**Writing after Aphasia: Toward an Embodied Theory of Literacy**

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**Abstract**

This dissertation uses qualitative, empirical methods to update theories of literacy to account for the experiences of people with aphasia, or language disability caused by stroke or other brain injury. Aphasia reveals how bodily change affects literacy, nuancing how rhetoric, composition, and literacy studies understand the body's ever-present role in reading and writing. Specifically, this study contributes a much-needed disability perspective, exposing how the material, bodily, and social aspects of literacy intertwine and often conflict for readers and writers.

Drawing on disability theory and the experiences of people with aphasia, I argue for an embodied theory of literacy, one that foregrounds 1) the often invisible role of the body and 2) expands our view of literacy as a process in which individuals must negotiate the needs of their bodies with the materials of reading and writing, all against a backdrop of social values delimiting what it means to be or not be literate.

To develop this theory, I conducted 17 in-depth literacy history interviews and participant observation in a semester-long multimodal memoir composing group for 10 people with aphasia. Throughout my analyses, I track how individuals with aphasia read and write before and after aphasia, what challenges they encounter, what strategies they develop, how they reconcile with changes to their literate practices and identities, and what their experiences have to tell us about literacy more broadly.

Building an embodied theory of literacy, each chapter focuses on a different facet of how bodily change affects literate practice and identity—and how individuals negotiate that change. Chapter 1 links disability and literacy studies. Chapter 2 elaborates upon the study's design: 1) focusing on direct observation and life-history interviewing, and 2) foregrounding accessibility

in data collection and analysis. Chapter 3 explores the relationship between bodies and materials, developing a theory of "literate misfitting." Chapter 4 shows the enduring pressure of social values on bodies, and Chapter 5 features how people with aphasia in a multimodal composing group rework social norms around literacy to support the needs of their bodies. I close by reviewing primary findings and contributions for literacy theory and teaching.

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# Chapter 1

## Introduction: Aphasia, Disability, and an Embodied Theory of Literacy

*"I think it's not being able to do it. You know, it's like your whole life is gone, especially being a teacher. I mean, I couldn't do what I could do before."— Jean*

*"I've always felt like I've been a child since the stroke. And basically we're talking about skills. Skills of reading, skills of writing. And, you know, I am always aware that this, these are skills and they can be built up." — Rose*

*"Yeah. It's hard reading. You aren't getting the. One last.... What did I read again? It's hard to read like reading with you don't hear it. You read it. And then wait, what did he say? Hearing I remember what. You know he's. I'm like paper and pens and reading. And I'm like what happened. I'm just reading because I read it. I don't know. And then all of a sudden it's like, Oh, what? Oh, shoot." — Melissa*

*"I did, I tried to, [mimes reading] I can't do it. I can't read it. Read it here, can't here. I can say the [something] I can say, but that didn't." — Rob*

*"I wrote my name and I wrote my address, and I wish I could find the pieces of paper. I wrote very making mistakes and I wrote. Unbelievable. Unbelievable. They seem not letters. It looks like hieroglyphics."— Andrea*

*"That is one thing that determined that there was something wrong because I would read sometimes at night or whatever, during the day, and I got up in the morning and I went to read and I could see the words and I could see that they made sentences, but none of it made any sense. And so I tried to force myself to read and then the front of my brain actually started to hurt." — John*

*"I left the writing behind, you know?" — Judy*

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Reading and writing after aphasia is, as Melissa says above, hard. Aphasia is, by definition, a variety of difficulties generating and comprehending language—in speech, writing, and reading—caused by stroke or other brain injury. Reading and writing, indeed, is hard. Handwriting transforms to "hieroglyphics." Brains "hurt." Trains of thought fall away and into confusion. These changes affect individuals' understanding of their roles as teachers, daughters, and even as adults. Some practice literate skills, viewing literacy as something that "can be built

up." Others, like Judy, decide to leave it behind.

In this dissertation, I look at the struggles and successes of people who negotiate reading and writing after aphasia. Drawing from the experiences of Judy, Melissa, and others, my dissertation uses qualitative, empirical methods to update theories of literacy to account for the experiences of people with aphasia. The past several decades of research in rhetoric, composition, and literacy studies have established literacy as a multifaceted, ecological practice. Various strands of research separately explore literacy as social and cultural—used for particular purposes in certain contexts; material—facilitated by tools such as pencils, keyboards, and the Internet; embodied and cognitive—grounded in the processes and actions of the bodies and minds of readers and writers. I join this work by foregrounding the role of the body in literate practice. To do so, I draw on central insights from disability theory and from the experiences of people with aphasia. Ultimately, I argue for an embodied theory of literacy, one that foregrounds 1) the often invisible role of the body and 2) expands our view of literacy as a process in which individuals must always negotiate the needs of their bodies with the materials of reading and writing, all against a backdrop of social values delimiting what it means to be or not be literate.

Disability and aphasia in particular are generative sites for considering the role of the body in literacy. For the millions of people with aphasia, disability has real consequences for daily life, for conceptions of identity, and for reading and writing (Shadden; Shadden & Hagstrom; Garcia Obregon; Parr). An acquired disability, aphasia is most commonly caused when a clot blocks blood supply to, or an aneurysm creates bleeding in, the brain. The effects of aphasia also vary widely in severity, from global aphasia, which renders all spoken language impossible to understand or to generate, to more minor word-finding issues that may be perceptible only to the individual affected. While such language disruptions radically affect

communication, Parr et al assert that "[a]phasia damages the lines of communication going in and out, not the thought, intelligence and experience of the person" (5). Still, they note that language and intelligence tend to be understood as one and the same, making aphasia "hard to grasp, especially in a society that places value on the ability to communicate through speech and writing, and indeed which considers these skills to be signs of intelligence" (5).

