

ABSTRACT

Title of Dissertation: LIBRARY AND INFORMATION SCIENCE RESEARCH AND
NEURODIVERSITY: SO MUCH POTENTIAL IF WE'D JUST
APPLY OURSELVES

Kelly M. Hoffman, Doctor of Philosophy, 2023

Dissertation directed by: Professor Paul T. Jaeger, College of Information Studies
Professor Beth St. Jean, College of Information Studies

Neurodivergent people consistently face less optimal outcomes than neurotypical people in education, their careers, and other areas of life. Anecdotally, personal knowledge management (PKM) is a useful tool for neurodivergent individuals. However, there is sparse research involving the information practices of neurodivergent adults in the field of library and information science (LIS). A survey with both close-ended and open-ended questions, partially based on Dervin's Sense-Making Methodology (Dervin, 1992, 2000), was distributed online and received over 300 self-identifying neurodivergent participants. The results indicated that neurodivergent people use PKM most heavily in the *Learning*, *Job*, and *Everyday* domains for the purposes of *Managing Tasks and Projects*, *Building Knowledge*, *Creating*, and *Self-Improvement*. Common PKM activities engaged included *Storing Information and Using It Later*, *Remembering What Needs to be Done*, *Understanding and Ideating*, and *Planning and Prioritizing*. The most helpful benefits of PKM that were described were *Connecting Ideas*,

Improving Thinking, and *Having Fun*. Overall, key themes regarding neurodivergent individuals' PKM usage included *Reducing Stress*, *Memory*, and *Externalizing*. These findings provide a foundation for a much-needed LIS research agenda exploring the PKM practices of neurodivergent adults.

LIBRARY AND INFORMATION SCIENCE RESEARCH AND NEURODIVERSITY:
SO MUCH POTENTIAL IF WE'D JUST APPLY OURSELVES

by

Kelly M. Hoffman

Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, College Park, in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2023

Advisory Committee:

Professor Paul Jaeger, Chair

Professor Beth St. Jean, Chair

Professor Mega Subramaniam

Associate Professor Shannon Jette

Assistant Professor Gulnoza Yakubova

© Copyright by
Kelly M. Hoffman
2023

Acknowledgements

Earning a Ph.D. is difficult enough for neurotypicals, and people with ADHD are even less likely to complete a doctoral program. The fact that I have managed to do so is a testament to the tremendous support and encouragement that I have been privileged to receive from family, friends, and mentors throughout my life.

My deepest and most profound thanks to my advisor, Dr. Paul Jaeger, for not only putting up with me through a master's degree, but also welcoming me to the doctoral program. I'm sure I was not the easiest student to advise, yet he always did so with wisdom and compassion. I am also grateful to Dr. Beth St. Jean for her invaluable guidance in constructing this dissertation and, very importantly, finishing it. A huge thanks also to Dr. Mega Subramaniam, with whom I have worked on multiple grant projects and who never hesitated to give me counsel and support. I am also grateful to Dr. Shannon Jette and Dr. Gulnoza Yakubova for their advice and support, and for serving on my dissertation committee.

This dissertation would not have been possible without the emotional and physical support of my partner Matt, who provided encouragement and confidence when I needed it the most (not to mention all the household chores and delicious dinners). I am also indebted to my cat friend PK (which stands for Patrol Kitty, not Personal Knowledge) for all the cuddles while I wrote, and for being the participants' "reward" at the end of the survey (see [Appendix A](#)). I must also give begrudging gratitude for all the neurodivergent genes that I inherited from my forebearers. I may not always appreciate them, but they make me who I am—without them, I would be someone else entirely.

Finally, a big thank you to everyone in the PKM enthusiast community who shared and signal-boosted my survey, or just served as inspiration for my own PKMS, especially Bryan Jenks and Nicole van der Hoeven. And most of all, my most heartfelt gratitude goes out to the 304 people who spent their time and cognitive energy to take my survey with such care and thoughtfulness (and even more so to those who shared photos of their own fur friends). They made this whole project possible, and this dissertation is dedicated to them.

Table of Contents

Acknowledgements	ii
Table of Contents	iv
List of Tables	viii
List of Figures.....	ix
List of Abbreviations	x
Chapter 1: Introduction	1
1.1 Background Information.....	4
1.1.1 Neurodivergence.....	4
1.1.2 Personal Knowledge Management	7
1.1.3 Why LIS Should Pay Attention to Neurodivergence	8
1.2 Problem Statement.....	9
1.2.1 Perspectives on Disability	9
1.2.2 Neuro-liberal Capitalism: We Can All Be Alienated From the Product of Our Labor!.....	11
1.2.3 Transdiagnostic Research: Maybe Paying Attention to Impairments Isn't All Bad	12
1.2.4 Inadequate Support for ND Adults	13
1.2.5 PKM Might be a Key to Improving Outcomes for NDs	14
1.3 Research Questions	15
1.4 Researcher Positionality.....	16
1.4.1 Insider or Outsider?	16
1.4.2 My Distance from the "Accepted Norm"	17
1.4.3 My Experience.....	18

1.5 Dissertation Structure	20
Chapter 2: Background.....	21
2.1 Neurodivergence	21
2.1.1 Neurodivergence and LIS	23
2.1.2 Neurodiversity	24
2.1.3 Talking about Neurodivergence	25
2.1.4 Goals of Researching Neurodiversity.....	26
2.2 Personal Knowledge Management	27
2.2.1 PKM History and Definition	28
2.2.2 What Makes it Personal?	31
2.2.3 PKM and LIS.....	32
2.3 PKM and Neurodivergence	32
2.4 Sense-Making.....	34
2.5 The Gaps in Our Knowledge.....	37
Chapter 3: Methods	38
3.1 Research Design	38
3.2 Recruitment	39
3.3 Data Collection.....	41
3.3.1 Survey Development & Design.....	41
3.3.2 Survey Part 1	46
3.3.3 Survey Part 2	47
3.3.4 Survey Administration and Response Rates.....	48
3.4 Data Analysis	48

3.4.1 Quantitative Data.....	48
3.4.2 Qualitative Data.....	49
3.5 Ethical Considerations	50
Chapter 4: Results.....	53
4.1 Participants.....	54
4.2 Survey Results.....	55
4.2.1 Part 1: Quantitative Results	55
4.2.2 Part 2: Qualitative Results	65
4.3 Research Questions	68
4.3.1 Research Question 1: Outcomes and Life Domains.....	69
4.3.2 Research Question 2: Activities	78
4.3.3 Research Question 3: Benefits of PKM.....	81
4.4 To Be Continued	84
Chapter 5: Discussion and Conclusion	85
5.1 Summary of Results	85
5.2 Discussion	88
5.2.1 Reducing Stress	88
5.2.2 Memory	89
5.2.3 Externalizing.....	90
5.3 Implications	91
5.3.1 Support the Whole Life	91
5.3.2 Support Abilities and Disabilities Across Multiple Divergences	91
5.3.3 Support Connecting and Ideating	92

5.4 Significance and Contributions	92
5.4.1 Methodological Contributions.....	92
5.4.2 Theoretical Contributions.....	93
5.4.3 Practical Contributions	93
5.4 Limitations.....	94
5.5 Recommendations for Future Research	96
5.5.1 Future Work with This Dataset	96
5.5.2 My Research Agenda Moving Forward	97
5.5.3 An Agenda for LIS	99
5.6 Concluding Remarks.....	99
Appendix A: Informed Consent Form and Survey	101
Appendix B: Recruitment Language	113
Appendix C: Codebooks.....	116
Appendix D: Summary of Survey Response Counts	126
Appendix E: IRB Letter	129
References	130

List of Tables

Table 1 <i>Groups Targeted for Recruitment</i>	40
Table 2 <i>Life Domains and Descriptions</i>	42
Table 3 <i>PKM Activities</i>	43
Table 4 <i>Executive Functions</i>	45
Table 5 <i>Number of Participants by Employment and Education Status</i>	56
Table 6 <i>Number of Participants by Neurodivergent Condition</i>	57
Table 7 <i>Number of Participants by Neurodivergent Condition Combinations</i>	58
Table 8 <i>How Neurodivergence Affects Life Domains</i>	59
Table 9 <i>PKM Activities by Average Familiarity/Use</i>	61
Table 10 <i>PKM Activities by Response</i>	62
Table 11 <i>How PKM Affects Life Domains</i>	63
Table 12 <i>Mean Rating of Executive Functions</i>	64
Table 13 <i>Executive Functions by Rating</i>	65
Table 14 <i>Abbreviated Codes for Participant Characteristics</i>	67
Table 15 <i>Life Domains and Application Co-Occurrence by Question Responses</i>	72
Table 16 <i>Summary of Research Questions and Central Findings</i>	87

List of Figures

Figure 1 <i>Dervin's Sense-Making Metaphor</i> (Naumer et al., 2008)	35
--	----

List of Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention-Deficit/Hyperactivity Disorder
ADHD-C	Attention-Deficit/Hyperactivity Disorder, Combined presentation
ADHD-HI	Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive/Impulsive presentation
ADHD-PI	Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive presentation
ASD	Autism Spectrum Disorder
DID	Dissociative Identity Disorder
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
KM	Knowledge management
LIS	Library and information science
ND	Neurodivergent (noun or adjective)
NDD	Neurodevelopmental disorder
NT	Neurotypical (noun or adjective)
PIM	Personal information management
PK	Patrol Kitty
PKM	Personal knowledge management
PKMS	Personal knowledge management system
PTSD	Post-Traumatic Stress Disorder
SLD	Specific Learning Disorder

Chapter 1: Introduction

The term *neurodivergence* describes any neurological configuration that departs from what is considered “normal” (Walker, 2021a, p. 34). The coinage of the term is attributed to Kassiane Asasumasu around the year 2000 (Walker & Raymaker, 2021), and while *neurodivergence* is not a medically defined term, in common usage it largely overlaps with the presence of what are medically referred to as neurodevelopmental disorders (NDDs), so-called because they impact neurological functions and are present during childhood (American Psychiatric Association, 2013). Autism Spectrum Disorder (ASD), defined by the medical profession as “characterized by persistent deficits in social communication and social interaction across multiple contexts” (American Psychiatric Association, 2013, p. 31) and Attention-Deficit/Hyperactivity Disorder (ADHD), which exhibits as “inattention, disorganization, and/or hyperactivity-impulsivity” (American Psychiatric Association, 2013, p. 32), are perhaps the most prevalent and the most well-known NDDs, but the term encompasses a wide and variable range of behaviors and symptoms; additionally, many NDDs co-occur (American Psychiatric Association, 2013), and in this case people may be called *multiply neurodivergent* (Walker, 2021b). Many of these neurodivergent behaviors and symptoms relate to differences in the way people perceive and interact with information, which should make neurodivergence a topic of interest to researchers in the field of library and information science (LIS).

Despite the relevance of neurodivergence to information practices and a rising awareness of neurodivergent (ND) conditions, LIS research has not given much attention to the information practices of this segment of the population. The “library” part of LIS is beginning to explore the experiences of autistic librarians (Anderson, 2021a, 2021b; Eng, 2017; Lawrence, 2013; Tumlin,

2019), and public libraries are exploring ND-friendly story times and services (Frick, 2018; Hickey et al., 2018), but on the “information science” side of LIS, the needs of ND information-seekers are just beginning to be studied and research into the broader information behaviors of ND individuals—particularly ND adults—is virtually non-existent.¹ A tradition of inclusive and equitable yet practical approaches to the intersection of neurodivergence and information has yet to be developed.

Through this study, I hope to inspire LIS researchers to pay more attention to the information behavior of neurodivergent minds by providing a demonstration of how neurodivergence can be studied using a commonly-used theoretical framework in LIS—Brenda Dervin’s Sense-Making (Dervin, 1992, 1998, 2000; Dervin & Naumer, 2017)—and a burgeoning LIS-related area of public interest, *personal knowledge management* (PKM): the ways people “gather, classify, store, search, and retrieve knowledge in [their] daily activities” (Razmerita et al., 2009, p. 1024; see also Grundspenkis, 2007). Many people use PKM tools and systems, which can be as simple as a single notebook or as complex as a network of connected applications and habits, as a “second brain” to help them understand, remember, use, and build upon information they’ve encountered (Forte, 2022). Anecdotally, PKM has been of great interest to some neurodivergent (ND) knowledge workers because of its function as a “second

¹ Many neurodivergent people use the term “ND” as a noun or adjective to refer to or describe themselves or the wider neurodivergent community, and “NT” to refer to or describe *neurotypical* individuals; for example, “I’m ND but I’m dating an NT” or “NTs always demand eye contact”). This terminology, though informal, is widely used in online communities formed around topics related to neurodivergence and it is also familiar and comfortable to me. Therefore, I will be using “ND” and “NT” as nouns and adjectives throughout this work to avoid the repetitive clunkiness of phrases like “neurodivergent people” and “neurotypical people.”

brain” to aid information and knowledge processing, creation, and recall (Forte et al., 2022; Jenks, 2020).

This project addresses, in a small way, the gap in our knowledge about ND information behaviors by exploring the reasons and ways ND participants use PKM strategies and tools. An online survey of over 300 self-identified ND participants provided insight into the research questions for this study: what outcomes ND people use PKM for in different life domains, what activities they engage in when they use PKM, and what benefits of PKM are identified as being most helpful. By centering ND minds and voices within an LIS-related framework, Brenda Dervin's Sense-Making (Dervin, 1992, 1998, 2000; Dervin & Naumer, 2017), it is my hope that this project will demonstrate that LIS has much to offer ND information users and that LIS researchers should pay more attention to ND information needs and practices. The title of this paper is a reference to a phrase that is so familiar to people with ADHD² that it has become an in-joke within ND communities: “You clearly have so much potential, but you just don’t *apply yourself*” ([BasedJoey_], 2014; [cheezy_tater], 2022; [igotsmeakabob11], 2023; and countless other examples). In a similar (but hopefully more accurate) vein, LIS as a field has so much to offer neurodivergence research—if only we, as researchers and practitioners, would just apply ourselves to the task.

The rest of this chapter provides some introductory information on neurodivergence, PKM, and why LIS researchers should be more involved in research involve neurodivergence, then segues into a discussion of some of the challenges and inequities faced by NDs and how

² “People with ADHD” often refer to themselves as ADHDers, for lack of a more elegant term, and this phrase will undoubtedly show up frequently in the following pages.

PKM and this project can help before presenting the research questions for this project. Chapter 1 closes with my researcher positionality statement, which is critical for understanding my perspective on and approach to this work.

1.1 Background Information

To understand the significance of studying the PKM habits of ND people, we first need an understanding of both neurodivergence and PKM. This section provides a brief overview of these concepts, although they will be discussed in greater depth in the next chapter.

1.1.1 Neurodivergence

As described in the previous section, “neurodivergence” is an umbrella term; it includes a wide variety of conditions that are not considered “normal” such as ASD and ADHD as well as dyslexia, dyspraxia, and Tourette Syndrome. Although there are few studies that look at the entire neurodivergent population—most look at a single diagnostic subset—academic and economic inequities are a common thread among such studies when outcomes are included in the findings. ADHD is well-known for adversely affecting academic and economic outcomes (Arnold et al., 2020; Barbaresi et al., 2007; Blase et al., 2009; DuPaul et al., 2009; Fletcher, 2013; Flores et al., 2022; Frazier et al., 2007; Gray et al., 2016; Halmøy et al., 2009; Lorenz et al., 2017), and many barriers exist for autistics in (or trying to be in) the workplace (Anderson, 2021b; Lorenz et al., 2017) as well as education and academia (Bolourian et al., 2018; MacLeod et al., 2018; Vincent et al., 2017)—and these citations barely scratch the surface of the existing literature.

One reason that studies tend to focus on a single diagnosis is that neurodiversity is, well, diverse. Even within a diagnostic label, there can be great variation—for instance, a specific

learning disorder (SLD) that affects reading (commonly known as dyslexia), can present very differently from an SLD affecting mathematical abilities (commonly known as dyscalculia) (American Psychiatric Association, 2013, p. 67). Likewise, ADHD is categorized into three *presentations* with slightly different diagnostic criteria—predominantly hyperactive/impulsive (ADHD-HI), predominantly inattentive (ADHD-PI), and a combination of both, called the combined presentation (ADHD-C) (American Psychiatric Association, 2013, p. 60). This variation within a diagnosis can mean that in some contexts someone with one diagnosis may be, in some aspects, more similar to a particular person with a different diagnosis than to some people with the same diagnostic label. For instance, a student with ADHD-PI and an autistic student with low support needs may benefit from similar educational accommodations if they are sensitive to distracting stimuli. To further complicate research focusing on a single diagnosis, many people have co-occurring NDDs as well as mental health conditions like anxiety or depression (Bental & Tirosh, 2007; CHADD, n.d.; Danielson et al., 2018). All these variations suggest that in some contexts, it may be worth ignoring diagnostic labels in favor of looking more specifically at individual abilities—in other words, a *transdiagnostic* approach (Astle et al., 2021; Fletcher-Watson, 2022; Harvey, 2004). Such an approach makes sense for LIS: When a patron enters a library, the library staff cannot know if they have a neurodivergent diagnosis, or what that diagnosis is if they do. However, a library worker *can* observe signs of reading difficulties, or auditory sensitivity, or distractibility in a patron, and adjust their interactions accordingly to provide a better experience—without ever needing to know if the patron has ADHD, autism, dyslexia, or a combination of these conditions.

1.1.1.1 Neurodivergence and LIS. As a professional field, LIS has only recently been paying attention to the information needs and behaviors of people with neurodivergent conditions, with the focus still on services for people with particular diagnoses and associated impairments (Lawrence, 2013; Tumlin, 2019). For instance, a well-meaning 2000 article in *Public Library Quarterly* (Akin & O’Toole, 2000) about attention deficit disorder (ADD)³ makes a laudable argument: that people with ADD exist and use libraries, and that the library profession owes them the same level of accessible services as everyone else. However, the article is preoccupied with the impairments and disadvantages associated with ADD, going so far as to claim that people with ADD “suffer” and face “bleak predictions” for their futures (Akin & O’Toole, 2000, pp. 70, 72). That librarians were paying any attention at all to the idea of patrons with ADD in 2000 is laudable, but almost a quarter-century later, LIS needs a more evolved, more inclusive, and less patronizing approach. The best, if not the only, way to develop such an approach is to bring neurodivergent people themselves into the research process.

1.1.1.2 Neurodivergent Voices in Research. Although fields outside of LIS, such as psychology and education, have paid much more attention to neurodivergence, research relating to neurodivergence has often included the voices of everyone but the populations being studied—parents, teachers, and caretakers, but rarely the ND people who are actually the objects of or inspiration for the studies. In recent literature, we see special education teachers talking

³ The American Psychiatric Association retired the term “attention deficit disorder” (ADD) in 1987, when the official name was changed to attention-deficit/hyperactivity disorder (ADHD). The term still lingers in unofficial usage in the US, and is still used as a diagnosis many countries, sometimes meaning the same thing as ADHD and sometime as a separate diagnosis that corresponds specifically to ADHD-PI (CHADD, 2018).

about autistic students (Charitaki et al., 2021), teachers of autistic children exploring knowledge co-creation (Guldborg et al., 2017), and parents talking about their children with recent autism diagnoses (Legg et al., 2023).⁴ These ND-adjacent groups certainly have valuable insight to contribute and can be significantly easier to interview, especially if the population of interest is very young and/or nonverbal. However, there remains a relative paucity of research that directly involves the subjective experiences of ND participants. A unique strength of this study is that everyone involved, researcher and participants alike, has the lived experience of being neurodivergent and facing information- and knowledge-related challenges for which they turned to PKM for help.

1.1.2 Personal Knowledge Management

PKM is a set of “collection processes that an individual needs to carry out in order to gather, classify, store, search, and retrieve knowledge in [their] daily activities” (Razmerita et al., 2009, p. 1024), or “a strategy for transforming what might be random pieces of information into something that is more systematic and expands our personal knowledge” (Frans & Hixson, 1998, p. 6). PKM can also be understood as *not* being *organizational* knowledge management (KM). Traditional KM, developed to benefit organizations and companies, “harvests” knowledge from individuals and distributes to others within the organization (Ives et al., 1997). Personal knowledge management is about “mak[ing] the most effective use of what [individuals] already know” (Forte, 2019). A literature review conducted in 2008–2009 by Razmerita, Kirchner, & Sudzina (2009) found little research regarding PKM. Although that amount has increased in the

⁴ See Sue Fletcher-Watson et al. (2019) for further discussion of this issue; for relatively rare exceptions, see Katta Spiel et al. (2022) and Yasamine Bolourian et al. (2018).

past decade, the field is still overshadowed by organizational KM, likely driven by the amount of capital that companies are willing to expend on KM systems and consultants. Discussions and research into PKM are dominated by industry and a few passionate practitioners as they create and use consumer products like Evernote,⁵ Roam,⁶ or Notion,⁷ with relatively few academics, even (or particularly) in LIS, researching the subject.

1.1.3 Why LIS Should Pay Attention to Neurodivergence

There are four equally compelling reasons that LIS as a discipline and a practice should be paying attention to neurodivergence as it relates to information. First, it is an issue of knowledge. We have a grossly incomplete understanding of the information practices of ND individuals, and as a field we should seek to fill in that knowledge gap through research. Secondly, it is an information literacy issue. It is quite clear (at least to ND people themselves) that when your brain is “wired” differently from the majority of people in the world, you use and access information differently and need to learn different strategies from “normal” people. Animal behaviorist and autistic Temple Grandin, for instance, calls the way she processes information “thinking in pictures” instead of in language (Grandin, 1995, 2006). Third, it is an equity issue, and LIS researchers and practitioners have long prided themselves (deservedly or not) for being forces for equality and accessibility. Fourth, and finally, it is an issue of having a healthy society, which is a key motivation for many LIS practitioners (Buschman, 2017).

⁵ <https://evernote.com>

⁶ <https://roamresearch.com>

⁷ <https://www.notion.so>

Diversity—whether biological, cultural, philosophical, or, yes, even neurological—is critical for the cultivation of a resilient, healthy democratic society. An inflexible, monolithic society is fragile and easily damaged. Ensuring that the ND segment of the population can access information, share and create knowledge, and engage in civic society to whatever extent they wish is in everyone’s best interest.

1.2 Problem Statement

As discussed in the previous section, ND people consistently face less optimal outcomes than NTs in education, their careers, and other areas of life. However, research involving neurodivergent people typically focuses more on how they can be more typically successful in school, or more productive for their employers. There is relatively little research in how ND people can best achieve their own goals and improve their quality of life and well-being.

1.2.1 Perspectives on Disability

Neurodivergence and its associated conditions have historically been considered and treated as disabilities, if not outright mental illnesses. However, many people inside and outside the ND community question whether being neurodivergent is inherently disabling. The *neurodiversity movement* is discussed at greater length in Chapter 2, but to even begin to answer the question “Is neurodivergence a disability?” we need to understand what we mean when we talk about “disabilities” and “impairment.” Precise definitions vary, but in general, the definitions provided by the World Health Organization (WHO) in 1980 are still dominant: Disability relates to a “restriction or lack of ability to perform an activity,” while impairment relates to the “loss or abnormality of psychological, physiological or anatomical structure or function” (Carter, 2018, paras. 3–5).

Two common models, or ways of thinking, about disability and impairment are the *medical model* and the *social model*. The medical model of disability is the most traditional and historied. The medical model focuses on an individual's impairments as deficits, and sees disability as a problem that needs to be fixed: As much as possible, disabled people must be "repaired" or "normalized" to look and act like non-disabled people (Wilson, 2003, pp. 20–21). From the perspective of the medical model, *disability* and *impairment* are virtually indistinguishable.

The social model of disability argues that it is society that is disabling to individuals through the existence of barriers and lack of accommodations in society, and that the "social environment" is what must be changed, not the disabled person (Wilson, 2003, p. 21). Disability is distinct from "impairment," which refers to "any loss or abnormality of psychological, physiological or anatomical structure or function" (Carter, 2018, para. 3). For instance, according to the social model of disability, someone with pronounced myopia has an impairment, but not a disability, because lenses that correct that vision are widely and cheaply available and wearing glasses is considered "normal" socially (Solomon, 2012). The social model is focused less on individual "deficits" (the focus of the medical model) and more on disabled people as a group with shared experiences (Wilson, 2003, p. 21). This communal approach to disability strengthened the disability rights movement that gained momentum in the 1970s and helped lead to the passing of the Americans With Disabilities Act of 1990 (Oliver, 2017).

Another way of thinking about disability is using a deficit-based approach as opposed to a strengths-based approach. A deficit-based approach focuses on what an individual can't do, or what they have problems doing and how we can compensate for those shortcomings; a strengths-

based approach focuses on what individuals *can* do and how we can build on the foundation of skills and abilities that already exists. A strengths-based approach doesn't mean denial of an individual's impairment or challenges, but it can uncover opportunities to take advantages of strengths that might be missed when focusing strictly on deficits.

1.2.2 Neuro-liberal Capitalism: We Can All Be Alienated From the Product of Our Labor!

As a response to the stigma and stereotypes surrounding neurodiversity associated with the deficit-focused medical model, there is often an attempt to show the positive side of neurodivergence, such as the ADHD ability to hyperfocus or the common autistic trait of being detail-oriented. Sometimes historical characters are labeled as neurodivergent without any actual diagnosis or real evidence—for instance, claiming that William Shakespeare had ADHD (Dalton, 2013). Coincidentally (or not) potentially “positive” traits (such as hyperfocus or attention to detail) are often described in terms that align with desirable traits for an employee. Although this trend is certainly a needed correction from the historical assumption that anything other than neurotypicality makes one a less valuable member of society, it buys into the belief that a person must be productive, useful, and profitable in order to have worth. In reality, the neurodiverse population displays a tremendous range of cognitive abilities and skills. Just as in the NT population, some NDs are “productive members of society” and others are less able to pursue traditional (capitalist) “success.” Still others are excluded from being as “productive” in society as they would like to be, because of barriers to access and inhospitable conditions. Many, if not most, studies involving neurodivergent adults seems to be motivated by this drive to make them more “productive” in a work setting.

