Money management practices among autistic adults

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In this position paper, I will argue that autistic adults are among the groups most likely to experience poor financial well-being and hardship. Yet, strikingly little is known about the economic practices and use of financial technologies amongst the autistic community. My research will centre the perspectives of autistic adults on how they manage their money. The first study aims to highlight how financial technologies are meeting the needs and preferences of autistic people and identify aspects that may exacerbate financial exclusion.

1 Introduction

Managing money and finances is a crucial part of life for anyone who is, in one way or another, part of the global economic system. This system requires people to pay with money for goods and services that ensure survival, such as sustenance and shelter. In addition, access to money enables people to afford things they value beyond survival and supports the creation of social bonds through exchanging gifts, borrowing, and similar practices. Within this system, having money means having a choice: the freedom to choose where and how you want to live, what to consume, and who you associate with. Therefore, it is not surprising that financial and general well-being are deeply intertwined [Pellicano et al. 2023], and research has repeatedly shown that economic hardship is connected to low general well-being and mental health issues [Barros Pena et al. 2021].

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 [Buckland 2024; Cai et al. 2023a]. According to Autistica's Employment Plan [Cusack 2022], 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 (based on data by the Office for National Statistics (ONS)). On average, autistic people in employment earn a third less than non-disabled employees [Cusack 2022]. In addition, living with autism comes with additional costs related to things such as healthcare, therapy, special education and (informal) care [Rogge and Janssen 2019].

The challenges associated with the imbalance between statistically low, irregular income and heightened costs make the research area of managing personal finances especially relevant. My research aims to **uncover how financial technologies are meeting the needs and preferences of autistic people** and **identify aspects that may exacerbate financial exclusion**. In this process, I aim to learn from the autistic community. I want to facilitate a participatory design process in which autistic adults can develop alternative approaches to financial technology that centre on the diverse voices and expertise of autistic people.

2 Related Research

Existing research on autism and finance focuses on the financial capabilities of autistic youth [Cheak-Zamora et al. 2017], financial management as an element of independent living in autistic adults [Ghanouni et al. 2021] and general financial well-being of autistic adults [Cai et al. 2023a,b; Pellicano et al. 2023]. In addition, there is research on how financial services are discriminatory against people with learning disabilities [Abbott and Marriott 2013]. However, as Ghanouni et al. found, autistic adults with an average or above-average IQ are also often overlooked because they may not qualify for support [Ghanouni et al. 2021].

Challenges of managing money with a low income have been researched in other contexts [Collins et al. 2009; Vines et al. 2014], which show people living in poverty are very inventive and, contrary to popular belief, have sophisticated systems managing their finances.

Since the world is moving away from physical currencies such as cash towards a diverse range of digital tools and services, the question of financial technology and the accessibility thereof becomes especially important [Dai et al. 2023]. Little is known how well commonly used software systems and tools, such as social media, work for autistic adults [Barros Pena et al. 2023], and even less is known about financial technology specifically.

3 Neurodiversity and Autism

Disability researchers broadly fall into one of two primary schools of thought. One is the 'medical model of disability', which has been the dominant view of in the academy for a long time and continues to be prevalent in many studies [Guberman 2023]. The medical model presumes a person is disabled by a condition of their body or mind, basically seeing disability as an individualized medical problem that

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needs to be solved by 'healing'. This view is usually rejected by autistic people themselves [Guberman 2023].

On the other end is the 'social model of disability'. In this view, disability is not inherent in the person, but in the environment, which does not accommodate for individual needs of people. Therefore, it is not the person that has a disability, but it is the world that disables the person [Gaudion 2014]. It is important to note, that the social model of disability acknowledges that certain conditions are impairments, but it is the interaction with external disabling factors that lead to disability [Barros Pena et al. 2023]. These barriers can be physical or material in nature (e.g. missing curb cuts), but also systemic and social (e.g. discriminatory policies) [Guberman 2023]. "Providing a non-speaking autistic person with an alternative method of communication may give them a voice, but they will only truly stop being disabled when others listen." [den Houting 2019].

Autism falls under the umbrella of neurodiversity, a concept that is aligned with the social model of disability and was coined to describe differences in experiencing the world through perception or cognition [Guberman 2023]. By viewing autism as an alternative cognitive style, the neurodiversity paradigm is recognising autism as a disability, while resisting a pathologizing and deficits-based view [Barros Pena et al. 2023; Guberman 2023].

4 Participatory Design

For the longest time autism research has focused on priorities set by non-autistic researchers [Pellicano et al. 2014], often centring questions of how to make autistic people more palatable to neurotypical sensibilities. Pellicano et al. Conducted a study on priority setting in autism-research, finding that research priorities in the UK are often heavily influenced by individual organisations, researchers and their funder's interests, rather than the interests of actual key stakeholders, which is autistic people and their direct network [Pellicano et al. 2014].

Much of the research on digital tools targets autistic children [Barros Pena et al. 2023], leaving the experiences and challenges of autistic adults more of a blind spot and especially vulnerable [Pellicano et al. 2014]. In addition to this, Guberman observed: "HCI has a historical (and contemporary) propensity to [...] to support technologies that undermine autistic safety and self-determination through surveillance, behavioral control, and outright physical restraint[...]" [Guberman 2023] (p. 4).

In my research I want to approach questions about challenges in personal money management as a failure of existing systems that need to be addressed by changing the system, not autistic people. Solutions should aim to supporting autistic people to navigate a neurotypical world in a way that promotes autistic safety and self-determination [Pellicano et al. 2014]. For this, Participatory Design is an especially suitable approach: The goal is to develop novel approaches to financial technology through a process of mutual learning between researchers/designers and autistic people [Bødker et al. 2022; Simonsen and Robertson 2013]. 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 [Bødker et al. 2022].

5 Study Plan

Participatory Design begins by understanding people's current, lived practice – before stepping into the field of imagining future alternatives [Bødker et al. 2022] . In a first exploratory study, I will explore the money management practices of autistic adults. This study will focus on gaining insights into autistic adult's experiences with 'moneywork', 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 [Barros Pena et al. 2021].

This study is trying to answer the following research questions that broadly align with themes defined by Pellicano et al. in their research on autistic adults' experience of financial well-being [Pellicano et al. 2023].

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 important?
- FUTURE PLANS: How do autistic adults think about and plan their financial future?
- TECHNOLOGIES: In what ways do autistic adults use and re-make systems and financial technologies to better suit their needs?

Using these questions as a guide, I will explore how autistic adults manage their money in the current landscape of financial practices and technologies. The aim is to uncover the challenges that autistic adults face, how they overcome them, and the changes they want to see in the current systems and tools.

This study will be conducted as the first part of my PhD research, "Reinventing the Future of Financial Technologies with Autistic Adults". The broader goal of the PhD is to engage in a participatory design process during which members of the autistic community develop novel approaches to financial technologies, following what Guberman phrased as "Centring the work of disabled people as knowers and makers shifts power and expertise from abled disability designers and "experts" to disabled people, their existing technological practices, and their embodied knowledges." [Guberman 2023](p. 19). The exploratory study will centre the inventiveness of the autistic community and give a first indication of the design priorities and pain points that should be followed up on in future research.

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