Aphasia-related disruptions to language highlight the necessity of reading and writing for individuals to function in society and even, say many literacy scholars, to attain status as a full citizen (Prendergast; Kliewer et al). Living in a highly literate society, individuals especially encounter the need and expectation to read, write, and speak about their reading and writing practices throughout the business of everyday living. They must fill out medical and other forms to secure necessary care and services; hand-write signatures to verify personhood and offer consent; read email and internet-based materials to engage with others in workplace; and read and write to keep in touch with family and friends locally and across the world. Because literacy sustains so many parts of life—from the quotidian to the formal—aphasia frequently isolates, shames, challenges, and excludes.

My study is designed to address and learn from these lived and embodied challenges with literacy—and how people with aphasia navigate the changes to their literate practices and identities.

I seek in this study, then, to answer three primary questions:

1) What are the communicative practices of people with aphasia?
2) How do the literate histories of people with aphasia influence their post-aphasia literacy practices and identities?

3) What can an understanding of the literate practices and experiences of people with aphasia offer to our understanding of literacy more broadly?

To answer these questions, I observed in-the-moment composing and communication occurring in a semester-long multimodal memoir group for 10 people with aphasia, collecting over 140 hours of videotaped interaction featuring people with aphasia. Then, to account for how aphasia affects individuals' relationship to literacy in the context of their life-long development and practices, I also conducted 18 in-depth literacy history interviews with 17 people with aphasia.

From these observations and interviews, I show how the communicative and literate practices of people with aphasia reveal to literacy researchers and educators how literacy, as an alphabetic use of reading and writing, is a deeply normative construct, privileging bodies and minds that process language in "normal" ways and excluding persons with aphasia and other language disabilities (Brueggemann, *Lend*; Dunn, *Talking*; Dolmage, "Mapping"). I then draw on the insights and experiences of people with aphasia as they read and write and on disability theory to establish an embodied theory of literacy.

By focusing on the experience of aphasia, what this study offers is the opportunity to interrogate literacy through the experiences of individuals whose bodies and minds have changed. Aphasia allows us to ask what happens when the body, one of the integral pieces that make reading and writing happen, doesn't work the way we—as everyday readers and writers, as well as literacy scholars and educators—expect it to. Specifically, when the body changes, how do people read and write? What do they choose to do—or not do? How do they do it? And why? After aphasia, what enables or constrains literate practice and identity?

In this dissertation, drawing on people with aphasia's experience of embodied change, I develop a theory of embodied literacy, based on two primary arguments:

1) In order to read and write, people with aphasia have to negotiate their changed bodies, the available materials of literacy, as well as the social expectations for what it means to be literate and to practice literacy. In this study, I show and analyze the various ways people negotiate: some develop new practices—ways of using tools and materials of literacy. Some quit reading and writing altogether. Others continue to read and write but find that their practices are weighed down by shame, panic, and anxiety. Others find themselves writing more, or more successfully.

   For people with aphasia, to read and write, and to do so without negative feelings, requires modification of virtually all of the aspects of literacy: bodily practices, materials of literacy, and certainly social values around literacy.

2) The experience of aphasia exposes how integral the body is to literacy. We come to understand, from this case of bodily change and acquired disability, how central bodies *always* are to literate practice and identity.

   An embodied theory of literacy therefore foregrounds

   - the role of the body in the practice of reading and writing—the body itself as a technology of literacy
   - the way literacy is embodied across the lifespan—as people repeat practices and form identities through the embodied literate actions: cultivating beautiful handwriting, for example
   - the intercorporeal, interdependent, and dispersed nature of literate practice and identity for all readers and writers

**Aphasia and Its Effects**

I am not interested in marking individuals with formal diagnoses in this dissertation. For that reason, I do not ask individuals for medical documents or ask how they have been diagnosed or labeled. However, I do want to give some background about aphasia broadly as a framework for contextualizing my participants' emic perspectives of aphasia, and my own interpretations. In part, that background is necessary because, though aphasia is relatively common, it also remains largely unknown and misunderstood. For instance, it is often misinterpreted—as I indicated above—as a problem of aging or cognition more broadly.

Aphasia generally falls into two types. Broca's aphasia, also known as expressive or non-fluent aphasia, inhibits individuals' production of speech and writing. That is, individuals know what they want to say, but they have difficulty coming up with the words. While individuals are usually aware that the words they are selecting are incorrect, they are unable to correct their language. The effects of Broca's aphasia may range from relatively minor word-finding issues that are noticeable only to the person with aphasia to global aphasia—which is the complete loss of the ability to produce or comprehend written or spoken language. The second type of aphasia, Wernicke's aphasia, also called receptive or fluent aphasia, affects individuals' production and comprehension of speech and writing. Individuals with Wernicke's aphasia use language with fewer pauses or starts and stops than those that show up in Broca's aphasia, and may even follow grammatical structure. However, they speak and write in what seem to be nonsensical strings of language. One former chemist with Wernicke's aphasia in the present study often produces sentences like "Well, you see I put the carbon in the neutron" when asked to answer a question about his taste in sports or other casual conversations.

Based on the location of the injury in their brains, persons with aphasia also frequently

experience hemiplegia, or one-side paralysis on the right side of their bodies. Because individuals are often right-handed, their physical impairment also affects their literate practices, particularly handwriting, which often becomes a source of frustration and shame (Garcia Obregon).