It is certainly not wrong to explore ways that neurodivergent people can be more productive for their employers, or for neurodivergent people themselves to strive for such. However, Lennard J. Davis (2011) suggests that the reason disability has been less widely celebrated as part of “diversity” than ethnicity or gender because it is incongruent with the ideals of neoliberalism, arguing that not only is disability underrepresented in modern discussions of diversity, but that it is essentially “antithetical” to the prevailing concept of diversity, which has been conveniently crafted to suit capitalism. My goal as a researcher, as a member of society, and as an ND person myself, is to explore ways to help neurodivergent people to meet their *own* objectives and their *own* definitions of success based on their *own* values. Simply put, my concern is with well-being, not productivity *per se*, except to the extent that being “productive” is helping someone achieve their goals.

1.2.3 Transdiagnostic Research: Maybe Paying Attention to Impairments Isn’t All Bad

If we recognize and reject the idea that a person’s value is based on their economic productivity, then a frank acknowledgement of impairment need not be taboo, as it does not diminish a person’s worth. Research that focuses on an individual’s combination of cognitive abilities and disabilities, rather than centering research on a diagnosis, could uncover deeper insights and help develop more impactful information services and products. The diagnostic-centric approach can be very useful and certainly has a lasting place among research paradigms, but stopping there is a mistake. There is a well-known saying that “if you’ve met one person with autism, you’ve met one person with autism”—meaning that while there are commonalities across people with autism, the individual expressions of symptoms and behaviors, and the individuals themselves, are so varied that making broad generalizations is impossible—“Infinite diversity in

infinite combinations,” to quote the philosophy of Star Trek’s Vulcans (“IDIC,” n.d.). Boiling down this diversity into “the average person with ADHD” or “the average person with autism” is better than ignoring the existence of neurodivergent minds altogether, but a great deal of nuance and variety may be lost in doing so. For example, just “unbundling” one level of ADHD gives us three presentation types: primarily inattentive, hyperactive/impulsive, and combination (both inattentive and hyperactive/impulsive). Research tells us that primarily inattentive ADHD seems to affect academic performance far more than the hyperactive/impulsive type (Flores et al., 2022). A knowledge worker or information systems designer with a monolithic idea of what “a person with autism” or “a person with ADHD” needs and wants will be ill-prepared to meet those needs. The idea of *transdiagnostic research*, which focuses on dimensions of disability and support instead of starting with a specific clinical label, is gaining ground in the study of neurodivergence where, as researcher Sue Fletcher-Watson described it in an interview, “everything’s messy” (Brookman-Byrne, 2022).

1.2.4 Inadequate Support for ND Adults

The prevailing inequities for ND people in education, career, and general well-being discussed earlier in this chapter are evidence that whatever accommodations, support, and treatment ND adults are able to take advantage of are often insufficient (Baeyens, 2021). Accommodations are frequently of limited efficacy in higher education (Baeyens, 2021) and are often non-existent at places of employment—or ND employees are too concerned about potential negative consequences that they aren’t willing to disclose to their employer. Stimulant medications, a common treatment for ADHD, can help improve focus and productivity, but on their own don’t seem to have long-term effects on educational achievement (Advokat, 2009;

Advokat et al., 2011; Rabiner et al., 2008). Arnold et al. (2020) found that *multimodal* treatment (involving both medication and non-medication intervention, such as study skills and strategy training) was most effective in improving educational outcomes for students with ADHD, suggesting that a more holistic, whole-life approach to supporting NDs will be more effective than a tunnel-vision focus on education. Instead, we should focus on making sure that NDs have access to the tools they need to be successful by their own definitions—whether that is systemic change, more inclusive human-computer interaction (HCI) design, or simply a focus on building ND-specific skills in addition to providing accommodations.

1.2.5 PKM Might be a Key to Improving Outcomes for NDs

I'm a horrible writer, admittedly. I am really bad at writing, and I think a lot of that stems from ADHD, being able to focus on writing, being able hold the ideas long enough in my head, connected together, to actually put it down on paper in a consistent manner. Like, I am just not good at writing. Not for lack of trying, not for lack of skill, or being able to write well, like words that make sense, I just have so many issues with it. So the way I'm getting around it is I'm... using that framework of external thinking to help me write so I don't have to focus on holding the ideas together as much, I can stay in the flow state, I can write text. (Jenks, 2020)

There is anecdotal information online that PKM—particularly a form of note-taking in which notes on different topics are conceptually linked to each other—is appreciated by many neurodivergent individuals. As Bryan Jenks (2020) describes in the quote above, “tools for

thought” such as this kind of networked note-taking allow, in a way, for information to be processed and knowledge synthesized to some extent outside of the human mind, or at least it allows for the results of the process to be kept somewhere other than the sometimes selective memory of ND people. A few studies have suggested that ND people may benefit from different note-taking strategies than NTs (Advokat et al., 2011; Boroson, 2018; Dror et al., 2011). Regular note-taking seems to benefit NT students more than ND students, suggesting that something is different about note-taking for ND students (Advokat et al., 2011). It is possible that note-taking is simply not helpful for students with ADHD, but it is also possible that note-taking *the way NT students take notes* isn't helpful, or that note-taking the way ADHD students intuitively take notes, without instruction, isn't helpful. In any case, *something* about note-taking is different for ND students.

1.3 Research Questions

Instead of centering neurotypical minds and researching neurodivergence in contrast to them, this study centers neurodivergent minds in all their diversity. Just as medical studies have historically treated white men as “default,” and described women and people of color in terms of their differences to what was considered “normal,” research involving ND individuals has frequently been framed in terms of their deviance from the average neurotypical. This project looks at the population of ND people as they are and will leave comparisons and contrasts to other researchers. While there is a time and place for studying differences, especially when one's goal is to modify a “normal” tool or resource for “abnormal” users, my intention is to focus on people's abilities and goals, not their conditions or labels.

To that end, this study asks and answers the following research questions:

Research Question 1 (RQ1): For what outcomes do neurodivergent people use personal knowledge management in different life domains?

Research Question 2 (RQ2): What activities do neurodivergent people engage in when they use personal knowledge management?

Research Question 3 (RQ3): What benefits of personal knowledge management do neurodivergent people identify as being most helpful?

1.4 Researcher Positionality

It feels like cultural appropriation to speak for those whose experiences are further out from the accepted norm than mine, but on the other hand, I'm unwilling to relinquish recognition for my own share in the pain of the oppression. (Singer, 2016)

I am approaching this study as a member (with some qualifications) of the population being studied. I was diagnosed with ADHD-PI in adulthood, with the result that I have the life-long experience of *being* neurodivergent without *knowing* it.

1.4.1 Insider or Outsider?

Research positionality statements usually contain some discussion of whether the researcher is an “insider” or an “outsider” in relation to the participants in or subjects of the study. Even aside from the broader conversation about whether the “insider-outsider” discourse is even helpful for analyzing positionality (Holmes & Gary, 2020), it is particularly complicated in the context of this researcher and dissertation, as I have elements of both an “insider” and an “outsider” in regards to the neurodivergent community. In some ways, I am an “outsider” to the

neurodivergent population because, like many women, my ADHD was “missed” when I was a child and I was not diagnosed until I was in my thirties.⁸ Therefore, I am not in the habit of thinking of myself as neurodivergent and aside from being considered “weird” and a “space cadet,” I have not been treated as such during my life. On the other hand, it is clear now that I am an “insider” in the sense that I do, in fact, have ADHD, a neurodivergent condition, and I am far from alone in my late diagnosis, particularly among women. This means I have seen neurodiversity from multiple perspectives, and I have therefore tried to be reflexive about my role as a researcher throughout this project.

I approached this study from a constructivist paradigm. According to Crotty (1998), the constructivist epistemology holds that our knowledge of the world is only accessible through our mental models and constructs of the world. Being entirely objective is not humanly possible, so rather than pretend my subjectivity does not exist, I decided to embrace it regarding the topic of this research and to be as reflexive as possible about how my constructed interpretation of the world is influencing my research.

1.4.2 My Distance from the “Accepted Norm”

Although I am in some ways an “insider” to the neurodivergent community, I feel that it is important to acknowledge that the social and physical challenges experienced by people with ADHD like myself are, on average, less severe in impact than the challenges experienced by people with other neurodivergences such as autism. Even in comparison with people with

⁸ The relationships between and among ADHD, autism, biological sex, and gender are not entirely understood and are far outside the scope of this study; however, it is known that ADHD and autism tend to present differently in girls than in boys, and boys are more frequently diagnosed with both conditions. The extent to which this is due to biological factors versus clinicians’ expectations and bias is uncertain. For more on this topic, see, among many others, Young et al. (2020) and Lapalme et al. (2018).

ADHD, I have the less obvious “primarily inattentive” presentation. I have also had many privileges in life that allowed me to unconsciously mask and to “slide by” in school and work for most of my life. In Judy Singer's words, there are many people whose experiences are “further out from the accepted norm” than mine (Singer, 2016, loc. 715).

1.4.3 My Experience

While I was growing up, I always felt different from most of my peers, but I didn't know why—like many neurodivergent people, I now understand. I was the smart but weird kid, the one who got too interested in reading every Daniel Boone biography in the public library, memorizing facts about every breed of horse, and thinking up new classification systems for my personal book collection. I was homeschooled the entirety of my childhood, so there was no real chance for my symptoms to be noticed and diagnosed—which would have been unlikely to happen for a girl at that time anyway. It was just well-known that I was socially awkward, “spacey” like my father and “klutzy” like his mother (ADHD has a strong hereditary component). In college, I rarely studied and simply relied on my cleverness and decent attendance (albeit consistently five minutes late) to help me pass exams; my essays were usually written hastily in miserable “all-nighters.” Professors were stymied; feedback was usually along the lines of “these are great ideas and you're clearly quite smart, but you need to organize your thoughts more effectively.” My post-college career progressed similarly: My puzzled managers always had high expectations for me that I was never quite able to reach, and even though I always did good work and had an over-abundance of creative ideas, they were never quite able to articulate why I was falling short. At every job, I would become bored out of my mind after a few years, and eventually I returned to academia to pursue a doctorate.

There are two reasons why this topic—of PKM and neurodivergence—is so important to me. The first reason is that, as a graduate student with ADHD, PKM principles have been incredibly important to me. For much of my program, I was full of research ideas, none of which I could hold onto long enough to develop into a fully-fledged concept. I knew that I needed something like PKM to help me remember what I've read and the ideas I've had, and to piece them together into a meaningful whole, but I didn't know how to make it work. Discovering the concept of PKM, and especially the online community of enthusiasts sharing their setups and swapping tips, quite honestly saved my academic career. I began recording notes on readings and ideas and questions and storing them in a sensible and re-findable way; I would still be distracted by shiny new ideas (sometimes referred to as “squirrels” by ADHDers), but I could be confident knowing that I would find my old ideas again, ready to be built up into research questions and theories.

The second reason is that I came to the realization that I am not alone in these struggles, a realization I had even before I could put a name to my challenges. The first time I taught a class of undergraduates—mostly freshmen and sophomores—a student who was particularly struggling came to my office hours. He was on the verge of tears as he described his seeming inability to be on time for anything—a challenge I knew very well. I told him as much; he nodded, but I could tell he was skeptical. After all, here I was, a doctoral student facing the “final boss” level of the educational system—how could I have gotten to this point while facing such “basic” difficulties as *being on time*? As I encountered more and more students who, to varying degrees, shared their feelings of shame and aloneness for not being able to manage the “simple” responsibilities of student life, I realized that when I was an undergraduate—and probably even

now—I was almost certainly surrounded by other neurodivergent students in the same “fish out of water” situation that I was. But as a researcher, I am now in a position to help neurodivergent people like me, whether they are students or not.

It is my hope that this project will not only answer some important questions about how neurodivergent people can and do leverage PKM to achieve their goals, but also that the answers to these questions will provide knowledge, direction, and inspiration to anyone developing tools and resources for neurodivergent people. Beyond the immediate impact of my research, however, I hope that my work will spur greater interest in more LIS research regarding neurodivergence.

1.5 Dissertation Structure

This first chapter has introduced the concepts of neurodivergence and personal knowledge management and discussed some of the challenges faced by ND adults, as well as suggesting that PKM might be a productive strategy for NDs to use while pursuing their goals. The next chapter will further explore neurodivergence and neurodiversity, PKM, and the theoretical framework behind this study—Brenda Dervin’s Sense-Making (Dervin, 1992, 1998, 2000; Dervin & Naumer, 2017). Chapter 3 describes the study methods, including the design and administration of the survey, and how the results were analyzed. Chapter 4 explores the results of the survey and discusses the answers to the research questions introduced earlier in this chapter. Finally, Chapter 5 discusses the implications and significance of this project, as well as the many possibilities for future research.

Chapter 2: Background

Neurodivergence and its place in society is a complex topic. Although it has garnered a small amount of attention in LIS, our field's approach to neurodivergence has much room to grow and mature. In particular, the way neurodivergence is approached in relation to disability and diversity is more nuanced than it is often treated in everyday discussion. This chapter will tackle that subject, then discuss PKM and how it relates to both neurodivergence and LIS. Finally, this chapter will conclude with a discussion of Dervin's Sense-Making (Dervin, 1992, 1998, 2000; Naumer et al., 2008) and why it is an appropriate approach for this research.

2.1 Neurodivergence

Autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), dyspraxia, dyslexia, and Tourette's syndrome are usually included underneath the umbrella of “neurodivergence” or “neurodevelopmental disorders.” Because it is not a strictly defined medical term, there is some variation in what people consider to be “neurodivergent” — for instance, some people exclude some learning disorders, while others expand the definition to encompass epilepsy, bipolar disorder, and obsessive-compulsive disorder (OCD) (Fenton, 2007). Less frequently, mood disorders such as anxiety and depression are described as neurodivergent. The autistic activist who coined the term, however, insists that:

Neurodivergent just means a brain that diverges.

Autistic people. ADHD people. People with learning disabilities. Epileptic people. People with mental illnesses. People with MS or Parkinsons or apraxia

or cerebral palsy or dyspraxia or no specific diagnosis but wonky lateralization or something.

That is all it means. It is not another damn tool of exclusion. It is specifically a tool of inclusion. (sherlocksflataffect, 2015)

This research study focuses on neurodivergence in the form of neurodevelopmental disorders.

From the medical perspective, neurodevelopmental disorders (NDDs) are so called because they typically appear during the developmental period of life (i.e. childhood) and are related to changes in the way the brain functions (American Psychiatric Association, 2013). As defined in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) (2013), NDDs include intellectual disabilities, communication disorders, autism spectrum disorder (ASD), attention deficit/hyperactivity disorder (ADHD), specific learning disorders (SLDs), and motor disorders; the World Health Organization's International Statistical Classification of Diseases and Related Health Problems (ICD) roughly aligns with these categorizations but distinguishes between motor coordination disorders and stereotyped movement disorder (World Health Organization, n.d.). Among the most common and most commonly discussed NDDs are ASD, ADHD, and dyslexia (an SLD).

Although they have some etiological similarities, the many conditions that fall under the umbrella term "neurodivergence" are indeed diverse. The term "spectrum", commonly used to refer to autism spectrum disorder (ASD), is not particularly apt for describing neurodiversity (or even autism, although that is another discussion). "Spectrum" implies two extreme points at opposing ends from each other; for instance, the visual light spectrum from red to violet, or a

political spectrum from liberal to conservative. Autistic archivist Zachary Tumlin (2019) likens neurodiversity to a “circular color spectrum,” rather than a two-dimensional spectrum (like wavelengths), “with each color representing a different ability, like red for executive functioning and blue for motor skills. Everyone, disabled or not, has every color, but our shades differ” (p. 14).

2.1.1 Neurodivergence and LIS

As a professional field, LIS has only recently been paying real attention to the full range of neurodivergent conditions. This attention still tends to concentrate on one diagnostic condition at a time, often framed exclusively with the medical model of disability, and focusing heavily on public library services (Lawrence, 2013; Tumlin, 2019). A well-meaning 2000 article in *Public Library Quarterly* (Akin & O’Toole, 2000) makes a good basic point: that people with ADD exist and use libraries, and that the library profession owes them the same level of accessible service as everyone else. However, it is clearly entrenched in the medical model, even going so far as to say that people “suffer” from ADD and face “bleak predictions” for their future (p. 70, p. 72).

Kimberley Douglass and Bharat Mehra (2016) turned away from the tunnel vision typically exhibited in LIS literature about neurodivergence up to that point by using the Four Frames analysis to look at the sources of power and related information needs relevant to ADHD-affected families' decision-making. While still focused on “meeting needs” of a single diagnosis, the researchers acknowledge the diversity to be found within the ADHD-affected population and take a much broader, social justice-oriented look at how information can help.

2.1.2 Neurodiversity

In contrast with “neurodevelopmental disorders,” the terms *neurodiversity*, *neurotypical*, and *neurodivergent* did not originate in the medical community. “Neurotypical” grew out of the online autism activism communities in the 1990s as a way to speak of non-autistics without using the term “normal.” People without autism were called neurotypicals, or NTs, and people with autism were called neuroatypical. Eventually, “neuroatypical” came to mean anyone with a range of neurodevelopmental disorders, not just autism. The neurodiversity movement, taking off in the 1990s, approached autism as a “hardwired” difference, not a “psychological problem” to be fixed or cured (Singer, 2016, loc. 109). Hoping to facilitate an advocacy movement similar to that of the gay rights movement that was gaining ground at the time, Australian sociologist Judy Singer (2016) coined the term “neurodiversity” in a search for a more marketable alternative to “neurological diversity,” which she describes as “a mouthful” (loc. 304). The term “neurodivergent” or “neurodivergence” is used to represent the presence of neurological differences, while “neurodiversity” is used in relation to the advocacy movement itself (Walker, 2021a). As with neurodivergence, because it is not a defined medical term, there is some variation in what people consider to be part of “neurodiversity”—for instance, some people exclude some learning disorders, while more expansive definitions encompass epilepsy and obsessive-compulsive disorder (OCD).

Autistic researcher Nick Walker (Walker, 2021c) describes a “paradigm shift,” which she likens to the shift from an earth-centered view of the solar system to a sun-centered view. This profound reorientation of belief is from a “pathology paradigm” of diversity, in which there is a single right and normal way for a human brain to work, to a “neurodiversity paradigm” that

holds that there is no “normal” when it comes humans, and the diversity we see is “natural, healthy, and valuable” (Walker, 2021c). Just like changing from a geocentric to heliocentric model of the solar system, embracing the neurodiversity paradigm requires us to re-evaluate all scientific evidence, assumptions, and interpretations. Failing to do so, Walker says, is—borrowing Audre Lorde's famous metaphor—trying to use the master's tools to dismantle the master's house (Lorde, 2018; Walker, 2021c).⁹

2.1.3 Talking about Neurodivergence

Identity is a key defining topic for the neurodiversity movement. A key tenet of the neurodiversity movement is that, as autistic advocate Jim Sinclair (2012) explains, “it is not possible to separate the person from the autism [or other neurodivergent condition],” and efforts to “cure” neurodivergence are in fact an attempt to change the person into someone else. Person-first language—such as “a person with autism” can be objectionable since it implies that the autism is something extra that the person has (like a disease) instead of something the person is. People who think of it this way generally prefer to use identity-first language—“Autistic people” or “Autistics” rather than “people with autism.” On the other hand, some people with autism wish to emphasize their identity as “their whole person,” and not primarily defined by their autism (Micallef, 2022).

⁹ Audre Lorde was an American civil rights activist who lived from 1934-1992. Micah White, co-creator of Occupy Wall Street, explains her famous phrase as meaning “we cannot disrupt our oppression using the logic that justifies our oppression” (White, n.d.).

Neurodivergent people use both person-first and identity-first language, depending on their personal perspectives and feelings (Micallef, 2022). In this dissertation, I will attempt to alternate more-or-less equally between both styles, in acknowledgement of the differing opinions within the neurodivergent community and to achieve language variety for ease and enjoyment of reading. Speaking specifically about autism, although the term “Autism Spectrum Disorder” is the medically accurate term in the United States, many autistic people eschew the phrase and in particular the word “disorder.” Some people prefer to use the term Autistic as a noun, and still others use the word Autist. Autistic coach and advocate Paul Micallef recommends using identity-first language “unless informed otherwise” (2022).

There are varied, complex and nuanced perspectives regarding the terminology used to describe autism and autistic people (as well as disability in general). For the sake of readers who may not be aware of the context surrounding many of these terms, I have chosen to use conventional, widely-understood terminology such as “Autism Spectrum Disorder,” while acknowledging that “spectrum” and “disorder” are not considered accurate by many, including people who are labeled with this diagnosis. I also acknowledge the pros and cons of both people-first and identity-first language, and I use both approaches in this project depending on what seems most appropriate, readable, and precise in a given context.

2.1.4 Goals of Researching Neurodiversity

Although the Disability Movement's battlecry is “nothing about us without us,” the literature has been dominated by the voices of people around neurodivergent people—such as their parents and teachers—rather than the autistic people themselves. Some researchers argue that including disabled voices in the research data is not enough; they should be involved in the

analysis of that data as well, even if that means making adjustments to the analysis process (Nind, 2011; Vincent et al., 2017).

The perspective of autistic students is a critical part of finding a solution to make higher education more accessible, because individual experiences are varied and “insiders” can provide insights that “outsiders” simply cannot. For instance, Vincent et al. (2017), by including autistic students as data analysts and co-authors, uncovered nuances in terminology, such as replacing the common term “social anxiety” with “social discomfort”, which the students felt was distinct and more authentic to their experience. Fletcher-Watson attributes the growing realization that “clean categories” do not reflect reality to greater involvement of non-researchers (e.g., parents, teachers, therapists, ND children and adults) in research (Brookman-Byrne, 2022).

This study involved the direct input of ND adults regarding their goals and objectives, and how they use a particular information practice—personal knowledge management—in order to achieve them. PKM is discussed in the following section.

2.2 Personal Knowledge Management

In writing this dissertation, I made heavy use of Zotero, a citation manager that allows you to file and tag articles and papers for future reference. I highlighted key passages, and Zotero extracted my annotations so that I could copy them into notes I created in Obsidian for each relevant paper I read. I made notes about the key points and my reactions to the findings, and linked each literature note to a topic note, such as “ADHD Treatment” or “PKM and neurodivergence.” From these topic notes, I began organizing a rough outline in Obsidian. Then I remembered that I had some notes left over in an old OneNote file—a program I used before

switching to Obsidian. This network, for better or for worse, is my personal knowledge management system (PKMS).

Within the past decade, personal knowledge management (PKM) has developed a small but passionate and growing group of enthusiasts. While the term can broadly refer to a number of activities, one of the most commonly discussed activities is note-taking with the end goal of gaining insights into the development of a creative product or piece of content. While “regular” knowledge management (KM) is widely recognized as being relevant to, or even part of, the field of library and information science (LIS), it appears that the connection to *personal* knowledge management has not been so obvious. This may be due to the fact that LIS and KM have both traditionally been approached as top-down organizational and management activities, while *personal* knowledge management is by definition a bottom-up system.

2.2.1 PKM History and Definition

PKM can be understood in comparison to knowledge management (KM). Knowledge management (KM) is—or ought to be— “enabling people to obtain relevant, context-rich information, and connection with appropriate experts easily, when they need it, so that they can be more effective doing their unique jobs” (Pollard, 2008, p. 97). In reality, there is a growing consensus in the information profession that organizational, top-down KM has been “a failure,” frequently being implemented as simple “automat[ing] existing information processes” that at best made information more accessible digitally, and at worst stripped it of meaning and context (Forte, 2019; Pollard, 2008, pp. 95–98).

While KM focuses on knowledge at an organizational level, PKM focuses on an individual’s interactions with and behaviors regarding knowledge. Instead of bounding itself

within the context of a single business entity, personal knowledge management allows for engagement across boundaries. For instance, a doctoral student may encounter important and personally relevant information from their advisor and other faculty, from journal articles, from various sources on the internet, from conversations with other students, from professional organizations, or from insights that spring to mind as they commute to campus. Instead of expending effort into organization-centric knowledge management systems, many modern knowledge workers would benefit more from developing and enhancing their own practices around knowledge and information management.

A literature review conducted in 2008–2009 found little research regarding personal knowledge management (Razmerita et al., 2009). Although that number has increased somewhat in the past decade, the field is still overshadowed by organizational knowledge management, likely driven by the amount of capital that companies are willing to expend on KM systems and consultants. Discussions and research into PKM are dominated by industry and practitioners as they create consumer products such as Evernote, Roam, or Notion. Despite being far out-budgeted by traditional KM, over the past decade, PKM developed a small but passionate and growing group of amateur—and what can now be called professional—PKM enthusiasts. Within this community, one of the most commonly discussed activities is currently note-taking, usually with the end goal of gaining insight and sometimes creating a product or piece of content. Largely inspired by the index card-based *Zettelkasten* method popularized by Niklas Luhmann, where each card contained references to other related cards, digital versions of networked notes (which may also be called linked notes, evergreen notes, or even digital gardens) have captured the attention of many knowledge workers (Fast, 2020).

PKM grew out of a related concept, *personal information management*, or PIM. PIM, while often studied on its own, can be considered an element of today's PKM. Today's study of PKM owes at least as much to the PIM body of literature as it does to KM literature. Briefly put, information management deals with the raw information that can be easily stored and transferred; knowledge management is less tangible and deals with enabling the synthesis of information into a new and actionable form.

PIM has a longer history of research than PKM. A high-level definition of PIM is that it is an individual's strategy to "maintain a mapping between information and need" (W. Jones, 2007, p. 464) (Jones, 2007, p. 464). It encompasses "the methods and procedures by which we handle, categorise, and retrieve information on a day-to-day basis" (Lansdale, 1988, p. 55) in order to "keep found things found" (W. Jones et al., 2002, p. 391).

PIM research began by studying piles of paper on (literal) desktops (Lansdale, 1988), but quickly started incorporating electronic mail and computer files (Barreau & Nardi, 1995; Whittaker & Sidner, 1996). Although Deborah Barreau (Barreau, 1995) found similarities between the way people organized paper documents and electronic files, adoption of digital forms of PIM was relatively slow; in 1997, few people were using digital PIM tools (S. R. Jones & Thomas, 1997, p. 158) and a few years later people were still using such techniques as printing out web pages or writing URLs on paper as part of their PIM practices (W. Jones et al., 2002).

