]. Autistica is a UK-based charity specialising in connecting autistic people with autism research, ensuring studies are relevant to the autism community. My study was accepted, and my call for participation was distributed in the Autistica Newsletter. Within two weeks, **the study got 413 responses**. The **exceptional number of sign-ups** and attached comments emphasise the relevance of the topic to the autistic community. Having access to this group of engaged autistic adults opens new possible avenues for future research.

209 5.3 Developing a Methodological Approach

210 To answer the research question, “How are autistic adults managing their money?” I needed to develop a method
211 that would suit the specific context of studying financial practices and consider the needs and preferences of autistic
212 participants. In the following section, I will discuss the considerations and iterations that went into developing the
213 method.
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216 5.3.1 *Collaborative Visualisation as an interview method.* The core of my first study is a one-to-one research session that
217 centres on mutual learning. The method for my exploratory study is a semi-structured interview supported and guided
218 by visualisation and mapping techniques on a digital or physical whiteboard. The resulting interactive conversation
219 aims to give insights into how autistic adults make sense of their finances, their strategies, challenges and technologies
220 used. Mapping and visualisation techniques are used for two reasons. The first one is the sensitivity of the topic. When
221 discussing abstract concepts such as (personal) finance, referring to physical and visual items is helpful, as often done in
222 consumer finance research using object-centred methods [39]. However, asking participants to grant insights into their
223 finances does require a high level of trust and can cause worries about fraud. Using abstract visualisation helps with
224 privacy and trust issues while gaining the benefits of what Crilly *et al.* call graphic elicitation and ideation [15]. Given
225 the participatory angle of my research, visual representations are not just presented to participants to elicit thoughts
226 but created by the participants. The goal is to co-create a visual representation of the participant’s mental model of
227 their financial lives and to allow participants to “impose their own forms of organization, bringing into expression
228 their needs, motives, emotions and the like” [2], p. 548. The other reason for using visual methods is to follow proven
229 practices in doing research with autistic people [7, 13, 32]. Bennett, as an autistic researcher herself, describes her
230 approach of ‘collaborative drawing’ as being more closely aligned with the communication style of autistic adults [7].
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236 5.3.2 *Pilot-Iterations of the Methodological Approach.* The double empathy problem raises the question of whether
237 non-autistic researchers can produce meaningful autism research [3]. As a non-autistic researcher, I must be mindful of
238 my role, give space to and amplify autistic voices, and reflect on possible challenges. To establish some kind of mutuality,
239 I started volunteering for an autistic-led performance company that exposed me to the creative work of autistic and
240 learning-disabled performers. Beyond general immersion into autistic culture, it was crucial to get input from autistic
241 adults on my research early on. During the development of my methodological approach, I involved two autistic adults
242 as my ‘experts by experience’ board from my personal network.
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245 To develop the method, I initially mapped out my own financial life. I defined high-level categories based on the
246 research questions and started putting them in relation to one another to elicit a new perspective on my financial
247 practices. Doing this exercise helped me reflect on my financial practices and stories of moneywork that I would not
248 have thought of otherwise. It showed that the method was effective in providing a structure for a topic that looks very
249 different depending on the person and their context. Moreover, it is suitable for gathering tangible insights into a topic
250 as abstract as finances.
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252 The next essential step was engaging with autistic ‘expert by experience’ consultants to gather input and feedback.
253 The conversations helped me further develop and fine-tune the method and materials. We arrived at the following steps:
254 During an introductory call with participants, I share the high-level categories we will discuss during the research
255 session: *Income*: Where do I get money from? *Storage*: Where does my money live? *Outgoings*: Where do I spend or
256 share my money? *People*: Who is involved in financial practices and decisions? *Tools*: Where do I plan and manage
257 my financial assets? In the subsequent research session, the participant and the researcher collaborate to arrange the
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261 items related to the above categories on a whiteboard, drawing connections, identifying relations and highlighting
262 important areas. The participant is asked to share thoughts and examples. In a pilot session with one of my autistic
263 consultants, we developed follow-up questions to be answered after the mapping exercise, such as "Where does this
264 structure/technology become more difficult for autistic people like you?" or "If you could change anything in the way
265 your manage your money, what would you change?"
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268 **5.4 Academic Engagement**

269 In addition to the discussed contributions directly related to my PhD research, I have made several other related
270 academic contributions. I submitted a position paper on my methodological approach (not published) to the "Designing
271 Human Technologies DHT 10.0" Summer School, which got accepted. There, I developed my method further and
272 refined my view on Participatory Design in discussions with peers and experienced academics. I am also part of a
273 group of researchers that successfully submitted a workshop proposal to ASSETS'24 [17]. We ran "AccessFintech", a
274 virtual workshop between the 21st and 25th of October on designing accessible financial technology. My position paper,
275 'Money management practices among autistic adults' [28], got accepted to the workshop. In addition, I am involved in
276 teaching in the HCI Design MSc programme, where I am lecturing in a module on inclusive design.
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280 **6 Next steps and open questions**

281 I am currently in the process of conducting the interviews for my first study. This means my analysis will be done early
282 next year, concluding the exploratory phase and leading to the co-creation phase. The doctoral consortium would be an
283 ideal chance for me to get input at a critical point in time when I am deciding on the direction of the second half of my
284 PhD. Access to the mailing list of 400 autistic adults who responded to my call for participation opens possibilities for
285 further research with broader engagement. One of the crucial questions I will need to answer is how I will ensure a
286 tangible impact for the community. What does the co-creation process need to look like to bring solutions into existence
287 beyond just being 'a nice idea'? How do I make my results tangible enough so that autistic people benefit from them?
288 Autistica is interested in featuring my findings and sharing them with their community. I also would like to explore
289 collaborations with industry, charities, and activist/solidarity communities to ensure my research has an impact beyond
290 academia.
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296 **7 Dissertation Status and Long-term Goals**

297 I started my PhD at City St. George's, University of London, in in February 2024 and am entering the second year of
298 my 3-year PhD studentship before the Doctoral Consortium. The expected end date of my research is February 2027
299 with an option to extend to February 2028. I have not yet participated in any doctoral consortium. The first study is
300 underway, addressing RQ1 and RQ2, with the analysis due to be completed in early 2025. The doctoral consortium is,
301 therefore, happening at a critical time for my research and may help me steer the direction before I dive into the second
302 half, tackling RQ3 and RQ4 through a co-creation process focusing on designing alternative solutions with autistic
303 adults. The long-term goal of my research is to produce valuable and actionable insights from the autism community
304 for the autism community. Beyond that, the goal is to shape design implications for existing financial technologies that
305 may give guidance to financial service providers and FinTech developers.
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