As might be expected, the communicative and social effects of the acquired disability of aphasia are significant. "Literally overnight, aphasia changes everything," explain Shadden and Agan (175). "What was known becomes the unknown. What provided the tool, communication, for interacting with the larger social milieu is now flawed. […] [L]ife has become an obstacle course to which the individual, family, and friends must adjust." Unfortunately, there is no manual or rulebook accompanying this journey (Shadden & Agan 175). Elsewhere, Shadden likens aphasia to a kind of "identity theft," "creep[ing]n like a thief in the night, stealing the carefully constructed identities of all those affected" (215-216).

The extreme changes to one's sense of identity extend to the literate practices of people with aphasia. Identity is central to much discussion in literacy studies, revealing how literacy marks and maintains personal and group identity (Young, M.; Young, V.; Gee, *Social*). My study of the literate practices of people with aphasia joins important conversations about literacy and aphasia started by Susan Parr in the field of aphasiology and Andrea Garcia Obregon in psycholinguistic literacy studies. Drawing on work in New Literacy Studies, Parr turns discussion in aphasiology, or the clinically based study of aphasia and its therapies, from literacy as a discrete language skill to a complex, ideologically loaded practice. Accordingly, she works to analyze both the "losses" and the "gains" in life roles experienced by persons with aphasia and the related changes in literate practices. She traces how both aphasic and non-aphasic individuals often receive assistance with reading and writing practices from other people or other tools, and

she, ultimately argues against "the unquestioning acceptance of independence as the primary goal of therapy" ("Everyday," 234).

Similarly performing a sociocultural, psycholinguistic exploration of reading and writing in the life of one man with aphasia, Garcia Obregon notes that attention to literacy in studies of aphasia has been limited, observing that "[m]uch of the resistance to investigating written language comes from the commonly held belief that written language is not as important as oral language" ("Reimagining," 89). Such a resistance also reflects a narrow view of literacy, again, as a discrete skill, assessed most accurately by "closely controlled experimental tasks in which researchers attempt to map or to document the performance of those who suffer from aphasia while they participate in reduced clinical reading and writing activities with decontextualized language" ("Reimagining," 89). As an illustrative example, commenting on "aphasia and artistry," in her clinical guide Acquired Aphasia, Martha Taylor Sarno argues that "In no case has an aphasic writer been able to continue to write," citing Charles Baudelaire as an example of a literate life ended by aphasia (395).

While both Garcia Obregon and Parr do much to counter this skills-based view of literacy and the way it excludes persons with aphasia, my study seeks to push the exploration of literacy and persons with aphasia even further. I foreground how literate lives are far from ended by aphasia, accounting for the multiple creative ways people with aphasia continue to write, the norms they expose about literacy and the body, and the ways they push at the boundaries of what we mean by literacy in general. In a similar attempt to reject foreclosing the practice or identity of literacy to people with aphasia, I also strive, in this study, to include a broad range of people with aphasia. Parr and Garcia Obregon have limited much of their work to persons with "mild/moderate aphasia" who may "regain" pre-aphasia literate practices (Parr, "Everyday,"

225). I am committed to including individuals with a range of language disability—from mild conditions perceptible only to the affected individual to persons who have very little access to language. In this way, I align myself with researchers in literacy, disability, and education who refuse to use labels of "severity" or "incompetence" (Kliewer & Biklen) in favor of remaining open-minded to finding literate practices and competence in various forms. That is the spirit and practice of this study (See Chapter 2 for more discussion on methods, methodology, and participants).

## Bodies in Context: Social and Material

In that same spirit, I contend that literacy and writing studies has a great deal to learn from readers and writers with aphasia. This study reveals how literate lives are far from ended, and aphasia is not exclusively a physical or medical condition. As Julie Hengst and Cynthia Johnson argue, "Viewing writing from the perspective of communication disorders highlights the intersections among physical, physiological, cognitive, linguistic, behavioral, and social dimensions of writing" (471). In bringing those intersections to light through a theory of embodied literacy, I build on scholarship on the body in literacy, literacy as systemic or ecological, and recent work on the sociomateriality of literacy. In this section, I briefly review and situate my study in that literature.

### *The Body in Literacy*

My study of the literate practices of people who have experienced embodied change is helped by work already done on "the body" in writing, rhetoric, and literacy studies. The "body" and "embodiment" are generally thought to play important—even vital—roles in literacy, rhetoric, and composition. We read and write from bodies, with bodies, as bodies (Fleckenstein).

Research in rhetoric, composition, and literacy has primarily focused on two separate approaches to interpreting the body in relation to literacy: 1) body as an "epistemological site" (Owens & Ittersum 88) and 2) the body in the real-time, material practice of writing. In these ways, the body is interpreted alternately as first "social" and second as "material."

1) The body as "epistemological site"

The *Rhetorical Bodies* collection in 1999 initiated a turn toward the material and embodied in rhetorical work, identifying—in the midst of the postmodern, linguistic turn—a dearth of work on the material and embodied. In his introduction to the collection, Jack Selzer worries over the conflation of "things" with language, fearing that "Words have been mattering more than matter" (4). Sharon Crowley, similarly, closes the collection with a claim that "no body is disinterested" (363), but, rather, all bodies are "marked in ways that carry a great deal of cultural freight" as they "are sexed, raced gendered, abled or disabled, whole or fragmented, aged or young, fat, thin, or anorexic" (361).