William Jones (2007) defined three types of PIM activities: finding and reminding activities, keeping activities, and meta-level activities (like management and organization) (p. 464). However, the types of activities people spend more or less time on seems to be changing

with technology. Increased automation of PIM tasks (for example, automatic “keeping” of exercise data from wearable activity trackers) has decreased the time people spend on “keeping and finding” activities (Feng & Agosto, 2019). This longitudinal evolution supports the longstanding argument that much of PIM behavior can be attributed to the features of supporting technologies, rather than on cognitive attributes of the users. Scott Fertig, Eric Freeman, and David Gelernter (1996) argued that many of the preferences Deborah Barreau & Bonnie Nardi (1995) found were an artifact of how the technology was designed, rather than primarily users’ psychology. In addition, research has found that people find affordances beyond the intended use of personal ICTs. The e-mail inbox has been used as a task list almost since the beginning (Whittaker & Sidner, 1996, p. 276), although not without significant challenges (Bellotti et al., 2005).

2.2.2 What Makes it Personal?

Part of the “personal” in PKM is that people demonstrate different habits and practices in managing their information. Some of this variation is due to the individuals’ roles and tasks (W. Jones et al., 2002). For instance, in exploration of the reasons academics create personal archives, Joseph Kaye et al. (2006) concluded that “personal archiving is by nature a personal system” that does not lend itself to broad generalizations or “best practices” (p. 284). In fact, they found that people took their personal systems very personally and considered them points of pride or personal failures (p. 277).

A major variation seen among PIM systems is the approach to how much data to preserve and how much effort to put into organization. Steve Whittaker & Candace Sidner (1996) found that email users fell into three basic types: nonfilers, frequent filers, and spring cleaners (p. 280),

and that “email overload” was a significant issue. Francesco Vitale, Isabelle Janzen, & Joanna McGrenere (2018) found that people lie along a spectrum from digital hoarding to digital minimalism that varies not only based on the person, but also on the type of content in question.

2.2.3 PKM and LIS

Like other disciplines, LIS has been lagging behind non-academic enthusiasts in the study of PKM. A quick search conducted in May 2022 of “Library & Information Science Source” (LIS Source), a database of top LIS journals and research, resulted in only 51 academic journal results for “personal knowledge management” and 298 for “personal information management,” compared with, for example, 13,123 academic journal results for more commonly discussed LIS topics like “information literacy” and 1,026 for “homework.” PKM is increasingly critical for 21st century knowledge work, to the extent that curating and managing one’s own accumulated knowledge begins to resemble that of a librarian more and more. As one of the leading advocates and practitioners of PKM, Tiago Forte, states: “It’s like we each have a part-time job as a reference librarian” (2019, loc. 3:05). Since PKM can use some or all of searching, browsing, taxonomies, classification, and other topics traditionally in the LIS domain, the field could surely benefit from the expertise of LIS researchers, if only we can let go of top-down approaches to information management and allow individuals to be “in the driver’s seat” (Forte, 2019, loc. 7:44).

2.3 PKM and Neurodivergence

Personal knowledge management strategies and techniques in regards to neurodivergence has emerged as a topic of interest to PKM hobbyists and practitioners (Forte et al., 2022; Jenks, 2020), but have only been tangentially touched on by academic researchers. Most relevant

research focuses on the effects of note-taking. Note-taking skills can be taught to improve the efficacy of the process, and they are often included in instructional and training programs for neurodivergent people (Boroson, 2018; Dror et al., 2011; S. Evans et al., 2002; S. W. Evans et al., 1994, 2016; Harrison et al., 2020; Mortimore & Crozier, 2006; Reed et al., 2016; Sibley et al., 2018; “Study Skills Boost for Students Who Have Dyslexia,” 2009). Most studies on note-taking focus on students in formal education and specifically notes based on lectures (S. W. Evans et al., 1994; Reed et al., 2016), but not exclusively (Dror et al., 2011). The results of these studies can be broadly summed up as finding that instruction on note-taking skills is generally beneficial to ND students.

Note-taking can be described as linear or non-linear (Dror et al., 2011). The effectiveness of specific note-taking strategies has been shown to vary based on individual differences, including neurotypes (Boroson, 2018; Dror et al., 2011). There is some evidence that ND note-takers may benefit from the practice differently than NT learners. For instance, in one of the rare studies involving working adults instead of college students, dyslexic participants performed as well as non-dyslexic participants on cognitive and memory tests when using a non-linear note-taking system that they were trained on; the non-linear system was organized and semi-structured but also more graphical than the linear system (Dror et al., 2011). There is also evidence that autistic students can benefit from learning alternative note-taking strategies, such as *sketchnoting*, which is “directed doodling. . . an active, proactive, and productive strategy for recording ideas visually to boost engagement, comprehension, and retention” (Boroson, 2018, p. 35). Claire Advokat's (2011) research found that neurotypical students who say they take notes more frequently than other students have higher GPAs than those who don't; however, the same

study found that students with ADHD who believe they take notes more frequently do not have higher GPAs than their counterparts.

2.4 Sense-Making

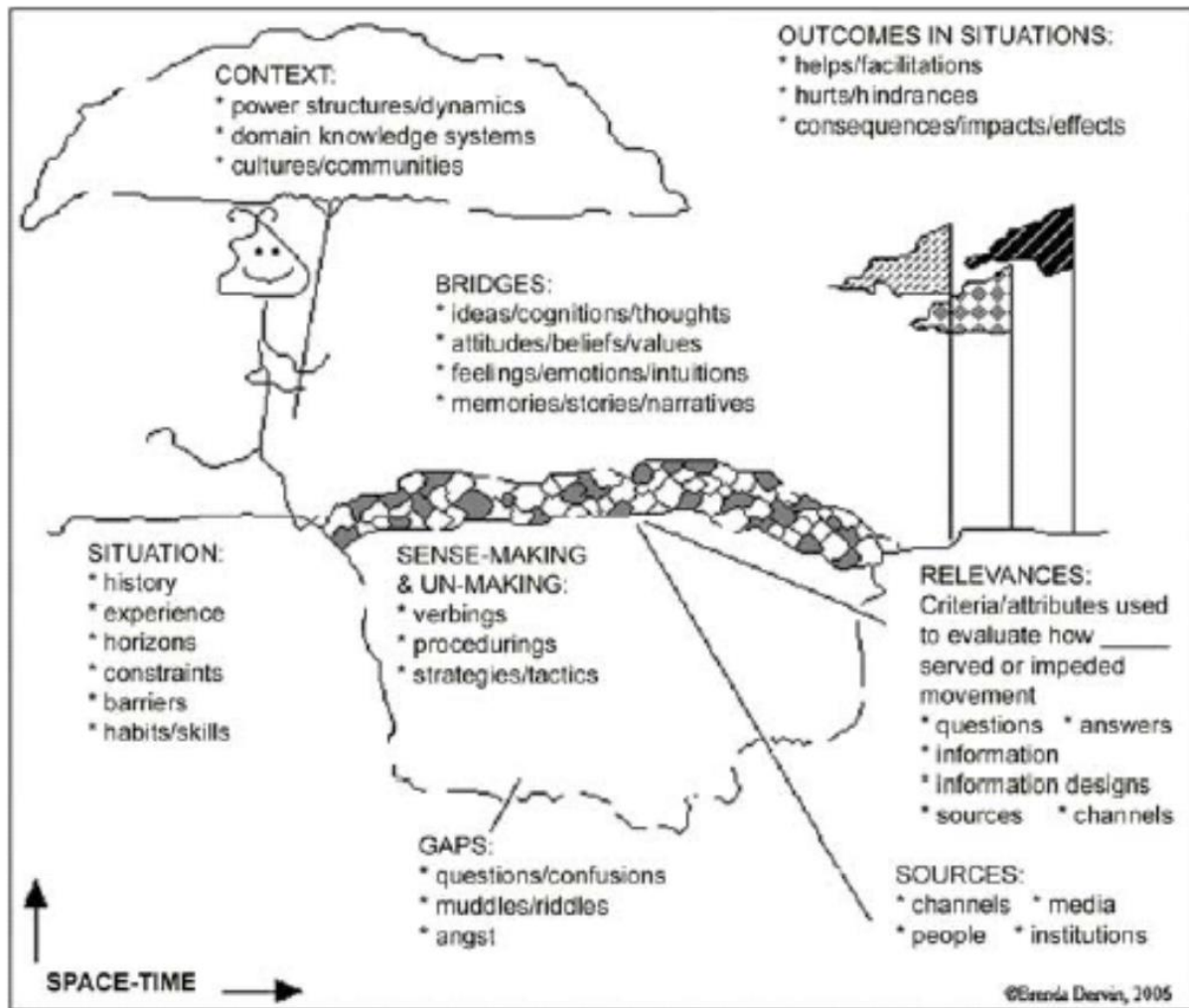
The theoretical framework for this dissertation is Brenda Dervin's Sense-Making Theory (Dervin, 1992, 1998, 2000; Naumer et al., 2008). Sense-Making (typically spelled with one or two capitals to keep it distinct from the concept of the act of "sense-making") encompasses, "in the most general sense," Dervin says, a theory, a set of methods, a methodology, and a set of findings. Sense-Making is an appropriate theoretical framework for this dissertation for the following reasons: it looks beyond the typical "information seeking" question-and-answer framework; it emphasizes the active and indeed central role of the human in any interactions with information systems; it emphasizes the practical applications of the theory; it is compatible with my constructionist outlook; and finally, somewhat unusually for an information theory that got started in the 1970s, it acknowledges the power differentials between system designers and users, between people with information and people without it.

Small-S "sense-making" or "sensemaking" or "sense making" is a concept that predates Dervin, but Dervin created an approach and methodology called Sense-Making for studying it. From the late 1970s to her retirement, Dervin spent several decades refining and deepening the methodology and the theory behind it (Naumer et al., 2008). Sense-Making is most commonly explained using the Sense-Making Metaphor (Figure 1). A human, existing within a particular context, is moving from one situation state to an outcome, with a gap in between. Moving across the gap requires the human to construct a bridge (via sense-making and unmaking) to reach an

outcome. This metaphor can be simplified into the Sense-Making Triangle, which shows a situation leading to an outcome, by way of a bridge over a gap (Naumer et al., 2008).

Figure 1

Dervin's Sense-Making Metaphor (Naumer et al., 2008)



Sense-Making is a good fit for this research for three main reasons: It accommodates information practices beyond information seeking; it centers the role of humans in information; and it acknowledges power dynamics in information interactions. Many information behavior

models, particularly early ones, focus on the formal information seeking process, from identifying an information need, working through a search process, and identifying success or failure at the end. While PKM can involve intentional seeking, it also may include encountered information. By definition, PKM includes information organization and management, and often involves information sharing as well. The Sense-Making Triangle can accommodate these behaviors where more detailed and formal information seeking models cannot.

Secondly, Dervin's Sense-Making centers the active role of humans in information, not the system or organization (Dervin, 1992, p. 64). From the Sense-Making perspective, users are creating information as a byproduct of making sense of the reality they only partially perceive, rather than seeking objective information to consume. Dervin says that the traditional western view is that information and knowledge “could describe and fix reality” (1998, p. 37). But now, instead of looking to knowledge for “answers, homogeneity and centrality,” the modern use of knowledge is for “empowering and releasing creativity and diversity” (1998, p. 37). This perspective is very much in sync with the ethos of the modern PKM movement, with its focus on individual creativity.

Finally, sense-making acknowledges the power differentials inherent in information interactions. Sense-Making acknowledges the influence of “power” on the sense-making and -sense-unmaking process (Dervin, 1998), and one of the key goals of Sense-Making is to design systems that are “based on frameworks that are meaningful to everyday actors rather than by using only frameworks rooted in an expertise imposed on users” (Naumer et al., 2008, p. 3).

2.5 The Gaps in Our Knowledge

This study was designed to fill three main gaps in our knowledge of neurodivergence, PKM, and LIS. First, this study adds significantly to what we know about the full lives of NDs by exploring all areas of their lives, not just work and school. It also lays a groundwork for more rigorously studying how and why people use PKM—something that has not been well-researched academically for NDs or NTs alike. Finally, this study shows that neurodivergence and PKM have a place within the LIS research agenda and are highly relevant to the study of information behavior.

Chapter 3: Methods

This chapter describes the methods used to conduct the project, beginning with the research design and continuing onto recruitment, data collection, and data analysis before concluding with a brief overview of ethical considerations. This chapter follows the recommendations of the *Checklist for Reporting Results of Internet E-Surveys* (CHERRIES), which was developed “in an effort to ensure complete descriptions of Web-based surveys” (Eysenbach, 2004, p. 1). See [Appendix A](#) for a copy of the full survey.

3.1 Research Design

The research questions posed in this study center the voices of NDs in an attempt to understand how they use PKM to pursue their goals. As discussed in the previous chapters, common supports and accommodations for NDs are frequently inadequate or simply nonexistent, depending on the context and situation. The research questions formulated in Chapter 1 are as follows:

RQ1: For what outcomes do neurodivergent people use personal knowledge management in different life domains?

RQ2: What activities do neurodivergent people engage in when they use personal knowledge management?

RQ3: What benefits of personal knowledge management do neurodivergent people identify as being most helpful?

To answer these questions, I designed an online survey that would collect information and insights from NDs about their PKM practices. Given the variety of minds that fall under the “neurodivergent” umbrella, I attempted to design a highly accessible survey to reach as diverse

of an ND population as possible. First, knowing that at least part of my audience would be in possession of a dysregulated attention span, I designed the survey in two parts: Part 1, which had only multiple-choice answers, and Part 2, which had more open-ended short-answer questions. After completing Part 1, participants were given a choice to continue to Part 2, or to submit their answers to Part 1 and leave the survey. This way, people who find composing answers to open-ended questions tedious could still contribute to the study in a less onerous fashion. Also, in consideration of the potentially sensitive nature of the responses, which I anticipated might be intertwined with some amount of anxiety or shame (as was my own positionality statement in section 1.4), I decided to make the survey as anonymous as possible, not recording any information about the participants—not even their IP addresses.

3.2 Recruitment

The survey was an “open survey,” with no access restrictions; anyone with the link could respond to the survey. Participants were recruited through posts on PKM- and neurodivergence-related Facebook and Reddit groups, as well as through my professional networks on Twitter. Moderator approval was obtained for posting on certain groups as necessary, and the recruitment language was modified very slightly depending on the focus and norms of each community (for instance, language explaining PKM was removed for the post in r/PKMS, a subreddit dedicated to discussing PKM systems). The posts were made between August 16, 2022 and September 1, 2022 (see [Appendix B](#) for the recruitment language). Some amount of snowball sampling was also incorporated, as participants were encouraged to share the survey link with other people who might be interested, and several friends, colleagues, and fellow PKM enthusiasts “signal boosted” the invitation on their social media accounts.

Each posting indicated that participants should be 18 years of age and older and self-identify as neurodivergent. Professional diagnosis was not required, since this is not a medical study, but rather a study of characteristics and behaviors.

Table 1

Groups Targeted for Recruitment

Platform	Group	Membership
Facebook	Bullet Journaling with ADHD	9,200
	Notion for Students	28,700
Reddit	r/PKMS	4,500
	r/Evernote	16,500
	r/ObsidianMD	34,400
	r/Autism	184,000
	r/AutisticAdults	21,500
	r/Notion	272,000
	r/RoamResearch	13,800
	r/Neurodiversity	54,400
	r/OneNote	42,700
	r/ADHD	1,400,000
	r/GradSchool	295,000

The study was explicitly designed to exclusively involve neurodivergent participants. This means that there were no NTs to serve as a “control group,” and the study does not seek to make comparisons between NTs and NDs. NTs are studied with tremendous frequency; this study purposefully centers NDs and treats them as a population worth understanding on their

own, without being compared to others. The point of this research is fundamentally to learn how NDs use PKM, not how NDs differ from NTs in their use of PKM. In other words, this project is not looking for deviance from any kind of norm. Such a study may be interesting and worthwhile, but a comparison between NDs and NTs is outside the determined and desired scope for this study.

3.3 Data Collection

This section describes the development of the two-part survey as well as the survey administration. Before administering the survey, the questions, answer options, and overall structure were reviewed by Dr. Beth St. Jean of the University of Maryland, College Park, who has extensive experience in the design of studies, surveys, and questionnaires exploring information behavior (St. Jean, 2012, 2017; St. Jean et al., 2012, 2017; and many more).

3.3.1 Survey Development & Design

Given the diverse nature of the expected participants, I felt it was important to provide a survey experience that was not too extensive, taxing, or boring. The survey was comprised of two parts to accommodate the preferences and/or abilities of potential respondents. Part 1 of the survey consisted of 6 close-ended questions (i.e., questions with selectable answers), while Part 2 of the survey consisted of 5 open-ended questions, with answers up to 1000 characters (about 200 words). If participants indicated in Part 1 that they engaged in some form of note-taking as part of their personal PKM practices (I've done this a little, I do this sometimes, or I do this frequently), they were asked if they would like to take Part 2 of the survey, and were promised to be shown a photo of the researcher's tabby cat as a reward. This allowed for a large amount of quantitative data to be collected from Part 1, while ensuring that only people who were interested

in and willing to provide more extensive qualitative responses moved on to Part 2. Each part of the survey was presented on a different page and questions were displayed in the same order for all participants.

Life Domains. Questions 3 and 5 reference seven *life domains*, or areas. The life domains used in the survey were as follows: *Academic*, *Everyday Routines and Obligations* (shortened to *Everyday* in the following discussion), *Family and Partnership* (shortened to *Family*), *Health*, *Job*, *Leisure*, and *Social Contacts* (shortened to *Social*). These life domains and the descriptions used for them in the survey are shown in **Table 2**. The life domains used here, along with their descriptions, are almost identical to the list developed by Katrin Klingseick (2013) for a study on procrastination. However, for this study, Klingseick’s “academic and work” domain was split into two, *Academic* and *Job*. Since these two areas were expected to have some of the most heavy PKM usage, splitting them apart would help capture any differences in PKM usage between the two domains.

Table 2

Life Domains and Descriptions

Life Domain	Description
Academic	Studying, research, academic writing
Everyday routines and obligations [shortened to Everyday]	Outside of academic and job activities; for instance, household chores, paying bills
Family and partnership [shortened to Family]	Activities with or for family or partners

Health	Exercise, doctor’s appointments, etc.
Job	Work activities, including job-seeking
Leisure	Entertainment, volunteer work, hobbies
Social contacts [shortened to Social]	Building and maintaining friendships

PKM Activities. Question 4 refers to a list of individual PKM activities. This list is based on a report from Ness Labs (2020), with some modifications. The PKM activities listed include: synthetic note-taking, note-taking for long-term use, note-taking for short-term use, augmented content, curation, project/task management, “Read-It-Later” management, reference/citation management, visual thinking, web bookmarks, and word processing. The full list of activities and their descriptions is provided in **Table 3**.

Table 3

PKM Activities

PKM Activity	Description
Synthetic note-taking or “digital gardening”	Notes that combine ideas from multiple sources, used for creating new knowledge or content; usually involves linked notes and/or backlinking; frequently managed or created in Obsidian, Roam Research, Logseq, Evernote, etc.
Note-taking, note-making, and note-management for long-term use	Handwritten notes, notes organized and/or stored in Evernote, Obsidian, Notion, Google Docs, etc.)

Note-taking for short-term use	Post-it notes, some forms of bullet journaling, quickly captured notes in apps like Apple Notes, Google Keep, etc.
Augmented content	Highlighting and note-taking directly on a piece of content; could be on a paper, in a PDF reader, or using an app to annotate web content.
Curation	Lists and/or collections of books/movies/articles/other media or items, selected and arranged by personal criteria.
Project/task management	To do lists, on paper or in dedicated apps
“Read-It-Later” management	Keeping a list of web content to read at a later time, can involve apps like Instapaper, Pocket, Feedly, Newsblur
Reference/citation management	Bibliographic management such as Zotero, Mendeley, EndNote
Visual thinking	Mind maps, flowcharts, diagramming, either on paper or in an app.
Web bookmarks	Browser bookmarks or a separate bookmarking app.
Word processing	Writing using a dedicated application for writing, such as Word, Google Docs, Scrivener, etc.

Executive Functions. Question 6 asked participants to evaluate their ability to perform eleven executive functions. *Executive function* is something of a catch-all term that refers to a

group of interrelated (and inconsistently defined) cognitive tasks that relate to planning, taking action, and achieving goals, most commonly response inhibition, working memory, and shifting or task switching. (Baggetta & Alexander, 2016). The executive functions used in the survey were drawn from a list developed by Dawson & Guare (2010) and are listed with their descriptions in **Table 4**.

Table 4

Executive Functions

Executive Function	Definition
Emotional Regulation	Managing your emotions and reactions
Flexibility	Adapting and revising plans when things change or you get new information
Goal-Directed Persistence	The ability to finish projects and complete goals
Organization	Creating and maintaining systems and structures to keep track of information or objects
Metacognition	Understanding of your own thought processes; awareness of how you solve problems; self-evaluation and monitoring; asking yourself “how am I doing?”
Planning	Determining a set of steps to complete a task or goal; prioritizing tasks; deciding what’s important to work on next
Response Inhibition	Thinking before you act
Sustained Attention	Staying focused even when you’re tired, bored, or being distracted

Task Initiation	Getting started without procrastination
Time Management	Estimating how much time you have to complete a task; deciding how to allocate time; knowing how to stay within time limits and meet deadlines; accurately perceiving the passage of time
Working Memory	Keeping relevant information in your mind while performing tasks or thinking through problems

3.3.2 Survey Part 1

Question 1 asked about the respondents' employment status; multiple options could be selected, and participants could also indicate "Other" (with an explanatory comment) or "I prefer not to answer." These answers provide some additional context to the response.

Question 2 asked "Please select the condition(s) that you identify with (choose all that apply)." The answer options for this question were intentionally broad and not diagnostically precise (for instance, "anxiety (including obsessive compulsive disorder)" and "depression or other mood disorder (including bipolar disorder)"). These answers again provided some context for the responses and gave some indication of what neurotypes the participants expressed. However, I did not want respondents to be distracted or bogged down in precise diagnoses. This question also left it open whether participants had received an official diagnosis or not. Given the highly anonymous and unverifiable nature of the survey, I decided it was not worth requiring participants to claim to be officially diagnosed.

Question 3 asked "To what extent do you feel your neurodivergence affects your quality of life in the following areas?" Seven life domains were listed, based on those used by Klingsieck (2013), with an "other" option. The impact of each domain could be rated on a Likert

scale with the choices *Extremely Negatively*, *Somewhat Negatively*, *No Effect*, *Somewhat Positively*, or *Extremely Positively*.

Question 4 asked “How often do you engage in each of the following types of personal knowledge management activities for any reason (personal, educational, or professional)?” Eleven types of PKM activities followed, with very brief examples in parentheses. The Likert options for this question were “I’ve never heard of this,” “I’ve heard of this, but never tried it”, “I’ve done this a little”, “I do this sometimes,” and “I do this frequently.” The categories were based on a Ness Labs report (2020).

Question 5 asked “To what extent do the personal knowledge management activities indicated in Question 4 affect your quality of life in the following areas?” This was followed by the same list of life domains and rating choices as Question 3.

Question 6, the final question in Part 1 of the survey, asked “How would you rate your skills in the following areas?” The answer options were eleven areas of executive functions as described by Dawson & Guare (2010). The answer options included *Very Poor*, *Poor*, *Fair*, *Good*, and *Excellent*.

3.3.3 Survey Part 2

Questions 7-10 were based on the standard structure of a Sense-Making interview, which typically explores the context, gaps, bridges, and outcomes of Sense-Making (Dervin, 1992; Naumer et al., 2008). Although they are traditionally asked in a semi-structured interview setting, this study used them in a larger-scale survey setting. The final question, “What is one piece of advice you would give to a neurodivergent person starting out with note-taking for

personal knowledge management?” gives participants a space to “sum up” their thoughts about note-taking.

3.3.4 Survey Administration and Response Rates

The survey was administered through Qualtrics, a survey platform provided by the University of Maryland. Survey responses were collected between August 16 and October 2, 2022. Since every question was optional, there are an uneven number of responses for individual questions. Because of the highly anonymous nature of the study, with no collection of system information or IP addresses, no measures were taken to prevent multiple responses from the same person. 304 people took the survey; 302 gave at least one response to every question in Part 1, and 280 people answered every line of every question in Part 1. 201 people continued on to provide at least one answer in Part 2, and 198 people gave an answer to every question in Part 2.

3.4 Data Analysis

The data resulting from the survey was downloaded from Qualtrics and analyzed using both quantitative and qualitative analysis. The processes for both types of analysis are described below.

3.4.1 Quantitative Data

Simple quantitative analysis (descriptive statistics, such as averages and counts) was performed using Microsoft Excel¹⁰ along with PostgreSQL¹¹ (an open-source relational database) using the PGAdmin¹² client. More extensive quantitative data analysis in order to answer additional research questions will be conducted and reported in future publications.

¹⁰ <https://www.microsoft.com/en-us/microsoft-365/excel/>

¹¹ <https://www.postgresql.org>

¹² <https://www.pgadmin.org>

The Pearson correlation coefficient was not appropriate for use with the qualitative codes, so for some questions the *code co-occurrence coefficient*, or c-coefficient, was calculated to achieve a sense of how strongly two codes were related. The c-coefficient, which “indicates the strength of the relation between two codes,” was calculated with ATLAS.ti using the formula:

$$c = n12 / (n1 + n2 - n12)$$

where $n12$ = number of co-occurrences for code $n1$ and $n2$ (ATLAS.ti, n.d.). The c-coefficient can range from 0 to 1, with 0 being no relation and 1 being the strongest relation. Unlike Pearson’s r , the c-coefficient does not have negative values or p-values.

3.4.2 Qualitative Data

The qualitative responses—that is, the responses to Part II of the survey—were analyzed using thematic analysis, following the six-step process outlined by Braun and Clarke (2006, 2014). Thematic analysis is highly flexible and is easily adapted for use with a wide range of theoretical frameworks and approaches (Braun & Clarke, 2006; Clarke & Braun, 2014). Thematic analysis can be inductive or deductive and can be conducted at a semantic level or a latent level (Braun & Clarke, 2006; Clarke & Braun, 2014).