That "cultural freight" marks individuals as differentially literate, illiterate, or capable of—and or suitable for—acquiring literacy. Literacy has long been encouraged, discouraged, or otherwise monitored (in Brandt's terms, "sponsored") based on identities marked on the body such as race, gender, class, and disability. Indeed, "where 'a literacy' is identified, those with an interest in finding the corresponding illiterates are never far behind" (Street & Kress vii). Certainly much of our central works of literacy and composition track how individuals' perceived incompatibility, outsider status, or impossibility for literate results from the embodied identities of women, people of color, and working class people (Daniell & Mortensen; Prendergast, *Literacy*; Rose).

2) The body in real-time literate practice

In addition to identities marked on the body that affect one's access to literacy education, resources, and benefits, a great deal of scholarship in composition and literacy studies identifies the role of the body in "real-time" literate practice. In their study of technical writing practices, Haas and Witte argue that while "the *body* is a cultural, social, and linguistic construct, *embodiment* is lived experience" (417). Recent studies of literacy have explored writing as an embodied experience, occurring "in real time and in specific physical spaces," including "skillful and often internalized manipulation of an individual's body and of tools that have become second nature, virtual extensions of the human body" (Haas & Witte 416). These scenes of literacy are of interest to literacy activity theory as composing is examined as dispersed across time and tools and "remediated" across multiple communicative modes (Prior and Shipka).

Bodies are often investigated in relation to the tools or technologies of literacy. Indeed New Literacy Studies' thorough rejection of the idea of literacy as a "Technology" in and of itself, increasing intelligence, making room for abstract thought, building more complex civilizations (Street) turns attention to the "technologies" of literacy . Individuals read and writing with various technologies – paper, pens, keyboards – the stuff of literacy. And this "stuff," or "ordinary writing props…have long ceased to be novel, and are mostly unrecognizable as technologies" (Micciche 496). Making visible these technologies rendered invisible by their very ubiquity and familiarity has been a significant task of research in New Literacy Studies and subsequently in materialist or new materialist explorations of literacy. Work on technologies of literacy, including pencils and computer technology (Baron, Haas) as well as the economic consequences of paper production (Mortensen, "Reading"; Prendergast & Licko)

Haas's *Writing Technology* brings into bright relief the role of both the body and technology in literacy: writing is simply not writing without technology and "[q]uestions of

technology always and inescapably return to the material, embodied reality of literate practice" (xv). That is, on the micro level of the very practices of reading and writing, literacy is both embodied and material. Embodiment "can provide a necessary corrective" to studies of literacy that focus on the "cultural at the expense of the cognitive, or that focus on writing as only an act of mind" (xv). Similarly, as Haas examines the interaction of tools and bodies in literacy, Owens and Ittersum point out the need to explore "varied relationships between writers' bodies, writing tools, and writing practices," particularly when "bodies must come to mind for writers: when writing causes bodies pain" (89). In these ways, literacy and writing studies has established that bodies are present on the scenes of writing, and they align with tools and technologies.

My study draws from both understandings of the body in literacy and reveals how body and material are, in fact, inextricable. I show how the body is social for people with aphasia. Bodies are weighted with values for what they should do in literacy—many of which are visible through the materials of literacy. At the same time, the body is material. The body itself, as I show in Chapters 3 and 5 acts as a technology of literacy—interacting with and supplementing materials of literacy and serving as a tool for invention. When bodies change, I show throughout the dissertation, bodies, materials, and social values come into conflict and put pressure on readers and writers.

### *Bodies in Literacy: "Withness" and Conflict*

The conflict and tension I show between bodies, materials, and social values in this dissertation importantly builds on and diverges from work in literacy and writing studies that gets at these aspects of literacy as separate strands operating "with" one another. Since the growth of New Literacy Studies and the social turn it has cultivated over the past few decades,

the field of literacy studies has looked beyond reading and writing itself toward the activities surrounding literacy events, practices, and values (Gee, Foreword). That move has influenced scholars to look around and next to the acts of reading and writing, tracing the involvement of bodies, technologies, objects, other people, other resources. In these ways, scholars have established various facets of literacy: social and cultural—used for particular purposes in particular contexts (Street; Heath, *Ways*; Daniell; Scribner & Cole); material—uses tools such as pencils, paper, keyboards, and the internet (Haas, Baron); embodied and cognitive—draws on the processes and actions of the bodies and minds of readers and writers (Haas & Witte; Purcell-Gates; Lindgren; Owens & Ittersum). Literacy, indeed, is defined by its "strange and unique status" as simultaneously a "technology, a process, a product, a form of work and play, a currency, an energy source, all-in-one" (Brandt, *Literacy* 183). Indeed, I also find that social, embodied, and material together suffuse, delineate, and define literacy. Literacy is ecological, distributed, and web-like (Barton; Syverson; Cooper)—as individuals' reading and writing occurs in and is influenced by surrounding environments (Barton 29).

However, in this dissertation I join these moves to interrogate the multiple facets of literacy while diverging from an understanding of literacy's "withness" (Micciche 50). From the literate experiences of people with aphasia, I find that the social, material, and embodied aspects of literacy are not so much *with,* but always in tension, dialogue, conflict, and telling intersection. I am helped in that analysis of intersection and confliction by recent scholarship interrogating the aspects of literacy as mutually constitutive. Materials of literacy intertwine with, and bump up against, the social. Materials are social, Kate Vieira shows in her exploration of immigrants and their interaction with documents granting or certifying citizenship. The documents that mark individuals as citizens and carry the weight and power of the state's

authority to include or exclude. Literacy is, Vieira says, "socio-material"—a social practice and a material product (*American*). In this way, the materiality of literacy is "radically social" (Vieira, On the Social," 5). Similarly, Victoria Purcell-Gates, et al argue for a "widened lens" to literacy theory, accounting for both social and cognitive views. They show how failing to account for the intersection of the two views alternately ignores the influence of social factors that provide disproportionate access to literacy education and real bodily and cognitive variation affecting individuals' literacy "skills." As I argue in this dissertation with an embodied theory of literacy, these intersections, conflicts, and tensions between aspects of literacy are essential in exposing the norms around literate practice and identity and in working toward more just access to education and resources.