I used both inductive and deductive analysis when analyzing the qualitative data. Deductive analysis is “top-down”—that is, codes are based on preconceived theories and frameworks—while inductive analysis is “bottom-up,” using codes that are developed based on meaning the researcher interprets from the data (Braun & Clarke, 2006, p. 83). Codes for the Sense-Making, Life Domains, and Executive Functions were based on pre-existing frameworks (Dawson & Guare, 2010; Dervin, 1992, 2000; Dervin & Naumer, 2017; Klingsieck, 2013), while the codes for Outcomes, Activities, and Benefits were developed inductively, based on my

interpretation of the responses. Even in the case of the deductive analysis, though, I was open to thinking beyond the selected frameworks when the data called for it—see the discussion of Life Domains in Chapter 4.

Thematic analysis for this project was conducted at a semantic level rather than at a latent level. Semantic analysis means that the focus is on the “explicit or surface meaning of the data;” latent analysis, which “examine[s] the underlying ideas, assumptions, and conceptualisations” behind the semantic level, is somewhat akin to discourse analysis (Braun & Clarke, 2006, p. 13).

As outlined by Braun and Clarke, the process of thematic analysis is recursive but involves the following six phases: familiarizing yourself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report (Braun & Clarke, 2006; Clarke & Braun, 2014).

3.5 Ethical Considerations

“As I see it, the ethical challenge for the disability rights movement, as for all social movements, is whether its adherents can see the world for what it is, and still resolve to act with justice and compassion.” (Singer 2016, loc. 634).

Ethical considerations were at the forefront of my mind from the first moment I started planning this project. Respect for the participants of the study as well as for the greater neurodivergent community were my highest priority, and I aimed for that respect to be woven through the entire fabric of the project, from the research questions to the methods and analysis, as well as in how I will use this project to inform my future endeavors. I constantly reminded myself that simply because I am part of the group being studied, that did not mean that my

choices regarding researching the community will be automatically ethical. Despite being ND myself, I am just as prone to stereotyping and making naïve or ignorant assumptions about neurodivergence as anyone else. At the same time, while being neurodivergent may not automatically mean one is vulnerable, disadvantaged, or disabled, given what is known about conditions that co-occur with neurodivergence, I did work under the assumption that a significant number of the participants would have mental health concerns such as anxiety and depression as well, and I tried to structure the survey in a way that would not exacerbate such conditions.

No personally identifying information (PII) was collected as part of this study, since this study would benefit more from a large number and variety of responses than from rigorously profiled participants. It seemed highly unlikely that anyone would be inclined to “stuff” or skew the survey by filling it out repeatedly, and keeping it entirely anonymous might encourage more people to participate, and to share their challenges more honestly. Although no PII was collected, care was still taken to protect the security of the collected data. Survey answers were stored within the Qualtrics system administered by the University of Maryland, on a secure cloud storage server (Box) also administered by UMD, and temporarily on my own password-protected computer for analysis.

Finally, the study was submitted to the University of Maryland Institutional Review Board. It was determined that because of the minimal risk posed by the survey questions, and since no PII (including IP addresses) would be collected or recorded, the study was exempt from IRB according to federal regulations (see Appendix E for the IRB letter). Because of this, participants did not have to sign consent forms; however, potential participants were still presented with an informed consent form to read before deciding whether to participate. The

form, which was based on the university's standard consent form, described the purpose of the study, the potential risks and benefits, the expected time it would take to complete the survey, and the two-part structure of the survey (see Appendix A: Informed Consent Form and Survey for the informed consent form).

Chapter 4: Results

This chapter presents the results of the survey. In order to compare the results of each question more easily, for some questions in Part 1 (specifically questions 3–6) the response choices were converted into numerical values (for instance, “extremely negatively” was converted to -2, and “I do this frequently” became 4). The exact process and the numerical values used will be described question-by-question in the following pages. Part 2 of the survey, the open-ended questions, was analyzed qualitatively using the thematic analysis approach and the qualitative research tool ATLAS.ti.¹³ Coding was done by a single researcher (myself). The codebooks can be found in [Appendix C](#) and consist of three sets of “top-down” codes and three sets of “bottom-up” codes. The three “top-down” codebooks, which are related to the relevant answer choices in the survey, are C-1: Life Domains, based on Klingsieck (2013); C-2: Executive Functions, based on Dawson & Guare (2010); and C-3: PKM Techniques, based on a report from Ness Labs (2020). The three “bottom-up” codebooks were developed through the process of thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2014) and included C-4: Outcomes (RQ1 1), C-5: Activities (RQ2), and C-6: Benefits (RQ3).

The rest of this chapter presents the results of the survey in two parts. Part 1 of the survey is presented question-by-question; Part 2 of the survey is presented in terms of major themes that were interpreted across the open-ended questions. This chapter closes with the answers to the research questions based on the findings. The analysis presented here only scratches the surface of the potential findings in this dataset. The response to the survey was enthusiastic and the open-ended responses were full of insights, resulting in far more data (and richer data) than was

¹³ <https://atlasti.com>

anticipated at the beginning of the project. At the advice of my advisors, I decided to focus this dissertation on fairly broad research questions involving the qualitative portion of the survey; I will continue analyzing the responses in more detail as part of my future research, some of which will be described in Chapter 5.

4.1 Participants

Since the survey was anonymous, few participant characteristics were collected. By participating in the survey, all participants attested that they were at least 18 years old. The survey also asked for employment and student status, as well as what neurodivergent conditions they identified with. Participants were not asked whether they had received an official medical diagnosis of any neurodivergent (or associated) conditions. Rather, they were asked what conditions they “identify” with.

There were no questions related to gender on the survey. Although anything other than a binary concept of gender is not well-represented in research about neurodivergence, there is anecdotally (increasingly backed up by research) a fair amount of gender diversity within the neurodivergent community (Janssen et al., 2016; Strang et al., 2014). Gender requires a more in-depth and nuanced examination that is out of the scope of this study, and therefore it is not mentioned in this dissertation. All participants will be referred to with they/them/their pronouns since their gender identity is unknown. Minimizing data collection is a key component of both research ethics and data collection ethics (General Services Administration, 2020), and since my research questions do not involve gender, race, or other similar demographic information, it was my decision not to ask participants to provide that data.

The results to some questions were calculated not only across all results, but also (where relevant) as two subgroups: participants with ADHD and participants with ASD (some participants fall into both categories). Although there are many other diagnoses that fall under the ND umbrella, these two were the most heavily represented in the survey and thus were the most likely to exhibit meaningful differences: about 100 autistic participants responded (depending on the question) and over 200 participants with ADHD responded, compared with only 39 participants with an SLD like dyslexia. It is important to bear in mind that this survey is not and was never intended to be representative of all neurodiverse people; rather, the quantitative data provides context for understanding the 304 people who chose to respond to the survey.

4.2 Survey Results

None of the questions were required, so there are an uneven number of responses from question to question. [Appendix D](#) breaks down the number of responses for each question.

4.2.1 Part 1: *Quantitative Results*

Part 1 of the Survey was made up of 6 multi-part but close-ended questions along with some information about Part 2 and a question asking if participants wished to continue or stop the survey and submit their responses. Simple descriptive statistics were calculated for each question, and those results are presented question-by-question here.

Question 1: Employment. Question 1 asked “What is your employment status (choose all that apply)?” Out of the 304 responses to this question, 55 participants (18.1%) indicated more than one status, and 4 participants (1.3%) indicated 3 or more statuses. The most common status selected was Employed Full-Time with 158 participants (52.0%), followed by

Undergraduate Student with 43 responses (14.1%), Graduate Student with 39 (12.8%), and Not Employed with 32 (10.5%). Table 5 lists the full count of responses. Since participants were able to select more than one status, the numbers add up to more than 304. A majority of participants—243, or 79.9%—were either students or were engaged in some level of employment. A few participants that selected “Other” provided explanations that fit into existing category options, and these were reclassified before analysis.

Table 5

Number of Participants by Employment and Education Status

Status	Participants		With Additional Statuses	
	n	%	n	% of Status
Employed Full-time	158	52.0	23	14.6
Undergraduate Student	43	14.1	19	44.1
Graduate Student	39	12.8	20	51.2
Not Employed	32	10.5	10	31.2
Self-Employed Full-Time	29	9.5	3	10.3
Employed Part-Time	23	7.6	16	69.6
Self-Employed Part-Time	21	6.9	13	61.9
Disabled	6	2.0	4	66.7
Prefer Not to Answer	5	1.6	n/a	n/a
Caretaker	4	1.3	3	75.0
Retired	2	0.7	2	100.0
Other	1	0.3%	1	100.0

Question 2: Conditions. Question 2 asked “Please select the condition(s) that you identify with (choose all that apply).” All 304 survey participants responded to this question.

Table 6 displays the number of participants who indicated they had each neurodivergent condition, along with the numbers of participants who also indicated they had anxiety and/or depression. Two non-ND mental health conditions—anxiety and depression—were included as options, since these are commonly co-occurring with ND conditions. Some participants included Post-Traumatic Stress Disorder (PTSD) and Dissociative Identity Disorder (DID) as explanations for their choice of “other.” These are included in the table of results since they were clearly important to the respondents; however, since they were not specifically named in the survey, these are almost certainly undercounts of the true prevalence of PTSD and DID in the respondents.

Table 6

Number of Participants by Neurodivergent Condition

Condition	Participants		With Anxiety		With Depression	
	n	%	n	% of Condition	n	% of Condition
ADHD	219	72.0	125	57.1	96	43.8
Autism	105	34.5	56	53.3	49	46.7
Sensory Processing Disorder	40	13.2	31	77.5	24	60.0
Learning Disorder	39	12.8	25	64.1	20	51.3
Prefer Not to Answer	2	0.7	n/a	n/a	n/a	n/a
Other: DID	2	0.7	1	50%	2	100%
Other: PTSD	7	2.3	5	71.4	5	71.4

Note. DID and PTSD were write-in answers, so these numbers almost certainly undercount the true prevalence of DID and PTSD among respondents. PTSD is no longer classified as an

anxiety disorder and therefore is not treated as a type of anxiety for the purposes of this study.

ADHD and Autism were clearly the prevailing conditions, with 264 participants having one or both conditions (86%).

Table 7

Number of Participants by Neurodivergent Condition Combinations

Conditions	Participants	
	n	%
ADHD alone	133	43.8
Autism alone	35	11.5
Sensory Processing Disorder alone	5	1.6
Learning Disorder alone	15	4.9
ADHD & autism	42	13.8
ADHD & SPD	14	4.6
ADHD & LD	12	3.9
ADHD, autism, & SPD	8	2.6
ADHD, autism, & LD	5	1.6
ADHD, autism, SPD, & LD	5	1.6
Autism & SPD	8	2.6
Autism & LD	2	0.7
Autism, LD, & SPD	0	0.0
LD & SPD	0	0.0

Question 3: Life Domains. Question 3 asked “To what extent do you feel your neurodivergence affects your quality of life in the following areas? If you feel your neurodivergence has both negative and positive effects on your quality of life, choose an option

that best represents the overall impact.” For each life domain, participants could choose from *Extremely Negatively*, which was given a value of -2 during analysis, *Somewhat negatively* (-1), *No effect* (0), *Somewhat positively* (1), or *Extremely positively* (2).

In general, participants perceived their neurodivergence as negatively affecting most areas of their lives, with a few notable exceptions. Across all ND conditions, *Everyday* was rated as most negatively affected by neurodivergence ($M = -1.2$, $SD = 0.8$), followed by *Social* ($M = -0.9$, $SD = 0.9$) and *Health* ($M = -0.9$, $SD = 0.8$), *Family* ($M = -0.8$, $SD = 0.8$), *Job* ($M = -0.7$, $SD = 1.1$), and *Academic* ($M = -0.6$, $SD = 1.2$). *Leisure* (mean = 0.0, $SD = 1.2$) was reported as being noticeably less negatively affected than the rest of the life domains. Some interesting discrepancies emerged when the averages of participants with autism ($n = 105$) and participants with ADHD ($n = 219$) were calculated separately. Autistic respondents reported that their *Academic* life domain was less negatively affected ($M = -0.2$, $SD = 1.3$) than ADHD respondents ($M = -0.8$, $SD = 1.1$), and indicated that the *Leisure* life domain was actually *positively* affected by their neurodivergence ($M = 0.3$, $SD = 1.2$; the ADHD mean for *Leisure* was -0.1 , $SD = 1.2$). Table 8 provides the means for each life domain for all participants, as well as for autistic and ADHD participants.

Table 8

How Neurodivergence Affects Life Domains

Life Domain	All Participants n = 304		Autistic Participants n = 105		ADHD Participants n = 219	
	M	SD	M	SD	M	SD
Everyday	-1.2	0.8	-1.0	0.9	-1.3	0.7

Social	-0.9	0.9	-1.1	0.9	-0.8	1.0
Health	-0.9	0.8	-0.9	0.8	-0.9	0.8
Family	-0.8	0.8	-0.8	0.8	-0.8	0.8
Job	-0.7	1.1	-0.6	1.1	-0.8	1.1
Academic	-0.6	1.2	-0.2	1.3	-0.8	1.1
Leisure	0.0	1.2	0.3	1.2	-0.1	1.2

Question 4: PKM Activities. Question 4 asked “How often do you engage in each of the following types of personal knowledge management activities for any reason (personal, educational, or professional)?” For each activity, participants could choose from *I’ve never heard of this*, which was given a value of 0 during analysis, *I’ve heard of this, but never tried it* (1), *I’ve done this a little* (2), *I do this sometimes* (3), or *I do this frequently* (4).

Across all participants, the most commonly practiced PKM activity was the use of Short-Term Notes ($M = 3.5$, $SD = 0.8$), Long-Term Notes ($M = 3.5$, $SD = 0.8$), and Project/Task Management ($M = 3.5$, $SD = 0.8$), followed by Word Processing ($M = 3.3$, $SD = 1.0$), Web Bookmarks ($M = 3.2$, $SD = 0.9$), Curation ($M = 2.9$, $SD = 1.1$), Read-It-Later ($M = 2.8$, $SD = 1.1$), Augmented Content ($M = 2.8$, $SD = 1.1$), Synthetic Notes ($M = 2.4$, $SD = 1.4$), Visual Thinking ($M = 2.4$, $SD = 1.1$), and Citation Management ($M = 2.0$, $SD = 1.3$). Similar patterns were observed among autistic and ADHD participants. Table 9 shows the average rating of each PKM activity across the entire group, as well as the Autistic and ADHD subgroups.

Table 9*PKM Activities by Average Familiarity/Use*

PKM Activity	All Participants n = 304		Autistic Participants n = 105		ADHD Participants n = 219	
	M	SD	M	SD	M	SD
Short-Term Notes	3.5	0.8	3.5	0.9	3.5	0.8
Long-Term Notes	3.5	0.8	3.4	0.8	3.5	0.7
Project/Task Management	3.5	0.8	3.4	0.9	3.5	0.8
Word Processing	3.3	1.0	3.3	0.9	3.3	1.0
Web Bookmarks	3.2	0.9	3.1	1.0	3.2	1.0
Curation	2.9	1.1	3.0	1.0	2.9	1.1
Read-It-Later	2.8	1.1	2.7	1.2	2.9	1.1
Augmented Content	2.8	1.1	2.6	1.1	2.9	1.0
Synthetic Notes	2.4	1.4	2.3	1.5	2.5	1.4
Visual Thinking	2.4	1.1	2.2	1.0	2.5	1.0
Citation Management	2.0	1.3	2.0	1.4	1.9	1.3

Of all the PKM activities, Synthetic Note-Taking and Citation Management were the least familiar to participants, with 52 (17.1%) and 44 (14.5%) participants respectively reporting that they had never heard of those techniques. All participants reported at least some familiarity with Long-Term Notes and Project/Task Management, followed closely by Short-Term Notes, Augmented Content, Word Processing, Curation, Visual Thinking, Web Bookmarks, and Read-It-Later, each with fewer than 10 people responding “I’ve never heard of this.” The activities

with the most “I do this frequently” replies were Short-Term Notes (202, or 66.4%), Project/Task Management (190, or 62.5 %), and Long-Term Notes (184, or 60.5%). Table 10 shows the results of Question 4 broken down by activity and response.

Table 10

PKM Activities by Response

PKM Activity	I’ve never heard of this		I’ve heard of this, but never tried it		I’ve done this a little		I do this sometimes		I do this frequently	
	n	%	n	%	n	%	n	%	n	%
Short-Term Notes	1	0.3	8	2.6	34	11.2	59	19.4	202	66.5
Project/Task Management	0	0.0	9	3.0	32	10.5	72	23.6	189	62.2
Long-Term Notes	0	0.0	4	1.3	36	11.8	80	26.3	184	60.5
Word Processing	3	1.0	15	4.9	38	12.5	78	25.7	170	55.9
Web Bookmarks	6	1.9	16	5.3	58	19.1	87	28.6	144	47.4
Read-It-Later	9	3.0	32	10.5	73	24.0	75	24.5	114	37.5
Curation	3	1.0	38	12.5	62	20.4	88	29.0	111	36.5
Augmented Content	3	1.0	38	12.5	82	27.0	80	26.3	101	33.2
Synthetic Notes	52	17.1	21	6.9	66	21.7	70	23.0	95	31.3
Visual Thinking	4	1.3	58	19.1	109	35.9	70	23.0	63	20.7
Citation Management	44	14.5	85	28.0	74	24.3	44	14.5	57	18.8

Question 5: PKM and Life Domains. Question 5 asked “To what extent do the personal knowledge management activities indicated in Question 4 affect your quality of life in the

following areas?” As with Question 3, for each life domain, participants could choose from *Extremely Negatively*, which was given a value of -2 during analysis, *Somewhat negatively* (-1), *No effect* (0), *Somewhat positively* (1), or *Extremely positively* (2).

According to participants, *Academic*, *Job*, and *Everyday* were the most positively impacted by PKM, with means of 1.2 (SD = 0.8), 1.1. (SD = 0.9), and 1.0 (SD = 0.9) respectively. Table 11 includes the means for the overall results as well as the ASD and ADHD subgroups.

Table 11

How PKM Affects Life Domains

Life Domain	All Participants n = 304		Autistic Participants n = 105		ADHD Participants n = 219	
	M	SD	M	M	SD	M
Academic	1.2	0.8	1.3	0.9	1.2	0.8
Job	1.1	0.9	0.9	1.0	1.1	0.9
Everyday	1.0	0.9	1.0	0.9	1.0	0.9
Leisure	0.7	0.8	0.7	0.9	0.8	0.8
Health	0.5	0.8	0.5	0.8	0.6	0.8
Family	0.4	0.7	0.3	0.8	0.5	0.7
Social	0.3	0.7	0.2	0.8	0.3	0.7

Question 6: Executive Functions. Question 6 asked “How would you rate your skills in the following areas?” Participants rated their skills in 12 different areas of executive function

with the options very poor (equivalent to 0 for the purposes of quantitative analysis), poor (1), fair (2), good (3) and excellent (4).

Among all participants, Task Initiation had the lowest mean rating ($M = 2.0$, $SD = 1.0$), followed by Sustained Attention ($M = 2.2$, $SD = 1.1$) and Time Management ($M = 2.2$, $SD = 1.1$), and then Goal Persistence ($M = 2.7$, $SD = 1.2$) and Working Memory ($M = 2.8$, $SD = 1.2$). Metacognition was the highest rated ($M = 3.8$, $SD = 1.1$), followed by Organization ($M = 3.3$, $SD = 1.2$). Autistic and ADHD participants followed a similar pattern, with the most noticeable difference being that Flexibility was rated lower by autistic participants ($M = 2.7$, $SD = 1.0$) than by ADHD participants ($M = 3.2$, $SD = 1.1$). Table 12 contains the mean rating of executive functions for all participants as well as autistic and ADHD participants, while Table 13 provides the breakdown of responses by rating level.

Table 12

Mean Rating of Executive Functions

	All Participants n = 304		Autistic Participants n = 105		ADHD Participants n = 219	
Executive Function	M	SD	M	SD	M	SD
Metacognition	3.8	1.1	3.8	1.1	3.7	1.1
Organization	3.3	1.2	3.4	1.3	3.1	1.2
Flexibility	3.2	1.1	2.7	1.0	3.2	1.1
Response Inhibition	3.2	1.1	3.4	1.2	3.1	1.1
Emotional Regulation	3.2	1.0	3.0	1.0	3.2	1.0
Planning	3.2	1.2	3.3	1.2	3.1	1.2
Working Memory	2.8	1.2	2.9	1.3	2.6	1.2

Goal Persistence	2.7	1.2	2.8	1.3	2.5	1.2
Sustained Attention	2.2	1.1	2.3	1.2	2.0	1.0
Time Management	2.2	1.1	2.3	1.3	2.0	1.0
Task Initiation	2.0	1.0	1.9	1.0	1.8	1.0

Table 13*Executive Functions by Rating*

	Very poor		Poor		Fair		Good		Excellent	
Executive Function	n	%	n	%	n	%	n	%	n	%
Metacognition	11	3.6	34	11.2	67	22.0	97	31.9	93	30.6
Organization	27	8.9	59	19.4	79	26.0	83	27.3	55	18.1
Planning	26	8.6	66	21.7	69	22.7	98	32.2	44	14.5
Response Inhibition	22	7.2	68	22.4	87	28.6	88	28.9	38	12.5
Flexibility	18	5.9	71	23.4	97	31.9	77	25.3	38	12.5
Working Memory	53	17.4	80	26.3	80	26.3	59	19.4	31	10.2
Emotional Regulation	9	3.0	64	21.1	109	35.9	95	31.3	26	8.6
Goal Persistence	60	19.7	80	26.3	81	26.6	60	19.7	21	6.9
Time Management	101	33.2	97	31.9	63	20.7	27	8.9	15	4.9
Sustained Attention	97	31.9	112	36.8	55	18.1	29	9.5	10	3.3
Task Initiation	124	40.8	106	34.9	43	14.1	21	6.9	8	2.6

4.2.2 Part 2: Qualitative Results

The second part of the survey consisted of 5 open-ended questions, capped at 1000 characters, or approximately 150 to 250 words. The first three open-ended questions were

modeled after the Sense-Making interview format. Question 7 roughly aligns with the Situations of the Sense-Making triangle, Question 8 with the gaps, and Question 9 with the bridges. The full set of open-ended questions were as follows:

- Question 7: What are the goals or projects your note-taking activities help you work towards? (198 responses)
- Question 8: What are the problems or obstacles you face in achieving the goals and projects you listed in Question 7? (196 responses)
- Question 9: How do your note-taking activities help you in achieving the goals and projects you listed in Question 7? (196 responses)
- Question 10: If you could wave a magic wand, what would change or appear to help you achieve the goals and projects you listed in Question 7? (Your answer might or might not relate to note-taking.) (186 responses)
- Question 11: What is one piece of advice you would give to a neurodivergent person starting out with note-taking for personal knowledge management? (198 responses)

Participants will be described in this chapter in the following manner. They will be referred to as P-X, where X is the ID number automatically assigned to them by the qualitative coding software ATLAS.ti. In parentheses following the participant ID, relevant participant characteristics from part 1 of the survey will be included. These will always include employment/educational status and their identified conditions (Questions 1 and 2) and may include information from other questions if it seems relevant to understanding their response. To save space and facilitate more rapid comprehension, the codes listed in

Table 14 will be used in the parentheses. Additionally, percentages in this section refer to the percent of Part 2 respondents, the total of which is 201 (66.1% of the total 304 participants). Quotes from survey responses are mostly provided verbatim, with typos and misspellings intact; only very minor modifications were made if necessary to provide clarity.

Table 14

Abbreviated Codes for Participant Characteristics

Code	Meaning
Employment/Education Status	
CT	Caretaker
DIS	Disabled
EMP-FT	Employed Full-Time
EMP-PT	Employed Part-Time
GRAD	Graduate Student
NE	Not Employed
RET	Retired
SE-FT	Self-employed Full-Time
SE-PT	Self-employed Part-Time
UG	Undergraduate Student
Conditions	
ADHD	Attention-Deficit/Hyperactivity Disorder
ANX	Anxiety
ASD	Autism

DEP	Depression
DID	Dissociative Identity Disorder
SPD	Sensory Processing Disorder
LD	Learning Disorder
PTSD	Post-Traumatic Stress Disorder

4.3 Research Questions

There is no one-to-one relationship between the research questions and the survey questions; each research question was answered by looking at the entirety of responses to the survey, not just individual open-ended questions. From the analysis of these responses, it is immediately obvious that the participants in the study use PKM in a wide variety of ways across many areas of their lives and for many purposes. P-142 (E-FT, ADHD, DEP) summed up their typically varied PKM usage across life domains:

For my profession, keeping track of both main and side projects. Creating educational materials for junior staff and contributing to committees. I work in inspections and plan reviews for government agencies and saving information from a deep dive into a specific topic is very helpful for others.

For my personal life, it's more for cataloguing philosophical ideas, interests, resources, and notes taken from my hobbies. I also use task and project management apps though for reminders for things I'm not interested in or have a lot of resistance built up against like mundane bill paying, calls to the insurance, finding out why my mortgage didn't get paid by my mortgager, etc.

Although many participants reported using PKM in comparatively narrow contexts, the range of activities and purposes described by P-142 above was also common in the responses. The same kind of diversity can be seen in the analysis of the research questions below, regarding outcomes and life domains, PKM activities, and reported benefits of PKM.

4.3.1 Research Question 1: Outcomes and Life Domains

The first research question asked “For what outcomes do neurodivergent people use personal knowledge management in different life domains?” The survey asked two questions directly relating to life domains (Q3 and Q5), and all of the open-ended questions (Q7 thru Q11) were coded in relation to life domains. This question is asking what the *end goals* are for ND people when they are using PKM. Along with insights about the reasons for using PKM in various life domains, the data analysis uncovered evidence that some adjustments to the life domains used in the survey were needed.

Life Domains. Regarding life domains, there were three points of particular interest in the results. First, during the process of coding, the *Academic* domain was discovered to be inadequate and the concept of a more expansive domain called *Learning* was developed. Second, the need for a completely new domain which I called *Inner Life* arose. Finally, the *Social* domain was very sparsely represented in the results. Each of those points will be discussed in more depth below.

Academic vs. Learning. Much of the earlier research involving life domains did not make specific reference to formal education, instead using a broad “performance” or “work/achievement” category (Gröpel, 2005; Gröpel & Kuhl, 2006; Seiwert, 2005; Warren, 2004). In 2013, Katrin Klingsieck (2013) used the category “academic and work” in their study

of procrastination. For this study, the category “Academic and Work” was split into two domains, *Academic* and *Job*, to hopefully obtain more precision in the results. However, in the initial phase of thematic analysis, *Familiarizing yourself with your data* (Braun & Clarke, 2006; Clarke & Braun, 2014), it quickly became obvious that *Academic* was not an adequate descriptor. The word “academic” can be defined as “associated with an academy or school especially of higher learning,” “of or relating to performance in courses of study,” or “based on formal study especially at an institution of higher learning” (Merriam-Webster, n.d.). Although formal academic contexts were often mentioned in the responses, there was also a strong presence of either unspecified or informal learning contexts. For instance, P-133 (UG, ADHD, SPD), despite being enrolled in an undergraduate program, used the phrase “learning for learning’s sake” several times; P-155 (EMP-FT, ADHD, DEP) said they were “considering-preparing to enter a PhD program and use PKM to refresh subject knowledge (MA was 8 years ago) and refine my research interest/questions.” P-123 (NE, ADHD, ANX, ASD) used PKM for “studying computer science and psychology on my own.” P- 246 (UG, ADHD, DEP) provided possibly the most expansive context when they said “My ultimate goal is to establish a single source of truth that contains everything I have learned, when I learned it and where I learned it from because I can’t really rely on my memory for that.”

Inner Life. In the initial steps of coding, responses relating to mental health were coded as *Health*. As coding progressed, however, it seemed that there was a life domain that was not adequately captured by any of the established codes. This domain seemed to have more to do with self-reflection and self-understanding broadly, not just mental health. It encompassed broad goal-setting and self-improvement, mental health thought exercises, and reflective journaling. I

decided to call this domain *Inner Life*. Several participants mentioned note-taking as a way to understand the self; for instance, P-280 (UE, ADHD, ANX, ASD, DEP) said they use it for “exploring ways of understanding my self and what I need to be able to function and live out creative dreams and whims and not suffer as I do now,” and P-144 (GRAD, ADHD, LD) said they are “always aiming to develop a better understanding of self.” P-226 (UG, ADHD, ANX, ASD, DEP) explained in greater depth:

Manage my thoughts, track patterns in my thoughts/ideas/habits, link with what I already know about myself, keep track of anything I might find interesting, ideas I want to explore. I also struggle with a lot of emotional regulation and understanding what I'm actually feeling so in times like those, I just free-write any and everything that comes to mind until I can make sense of it. I just want to understand myself and to understand other people.

P-205 (GRAD, ANX, DEP) took it even further: “It feels like the notes are a part of me. The lists are my achievements. The notes my thoughts. I can't imagine “myself” without them. Notetaking is essential to feeling like I have some control.”

Social Contacts. Only 10 participants mentioned using PKM in relation to the *Social* life domain. One (P-153, E-FT, ANX, ASD) was a pastor who described how he used PKM to help him remember interactions with congregation members:

Notes help me recall past conversations and issues with church members. If I skim my note file for that person before a conversation, it's fresh on my mind

and I come off like a genius with a super memory, which is better than the alternative of being able to recall nothing.

P-161 (E-FT, ASD, PTSD), who described themselves as unable to “understand emotional cues, and read nonverbal communication,” said that they “keep notes on objective behaviour responses to better predict future responses,” but noted that “in general within close interpersonal relationships this behaviour has been poorly received.” Otherwise, the few participants who mentioned anything relevant to the *Social* domain used PKM to assist in scheduling and tracking things like interactions and gifts. P-226 (UG, ADHD, ANX, ASD, DEP) used a similar technique: “It helps me find the little logic that exists in emotions and behaviour. I also will sometimes try to use note taking to observe what I know about someone to make sense of behaviour when I find it confusing.”

Outcomes. The survey respondents said that PKM helped them accomplish *Building Knowledge, Creating, and Self-Improvement*. They also described how PKM helps them with *Managing Tasks and Projects* for a variety of purposes. Some of the purposes fed into each other, making the borders and boundaries of these categories fuzzy. For instance, many people would describe a process of *Building Knowledge* that would inform *Creating*, and using PKM for *Managing Tasks and Projects* along the way. Table 15 describes the number of responses with co-occurring life domains and applications (Life Domains were sometimes mentioned without an Application, and vice versa; these mentions are not included in the table.)

Table 15

Life Domains and Application Co-Occurrence by Question Responses

Life Domain	Building Knowledge		Creating		Self-Improvement		Managing Projects and Tasks	
	n	c	n	c	n	c	n	c
Everyday	17	0.10	10	0.07	58	0.34	15	0.14
Family	3	0.03	3	0.04	8	0.05	1	0.02
Health	9	0.08	4	0.05	15	0.10	14	0.29
Inner Life	18	0.14	9	0.09	26	0.16	24	0.38
Job	27	0.13	21	0.12	70	0.34	14	0.09
Learning	68	0.42	29	0.18	61	0.29	14	0.09
Leisure	17	0.13	17	0.18	29	0.18	6	0.07
Social	5	0.05	2	0.03	2	0.01	3	0.06

Managing Tasks and Projects. This most frequently appearing category could just as easily have been called *Actually Doing Things*. Of the times project or task management was explicitly referenced in a response to a question (139 times), it was most frequently alongside the *Job* (70, or 50.4% of references), *Learning* (61, or 43.9%), or *Everyday* (58, or 41.7%) domains. These three life domains are also the most commonly referenced domains, so this result is not unexpected. Project and task management appears to be the foundational “bread and butter” of NDs’ PKM use. Although lists of tasks and projects are mentioned fairly often, supporting information and documents are also mentioned as being part of the PKM strategy. For instance, P-295 (E-FT, ADHD, ANX, DEP) said:

Work related goals primarily, such as listing the MANY projects that I have going at the same time at work. I... have intersections with multiple

stakeholders and have a LOT of details that I have to manage. I don't have any other staff working with me so having those lists is important.

Several people described using PKM task management strategies to manage and balance among “everyday” tasks, tasks they were interested in or enjoyed doing, and tasks they very much did not want to do—as P-139 (S-FT, ADHD, ANX, DEP) put it, “Every day tasks like getting the washing done, then horrible tasks like taxes, fun tasks like formatting books for others.” P-142 (E-FT, ADHD, DEP) also relied on “task and project management apps though for reminders for things I'm not interested in or have a lot of resistance built up against like mundane bill paying, calls to the insurance, finding out why my mortgage didn't get paid by my mortgager, etc.”

Building Knowledge. Unsurprisingly, there was an overlap between the *Building Knowledge* outcome and the *Learning* life domain. However, *Building Knowledge* also occurred with some frequency in the *Job*, *Inner Life*, *Everyday*, and *Leisure* life domains. There appeared to be two sub-outcomes within the *Building Knowledge* outcome, which are called *Learning* and *Exploring* in this study. However, all three of these outcomes (*Learning*, *Exploring*, and *Building Knowledge*) were too interrelated and sometimes even described in sequence that treating them as separate codes was not practical. The *Learning* outcome describes the goal of learning a defined concept or skill. This was most often seen in the contexts of education (“I am a university student so I take notes in lectures every day to study from them for exams and get good grades,” says P-154 [GRAD, ADHD, ANX, ASD, DEP]) or employment (“achieving good performance in school/work,” as P-125 [EMP-PT, ADHD, ANX, ASD, DEP] put it, or “getting specific technology knowledge” in P-131’s [SE-FT, ADHD, ANX] words). The *Exploring* sub-

outcome was reflected in responses such as P-137 (EMP-FT, ADHD, ANX), who said they use PKM for “understanding more about topics I don't study in my degree, such as psychology and economics.” People fully engaged in *Building Knowledge* talked about gaining new insights, connecting concepts, “idea development” (P-131 [SE-FT, ADHD, ANX]) and coming up with “big insights” (P-117 [E-FT, ADHD]). P-147 (NE, ADHD, ANX, ASD, DEP, LD) describes it as “developing and expanding new ideas through linking existing concepts and thoughts”. P-275 (EMP-FT, SE-PT, ADHD) describes how they use their PKM notes to develop their knowledge around medicinal herbs:

Storing information on all my hobbies and information that cross references each other. For example: holistic approach to personal health[...] take essential oils, break it down into contraindications, uses whether topical, aromatic. The properties within in it. Now to connect that to another topic say... ‘witchcraft’ or in other words personal rituals using centuries of ‘intention’ that adds meaning to properties of herbs and essential oils: pepper - “speeds things up” rose helps with “romance” Rosemary for example has a multitude of benefits. Food, hair, skin, and I forget the ‘spell’ benefits. But ya... that’s why I started using obsidian like 3 days ago and I’m itching to dump all my info into a zettlekasten.

Learning and *Exploring* often led into *Building Knowledge*, as was the case for P-252 (NE, ADHD, ANX, LD): “Learn and synthesize knowledge in mathematics.” P-198 (UG, ADHD, ASD) illustrated how they move from *Learning* to *Building Knowledge* (seeing new connections)

and on to *Creating* (Things To Say) and *Self-Improvement* (working towards goals, career impact):

Just living generally. . . I get so much life fulfillment from learning new stuff. Connections that are obvious to me seem completely obscured to other people sometimes, but then I suppose it makes sense because I've spent most of my life with neurotypical society asking me how I could miss [x thing] when it's so obvious. . . Increasingly I am realising that I have Things To Say and I'm not quite sure what they are yet. . . words are a tool I can use to build on the shoulders of giants when it comes to pushing forward in my goals. I think my note taking and learning approach will significantly impact my career trajectory.

Creating. Most mentions of *Creating* occurred in the contexts of *Learning* (most frequently papers for school) and *Job* (ranging from reports to training materials), but there were also frequent mentions of it in the life domain of *Leisure*. In this combination of categories, there were many creative writing projects such as short stories or novels. Other creative activities included “worldbuilding” (P-106 [E-FT, ASD]), software development, game design (both computer games and board games), art projects, and crafts. P-272 [E-FT, ADHD, ANX] describes the system they’re working towards:

Right now my note-taking systems mainly help me with two areas: my creative projects / hobbies and research projects. These two sometimes overlap, but when it comes to creative projects it mainly serves as a repository / index of

everything that I want to do or have ideas for creatively and then links out to pertinent items / inspiration / reference based on the project (ex. a painting project with links to references or inspiration, a writing project with character details I wouldn't remember otherwise, quick notes area to build up project ideas later etc.).

Self-Improvement. Some people used their PKM notes for self-improvement tasks or projects of varying sizes. Many of these mentioned things like “establishing self-care habits” (P-138 [GRAD, ANX, DEP]) or “maintaining exercise and self-care” (P-140 [E-PT, SE-PT, ADHD]), or “maintain healthy routine and realise potential” (P-144 [GRAD, ADHD, LD]). P-205 (GRAD, ANX, DEP) described one of their efforts: “Taking notes of therapy sessions to further understand causes-effects and reminding myself of the exercises I'm supposed to do.” Similarly, P-248 (E-FT, ADHD) said “It's historically been hard for me to journal or otherwise engage in sustained and structured reflection on new things I've learned, including new insights from therapy. Knowing that I can encode these new ideas and the valuable connections between them makes it feel like I'm not wasting effort.”

Goal-setting came up in relation to PKM as well often in the context of self-improvement or life satisfaction, including “annual goals, long-term dreams” (P-122 [SE-FT, ADHD, ANX]) and “Personal development/self improvement goals” (P-254 [E-FT, LD]). Some participants used PKM to keep track of habits and routines that were part of larger efforts of self-improvement. P-144 (GRAD, ADHD, LD) expanded on their previous comment, saying that their notes help them “maintain healthy routine and realise potential,” while P-168 (E-FT, ADHD, ASD) uses them for “tracking habits I want to reinforce and build upon.” P-225 (SE-FT,

ADHD, ANX, ASD) shared how reflective writing was a long-term tool that helped set him on the road to recovery:

I kept notes for 2 years with the #Alcohol tag, re-read them and linked together #alcohol tags with others such as #happy , #sad, #frustrated etc. Wrote a 4000 word analysis and managed to use logic to get myself out of addiction. This would have been impossible without note-taking as I had tried for 15+ years. It was the only thing that worked.

4.3.2 Research Question 2: Activities

RQ2 asks: What activities do neurodivergent people engage in when using personal knowledge management? The key themes that were observed in relation to this question are: *Storing Information and Using it Later, Remembering What Needs to be Done, Understanding and Ideating, and Planning and Prioritizing.*

Storing Information and Using It Later. Unsurprisingly, the most commonly described activities—*Storing Information and Using It Later*—align with the fundamental definition of personal knowledge management: a set of “collection processes that an individual needs to carry out in order to gather, classify, store, search, and retrieve knowledge in [their] daily activities” (Razmerita et al., 2009, p. 1024). P-106 (E-FT, ASD) describes how they use PKM in their teaching work:

Lesson planning: Here I tend to write more long form notes, one per class per semester. But Obsidian is such a fast program that I can quickly move through

my outline to different dates, save future resources and class activity ideas in their own notes, etc., without breaking my mental flow while lesson planning.

P-109 (E-FT, ADHD, ASD) uses the popular app Notion for “skill improvement”:

I don't know how to answer this question succinctly so I'll just explain how it helps me with one of my goals, which is skill improvement. I use Notion to create databases of resources (like YouTube videos, blog posts, etc.) of educational resources that I want to learn from. When I'm studying from a resource I'll take notes in Notion so that I can reference it again later.

Before I started doing this, I had a bunch of disorganized bookmarks that made it hard to choose what to do next. I also didn't have a place to take notes.

There are a lot of things that annoy me about Notion, but I think it's useful for creating a centralized place to go to when I want to work on one of my skills.

P-173's (SE-FT, ADHD, ANX) dissertation relied on their PKM processes: “I never would have finished my dissertation if I hadn't taken lots of notes and used citation-management software. I tend to forget things that I read, so taking notes is a way of coping with that.”

Remembering What Needs to be Done. Another common application of PKM was simply *Remembering What Needs to be Done*. Simply having a list of active tasks or projects was a key reason to use PKM for many participants. P-160 (CT, SE-FT, ANX, ASD) described this benefit:

I have a lot of long-term goals or high-effort projects that I don't get to on a day-to-day basis. Keeping them “corralled” in a consistent space reduces both the probability that I will forget them, and the level of anxiety I have over forgetting them. On a day-to-day basis, note-taking activities are vital to remembering what I'm working on, or what i need to do next.

Some participants described how their notes could help them reorient themselves when returning to a project after some time. P-302 (NE, ADHD, ANX, ASD, DEP) said, “It gives me a reference point to look back to in case I get lost or derailed during a project,” which is similar to what P-213 (NE, ADHD) said: “They help me remember where I was when I last got bored with a project or goal and stopped working on it.” P-295 (E-FT, ADHD, ANX, DEP) says that their notes

. . . remind me of details that often slip my mind or get confused between projects. For example - if I am working on three programs that will travel in the spring, the notes will tell me if I've already bought airline tickets or reached out to an in-country partner.

Understanding and Ideating. Participants described using their PKM systems to help them understand concepts and ideate upon them. This is strongly related to the *Building Knowledge* outcome from RQ1. P-279 (E-FT, ADHD, ASD) says their PKM notes “. . . help me try new ways of doing or understanding things by fiddling with the way I organize them and think about them.” P-120 says that their notes “clear my mind as I often think in details instead of abstractions, so writing them down helps me find the root/parent for those ideas.” P-259

(GRAD, ADHD, ANX, ASD, DEP) says “With Obsidian, I feel like I have multiple ways to show the same information, so depending on my mood and understanding of the content, I can work towards. . . really knowing what my research means/what my research adds.”

Planning and Prioritizing. Participants often mentioned using their PKM for *Planning and Prioritizing*. For some, like P-112 (E-FT, ADHD, ANX, SPD), this meant “remembering that a deadline is looming” and “chunking large tasks into smaller ones with incremental deadlines.” P-129 (SE-PT, ADHD, ANX, ASD, DEP) described their process: “It helps me organize the tasks that need to get done and 'sort' them by urgency, which helps me achieve the goals/accomplish the tasks.” P-233 (E-FT, ADHD, ASD) discussed the “structure” that was possible to create through their notes, saying “Making notes provides structure to my thinking now. That helps me make and present plans.”

4.3.3 Research Question 3: Benefits of PKM

RQ3 asks: What benefits of PKM do neurodivergent people identify as being most helpful? Most of the benefits that participants described can be grouped into three major themes: *Connecting Ideas*, *Having Fun*, and *Improving Thinking*.

Connecting Ideas. Many people described how PKM helped them connect ideas in new and creative ways. P-106 (E-FT, ASD) describes how they connect ideas via their academic notes: “Through linking with Obsidian, I can link ideas and references to multiple topics and projects. This makes the individual projects more fruitful by conversing with each other.” P-296 (E-FT, ADHD) says:

links between notes helps me tie together research and personal inquiry in ways that help me work over longer time periods without relying on short term memory of the material I've read or has been meaningful.

This sentiment is echoed by P-272 (E-FT, ADHD, ANX), who says “even when I have half-baked ideas I've found it's easier to connect them to larger projects / goals / interests because of my note-taking system.”

P-183 (SE-FT, ADHD) uses a more visual method to connect their ideas: “Scrivener¹⁴ has been such a blessing. I've written books and articles with it. However, I'm also VERY visual. I end up making diagrams and reinterpreting information, mostly in Adobe Illustrator, so it makes sense to me.”

Having Fun. Several participants mentioned how much they enjoyed working with their PKM systems, or how satisfying it was to have “something to cross off the list” (P-141 [E-FT, ANX, ASD, DEP]). P-129 (SE-PT, ADHD, ANX, ASD, DEP) says they “really enjoy checking items off of a list.” P-285 (E-FT, ADHD, SPD), whose hobbies include building custom mechanical keyboards, says

I also set up charts and tables to track purchases and components for my hobbies. I do this partly because I enjoy organizing information in this way, but also because some of my many hobbies have a lot of smaller purchases to track.

¹⁴ <https://www.literatureandlatte.com/scrivener/overview> A word processing program with advanced outlining features designed for long-form writers.

P-243 (SE-FT, ADHD, ASD) cautions against having more fun setting up the system than actually using it:

The most powerful thing I've learned about personal knowledge management is this: creating the system is FUN. Planning out a perfect system, getting the supplies, reading about how other people have made their systems is all high-level creative thinking that will give you a massive hit of dopamine all at once.

Improving Thinking. Another key benefit to PKM seems to be improving or enhancing the way people think either by making thoughts seem physical and therefore more easily manipulated, or by clearing the mind and reducing cognitive load. Although no one used the phrase “making thoughts physical,” the metaphor appears over and over in the responses. For instance, P-160 (CT, SE-FT, ANX, ASD) said “I have a lot of long-term goals or high-effort projects that I don't get to on a day-to-day basis. Keeping them “corralled” in a consistent space reduces both the probability that I will forget them.” P-193 (SE-PT, ADHD) said they “organize my brain externally in a way I can't internally,” while P-202 (E-FT, ADHD) said their notes help them “understand in a more solidified format than just mentally.”

Another frequent metaphor was that of getting thoughts and ideas “out” of the mind and “putting them” somewhere else. P-156 (E-FT, ADHD, ANX, DEP) said they like to “get all of the information out of my brain so I can take in new information.” P-196 (NE, ADHD, ASD) describes their process:

It takes a load off my brain to actually focus on the task on hand. I know and have been exposed to a lot of information, it's nice to have it physically instead

of me having to recall. I keep track of a lot more. I'm better able to make recommendations, solve problems without looking to others streamlining processes, and remember the small stuff.

Similarly, P-169 (E-FT, ADHD, ANX) said:

I don't like the feeling of having to 'remember' anything, miss a deadline because I forgot, etc. so keeping it 'in system' helps me feel more relaxed and confident that what I've committed to will at least be addressed, (if not always completed).

P-123 (NE, ADHD, ANX, ASD) emphasized that their thinking improved because of PKM: “I can't think inside my mind but I am capable of brilliance once I can pour it out of my mind.”

4.4 To Be Continued

As discussed in the introduction to this chapter, the preceding analysis is just the tip of the proverbial iceberg. There are many more insights to be gleaned from the wealth of thoughts that the survey participants generously shared. After summarizing the findings and discussing implications, significance, and limitations of this study, the final chapter will discuss some of the future analysis that should happen with this data set, as well as recommendations for potential future research studies.

Chapter 5: Discussion and Conclusion

The results of this study indicate that PKM can be a powerful strategy for neurodivergent people to improve their well-being and quality of life, whether they are students, knowledge workers, full-time caregivers, or gamemasters. In this concluding section, I will summarize the results of the study, discuss the implications of the findings and the contributions to research made by this project, review some of the study limitations, and recommend potential avenues for future research.

5.1 Summary of Results

This study consisted of a survey with over 300 self-identifying neurodivergent participants with the goal of answering three research questions: (1) *For what outcomes do neurodivergent people use personal knowledge management in different life domains?*; (2) *What activities do neurodivergent people engage in when using personal knowledge management?*; and (3) *What benefits of PKM do neurodivergent people identify as being most helpful?* The answers to these questions, which were identified through the process of thematic analysis, are summarized in Table 16.

Regarding RQ1, NDs used PKM in all life domains with the most positive impacts reported for *Learning*, *Job*, and *Everyday*. These were also the most-discussed life domains in Part 2 of the survey. *Learning* was an important life domain for many participants, not just for formal education but also for learning related to work and “learning for learning’s sake.” Cross-life domain learning was such a strong theme in the responses that the top-down code *Academic* was renamed to *Learning* to emphasize the diversity of learning that participants described. Across life domains, PKM is used for the purposes of *Managing Tasks and Projects*, *Building*

Knowledge, Creating, and Self-Improvement. These purposes often feed into or build onto one another, for instance, with *Managing Tasks and Projects* enabling *Building Knowledge*, and *Building Knowledge* informing *Creating* and *Self-Improvement*. Within *Building Knowledge*, there was evidence of more nuanced applications such as *Learning* pre-determined topics vs. *Exploring* general areas of interest, but the responses in this survey are not sufficient to drill down further into the nature of these different purposes.

The results of RQ2 indicate that NDs use PKM first and foremost for *Storing Information and Using It Later*, which mirrors the fundamental definition of PKM. Alongside this activity, participants also described *Remembering What Needs to be Done*, *Understanding and Ideating*, and *Planning and Prioritizing*. There was a particularly close relationship between *Remembering What Needs to be Done* and *Planning and Prioritizing*, with several participants describing how *Planning and Prioritizing* was only possible because PKM helped with *Remembering What Needs to be Done*.

The answers to RQ3, the most helpful benefits of PKM, include *Connecting Ideas*, *Improving Thinking*, and *Having Fun*. *Connecting Ideas* is one of the areas where the difference between personal *information* management (PIM) and personal *knowledge* management is most clear; it is also an area of particular interest to the PKM enthusiast community at the moment (relating to the concepts of *synthetic notes*, *evergreen notes*, or *Zettelkasten*). *Improving Thinking* is sometimes related to *Connecting Ideas*, but is less specific: People described being able to think more clearly and in a more organized fashion when their ideas were written down in some fashion. Finally, *Having Fun* was a common theme for participants, who often reported enjoying organizing their systems and checking items off of to-do lists.

Table 16*Summary of Research Questions and Central Findings*

Theme	Description
RQ1: For what outcomes do neurodivergent people use personal knowledge management in different life domains?	
Life Domains	<i>Learning</i> was a more appropriate label than <i>Academic</i> . A new <i>Inner Life</i> category was created to capture self-reflection and self-understanding. <i>Social Contacts</i> were rarely mentioned.
Managing Tasks and Projects	Seeing tasks and projects to completion on time; balancing “fun” and “necessary” tasks.
Building Knowledge	<i>Learning</i> (about a defined goal) and/or <i>Exploring</i> (an area of interest), often with the goal of developing new understanding or insight.
Creating	Producing outputs such as creative writing, game design, or software development.
Self-Improvement	Engaging in tasks or projects of varying sizes to improve self-care or self-understanding.
RQ2: What activities do neurodivergent people engage in when using personal knowledge management?	
Storing Information and Using It Later	“Keeping found things found,” as Jones (2008) calls this fundamental application of PKM
Remembering What Needs to be Done	Using lists of active projects and tasks as reminders of what needs to be done, or using notes to reorient to a project after time away from it.
Understanding and Ideating	Using the process of organizing and writing notes to understand and develop concepts in new ways.
Planning and Prioritizing	Breaking projects or tasks into smaller steps, and/or determining what is most important to do next.

RQ3: What benefits of PKM do neurodivergent people identify as being most helpful?

Connecting Ideas	Finding relations between concepts and representing those connections in the PKM system.
Improving Thinking	Enhancing cognition by making thoughts seem physical or getting thoughts “out” of the mind and “putting them” somewhere else.
Having Fun	Enjoying writing and organizing notes, “checking items off a list,” and/or developing the PKM system itself.

While each of these findings could be worth an entire paper on their own, taken as a whole, there are three main ideas that run throughout the responses and the analysis and are the most significant ideas that have been uncovered during this study: *Reducing Stress*, *Memory*, and *Externalizing*. These findings are discussed in the following section.

5.2 Discussion

Although the findings relating to each research question are of significance themselves, there are three themes that seem to run through many of the participant responses regarding the role of PKM for NDs. The first theme is the role that PKM can play in *Reducing Stress*. The second theme involves how PKM supports *Memory*. The final, and most intriguing theme, is that of how NDs use PKM for *Externalizing* thoughts and ideas. Each of these themes is discussed in greater detail below.