**Disability and Embodiment: Toward an Embodied Theory of Literacy**

For this dissertation's quest to expose intersections, conflicts, and norms, Disability Studies offers a particularly useful perspective on embodiment for literacy studies. The body in disability is simultaneously material and social:[1] individuals' material bodies—sometimes "non-normative" or "impaired" even while social values and the effects those values have physical environments are designed for certain kinds of bodies, excluding others. Both are true, and together they create tensions, conflicts, but also knowledge about norms and other ways of living and being in the world.

[1] The social model of disability studies and activism has reframed disability from a medical/individual model that puts the burden for impairment on the individual (multiple sclerosis disables/relegates people to wheelchairs, so they can't climb stairs) to a social model that situates disability as socially constructed (stairs disable people in wheelchairs). That reframing powerfully rejects individual blame and responsibility around embodied variation, turning attention toward how physical environments are built for "normal" bodies and minds, excluding others. Disability studies, then, focuses not on how to "treat disease or disability, hoping to cure or avoid them," but interrogates "the social meanings, symbols, and stigmas attached to disability identity" and "how they relate to enforced systems of exclusion and oppression" (Siebers 3).

Building on feminist standpoint theory arguing for embodied, situated knowledge stemming from disability, disability theorist Tobin Siebers claims that "a focus on disability makes it easier to understand that embodiment and social location are one and the same" (23). Lived, embodied experiences in fact form knowledges and identities. The lived, embodied experience of disability positions individuals outside of the "norm," revealing and opening those norms to critique. In this way, "oppressed social locations create identities and perspectives, embodiments and feelings, histories and experiences that stand outside of and offer valuable knowledge about the powerful ideologies that seem to enclose us" (8)[2]. People with aphasia featured in this study generate that knowledge and perspective on literacy: exposing norms about literacy (about values, values built into materials of literacy, about bodies, etc.) and open literacy norms, education, access, and more to critique. And those perspectives and critiques stem from embodied experience, generating an embodied theory of literacy. And from the embodied experience of disability, we learn how the "social representations of the body" and the material body are "reciprocal" and "mutually transformative" (Siebers 25).

**Chapter Overviews**

Together, the chapters that follow draw on the experiences of people with aphasia as they work to read and write. From those experiences, I establish an embodied theory of literacy. Each chapter focuses on a different facet of how bodily change affects literate practice and identity—and how individuals negotiate that change. Chapter 3 explores the relationship between bodies

[2] Siebers calls this embodied experience of disability "complex embodiment"—blending socially constructed identities lived—and thereby theorized—by people with disabilities. This lived experience "creates theories of embodiment more complex" than the socially constructed "invisible" norms of our world, "and these many embodiments are each crucial to the understanding of humanity and its variations, whether physical, mental, social, or historical" (Siebers 9).

and materials. Chapter 4 shows the enduring pressure of social values on bodies, and Chapter 5 features how people with aphasia rework social norms around literacy to support the needs of their bodies.

I turn first to "Chapter 2—"Research Design: Exploring the Literate Practices of People with Aphasia" to establish a methodological frame for studying and sketching out an embodied theory of literacy. To get at an embodied theory of literacy from the experiences of people with aphasia—who have experienced bodily change—I designed this study with two central goals: 1) accounting for material, embodied, and social aspects of literacy through direct observation and life-history interviewing accounting for literacy across the lifespan 2) conducting research with accessibility as a central concern. To be accessible, my methods also required attention to embodiment, challenging language as the most accessible mode of communication and thereby redesigning consent forms and interviewing.

Chapter 3, "Literate Misfitting: Disability Theory and a Sociomaterial Approach to Literacy," analyzes literacy history interviews to show how, after bodily change, people with aphasia find that their bodies no longer fit with the materials and expectations of literacy. I then show how, to practice literacy in the face of this *literate misfitting*, people with aphasia 1) draw on the materials of literacy to take on various uses or aspects of their bodies and minds, and 2) use their bodies and minds to take on various uses and aspects of the materials of literacy. For Writing Studies, these strategies deepen our understanding of the integral role of the body in the practice of reading and writing—pointing to the body itself as a technology of literacy. These strategies reveal an overlap between bodies and materials of literacy as the two share work and supplement one another in literate practice. However, I also show how, despite these productive strategies to read and write in the face of literate misfitting, social pressures from what

individuals understand as "real" reading and writing push back on and sometimes limit individuals' new strategies and, in turn, their literate potential.