5.2.1 Reducing Stress

The idea of using PKM to reduce stress and anxiety surrounding projects and tasks was evident throughout participant responses. In relation to RQ1, regarding outcomes, *Managing Tasks and Projects* was often associated with a sense of security in knowing that important to-dos would not slip through the cracks—that participants would be able to *Remember What Needs*

to be Done (one of the activities discussed in RQ2). One of the benefits identified in the answers to RQ3—*Having Fun*—directly relates to an improved emotional state. P-160 (CT, SE-FT, ANX, ADHD) describes this *Reducing Stress* effect:

I have a lot of long-term goals or high-effort projects that I don't get to on a day-to-day basis. Keeping them “corralled” in a consistent space reduces both the probability that I will forget them, and the level of anxiety I have over forgetting them. On a day-to-day basis, note-taking activities are vital to remembering what I'm working on, or what i need to do next. On a good day, it also helps me with prioritizing.

P-185 (NE, ANX, DEP) described a similar process: “[My notes] help me to keep worries out of my mind, allowing me to focus and with prioritization.” This finding is consistent with research suggesting that attention symptoms are correlated with increased stress, and that strategies to manage the effects of those symptoms, such as time management and task management, are linked with reduced stress (G. Coetzer, 2016; Graeme. H. Coetzer & Richmond, 2009; Fleischmann & Fleischmann, 2012).

5.2.2 Memory

With one of the most common neurodivergent conditions, ADHD, being strongly associated with memory issues, it is not surprising that memory was frequently referenced in the survey responses. Participants described forgetting things that needed to be done, things that they had already done (and would end up repeating), and ideas they wanted to explore or pursue. Many people, such as P-121 (SE-PT, ADHD, ANX, DEP, LD), talked about using their notes to

return to a project more easily after having stepped away from it (or being distracted from it) for a while: “A well captured note also allows me to put the project down and return to it later, because I almost inevitably lose focus/motivation/interest in the middle somewhere.” These observations are in keeping with findings that memory difficulties and differences are associated with some ND conditions, particularly autism and ADHD (Norris & Maras, 2022; Skodzik et al., 2017; Williams et al., 2006). Researchers in HCI are exploring the use of “personal knowledge management applications” (PKMA) as “memory prosthesis” or memory augmentation aids (Schneegass et al., 2021)

5.2.3 Externalizing

An unexpected but intriguing result of the qualitative analysis was how often participants described a process of *externalizing*; of making ideas and thoughts metaphorically or literally *physical*. This was strongly connected to the *Improving Thinking* benefit identified in RQ3 and can be seen throughout the open-ended responses. Along with the analogy of getting thoughts “out” of the mind (or even “dumping” them out) and “keeping” them somewhere else, the concept of ideas being given a physical form and even a physical movement showed up over and over. Participants talked about ideas “resurfacing” when they reviewed their notes, or “putting a project down” and returning to it later, struggling to manage “moving parts” or finding it helpful to “map out” ideas or plans. More literally, some participants described leaving short notes or calendars in visible places to be reminded by their actual physical presence. Some elements of this finding are reminiscent of the idea of “concept mapping” in education, which is theorized to “externalize understanding” and “facilitate learning through self-reflection” (Kandiko et al., 2013), but further research into this area is needed.

All three of these elements: *Reducing Stress*, *Memory*, and *Externalizing*, deserve further study and exploration, and could have significant implications for the design of information systems and services.

5.3 Implications

The results and findings of this project, discussed in chapters 4 and 5, have several implications for people or organizations who support or wish to support NDs (including libraries) as well as implications for people designing information systems or knowledge tools that are inclusive of NDs. These implications are discussed below.

5.3.1 Support the Whole Life

First, researchers, system designers, and others must acknowledge that there is more to life and success than just school and work. This is not to say that every service or tool must support every area of life. Rather, we should look to the life domains that are less commonly discussed in research, such as Everyday, Social, and Leisure, for overlooked opportunities to provide support for NDs. In particular, supporting the Inner Life and self-improvement projects seems like it might be a particularly impactful line of research. Libraries should offer ND-friendly programs and resources that support a variety of goals, activities, and interests, while system designers and software developers should look for opportunities to create products that can be used in different life domains.

5.3.2 Support Abilities and Disabilities Across Multiple Divergences

Anyone creating products and services relating to neurodivergence must acknowledge the frequent presence of multiple ND conditions as well as mental health concerns such as anxiety and depression. The results of this survey are consistent with existing knowledge about co-

occurring conditions and may not be new or unique, but it is worth emphasizing that designing for the average individual with a single ND condition (e.g., the “average” autistic) is unrealistic. Instead of researching different conditions as if they exist in isolated siloes, transdiagnostic research and design that recognizes that depending on their particular expression of neurodivergence, people have a range of not just disabilities but also abilities, with both weaknesses and strengths in varying dimensions, such as the executive functions researched in this project.

5.3.3 Support Connecting and Ideating

Finally, information and knowledge-related software and systems should accommodate the activities that ND people engage in when they are managing knowledge. Any PKMS, but particularly one that is inclusive of ND people, should allow users to discover and document connections between ideas and concepts. It should facilitate ideation and the building of new ideas from existing ones. It should help users externalize their thoughts and memories, and somehow “resurface” them easily at the right time.

5.4 Significance and Contributions

5.4.1 Methodological Contributions

From a methodological standpoint, this research provides an example of the Sense-making Method, typically conducted as a semi-structured interview or observational format, as a survey. This project demonstrates both pros and cons to this strategy. There are limitations to the survey format that are discussed in the Limitations section below; as discussed there, the depth of understanding that is allowed by an interview with the opportunity for clarifying follow-up questions was not fully obtained in this project. However, this research does illustrate the much

larger scale that is made possible by the survey format, as well as the surprisingly rich data that can be obtained from open-ended survey questions. This shows that the Sense-Making method can be used in a survey format to good effect.

5.4.2 Theoretical Contributions

An important component of this project was bringing PKM and neurodivergence into the domain of LIS research. Although it has roots in the field of communication, the theoretical foundation of Sense-Making is also well-known in LIS. Although more research needs to be done, this project has shown that Sense-Making can be a useful framework from which to view not just PKM but also the information behavior of NDs. The Sense-Making concepts—of which the gaps, outcomes, and bridges were most thoroughly investigated here—worked very well as framing devices for PKM behavior.

5.4.3 Practical Contributions

This study would be significant if only for the fact that it is one of the first times the information practices of neurodivergent adults have been looked at broadly through an LIS lens at such a large scale. It is also one of the first expansive studies of PKM in practice from an LIS perspective. Although the field of LIS typically prides itself on prioritizing inclusivity more than society at large, there is only a nascent awareness in LIS that traditional approaches to neurological differences have significant limitations. This dissertation lays forth the case for an updated approach to neurodivergence-related research in LIS and demonstrates how LIS can contribute to the well-being of ND adults by exploring personal knowledge management, with the end result, hopefully, of sparking interest in moving LIS research forward in addressing information wants and needs of neurodivergent populations.

This project is also significant for its findings, which contribute to our knowledge of both PKM and neurodivergence. Of greatest significance is the implication that PKM can play a tremendous role in the well-being or quality of life of neurodivergent individuals, particularly in regards to stress and anxiety. The *externalizing* metaphor, and the way that survey respondents talked about making information seem physical, is also a significant finding.

5.4 Limitations

The most prominent limitation of this study is the methodology itself. Researching information practices as nuanced and qualitative as personal knowledge management through an anonymous survey is in some ways far more limiting than a traditional semi-structured Sense-Making interview, or any of several other more hands-on research methods. In particular, there were many times I wished to ask a follow-up question to clarify a response; this would have been possible in an interview, but not with this survey. However, it would have been impossible to achieve the scale of this study—over 1000 individual responses to open-ended questions—with a single researcher conducting interviews or observations. Future research that focuses on a narrower topic (such as those recommended in the next section) would benefit from using more in-depth and contextual methods. Another limitation is that a single survey describes a single point in time; the participants were at varying stages of their PKM development, and unlike a longitudinal study, this study did not capture how their practices may have changed and matured over time. Additionally, the self-reported nature of the responses is only as accurate as the participants were both perceptive and truthful.

Aside from the limitations of surveys described above, the most significant limitation is that this study does not involve a representative sampling of neurodivergent individuals. This

fact was understood from the beginning of the study design and does not compromise the intended purpose of the research, but it is important to acknowledge this limitation when making use of the findings in systems design or future research. These results provide a deep-dive into the PKM practices of a selection of NDs, but the qualitative and quantitative analyses should not be regarded as statistically representative of the entire neurodivergent population. Additionally, despite efforts to create a highly inclusive survey experience, some significant segments of the neurodivergent population were omitted largely or even entirely. For instance, feedback I received from the moderators of the subreddit r/dyslexia indicated that the UMD Qualtrics site that hosted the survey was not entirely accessible to participants using text-to-speech, which led the moderators of that subreddit to reject the recruitment post. Non-English-speaking NDs were also excluded, as well as nonverbal¹⁵ NDs, although the information practices and needs of the latter group would likely require a significantly different research experience. Another representation issue is that there was likely an over-representation of PKM enthusiasts compared to the general population, meaning that participants may have been more self-aware of and sophisticated with their PKM behaviors than the truly average ND adult.

Additionally, there are two flaws relating to the open-ended questions. The first is that while the open-ended questions asked specifically about note-taking, some respondents seemed to discuss multiple types of PKM, not just note-taking. The intention behind specifying note-taking alone was to narrow the focus of the responses, but this happened unevenly across the

¹⁵ Although the terms *nonverbal* and *nonspeaking* are sometimes used differently by different people or communities, *nonverbal* is used here to mean people who do not use language at all, as opposed to *nonspeaking* people who simply do not use spoken language but frequently communicate fluently in writing.

participants. Secondly, participants may have been somewhat primed by the close-ended questions in part one, particularly the lists of PKM activities and executive functions. This is not necessarily a net negative for the quality of responses, but it may have made the participants seem more self-aware of their PKM activities than they really were.

Finally, changing text responses to numbers for the sake of analysis (such as treating “fair” as “2” or “I’ve never heard of this” as “0”) is a highly imprecise way of quantifying what is essentially qualitative data. However, once again, as long as this analysis is acknowledged to be exploratory and not statistically generalizable, this is not a significant limitation.

5.5 Recommendations for Future Research

Neurodivergence and personal knowledge management are both fertile topics for future LIS research, along with the intersection of both areas. There are three levels at which future research can be discussed: first, additional research that will be conducted on this dataset; second, my personal research agenda building on this study; and finally, a broader set of recommendations for the LIS field more generally.

5.5.1 Future Work with This Dataset

There are at least three major research questions yet to be answered by analysis of this dataset. Each question, when answered, will provide insight and direction into the development of strategies, tools and supports for NDs.

How are Executive Function Skills Related to Different PKM Strategies? This question will be answered by quantitative analysis of Q4 and A6 (related to executive function and PKM strategies). The answers to this question will lay the foundation for my future transdiagnostic research that will focus on skills and abilities, not labels. For example, if people who report

having difficulty with organization also make heavy use of visual thinking tools, that will suggest a connection between those two concepts that would have strong design implications for anyone creating tools to support organizational challenges (regardless of what the person facing those challenges is diagnosed with).

What are the Major Obstacles NDs Face in Pursuing Their Goals? To answer this research question, I will take a deep dive into the analysis of Q8 (“What are the problems or obstacles you face in achieving the goals and projects you listed in Question 7?”). Although some of the obstacles have been touched upon in the previous pages, to answer this question fully I will do a more extensive analysis of Q8.

What Solutions or Supports do ND People Identify as Being Potentially Helpful in Achieving their Goals? The answer to this research question will be found through analysis of Q10 (“If you could wave a magic wand, what would change or appear to help you achieve the goals and projects you listed in Question 7?”) and Q11 (“What is one piece of advice you would give to a neurodivergent person starting out with note-taking for personal knowledge management?”). Together with the previous question about obstacles, the answers to these two questions will help identify the most promising avenues for research and development.

5.5.2 My Research Agenda Moving Forward

My personal research agenda focuses on understanding the information- and knowledge-related abilities and challenges of NDs with an aim towards developing tools, supports, and strategies that will make their goal-directed work easier and more successful. In particular, I am interested in the four research questions described below.

How Can Transdiagnostic Research and Design be Leveraged in LIS? An underlying question that was not adequately addressed by this project relates to the role that transdiagnostic research can play in designing LIS-related supports and services.

How Can PKM be Taught at Different Levels of Development? Libraries play a significant role in the development of information literacy and digital literacy skills (Behrens, 1994; Buschman, 2009; LaPierre & Kitzie, 2019). I would like to explore the extent to which PKM is already a part of literacy instruction, and how it might be incorporated more effectively, especially in school and academic libraries.

How Does PKM Support Memory? This study has shown that NDs report that PKM supports their memory; however, there are several different types of memory and ways of describing memory—for instance, sensory memory, working memory, short-term memory, and long-term memory, as well as semantic memory, episodic memory, and others (Hall & Stewart, 2010; Queensland Brain Institute, 2016). PKM likely plays different roles in supporting each type of memory.

How Does “Externalizing Thought” Interact with Knowledge-Building? Outside of the idea of explicit vs. implicit knowledge, perhaps, there has not been much LIS discussion of the kind of externalizing metaphor used by many of the participants. Although the idea of “getting ideas out of one’s head” is a familiar one, there has not been much research about precisely what that means, how it happens, and how we might help it happen more efficiently. Nor has there been much attention paid to the concept that one participant described as thinking “out[side] of my mind” and how that process plays out.

5.5.3 An Agenda for LIS

Finally, at the level of LIS as a discipline, LIS researchers need to pay attention to both neurodivergence and personal knowledge management, as well as the relationship between both concepts, instead of leaving those areas of study to education or HCI. It is my hope that this dissertation and the related work that is published in the future will demonstrate the rich knowledge that is waiting to be constructed in these areas. Additionally, research in any field that involves neurodivergence should take a broader perspective than focusing mostly on children and academics in order to support NDs as whole persons throughout their lifespans. Some of the questions that could be addressed in the field of LIS writ large include how traditional LIS services can leverage PKM literacy to fulfill their missions; what ND information behaviors can tell us about the nature of knowledge; and how HCI, Education, and LIS can combine strengths to create a dynamic, interdisciplinary study of both PKM and neurodivergence.

5.6 Concluding Remarks

Any uncertainty I may have had regarding the value of this project at the beginning was more than eradicated as I read through the responses to Part 2 of the survey. I was profoundly affected and humbled by how many people were willing and even eager to frankly and honestly share their thoughts and ideas, their hopes and fears, their triumphs and challenges with me with the goal of helping others like them—like us—use PKM to improve their lives. I am honored to be a part of this hard-working, earnest, tough-as-nails yet proudly vulnerable community of people, and I have no doubts that if my research can in even the smallest way help some members of that community empower themselves to get whatever it is they want out of life, then the world will have been made a better place.

As I develop my next research projects, I hope to continue learning more about how personal knowledge management can support NDs in different life domains, particularly focusing on the intertwined learning/exploring/building knowledge/creating aspects. Studying this process in academia is the most obvious starting point, and I would love to delve further into the experiences of ND researchers and faculty, as well as students of all levels. However, I would also like to explore this “learning to creating pipeline,” as I think of it, in other domains, such as on-the-job processes of knowledge workers, or even how it occurs during different leisure activities, such as creative writing or gaming.

Finally, my objective as I move forward in my career as an LIS researcher is to continue advocating for more and better research on the subject of neurodivergence and information practices with the goal of meeting neurodivergent minds “where they’re at” and creating systems, services, and products that will help them achieve their goals and improve their well-being, whatever that means for the individual. I believe that I will be able to magnify my impact on the world several times over by helping people build their own capacity to learn and create—or simply to *be*—on their own terms.

Appendix A: Informed Consent Form and Survey

2/15/23, 4:49 PM

Qualtrics Survey Software



Statement of Consent

This survey explores your personal knowledge management practices. Personal knowledge management is “a collection of processes that an individual needs to carry out in order to gather, classify, store, search, and retrieve knowledge in [their] daily activities” (Grundspenkis, 2007). If you have ever saved a bookmark in your browser for future reference, or taken notes in the margins of a textbook, you have engaged in personal knowledge management!

This survey is intended for individuals aged 18 years or older who identify as neurodivergent or neuroatypical (including but not limited to ADHD, autism, and dyslexia), regardless of how much you know about personal knowledge management.

CONSENT TO PARTICIPATE

Project Title: LIS Research and Neurodivergence: So Much Potential If We’d Just Apply Ourselves

Purpose of the Study: This research is being conducted by Kelly Hoffman, a Ph.D student at the University of Maryland, College Park. As a grad student with attention deficit hyperactivity disorder (primarily inattentive type), I am familiar with some of the challenges faced by people who “think different” when learning and creating. One of the hallmarks of the neurodivergent experience is processing and interacting with information differently than neurotypicals—and yet in my field, library and information science (abbreviated LIS) there is a surprising lack of research involving neurodivergent thinkers. The primary purpose of this research project is to start exploring neurodivergent information practices in a domain that is highly relevant to academics and creatives — personal knowledge management (PKM for short). This will lay a foundation for the development of products and services that are more useful and relevant to a variety of neurotypes. A secondary goal is to get more neurodivergent perspectives in front of a wider audience of researchers and developers.

Procedures: As someone with limited attention regulation, it’s important to me to let you

https://umdsurvey.umd.edu/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview?ContextSurveyID=SV_74knVF01j9z1UoK&ContextLibraryID=UR_aWgdxgz0cK... 1/12

2/15/23, 4:49 PM

Qualtrics Survey Software

know exactly what you're getting into! This research involves a survey in two parts. Part 1, which should take about 10 minutes to complete, consists of six close-ended questions with multi-select answers (no typing required!). Part 1 asks about your experiences with neurodivergence and PKM. After you have completed Part 1, depending on your answers, you may be asked if you would like to complete Part 2, which will have five more open-ended questions (with short written answers) and should take another 10 minutes or so to complete. Part 2 focuses specifically on note-taking. If you only want to complete Part 1, that is perfectly fine and is still tremendously helpful to my study.

Potential Risks and Discomforts: There is no more than minimal risk associated with participating in this project. You will be asked to think about the impact being neurodivergent has on your quality of life (on a scale from "very negatively" to "very positively"), and to evaluate your own executive functioning skills (on a scale from "very poor" to "excellent"). This may cause minimal emotional discomfort. You will not be asked to provide your name, email address, gender, or any other personally identifying information. You may choose to skip any question in the survey.

Potential Benefits: There are no direct benefits from participating in this research. However, I hope that there will be benefits to the larger neurodivergent community, including the development of more useful products and services, as well as more awareness of neurodivergence in the library and information science community.

Confidentiality: You will not be asked to provide identifying information and I will make no attempt to collect any. The data is collected through the Qualtrics survey software, which assigns you a random participant number, rather than identifying your responses by your name. The survey has been configured so that it will not collect your location or IP address. Data will be stored on the University of Maryland Qualtrics server, on my password-protected personal computer, and on password-protected cloud-based storage. Dr. Beth St. Jean, my dissertation advisor, will have access to the data in addition to me. Data from this study will be kept until the end of 2028 so that it can be analyzed in its entirety. At that time, the data will be destroyed. If I write a report or article about this study, your identity will be protected to the maximum extent possible (for instance, if you mention something potentially identifying in an open-ended answer, it will be redacted). Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else

2/15/23, 4:49 PM

Qualtrics Survey Software

is in danger or if I am required to do so by law.

Right to Withdraw and Questions: Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized. If you are an employee or student at UMD, your grades, standing or employability at UMD will not be positively or negatively affected by your decision to participate in the study.

If you have questions, concerns, or complaints, please contact the investigator:

Kelly M. Hoffman
University of Maryland College of Information Studies
4130 Campus Drive Hornbake Library, Ground Floor, Rm. 0220
College Park, MD 20742-4345
E-mail: kmhinmd@terpmail.umd.edu

Participant Rights: If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:

University of Maryland College Park Institutional Review Board
Office 1204 Marie Mount Hall
College Park, Maryland, 20742
E-mail: irb@umd.edu
Telephone: 301-405-0678

For more information regarding participant rights, please visit:
<https://research.umd.edu/research-resources/research-compliance/institutional-review-board-irb/research-participants>

This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.

Statement of Consent

By clicking "Yes," below, you indicate that you are at least 18 years of age, you have

2/15/23, 4:49 PM

Qualtrics Survey Software

read this consent form or have had it read to you, your questions have been answered to your satisfaction, and you voluntarily agree to participate in this research study. You may wish to save/print a copy of this consent form for your records.

- ☐ Yes
- ☐ No

Survey Part 1

Q1. What is your employment status (choose all that apply)?

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Self-employed full-time
- ☐ Self-employed part-time
- ☐ Stay-at-home caretaker
- ☐ Student (undergraduate)
- ☐ Student (graduate school)
- ☐ Not employed
- ☐ I prefer not to answer
- ☐ Other (please explain)

Q2. Please select the condition(s) that you identify with (choose all that apply):

- ☐ ADHD (attention deficit hyperactivity disorder)
- ☐ anxiety (including obsessive compulsive disorder)
- ☐ autism (including Autism Spectrum Disorder, Asperger's, pervasive developmental disorder)
- ☐ depression or other mood disorder (including bipolar disorder)
- ☐ any learning disorder (including dyslexia)
- ☐ any sensory processing disorder
- ☐ I prefer not to answer

2/15/23, 4:49 PM

Qualtrics Survey Software

☐ Other (Please Specify)

Q3. To what extent do you feel **your neurodivergence** affects your quality of life in the following areas? If you feel your neurodivergence has both negative and positive effects on your quality of life, choose an option that best represents the overall impact.

	Extremely negatively	Somewhat negatively	No effect	Somewhat positively	Extremely positively
Academic (studying, research, academic writing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Everyday routines and obligations (outside of academic and job activities; for instance, household chores, paying bills)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family and partnership (activities with or for family or partners)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health (exercise, doctor's appointments, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Job (work activities, including job-seeking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leisure (entertainment, volunteer work, hobbies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social contacts (building and maintaining friendships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please explain) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4. How often do you engage in each of the following types of **personal knowledge management activities** for any reason (personal, educational, or professional)?

2/15/23, 4:49 PM

Qualtrics Survey Software

	I've never heard of this	I've heard of this, but never tried it	I've done this a little	I do this sometimes	I do this frequently
Synthetic note-taking or "digital gardening" (notes that combine ideas from multiple sources, used for creating new knowledge or content; usually involves linked notes and/or backlinking; frequently managed or created in Obsidian, Roam Research, Logseq, Evernote, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Note-taking, note-making, and note-management for long-term use (Examples: handwritten notes, notes organized and/or stored in Evernote, Obsidian, Notion, Google Docs, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Note-taking for short-term use (Examples: post-it notes, some forms of bullet journaling, quickly captured notes in apps like Apple Notes, Google Keep, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Augmented content (highlighting and note-taking directly on a piece of content; could be on a paper, in a PDF reader, or using an app to annotate web content)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Curation (lists and/or collections of books/movies/articles/other media or items, selected and arranged by personal criteria)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Project/task management (to do lists, on paper or in dedicated apps)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"Read-It-Later" management (keeping a list of web content to read at a later time, can involve apps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2/15/23, 4:49 PM

Qualtrics Survey Software

	I've never heard of this	I've heard of this, but never tried it	I've done this a little	I do this sometimes	I do this frequently
like Instapaper, Pocket, Feedly, Newsblur)					
Reference/citation management (bibliographic management such as Zotero, Mendeley, EndNote)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visual Thinking (Examples: mind maps, flowcharts, diagramming, either on paper or in an app)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Web bookmarks (browser bookmarks or a separate bookmarking app)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Word processing (writing using a dedicated application for writing, such as Word, Google Docs, Scrivener, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q5. To what extent do the **personal knowledge management activities** indicated in Question 4 affect your quality of life in the following areas?

	Extremely negatively	Somewhat negatively	No effect	Somewhat positively	Extremely positively
Academic (studying, research, academic writing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Everyday routines and obligations (outside of academic and job activities; for instance, household chores, paying bills)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family and partnership (activities with or for family or partners)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health (exercise, doctor's appointments,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2/15/23, 4:49 PM

Qualtrics Survey Software

	Extremely negatively	Somewhat negatively	No effect	Somewhat positively	Extremely positively
etc.)					
Job (work activities, including job-seeking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leisure (entertainment, volunteer work, hobbies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social contacts (building and maintaining friendships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please explain) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6. How would you rate your skills in the following areas?

	Very poor	Poor	Fair	Good	Excellent
Emotional control/regulation (managing your emotions and reactions)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Flexibility (adapting and revising plans when things change or you get new information)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Goal-directed persistence (the ability to finish projects and complete goals)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Organization (creating and maintaining systems and structures to keep track of information or objects)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Metacognition (understanding of your own thought processes; awareness of how you solve problems; self-evaluation and monitoring; asking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2/15/23, 4:49 PM

Qualtrics Survey Software

	Very poor	Poor	Fair	Good	Excellent
yourself “how am I doing?”)					
Planning (determining a set of steps to complete a task or goal; prioritizing tasks; deciding what’s important to work on next)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Response inhibition (thinking before you act)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sustained attention (staying focused even when you’re tired, bored, or being distracted)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Task initiation (getting started without procrastination)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time management (estimating how much time you have to complete a task; deciding how to allocate time; knowing how to stay within time limits and meet deadlines; accurately perceiving the passage of time)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Working memory (keeping relevant information in your mind while performing tasks or thinking through problems)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you for participating in this survey! Your responses will help provide much-needed insight into how we neurodivergent folks interact with information and create knowledge, which will hopefully lead to better products, services, and resources for us in the future.

2/15/23, 4:49 PM

Qualtrics Survey Software

Would you like to provide even more helpful data for my study? If so, you can choose to participate in Part 2 of the survey. You will be asked five open-ended questions specifically about your note-taking for personal knowledge management, which can be answered in a sentence or two and should take about 10 minutes. (You can skip any question you don't want to answer.) There is also a cute photo of my cat at the end.

- ☐ Yes - continue with the survey
- ☐ No - I'm done with the survey

Survey Part 2

For the following three questions, think specifically about your note-taking, note-making, and note-management for long-term use (this could involve handwritten notes, "synthetic" notes, some forms of bullet journaling, or notes organized and/or stored in Evernote, Obsidian, Notion, Google Docs, etc.).

Q7. What are the goals or projects your note-taking activities help you work towards?

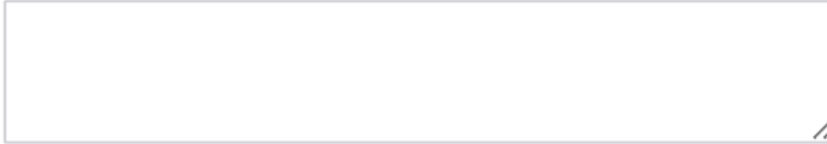
Q8. What are the problems or obstacles you face in achieving the goals and projects you listed in Question 7?

Q9. How do your note-taking activities help you in achieving the goals and projects you listed in Question 7?

LIS RESEARCH AND NEURODIVERSITY111

2/15/23, 4:49 PM

Qualtrics Survey Software



Q10. If you could wave a magic wand, what would change or appear to help you achieve the goals and projects you listed in Question 7? (Your answer might or might not relate to note-taking.)



Q11. What is one piece of advice you would give to a neurodivergent person starting out with note-taking for personal knowledge management?



Thank you so much for helping out with this project. As promised, here is a photo of my cat, Patrol Kitty!

LIS RESEARCH AND NEURODIVERSITY112

2/15/23, 4:49 PM

Qualtrics Survey Software



If you have any questions about this research, please feel free to contact me at kmhinmd@umd.edu.

Powered by Qualtrics

Appendix B: Recruitment Language

Messages to Moderators (slightly customized for each community or group)

Hello mods! I'm writing to ask your permission to post an invitation to participate in a research study in the [Facebook/Reddit] group you administer, [Name of Group].

I'm a doctoral student with attention deficit hyperactivity disorder (primarily inattentive type), and I'm conducting a survey to explore the personal knowledge management practices of people who identify as neurodivergent (for instance, people with ADHD, autism, or dyslexia). Personal knowledge management refers to the ways people “gather, classify, store, search, and retrieve knowledge in [their] daily activities” (Grundspenkis, 2007). The survey is anonymous (I'm not even collecting IP addresses) and reasonably brief (I'm not going to ask anyone to fill out something I wouldn't have the patience to respond to myself). Should you have any comments or questions, please feel free to contact me here or at kmhinmd@umd.edu.

I'm including the message I intend to post, if I get your permission. I think there are probably many members of this community who have a lot to contribute to this topic.

Thank you for your time and consideration!

Reddit/Facebook

Hello! I'm a PhD student with ADHD at the University of Maryland's College of Information Studies, and I'm trying to address my field's lack of knowledge about how neurodivergent people work use personal knowledge management. It's OK if you're not familiar with this term! Personal knowledge management is “a collection of processes that an individual needs to carry out in order to gather, classify, store, search, and retrieve knowledge in [their] daily activities” (Grundspenkis, 2007). If you have ever saved a bookmark in your browser for

future reference, or taken notes in the margins of a textbook, you have engaged in personal knowledge management!

If you are 18 years of age or older and identify as neurodivergent in some way (including but not limited to ADHD, autism, and dyslexia), your response is essential to helping me and many other future researchers understand how people like us find, use, store, and remember information. One of the future benefits could be the development of better products, services, and tools for neurodivergent knowledge workers.

As someone with limited attention regulation, it's important to me to let you know exactly what you're getting into! The survey is in two parts. Part 1, which should take about 10 minutes to complete, consists of five close-ended questions with multi-select answers (no typing required!). After you have completed this survey, and depending on your answers, you will be asked if you would like to complete Part 2, which will have one to six more additional questions that may include short written answers, should take another 5-15 minutes to complete. If you only want to complete Part 1, that is perfectly fine and is still tremendously helpful to my study.

Also, I'm not asking for or collecting any identifying information about you — I've even configured the survey not to collect IP addresses. Feel free to forward this invitation to other people who might be interested in participating!

Survey link (you can learn more here before you decide to participate): [\[link\]](#)

Your participation in the survey is completely voluntary and all your responses will be kept confidential. You must be 18 years old or older to participate. No personally identifiable information will be associated with your responses to any reports of these data. The University of

Maryland Institutional Review Board has approved this survey. Should you have any comments or questions, please feel free to contact me at kmhinmd@umd.edu.

Thank you very much for your time and participation.

Twitter (sample language, hashtags varied)

Calling all #adhd #autism #neurodiversity folks! I'm studying how we #neurodivergent people engage in knowledge management to #BuildASecondBrain! Taking this quick survey will help me learn about how ND people use and manage information in everyday life. [link]

Help an #ADHDacademic out... I'm studying how we #neurodivergent people engage in knowledge management! Taking this quick survey will help me learn about how ND people use and manage information in everyday life. [link] #PhDLife

Ever saved a bookmark, taken notes, or started to #BuildASecondBrain? Do you identify as #neurodivergent? If so, I need your help! Taking this quick survey will help me learn about how ND people use and manage information in everyday life. [link]

Appendix C: Codebooks

The codebooks consist of three sets “top-down” codes and three sets of “bottom-up” codes. The three “top-down” codebooks, which are related to the relevant answer choices in the survey, are C-1: Life Domains, based on Klingsieck (2013); C-2: Executive Functions, based on Dawson & Guare (2010); and C-3: PKM Techniques, based on a report from Ness Labs (2020). The three “bottom-up” codebooks were developed through the process of thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2014) and included C-4: Outcomes (RQ1), C-5: Activities (RQ2), and C-6: Benefits (RQ3).

C-1: Life Domains

Codes and descriptions based on Klingsieck (2013).

Code	Definition	Example
Everyday	Everyday routines and tasks outside of activities covered under <i>Learning</i> or <i>Job</i> . For instance, household chores, paying bills, generic references to routines, tasks, being organized, or personal life.	<p>“Tracking day-to-day tasks and appointments”</p> <p>“paying bills, applying for benefits, personal assistance, etc”</p> <p>“running my life”</p>
Family	Activities with or for family or partners not included in <i>Everyday</i> .	<p>“Coaching my kid through high school to get into university”</p> <p>“being a full time parent and caregiver for a teenager and my partner.”</p>

Health	Exercise tracking, notes on/for doctor's appointments, medical conditions. Mental health aspects were originally coded as <i>Health</i> but evolved into the new <i>Inner Life</i> domain described below.	<p>"Developing an exercise routine"</p> <p>"tracking my health and wellbeing"</p>
Inner Life	A new category not based on the domains identified by Klingsieck (2013). Encompasses mental health, self-reflection, spirituality, life goals and dreams, well-being, self-care, journaling, and generic references to self-improvement.	<p>"long-term dreams"</p> <p>"Journaling to help clear my mind and document my ideas."</p> <p>"Building context on myself and my history"</p>
Job	Work activities, including job-seeking, career development, meeting notes.	<p>"Generally I take notes when I have work projects that have several components and/or are rather complicated in scope."</p> <p>"I veer between distracted, scattered work habits and hyper focus to the point of skipping showers and meals."</p>
Learning	Originally "Academic." References to school and university, study, research, "understanding the world," and academic writing, as well as learning that is not explicitly associated with another domain (e.g., "learning for work" would be coded as <i>Job</i> .	<p>"Academic work is easier too, because I can note what information comes from what article."</p> <p>"i end up with a record of my 'learning for learnings sake', which also serves as quick and easily navigable reference material when writing"</p> <p>"'Academic' (personal): research notes on cognitive neuroscience"</p>

Leisure	Entertainment, volunteer work, hobbies. Includes references to passion projects, books to read, and movies to watch (or books and movies already read/watched).	<p>“remembering what I wanted to do in my free time (opposed to time wasting online)”</p> <p>“For my personal life, it's more for cataloguing philosophical ideas, interests, resources, and notes taken from my hobbies.”</p>
Not Specified	Any response that did not indicate a life domain or that was too ambiguous to be certain which life domain was being addressed	<p>“Getting my notes into a searchable system so I can find what I'm looking for quickly when I need it (rather than spending time looking for it)”</p> <p>“I'm trying to off-load my tasks to an external system. I need scheduled reminders for most things so I don't forget.”</p>
Social	Relating to building and maintaining friendships.	<p>“Keeping in contact with friends... reaching out to friends regularly”</p> <p>“my problem is remembering past conversations while in the midst of active socialization-- my brain won't recall while also busy navigating social cues.”</p>

C-2: Executive Functions

Codes and descriptions based on Dawson & Guare (2010).

Code	Definition	Example
Emotional Regulation	Managing emotions and reactions. Any reference to emotions or feelings causing or contributing to a problem.	“I often feel stressed. . . because disorganization feels like I'm not in control.”

		“getting hopeless and failing”
Flexibility	Adapting and revising plans when things change or new information is received.	<p>“Not being able to follow complex issues once I hit a stumbling block”</p> <p>“I find it easy to make processes to up my productivity and to remember things better, but if anything goes awry in my life, it takes a long time to get back in the groove of starting those processes again.”</p>
Goal-Directed Persistence	The ability to finish projects and complete goals. Any reference to having trouble “sticking to” an organizational system <i>or</i> getting too caught up in setting up a system to make real use of it.	<p>“not completing all projects to their logical conclusion”</p> <p>“Losing focus and forgetting I even have a bullet journal (my main tool)”</p>
Organization	Creating and maintaining systems and structures to keep track of information or objects.	<p>“My notes are scattered all over the place”</p> <p>“If my thoughts are a tangled mess that I can't untangle, then it's also hard getting that onto paper (or a screen) in a way that makes sense.”</p>
Metacognition	Understanding of your own thought processes; awareness of how you solve problems; self-evaluation and monitoring; asking yourself “how am I doing?”	<p>“Maintaining the appropriate level of focus and task commitment. Neither too much nor too little.”</p> <p>“I had compensating strategies but did not understand that my brain worked differently than others. [L] [SEP]”</p>
Not Specified	Used when the response does not seem to refer to an executive function.	“Chronic pain, being a full time parent and caregiver”

Planning	Determining a set of steps to complete a task or goal; prioritizing tasks; deciding what's important to work on next; handling multiple projects at once.	<p>“taking on too many projects simultaneously”</p> <p>“when I don't know what to do next, or who to ask, or which one of a dozen possible options to pick, or I doubt my abilities; it's game over.”</p>
Response Inhibition	Thinking before you act.	<p>“impulsivity results in switching tasks”</p> <p>“a huge obstacle is feeling like I'm missing something and need more to achieve it because what I have isn't doing the job. . . Example:... I need colours and gels with the right pigment and consistency. . . And I impulse shopped and bought 5 kits of 12 gels.”</p>
Sustained Attention	Staying focused even when tired, bored, or being distracted; hyperfocusing; needing to be interested in a task to complete it; motivation issues.	<p>“I'm easily distracted and prone to hyperfocusing.”</p> <p>“If I lose interest in a project, I have virtually zero ability to push through it.”</p>
Task Initiation	Getting started without procrastination.	<p>“Difficulty self-starting”</p> <p>“Extreme procrastination”</p> <p>“Whatever it is about ADHD that makes it hard to do a thing even if I actually genuinely want to do that thing”</p>
Time Management	Estimating how much time you have to complete a task; deciding how to allocate time; knowing how to stay within time limits and	<p>“Time blindness makes simple tasks seem like they will take much more longer than they should so I end up avoiding them.”</p>

	meet deadlines; accurately perceiving the passage of time.	“i struggle to complete or make significant progress on my personal projects and hobbies unless there is an external deadline. (So, I can make a baby quilt for a family member before the baby is born, but I cannot finish writing and illustrating a book for myself.)”
Working Memory	Keeping relevant information in your mind while performing tasks or thinking through problems. For this project, also includes references to “remembering” in general, since it can be difficult to tell the difference between long-term and working memory in the responses. Remembering a thought or idea long enough to write it down or otherwise use it.	<p>“knowledge distributed across multiple notes are difficult for me to remember/follow”</p> <p>“I mainly struggle with remembering what projects I'm currently working on or that they even exist”</p> <p>“in creative writing i drift from one thing to another too fast to get anything done, sometimes even failing to write any of the ideas down before im off down a different idea lane”</p>

C-3: PKM Techniques

Codes and descriptions based on Ness Labs (2020).

Code	Definition	Example
Augmented Content	Highlighting and note-taking directly on a piece of content; could be on a paper, in a PDF reader, or using an app to annotate web content.	“We highlight a lot. Color coding helps with establishing priority or indicating specific ideas or content of interest.”

Citation Management	Bibliographic management such as Zotero, Mendeley, EndNote.	“I have just discovered Obsidian and integrated Zotero. I almost cried with joy.”
Curation	Lists and/or collections of books/movies/articles/other media or items, selected and arranged by personal criteria.	“I make a lot of lists of movies/shows/books/podcasts/etc people recommend to me.”
Long-Term Notes	Note-taking, note-making, and note-management for long-term use (Examples: handwritten notes, notes organized and/or stored in Evernote, Obsidian, Notion, Google Docs, etc.).	“When I'm studying from a resource I'll take notes in Notion so that I can reference it again later.”
Project/Task Management	To do lists or project planning, on paper or in dedicated apps.	“Managing multiple work streams from multiple jobs, Managing delegation of tasks.”
Read-It-Later	Keeping a list of web content to read at a later time, can involve apps like Instapaper, Pocket, Feedly, Newsblur.	“The streak counter in Readwise is a helpful reminder to . . . read things from my backlog (in Zotero for scholarly papers, Matter for internet articles).”
Short-Term Notes	Note-taking for short-term use (Examples: post-it notes, some forms of bullet journaling, quickly captured notes in apps like Apple Notes, Google Keep, etc.)	“I also wish I could find a digital system that does the same thing as sticking a bunch of post-it notes on the wall.”
Synthetic Notes	Notes that combine ideas from multiple sources, used for creating new knowledge or content; usually involves linked notes and/or backlinking; frequently managed or created in Obsidian, Roam Research, Logseq, Evernote, etc.	“I save many articles & documents and create thematic vaults in Obsidian to uncover seemingly hidden connections and a richer understanding.”

Visual Thinking	Mind maps, flowcharts, sketchnoting, diagramming, either on paper or in an app.	“I like the visual note-taking aspects of a tool like Miro (diagrams, mind maps, and freehand drawing).”
Web Bookmarks	Browser bookmarks or a separate bookmarking app.	“Before I started using Notion, I had a bunch of disorganized bookmarks that made it hard to choose what to do next.”
Word Processing	Writing using a dedicated application for writing, such as Word, Google Docs, Scrivener, etc.	“I’ve leaned heavily and successfully on Scrivener for well-defined projects.”

C-4: Outcomes (Research Question 1)

Code	Definition	Example
Managing Tasks and Projects	Seeing tasks and projects to completion on time; balancing “fun” and “necessary” tasks; remembering what tasks and projects exist.	“I tend to forget to do stuff so if I keep notes I am more likely to remember to do those tasks.”
Building Knowledge	Learning about a defined goal and/or exploring an area of interest, often with the goal of developing new understanding or insight.	“I work in inspections and plan reviews for government agencies and saving information from a deep dive into a specific topic is very helpful for others.”
Creating	Producing outputs such as creative writing, game design, business reports, or software development.	“when it comes to creative projects it mainly serves as a repository / index of everything that I want to do or have ideas for creatively and then links out to pertinent items /

		inspiration / reference based on the project”
Self-Improvement	Engaging in tasks or projects of varying sizes to improve self-care or self-understanding.	“Instead of writing about my trauma essay-style, I am doing so wiki-style. Given the non-linear nature of my issues, this has been a boon for my healing.”

C-5: Activities (Research Question 2)

Code	Definition	Example
Storing Information and Using It Later	Writing down or tracking information and using it for future reference.	“Braindumping” “Long term information storage (both practical and less practical, driven by interests)”
Remembering What Needs to be Done	Simply being reminded of tasks and projects, e.g. by looking at a list; remembering where you are in a project when coming back to it.	“I can see all the projects I’m working on.” “They help me remember what’s important and to avoid forgetting a task.”
Understanding and Ideating	Using the process of organizing and writing notes to understand and develop concepts in new ways.	“Maintaining and developing ideas and references over long time periods, also developing research on non-active projects or projects at the conceptual stage - a sort of passive curiosity”
Planning and Prioritizing	Using PKM for planning time and work, choosing priorities to work on, project planning.	“Chunking large tasks into smaller ones with incremental deadlines” “Making sure that stuff that isn’t important or applicable right now

won't be forgotten and can be resurfaced when it's needed.”

“It helps me organize the tasks that need to get done and ‘sort’ them by urgency”

C-6: Benefits (Research Question 3)

Code	Definition	Example
Connecting Ideas	Finding relations between concepts and representing those connections in the PKM system.	“links between notes helps me tie together research and personal inquiry in ways that help me work over longer time periods without relying on short term memory of the material I've read or has been meaningful.”
Improving Thinking	Enhancing cognition by making thoughts seem physical or getting thoughts “out” of the mind and “putting them” somewhere else.	“I can’t think inside my mind but I am capable of brilliance once I can pour it out of my mind.”
Having Fun	Enjoying writing and organizing notes, “checking items off a list,” and/or developing the PKM system itself.	“I set up charts and tables to track purchases and components for my hobbies. I do this partly because I enjoy organizing information in this way.”

Appendix D: Summary of Survey Response Counts

Question	Responses
1. What is your employment status?	304
2. Please select the conditions that you identify with.	304
3. To what extent do you feel your neurodivergence affects your quality of life in the following areas?	
Academic	303
Everyday	303
Family	303
Health	302
Job	301
Leisure	302
Social	302
Other	61
4. How often do you engage in each of the following types of personal knowledge management activities for any reason (personal, educational, or professional)?	
Synthetic note-taking	304
Note-taking for long-term use	304
Note-taking for short-term use	304
Augmented content	304
Curation	302
Project/Task management	302
“Read-It-Later”	303
Reference/citation management	304

Visual thinking	304
Web bookmarks	301
Word Processing	304
5. To what extent do the personal knowledge management activities indicated in Question 4 affect your quality of life in the following areas?	
Academic	300
Everyday	303
Family	302
Health	303
Job	300
Leisure	302
Social	303
Other	53
6. How would you rate your skills in the following areas?	
Emotional control/regulation	303
Flexibility	301
Goal-directed persistence	302
Organization	303
Metacognition	302
Planning	303
Response inhibition	303
Sustained attention	303
Task initiation	302
Time management	303
Working memory	303
Continue to Part II	299
7. What are the goals or projects your note-taking activities help you work towards?	198

8. What are the problems or obstacles you face in achieving the goals and projects you listed in Question 7?	196
9. How do your note-taking activities help you in achieving the goals and projects you listed in Question 7?	196
10. If you could wave a magic wand, what would change or appear to help you achieve the goals and projects you listed in Question 7? (Your answer might or might not relate to note-taking.)	186
11. What is one piece of advice you would give to a neurodivergent person starting out with note-taking for personal knowledge management?	198

Appendix E: IRB Letter



1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE: August 8, 2022

TO: Kelly Hoffman, MLS
FROM: University of Maryland College Park (UMCP) IRB

PROJECT TITLE: [1438334-1] LIS Research and Neurodivergence: So Much Potential If We'd Just Apply Ourselves

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: August 8, 2022

REVIEW CATEGORY: Exemption category # 45CFR46.104(d)(2)(i)

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

References

- Advokat, C. (2009). What exactly are the benefits of stimulants for ADHD? *Journal of Attention Disorders*, 12(6), 495–498. <https://doi.org/10.1177/1087054708329781>
- Advokat, C., Lane, S. M., & Luo, C. (2011). College students with and without ADHD: Comparison of self-report of medication usage, study habits, and academic achievement. *Journal of Attention Disorders*, 15(8), 656–666. <https://doi.org/10.1177/1087054710371168>
- Akin, L., & O'Toole, E. (2000). The order of the public library and the disorder of attention deficit. *Public Library Quarterly*, 18(3–4), 69–80. https://doi.org/10.1300/J118v18n03_10
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th edition). American Psychiatric Association.
- Anderson, A. M. (2021a). Exploring the workforce experiences of autistic librarians through accessible and participatory approaches. *Library & Information Science Research*, 43(2), 101088. <https://doi.org/10.1016/j.lisr.2021.101088>
- Anderson, A. M. (2021b). Job seeking and daily workforce experiences of autistic librarians. *The International Journal of Information, Diversity, & Inclusion (IJIDI)*, 5(3), Article 3. <https://doi.org/10.33137/ijidi.v5i3.36196>
- Arnold, L. E., Hodgkins, P., Kahle, J., Madhoo, M., & Kewley, G. (2020). Long-term outcomes of ADHD: Academic achievement and performance. *Journal of Attention Disorders*, 24(1), 73–85. <https://doi.org/10.1177/1087054714566076>

- Astle, D. E., Holmes, J., Kievit, R., & Gathercole, S. E. (2021). Annual research review: The transdiagnostic revolution in neurodevelopmental disorders. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*. <https://doi.org/10.1111/jcpp.13481>
- ATLAS.ti. (n.d.). *Code co-occurrence coefficient*. ATLAS.Ti 9 Mac - User Manual. Retrieved March 30, 2023, from <https://doc.atlasti.com/ManualMac.v9/CodeCooccurrence/CodeCoOccurrenceTableCcoefficient.html>
- Baeyens, D. (2021). Effectiveness of reasonable accommodations in students with ADHD: an experimental and intervention study. *PEDAGOGISCHE STUDIËN*, 2021(98), 268–284.
- Baggetta, P., & Alexander, P. A. (2016). Conceptualization and operationalization of executive function. *Mind, Brain, and Education*, 10(1), 10–33. <https://doi.org/10.1111/mbe.12100>
- Barbarese, W. J., Katusic, S. K., Colligan, R. C., Weaver, A. L., & Jacobsen, S. J. (2007). Long-term school outcomes for children with attention-deficit/hyperactivity disorder: A population-based perspective. *Journal of Developmental & Behavioral Pediatrics*, 28(4), 265–273. <https://doi.org/10.1097/DBP.0b013e31811ff87d>
- Barreau, D. (1995). Context as a factor in personal information management systems. *Journal of the American Society for Information Science*, 46(5), 327–339. [https://doi.org/10.1002/\(SICI\)1097-4571\(199506\)46:5<327::AID-ASI4>3.0.CO;2-C](https://doi.org/10.1002/(SICI)1097-4571(199506)46:5<327::AID-ASI4>3.0.CO;2-C)
- Barreau, D., & Nardi, B. A. (1995). Finding and reminding: File organization from the desktop. *SIGCHI Bull.*, 27(3), 39–43. <https://doi.org/10.1145/221296.221307>
- [BasedJoey_]. (2014, October 8). *You really need to start applying yourself* [Reddit Post]. R/ADHD.

www.reddit.com/r/ADHD/comments/2ime0f/you_really_need_to_start_applying_yoursel
f/

Behrens, S. J. (1994). A conceptual analysis and historical overview of information literacy.

College & Research Libraries, 55(4), 309–322. https://doi.org/10.5860/crl_55_04_309

Bellotti, V., Ducheneaut, N., Howard, M., Smith, I., & Grinter, R. E. (2005). Quality Versus

Quantity: E-Mail-Centric Task Management and Its Relation With Overload. *Human-Computer Interaction*, 20, 89–138.

Bental, B., & Tirosh, E. (2007). The relationship between attention, executive functions and reading domain abilities in attention deficit hyperactivity disorder and reading disorder:

A comparative study. *Journal of Child Psychology and Psychiatry*, 48(5), 455–463.

<https://doi.org/10.1111/j.1469-7610.2006.01710.x>

Blase, S. L., Gilbert, A. N., Anastopoulos, A. D., Costello, E. J., Hoyle, R. H., Swartzwelder, H.

S., & Rabiner, D. L. (2009). Self-reported ADHD and adjustment in college: Cross-sectional and longitudinal findings. *Journal of Attention Disorders*, 13(3), 297–309.

<https://doi.org/10.1177/1087054709334446>

Bolourian, Y., Zeedyk, S. M., & Blacher, J. (2018). Autism and the University Experience:

Narratives from Students with Neurodevelopmental Disorders. *Journal of Autism and*

Developmental Disorders, 48(10), 3330–3343. [https://doi.org/10.1007/s10803-018-3599-](https://doi.org/10.1007/s10803-018-3599-5)

5

Borson, B. (2018). PICTURE THIS: “Sketchnoting”--taking notes through focused drawing--

can help students with autism assimilate new information in organically differentiated ways. *Educational Leadership*, 76(4), 34–39.

<https://search.ebscohost.com/login.aspx?direct=true&db=asn&AN=133489095&site=ehost-live>

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

Brookman-Byrne, A. (2022, January 27). Our changing understanding of neurodivergence. *BOLD*. <https://bold.expert/our-changing-understanding-of-neurodivergence/>

Buschman, J. (2009). Information literacy, “new” literacies, and literacy. *The Library Quarterly*, 79(1), 95–118. <http://www.journals.uchicago.edu/doi/abs/10.1086/593375>

Buschman, J. (2017). November 8, 2016: Core values, bad faith, and democracy. *The Library Quarterly*, 87(3), 277–286. <https://doi.org/10.1086/692305>

Carter, S. L. (2018). *Impairment, disability and handicap*. Emory University School of Medicine.
<https://med.emory.edu/departments/pediatrics/divisions/neonatology/dpc/impairment-mx.html>

CHADD. (2018, October 4). More fire than water: A short history of adhd. *CHADD*.
<https://chadd.org/adhd-weekly/more-fire-than-water-a-short-history-of-adhd/>

CHADD. (n.d.). *ADHD and coexisting conditions [infographic]*. CHADD.
https://d393uh8gb46l22.cloudfront.net/wp-content/uploads/2020/06/ADHD_and_Coexisting_Conditions.pdf

Charitaki, G., Soulis, S.-G., & Tyropoli, R. (2021). Academic self-regulation in autism spectrum disorder: A principal components analysis. *International Journal of Disability*,

Development and Education, 68(1), 26–45.