I further analyze how those social pressures around literacy affect people with aphasia in Chapter 4 "Negotiating Literate Identity after Aphasia: Normativity, Flexibility, and Relating to/Reworking Literacy Ideology." Here, I turn more explicitly to how individuals perceive, grapple with, and adjust to their literate identities after aphasia. In particular, I analyze life-history profiles of six diverse people with aphasia to track how pre-aphasia literate identities affect individuals' ability to adapt new senses of literate identity after aphasia. I find that people who have become attached to a "normative literate identity"—or strict guidelines based on practices, processes, and products of literacy—though they have often greatly benefitted from literacy before aphasia, have significant difficulty adapting after language disability. Conversely, I find that people with "flexible literate identity"—relatively broad and open expectations and standards around what it means to do literacy and be literate—adapt with relatively less strife. Even though this latter group has sometimes not been very successful with literacy prior to aphasia, they often display an ability to adapt and grow post-aphasia. These findings reveal how social values around literacy endure across the lifespan and affect individuals whose bodies have changed in particular—reflecting tension and dialogue between social and embodied aspects of literacy.

These social norms around literacy experienced by everyday readers and writers and putting pressure on people with aphasia are loosened in Chapter 5—"Beyond Misfit and Retrofit: Enacting Literate Access in a Multimodal Memoir Group." This chapter asks what makes literate action and access to literate practice and identity possible for people after aphasia? I track how literate access emerges in the multimodal memoir group not only through the resources for

composing available, but especially through how people with aphasia engage with those resources, with other people, and particularly with literate norms to enact literate access. By analyzing video data from this composing group, I show how people with aphasia rework social norms around literacy to fit the needs of their bodies, enacting literate access in-the-moment. I draw on disability studies and activist work in access and universal design to show how people with aphasia themselves design and enact literate access through their practices.

I close in Chapter 6 "Toward a Theory of Embodied Literacy" by reviewing primary findings from this dissertation and engaging in a discussion of the study's contributions for various academic and practical conversations, teaching, and research. Finally, I spend the bulk of that chapter noting the study's limitations and, particularly, directions for future research into the literate practices of people with aphasia and an embodied theory of literacy.

As a whole, across the chapters, this dissertation forwards an embodied theory of literacy characterized, again, by the following principles:

An embodied theory of literacy:

- reveals the integral role of the body as people read and write in everyday life—how their bodies fit or misfit with materials of literacy, how they work and rework their bodies as technologies of literacy in and of themselves, how they grapple with values and expectations around bodies in literacy, and how they work and rework those values to support the needs of their bodies

- makes the body apparent, accounting for the fact that all bodies are different, bodies are fallible and changeable across the lifespan and across ability/disability. Bodies are not neutral or "normal"

    - reveals the body itself as a technology of literacy (interacting closely with and taking on aspects of the materials of literacy [See Chapter 3] and acting as a tool for invention [See Chapter 5])

- exposes how materials of literacy, too, are not neutral or normal. They are designed to fit certain kinds of bodies—keyboards for ten fingers, dense newspaper text for eyes and a brain that processes language quickly

- emphasizes literacy is always valued in certain ways. What the experiences of people with aphasia add to that is how much social values around what bodies should do and be figure into individuals' understanding of themselves as literate or not literate

- above all, reveals how—in order to read and write—people with aphasia (and all readers and writers) must negotiate bodies, the available materials of literacy, and the social expectations for what it means to be literate and to practice literacy

# Chapter 2

## Embodied and Accessible Research Design:

## Exploring the Literate Practices of People with Aphasia

This dissertation was designed to explore the lived experiences of people with aphasia as they read and write—and to contextualize those experiences in their longer literate histories. Over the course of four years, I conducted two semester-long multimodal memoir groups, facilitated six semesters of a text-based aphasia writer's group. I collected data in two phases: 1) video-taping composing occurring in a multimodal memoir group for 13 weeks in Spring 2012, and 2) conducting 18 in-depth life history interviews with 17 people with aphasia. In those interviews, I asked individuals about reading and writing memories, experiences, and perceptions before and after aphasia, including the role of literacy in their childhood and in occupations as well as frustrating and productive experiences with literacy post-aphasia. The goal of this research as a whole was to understand how changes to the body that affect language ultimately affect readers and writers.

In this chapter, I discuss the origins of this research project, research questions, and phases of data collection. I then detail the social, material, and embodied research design and grounded theory methods of data analysis. I also give some background on the participants involved in the study. Finally, I close with an extended discussion of my attempts to make data collection and analysis as accessible as possible—with particular attention to consent and interviewing. I discuss the complexities, importance, and opportunities inherent to accessible research design.

### Origins of the Research Project

The driving question behind my research is, "What does literacy look like after aphasia—without language or with altered access to language?" This question arose for me from both personal and professional influences. A few weeks after accepting an offer to enroll in UW-Madison's PhD program in Composition and Rhetoric, my mother suffered a severe stroke, causing physical and language impairments. As she and my family grappled with these changes, my PhD work simultaneously engaged me in close study of the politics of language and the consequences and expectations attached to literacy. Moved by the way complications to language may isolate persons with aphasia, affecting self-identity and connection to others, I collaborated with a speech language therapist to create the "Telling Life Stories" multimodal memoir and writing groups.

As I was co-facilitating these memoir groups, I became interested in more closely examining how people with aphasia are writing and reading. I began, then, observing individuals' composing processes in the groups, videotaping one-to-one interactions between people with aphasia and MA students in communicative disorders as they put together multimodal memoirs. I also videotaped the sharing of memoirs happening between people with aphasia. I did this for each of the 10 participants with aphasia, every week for 13 weeks—collecting about 135 hours of video. I also collected images of hundreds of images of the pages of individuals' memoirs.

I observed people's in-the-moment composing, and I learned a great deal about how individuals composed across modes and with other people. But what's unique about aphasia is that it is an *acquired disability*. In this way, aphasia intervenes in individuals' already long histories with literacy before aphasia. Because people had literate lives before aphasia—and beliefs about literacy develop across the lifespan—I then decided to conduct in-depth literacy

history interviews with people with aphasia.