<https://doi.org/10.1080/1034912X.2019.1640353>

[cheezy_tater]. (2022, January 13). *JUsT aPpLy YoUrSeLf*. TikTok.

https://www.tiktok.com/@cheezy_tater/video/7052721716090424622

Clarke, V., & Braun, V. (2014). Thematic analysis. In A. C. Michalos (Ed.), *Encyclopedia of Quality of Life and Well-Being Research* (pp. 6626–6628). Springer Netherlands.

https://doi.org/10.1007/978-94-007-0753-5_3470

Coetzer, G. (2016). An empirical examination of the mediating influence of time management on the relationship between adult attention deficit and role stress. *Personnel Review*, 45(4), 681–706. <https://doi.org/10.1108/PR-04-2015-0105>

Coetzer, Graeme. H., & Richmond, L. (2009). An empirical examination of the relationships between adult attention deficit, personal task management systems and role stress. *Journal of Behavioral and Applied Management*, 10(2), 206–226.

<http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2011-25913-003&site=ehost-live>

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. SAGE.

Dalton, N. S. (2013). Neurodiversity & HCI. *CHI '13 Extended Abstracts on Human Factors in Computing Systems*, 2295–2304. <https://doi.org/10.1145/2468356.2468752>

Danielson, M. L., Bitsko, R. H., Ghandour, R. M., Holbrook, J. R., Kogan, M. D., & Blumberg, S. J. (2018). Prevalence of parent-reported ADHD diagnosis and associated treatment

- among U.S. children and adolescents, 2016. *Journal of Clinical Child & Adolescent Psychology*, 47(2), 199–212. <https://doi.org/10.1080/15374416.2017.1417860>
- Davis, L. J. (2011, September 25). Why is disability missing from the discourse on diversity? *The Chronicle of Higher Education*. <https://www.chronicle.com/article/why-is-disability-missing-from-the-discourse-on-diversity/>
- Dawson, P., & Guare, R. (2010). *Executive skills in children and adolescents: A practical guide to assessment and intervention* (Second). Guilford Press.
- Dervin, B. (1992). From the mind's eye of the user: The sense-making qualitative- quantitative methodology. In *Qualitative research in information management* (pp. 61–84). Libraries Unlimited.
- Dervin, B. (1998). Sense-making theory and practice: An overview of user interests in knowledge seeking and use. *Journal of Knowledge Management*, 2(2), 36–46. <https://doi.org/10.1108/13673279810249369>
- Dervin, B. (2000). Chaos, order, and sense-making: A proposed theory for information design. In R. Jacobson (Ed.), *Information Design*. MIT Press.
- Dervin, B., & Naumer, C. M. (2017). Sense-making. In J. D. McDonald & M. Levine-Clark (Eds.), *Encyclopedia of Library and Information Science, Fourth Edition* (0 ed., pp. 4113–4124). CRC Press. <https://doi.org/10.1081/E-ELIS4-120043227>
- Douglass, K., & Mehra, B. (2016). A four frames analysis to address the information challenges of families of children with adhd: Actions for public libraries to address embedded power imbalances. *Libri*, 66(1). <https://doi.org/10.1515/libri-2015-0078>

- Dror, I. E., Makany, T., & Kemp, J. (2011). Overcoming learning barriers through knowledge management. *Dyslexia (10769242)*, 17(1), 38–47. <https://doi.org/10.1002/dys.419>
- DuPaul, G. J., Weyandt, L. L., O'Dell, S. M., & Varejao, M. (2009). College students with ADHD: Current status and future directions. *Journal of Attention Disorders*, 13(3), 234–250. <https://doi.org/10.1177/1087054709340650>
- Eng, A. (2017, June 28). Neurodiversity in the library: One librarian's experience. *In the Library With the Lead Pipe*. <https://www.aane.org/neurodiversity-library-one-librarians-experience/>
- Evans, S., Raggi, V., & Paolitto, A. (2002). School-based treatment of adolescents with adhd. *ADHD Report*, 10(2), 10–11. <https://doi.org/10.1521/adhd.10.2.10.20564>
- Evans, S. W., Langberg, J. M., Schultz, B. K., Vaughn, A., Altaye, M., Marshall, S. A., & Zoromski, A. K. (2016). Evaluation of a school-based treatment program for young adolescents with ADHD. *Journal of Consulting and Clinical Psychology*, 84, 15–30. <https://doi.org/10.1037/ccp0000057>
- Evans, S. W., Pelham, W., & Grudberg, M. V. (1994). The efficacy of notetaking to improve behavior and comprehension of adolescents with attention deficit hyperactivity disorder. *Exceptionality*, 5(1), 1–17. https://doi.org/10.1207/s15327035ex0501_1
- Eysenbach, E. (2004). Improving the quality of web surveys: The checklist for reporting results of internet e-surveys (CHERRIES). *Journal of Medical Internet Research*, 6(3).
- Fast, S. (2020, October 27). *Introduction to the Zettelkasten method*. Zettelkasten Method. <https://zettelkasten.de/introduction/>

- Feng, Y., & Agosto, D. E. (2019). Revisiting personal information management through information practices with activity tracking technology. *Journal of the Association for Information Science and Technology*, 70(12), 1352–1367.
<https://doi.org/10.1002/asi.24253>
- Fenton, A. (2007). Autism, neurodiversity and equality beyond the ‘normal.’ *Journal of Ethics in Mental Health*, 2(2), 1–6.
- Fertig, S., Freeman, E., & Gelernter, D. (1996). “Finding and reminding” reconsidered. *SIGCHI Bulletin*, 28(1). <http://cpsc.yale.edu/sites/default/files/files/tr1090.pdf>
- Fleischmann, A., & Fleischmann, R. H. (2012). Advantages of an ADHD Diagnosis in Adulthood: Evidence From Online Narratives. *Qualitative Health Research*, 22(11), 1486–1496. <https://doi.org/10.1177/1049732312457468>
- Fletcher, J. (2013). *The effects of childhood ADHD on adult labor market outcomes* (Working Paper No. 18689; p. 39). National Bureau of Economic Research.
<http://www.nber.org/papers/w18689>
- Fletcher-Watson, S. (2022). Transdiagnostic research and the neurodiversity paradigm: Commentary on the transdiagnostic revolution in neurodevelopmental disorders by Astle et al. *Journal of Child Psychology and Psychiatry*, 63(4), 418–420.
<https://doi.org/10.1111/jcpp.13589>
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943–953.
<https://doi.org/10.1177/1362361318786721>

- Flores, J., Caqueo-Úrizar, A., López, V., & Acevedo, D. (2022). Symptomatology of attention deficit, hyperactivity and defiant behavior as predictors of academic achievement. *BMC Psychiatry*, 22(1), Article 1. <https://doi.org/10.1186/s12888-022-03714-8>
- Forte, T. (2022). *Building a second brain: A proven method to organize your digital life and unlock your creative potential*. Simon and Schuster.
- Forte, T. (Director). (2019, March 10). *Building a second brain: Capturing, organizing, and sharing knowledge using digital notes*.
<https://www.youtube.com/watch?v=SjZSy8s2VEE>
- Forte, T., Poulin, M., Anderson, J. J., & Jenks, B. (2022, March 24). *The ADHD Notetaker / Second Brain Summit 2022 / Marie Poulin, Jesse J. Anderson, Bryan Jenks*.
https://www.youtube.com/watch?v=7BfxRsW_Ezw
- Frاند, J. L., & Hixson, C. (1998, October 15). *Personal knowledge management: Who? What? Why? When? Where? How?* Educom 98.
<https://scholarsbank.uoregon.edu/xmlui/bitstream/handle/1794/24358/PersonalKnowledgePKM1.pdf?sequence=1&isAllowed=y>
- Frazier, T. W., Youngstrom, E. A., Glutting, J. J., & Watkins, M. W. (2007). ADHD and achievement: Meta-analysis of the child, adolescent, and adult literatures and a concomitant study with college students. *Journal of Learning Disabilities*, 40(1), 49–65.
<https://doi.org/10.1177/00222194070400010401>
- Frick, K. (2018, August 10). Sensory storytime: Tips and tricks for a successful program. *ALSC Blog*. <https://www.alsc.ala.org/blog/2018/08/sensory-storytime-tips-and-tricks-for-a-successful-program/>

- General Services Administration. (2020). *Data ethics framework*. GSA.
<https://resources.data.gov/assets/documents/fds-data-ethics-framework.pdf>
- Grandin, T. (1995). How People with Autism Think. In E. Schopler & G. B. Mesibov (Eds.), *Learning and Cognition in Autism* (pp. 137–156). Springer US.
https://doi.org/10.1007/978-1-4899-1286-2_8
- Grandin, T. (2006). *Thinking in pictures: And other reports from my life with autism*. Bloomsbury.
- Gray, S. A., Fettes, P., Woltering, S., Mawjee, K., & Tannock, R. (2016). Symptom manifestation and impairments in college students with adhd. *Journal of Learning Disabilities*, 49(6), 616–630. <https://doi.org/10.1177/0022219415576523>
- Gröpel, P. (2005). *On the theory of life balance: The relation to subjective well-being and the role of self-regulation* [Doctoral dissertation, University of Trnava].
https://osnadoes.ub.uni-osnabrueck.de/bitstream/urn:nbn:de:gbv:700-2005102518/2/E-Diss461_thesis.pdf
- Gröpel, P., & Kuhl, J. (2006). Having time for life activities: Life balance and self-regulation. *Zeitschrift Für Gesundheitspsychologie*, 14(2), 54–63. <https://doi.org/10.1026/0943-8149.14.2.54>
- Grundspenkis, J. (2007). Agent based approach for organization and personal knowledge modelling: Knowledge management perspective. *Journal of Intelligent Manufacturing*, 18(4), 451–457. <https://doi.org/10.1007/s10845-007-0052-6>
- Guldborg, K., Parsons, S., Porayska-Pomsta, K., & Keay-Bright, W. (2017). Challenging the knowledge-transfer orthodoxy: Knowledge co-construction in technology-enhanced

- learning for children with autism. *British Educational Research Journal*, 43(2), 394–413.
<https://doi.org/10.1002/berj.3275>
- Hall, J., & Stewart, M. E. (2010). Basic psychology. In E. C. Johnstone, D. C. Owens, S. M. Lawrie, A. M. McIntosh, & M. Sharpe (Eds.), *Companion to Psychiatric Studies (Eighth Edition)* (pp. 95–108). Churchill Livingstone. <https://doi.org/10.1016/B978-0-7020-3137-3.00005-X>
- Halmøy, A., Fasmer, O. B., Gillberg, C., & Haavik, J. (2009). Occupational outcome in adult ADHD: Impact of symptom profile, comorbid psychiatric problems, and treatment: a cross-sectional study of 414 clinically diagnosed adult ADHD patients. *Journal of Attention Disorders*, 13(2), 175–187. <https://doi.org/10.1177/1087054708329777>
- Harrison, J. R., Evans, S. W., Baran, A., Khondker, F., Press, K., Noel, D., Wasserman, S., Belmonte, C., & Mohlmann, M. (2020). Comparison of accommodations and interventions for youth with ADHD: A randomized controlled trial. *Journal of School Psychology*, 80, 15–36. <https://doi.org/10.1016/j.jsp.2020.05.001>
- Harvey, A. G. (Ed.). (2004). *Cognitive behavioural processes across psychological disorders: A transdiagnostic approach to research and treatment*. Oxford University Press.
- Hickey, K., Golden, T., & Thomas, A. (2018). Sensory play in libraries: A survey of different approaches. *Children and Libraries*, 16(3), Article 3. <https://doi.org/10.5860/cal.16.3.18>
- Holmes, D., & Gary, A. (2020). Researcher positionality—A consideration of its influence and place in qualitative research—A new researcher guide. *Shanlax International Journal of Education*, 8(4), 1–10. <https://doi.org/10.34293/education.v8i4.3232>

- IDIC. (n.d.). In *Memory Alpha*. Retrieved March 30, 2023, from <https://memory-alpha.fandom.com/wiki/IDIC>
- [igotsmeakabob11]. (2023, February 25). *If only you 'd apply yourself!* [Reddit Post]. R/Adhdmeme.
www.reddit.com/r/adhdmeme/comments/11bovxa/if_only_you_d_apply_yourself/
- Janssen, A., Huang, H., & Duncan, C. (2016). Gender Variance Among Youth with Autism Spectrum Disorders: A Retrospective Chart Review. *Transgender Health, 1*(1), 63–68.
<https://doi.org/10.1089/trgh.2015.0007>
- Jenks, B. (Director). (2020, October 5). *My 2020 comprehensive Obsidian workflow for Zettelkasten and evergreen notes*. <https://www.youtube.com/watch?v=Ewhfok91AdE>
- Jones, S. R., & Thomas, P. J. (1997). Empirical assessment of individuals’ “personal information management systems.” *Behaviour & Information Technology, 16*(3), 158–160.
<https://doi.org/10.1080/014492997119888>
- Jones, W. (2007). Personal Information Management. *Annual Review of Information Science and Technology, 41*(1), 453–504. <https://doi.org/10.1002/aris.2007.1440410117>
- Jones, W. (2008). *Keeping found things found: The study and practice of personal information management*. Morgan Kaufmann. <http://web.b.ebscohost.com.proxy-um.researchport.umd.edu/ehost/ebookviewer/ebook/bmxlYmtfXzIxMTQ0OF9fQU41?siid=6d7acbe7-a0eb-4f1c-bfe8-eef6c0d26974@pdc-v-sessionmgr03&vid=0&format=EB&rid=1>
- Jones, W., Dumais, S., & Bruce, H. (2002). Once found, what then? A study of “keeping” behaviors in the personal use of Web information. *Proceedings of the American Society*

for Information Science and Technology, 39(1), 391–402.

<https://doi.org/10.1002/meet.1450390143>

Kandiko, C., Hay, D., & Weller, S. (2013). Concept mapping in the humanities to facilitate reflection: Externalizing the relationship between public and personal learning. *Arts and Humanities in Higher Education*, 12(1), 70–87.

<https://doi.org/10.1177/1474022211399381>

Kaye, J. “Jofish,” Vertesi, J., Avery, S., Dafoe, A., David, S., Onaga, L., Rosero, I., & Pinch, T. (2006). To Have and to Hold: Exploring the Personal Archive. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 275–284.

<https://doi.org/10.1145/1124772.1124814>

Klingsieck, K. B. (2013). Procrastination in Different Life-Domains: Is Procrastination Domain Specific? *Current Psychology*, 32(2), 175–185. [https://doi.org/10.1007/s12144-013-9171-](https://doi.org/10.1007/s12144-013-9171-8)

8

Lansdale, M. W. (1988). The psychology of personal information management. *Applied Ergonomics*, 19(1), 55–66. [https://doi.org/10.1016/0003-6870\(88\)90199-8](https://doi.org/10.1016/0003-6870(88)90199-8)

Lapalme, M., Déry, M., Dubé, M., & Lemieux, A. (2018). Developmental course of ADHD symptoms based on multirater report in girls and boys with or without a disruptive behavior disorder. *Journal of Emotional and Behavioral Disorders*, 26(2), 106–118.

<https://doi.org/10.1177/1063426617712500>

LaPierre, S. S., & Kitzie, V. (2019). “Lots of Questions about ‘Fake News’”: How Public Libraries Have Addressed Media Literacy, 2016–2018. *Public Library Quarterly*, 0(0), 1–25. <https://doi.org/10.1080/01616846.2019.1600391>

- Lawrence, E. (2013). Loud hands in the library: Neurodiversity in LIS theory and practice. *Progressive Librarian*, 2013(41), 98–109.
- Legg, H., Tickle, A., Gillott, A., & Wilde, S. (2023). Exploring the Experiences of Parents Whose Child has Received a Diagnosis of Autistic Spectrum Disorder in Adulthood. *Journal of Autism & Developmental Disorders*, 53(1), 205–215.
<https://doi.org/10.1007/s10803-021-05296-y>
- Lorde, A. (2018). *The master's tools will never dismantle the master's house*. Penguin Books Limited.
- Lorenz, T., Reznik, N., & Heinitz, K. (2017). A different point of view: The neurodiversity approach to autism and work. In M. Fitzgerald & J. Yip (Eds.), *Autism paradigms, recent research and clinical applications*. IntechOpen.
<https://www.intechopen.com/books/autism-paradigms-recent-research-and-clinical-applications/a-different-point-of-view-the-neurodiversity-approach-to-autism-and-work>
- MacLeod, A., Allan, J., Lewis, A., & Robertson, C. (2018). 'Here I come again': The cost of success for higher education students diagnosed with autism. *International Journal of Inclusive Education*, 22(6), 683–697. <https://doi.org/10.1080/13603116.2017.1396502>
- Merriam-Webster. (n.d.). *Academic*. Retrieved March 12, 2023, from <https://www.merriam-webster.com/dictionary/academic>
- Micallef, P. (Director). (2022, April 28). *How to talk respectfully about autism (person-first language vs identity-first)*. <https://www.youtube.com/watch?v=RpRhgfRfXBM>

- Mortimore, T., & Crozier, R. (2006). Dyslexia and difficulties with study skills in higher education. *Studies in Higher Education*, 31(2), 235–251. <https://doi.org/DOI:10.1080/03075070600572173>
- Naumer, C., Fisher, K., & Dervin, B. (2008, April 6). Sense-Making: A methodological perspective. *CHI 2008*. ACM SIG CHI Conference, Florence: Italy.
- Ness Labs. (2020). *The state of personal knowledge management: 2020*. Ness Labs.
- Nind, M. (2011). Participatory data analysis: A step too far? *Qualitative Research*, 11(4), 349–363. <https://doi.org/10.1177/1468794111404310>
- Norris, J. E., & Maras, K. (2022). Supporting autistic adults’ episodic memory recall in interviews: The role of executive functions, theory of mind, and language abilities. *Autism*, 26(2), 513–524. <https://doi.org/10.1177/13623613211030772>
- Oliver, M. (2017). Defining impairment and disability: Issues at stake. In C. Barnes & G. Mercer (Eds.), *Disability and Equality Law* (1st ed., pp. 29–54). The Disability Press. <https://doi.org/10.4324/9781315094861-2>
- Pollard, D. (2008). PKM: A bottom-up approach to knowledge management. In Taverékere Srikantaiah & Michael E D Koenig (Eds.), *Knowledge management in practice: Connections and context*. <https://www.econbiz.de/Record/pkm-a-bottom-up-approach-to-knowledge-management-pollard-dave/10003708763>
- Queensland Brain Institute. (2016, December 2). *Types of memory*. <https://qbi.uq.edu.au/brain-basics/memory/types-memory>

Rabiner, D. L., Anastopoulos, A. D., Costello, J., Hoyle, R. H., & Swartzwelder, H. S. (2008).

Adjustment to College in Students With ADHD. *Journal of Attention Disorders*, 11(6), 689–699. <https://doi.org/10.1177/1087054707305106>

Razmerita, L., Kirchner, K., & Sudzina, F. (2009). Personal knowledge management: The role of

Web 2.0 tools for managing knowledge at individual and organisational levels. *Online Information Review*, 33(6), 1021–1039. <https://doi.org/10.1108/14684520911010981>

Reed, D. K., Hallett, A., & Rimel, H. (2016). Note-taking instruction for college students with autism spectrum disorder. *Exceptionality*, 24(4), 195–212.

<https://doi.org/10.1080/09362835.2015.1107833>

Schneegass, C., Wojcicki, Y., & Niforatos, E. (2021). Design for Long-term Memory

Augmentation in Personal Knowledge Management Applications. *12th Augmented Human International Conference*, 1–5. <https://doi.org/10.1145/3460881.3460931>

Seiwert, L. J. (2005). *Wenn du es eilig hast, gehe langsam: Mehr Zeit in einer beschleunigten Welt*. Campus Verlag.

sherlocksflataffect. (2015, June 11). PSA from the actual coiner of “neurodivergent” [Tumblr].

Tumblr. <https://sherlocksflataffect.tumblr.com/post/121295972384/psa-from-the-actual-coiner-of-neurodivergent>

Sibley, M. H., Coxe, S. J., Campey, M., Morley, C., Olson, S., Hidalgo-Gato, N., Gnagy, E.,

Greiner, A., Coles, E. K., Page, T., & Pelham, W. E. (2018). High versus Low Intensity Summer Treatment for ADHD Delivered at Secondary School Transitions. *Journal of Clinical Child & Adolescent Psychology*, 47(2), 248–265.

<https://doi.org/10.1080/15374416.2018.1426005>

- Sinclair, J. (2012). Don't mourn for us. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(1).
- Singer, J. (2016). *Neurodiversity: The birth of an idea*. Judy Singer.
- Skodzik, T., Holling, H., & Pedersen, A. (2017). Long-Term Memory Performance in Adult ADHD: A Meta-Analysis. *Journal of Attention Disorders*, 21(4), 267–283.
<https://doi.org/10.1177/1087054713510561>
- Solomon, A. (2012). *Far from the tree: Parents, children, and the search for identity*. Scribner.
- Spiel, K., Hornecker, E., Williams, R. M., & Good, J. (2022). ADHD and technology research – Investigated by neurodivergent readers. *CHI Conference on Human Factors in Computing Systems*, 1–21. <https://doi.org/10.1145/3491102.3517592>
- St. Jean, B. (2012). *Information behavior of people diagnosed with a chronic serious health condition: A longitudinal study* [Doctoral dissertation, University of Michigan].
https://deepblue.lib.umich.edu/bitstream/handle/2027.42/91570/bstjean_1.pdf?sequence=1
- St. Jean, B. (2017). Factors motivating, demotivating, or impeding information seeking and use by people with type 2 diabetes: A call to work toward preventing, identifying, and addressing incognizance. *Journal of the Association for Information Science and Technology*, 68(2), 309–320. <https://doi.org/10.1002/asi.23652>
- St. Jean, B., Greene Taylor, N., Kodama, C., & Subramaniam, M. (2017). Assessing the digital health literacy skills of tween participants in a school-library-based after-school program. *Journal of Consumer Health on the Internet*, 21(1), 40–61.

- St. Jean, B., Rieh, S. Y., Kim, Y.-M., & Yang, J. Y. (2012). An analysis of the information behaviors, goals, and intentions of frequent Internet users: Findings from online activity diaries. *First Monday*. <https://doi.org/10.5210/fm.v17i2.3870>
- Strang, J. F., Kenworthy, L., Dominska, A., Sokoloff, J., Kenealy, L. E., Berl, M., Walsh, K., Menvielle, E., Slesaransky-Poe, G., Kim, K.-E., Luong-Tran, C., Meagher, H., & Wallace, G. L. (2014). Increased Gender Variance in Autism Spectrum Disorders and Attention Deficit Hyperactivity Disorder. *Archives of Sexual Behavior*, 43(8), 1525–1533. <https://doi.org/10.1007/s10508-014-0285-3>
- Study skills boost for students who have dyslexia. (2009). *Nursing Standard*, 23(42), 11–11. <https://doi.org/10.7748/ns.23.42.11.s19>
- Tumlin, Z. (2019). “This is a quiet library, except when it’s not:” On the lack of neurodiversity awareness in librarianship. *Music Reference Services Quarterly*, 22(1–2), 3–17. <https://doi.org/10.1080/10588167.2019.1575017>
- Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., Mallon, B., & Ledger, T. (2017). ‘I think autism is like running on Windows while everyone else is a Mac’: Using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university. *Educational Action Research*, 25(2), 300–315. <https://doi.org/10.1080/09650792.2016.1153978>
- Vitale, F., Janzen, I., & McGrenere, J. (2018). Hoarding and Minimalism: Tendencies in Digital Data Preservation. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, 1–12. <https://doi.org/10.1145/3173574.3174161>
- Walker, N. (2021a). *Neuroqueer heresies*. Autonomous Press.

Walker, N. (2021b, August 1). *Neurodiversity: Some basic terms & definitions*.

<https://neuroqueer.com/neurodiversity-terms-and-definitions/>

Walker, N. (2021c, August 1). Throw away the master's tools: Liberating ourselves from the

pathology paradigm. *Neuroqueer*. <https://neuroqueer.com/throw-away-the-masters-tools/>

Walker, N., & Raymaker, D. M. (2021). Toward a neuroqueer future: An interview with Nick

Walker. *Autism in Adulthood*, 3(1), 5–10. <https://doi.org/10.1089/aut.2020.29014.njw>

Warren, T. (2004). Working part-time: Achieving a successful 'work-life' balance? *The British*

Journal of Sociology, 55(1), 99–122. <https://doi.org/10.1111/j.1468-4446.2004.00008.x>

White, M. (n.d.). *The master's tools: The wisdom of Audre Lorde*. Activist School.

<https://www.activistgraduateschool.org/on-the-masters-tools>

Whittaker, S., & Sidner, C. (1996). Email overload: Exploring personal information management

of email. *Proceedings of the SIGCHI Conference on Human Factors in Computing*

Systems Common Ground - CHI '96, 276–283. <https://doi.org/10.1145/238386.238530>

Williams, D. L., Goldstein, G., & Minshew, N. J. (2006). The Profile of Memory Function in

Children With Autism. *Neuropsychology*, 20(1), 21–29. [https://doi.org/10.1037/0894-](https://doi.org/10.1037/0894-4105.20.1.21)

[4105.20.1.21](https://doi.org/10.1037/0894-4105.20.1.21)

Wilson, S. (2003). A relational model of disability. In S. Wilson, *Disability, Counselling and*

Psychotherapy (pp. 19–40). Macmillan Education UK. [https://doi.org/10.1007/978-0-](https://doi.org/10.1007/978-0-230-21450-7_2)

[230-21450-7_2](https://doi.org/10.1007/978-0-230-21450-7_2)

World Health Organization. (n.d.). Neurodevelopmental disorders. In *ICD-11 for Mortality and*

Morbidity Statistics. <http://id.who.int/icd/entity/1516623224>

Young, S., Adamo, N., Ásgeirsdóttir, B. B., Branney, P., Beckett, M., Colley, W., Cubbin, S.,
Deeley, Q., Farrag, E., Gudjonsson, G., Hill, P., Hollingdale, J., Kilic, O., Lloyd, T.,
Mason, P., Paliokosta, E., Perecherla, S., Sedgwick, J., Skirrow, C., ... Woodhouse, E.
(2020). Females with ADHD: An expert consensus statement taking a lifespan approach
providing guidance for the identification and treatment of attention-deficit/ hyperactivity
disorder in girls and women. *BMC Psychiatry*, 20(1), 404.
<https://doi.org/10.1186/s12888-020-02707-9>