As I determined my sites of data collection, I also refined my research questions, getting at how aphasia affects individuals' reading and writing practices:

4) What are the communicative practices of people with aphasia?
5) How do the literate histories of people with aphasia influence their post-aphasia literacy practices and identities?
6) What can an understanding of the literate practices and experiences of people with aphasia offer to our understanding of literacy more broadly?

These questions direct vital attention to a population viewed as communicatively impaired and often understood as functionally illiterate: people with aphasia. Much remains, then, to be learned about the communicative and literate practices of people with aphasia and about individuals' pre-aphasia experiences with reading and writing. These questions begin to get at those experiences—to account for the every day composing and literacy needs of people with aphasia, and to build and enrich our understanding of literacy from those insights, challenges, and experiences.

This chapter describes how my research was designed to get at these questions and the important knowledge we stand to build about aphasia, language, literacy, embodiment, and more.

**Phases of Data Collection**

To address these questions, my study included two phases of data collection. ***Phase One*** consisted of video-taping, conducting brief interviews, and collecting artifacts from multimodal memoir and writing groups for people with aphasia. These materials are essential for documenting and analyzing the real-time composing, reading, and writing practices of persons with aphasia. In my second phase of data collection, I conducted 18 interviews with a total of 17

people with aphasia (I did one follow-up interview with one of the participants). These life history interviews are designed to provide insight into individuals' experiences with reading and writing before and after acquiring aphasia.

I completed the first phase of data collection over two years by gathering video and artifacts as a participant-observer in three multimodal composing and two text-based writing groups attended by a total of 27 persons with aphasia and taking place at a speech and hearing clinic at a large public university in the Midwest. In these groups, people with aphasia worked one-on-one with Masters student clinicians training in communicative disorders. The roughly 250 hours of video data I collected from these groups feature one-on-one composing of multimodal memoirs with student clinicians, full-group discussion and sharing with all group participants, and small-group workshop discussions of writing. Videotaping is an important method for collecting data about the communicative practices of persons with aphasia, many of which rely on nuanced gestures, facial expressions, drawing, or other modes outside of language.

I also conducted and video-recorded brief, 10 to 30 minute, interviews with the persons with aphasia in each group. During these conversations, I asked participants to tell me about their experiences composing multimodal memoirs or with writing and sharing in each group. I then interviewed each Masters student clinician separately, asking them to describe their role in participants' composing processes, using clinicians' language-based responses not to clarify gaps in the responses of the persons with aphasia, but to triangulate my data by offering additional perspectives on the communicative practices taking place in these groups. I have also collected hundreds of images from the life-story memoirs created by persons with aphasia, including drawing, writing, and a range of artifacts from web-pages to photographs to maps to family trees.

From the text-focused writer's groups, I collected hundreds of drafts of writing to explore participants' drafting processes and literacy development over the course of the groups.

Analysis of my video data from the groups and brief interviews revealed the important role of the body in the literate practices of persons with aphasia and the interdependent nature of literate action as meaning is co-created between multiple modes of expression (gestures, writing, speaking, drawing, using artifacts) and multiple people. These findings, however, raised further questions that could not be assessed within the scope of the groups and the video and brief interviews I collected there, including: What are the literate histories of people with aphasia? How do their reading and writing practices prior to acquiring aphasia influence or relate to their literate or communicative practices now? How do literate histories influence the re-learning of literate practices after acquired language disability? What reading and writing practices do people with aphasia use on a daily basis (when they're not in multimodal composing or writing groups)? What role do close communication partners—family members, friends—play in the literate practices of persons with aphasia?

To address these questions, ***Phase Two*** of my data collection consisted of conducting life history interviews with 17 people with aphasia. I used snowball sampling beginning with the participants in the Telling Life Stories multimodal memoir group, and requesting recommendations for other people to interview from the group's participants. To investigate the role of literacy across the life span of persons with aphasia, I asked participants to answer questions in three categories: reading and writing in youth, reading and writing in pre-aphasia adulthood, and reading and writing after aphasia. I designed a semi-structured interview protocol (See Appendix A) with the goal of offering enough flexibility to follow participants' responses and communicative preferences. These life story interviews, ranging from 1.5 – 3 hours, are

designed to acknowledge the important experiences and voices of people whose complicated access to language frequently isolates and renders them "invisible" (Carlsson et al.).

**Embodied Research Design**

Combining both video-data of in-the-moment composing practices and literacy history interviews that get at the experiences of literacy across the lifespan, I drew on traditions of phenomenological and socio-historic methods of literacy research. This combined approach is essential when considering the social, material, and bodily aspects of literacy. In doing so, I follow Paul Prior's assertion that "phenomenological and sociohistoric approaches work together, encouraging close attention to the fine-grained, embodied, situatedness of activity but also to the historical trajectories of material-semiotic objects, people, and environments that are folded into, and radiate out from, any situated event" ("Combining," 174). To argue for both methodological approaches, Prior builds on Deborah Brandt's metaphor of literate action as a "party" and on focusing entirely on texts as being "like coming upon the scene of a party after it is over and everybody has gone home, being left to imagine from the remnants what the party must have been like" (176). "Attending a party may reveal much about the events of the party," Prior interprets, "but it will only offer the barest of clues about how the food, drinks, smokes, music, electricity, language, and the people themselves came to exist, got to that event, and headed off after it" (180). Phenomenological and socio-historic approaches to literacy together provide information about the party and what led to it—to literate practices and identities as they occur in the moment and across time and context.

I find that studying communication, composing, and literacy practices in-the-moment allows me to understand how individuals with aphasia use text, writing, speech, and multiple communicative modes in innovative ways. These observations, specifically, follow

ethnomethodological approaches to researching social phenomena positing that individuals "construct social categories and orders" as they interact (Prior, "Combining," 169). That is, individuals create through their action and interaction social categories of "communicator," "writer," and "author." For instance, many of the people I interview claim to never read or write. I find that this rejection of the label "writer" or "reader" stems from a sense of the social identities that constitute being a writer. As I show in Chapter 4, individuals have developed and internalized these senses of identity across the lifespan. However, observation in the multimodal memoir groups reveals contrary evidence and uses for writing. One participant—a former pilot—Bill, though he hates writing and claims to never write, writes words in almost every conversation—using writing as part of his oral communication approach. Likewise, Judy, a former high school English teacher, claims to have "left the writing behind" after aphasia. However, in the multimodal group, I observe her writing extensively. She handwrites labels on post-it note placeholders in her multimodal memoir life book as a way of organizing ideas and composing collaboratively with the MA student clinician she is partnered with in the multimodal memoir group. These contradictions, revealed by both observation and literacy history interviews, expose conflicting ideologies around what constitutes writing and defines writerly identity. Direct observation of composing provides me with access to the ways "we not only come to inhabit made-worlds, but constantly make our worlds—the ways we select from, (re)structure, fiddle with, and transform the material and social worlds with inhabit" (Prior & Shipka 182).

In addition to these direct observations, life history interviews provide essential information regarding how the social, material, and embodied practices and values around literacy develop across lifespans. Stemming from biographical sociology (Brandt, *The Rise*), life

history interviews offer important insight into social, political, and cultural influences on literacy—putting literate experiences in the historical context of a lifespan couched in the "felt experience" of an individual (Brandt 8). Life history interviews are, thus, simultaneously "ethnographically specific and historically broad," enabling literacy researchers to link individuals' experiences to larger historical and social trends (Vieira, "Doing").

The "backward glance in literacy research," Lauren Marshall Bowen agrees, is essential in understanding how later-life literacy practices emerge not newly, but in the context of complex literate histories. As I discuss in Chapter 3, for Bowen, interrogating literate histories helps to account for "how embodied, affective sources of motivation endure and support literacy practices across the life course" (590). For instance, the digital literacy practices of senior citizens are suffused with affective, bodily motivations tied to their lifetime of experiences with literacy in non-digital forms. Literacy "is at once old and new, and…only by paying attention to the intermediation between the two can we begin to see what literacy might mean for the present" (Bowen 602). It is this "intermediation" between pre and post aphasia literacy practices and identities to which life history interviews uniquely provide access.

**Data Analysis: Grounded Theory**

I used grounded theory methods (Charmaz) to code my data from both phases of collection—video-taped interaction in multimodal memoir group and literacy history interviews. Grounded theory was originated by the sociologists Barney G. Glaser and Anselm L. Strauss as a counter to the quantitative analysis so pervasive in 1960s sociological research. Responding against positivist underpinnings in that research, Glaser and Strauss explain grounded theory as "*developing* theories from research grounded in data rather than *deducing* testable hypotheses from existing theories" (Charmaz, *Constructing*, 4). In this way, grounded theory is a

"methodology for inductive theory building from qualitative data" (Skeat and Perry 95). This method assumes "that people sharing a common circumstance will also share some common meanings attached to that circumstance" (Stanley and Cheek 144).

Grounded theory itself, however, has been critiqued as positivist (Charmaz, *Constructing*, 9). Specifically, Charmaz explains that Glaser and Strauss "talk about discovering theory as emerging from data separate from the scientific observer" (10). Like Charmaz, "I assume that neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We *construct* our grounded theories through our past and present involvement and interactions with people, perspectives, and research practices" (10). The commitment to induction and the underlying assumption that "people sharing a common circumstance will also share some common meanings attached to that circumstance" draw me to grounded theory (Stanley and Cheek 144). The method allows me to root my claims very closely in participants' actions and perspectives. And I find grounded theory to be an especially apt method for "listening" to the multiple communicative modes of persons with aphasia. To that end, I used grounded theory to code both language and multimodal communication.

Although exact practices vary among strands of grounded theory, they include most commonly (and in my current study) conducting multiple rounds of coding—or labeling and sorting of data for themes (Charmaz advocates for coding "gerunds" to track processes); conducting data collection and analysis simultaneously; composing memos throughout data collection and analysis; engaging in "constant comparison" at every level of analysis; and delaying literature reviews until well into data analysis to encourage development of new theory from the data. In the remainder of this section, I will briefly review how I coded, revised my interview protocol as a result of simultaneous data analysis, and used memo-ing to build a

grounded theory analysis from my data.

*Coding: Open, Focused, and Theoretical*

I began with open coding—marking each line of my interview transcripts with a code and marking the video of my multimodal group observations in roughly 2-3 minute intervals or every time I noted a theme of interest. I coded using gerunds—a practice recommended in grounded theory to "detect processes," "stick close to the data," and "gain a sense of action" (Charmaz, *Constructing*, 49). In the multimodal group, I coded, in part, for practices of composing and communicating. Therefore, some of my codes included, composing multimodally, creating meaning interdependently, using bodily resources, searching for a word, reflecting on previous literate practices, perceiving literate deficit, writing with alphabetic text, and reading with alphabetic text. For the interview transcripts—again coding for practices and also affective responses—some of my codes included feeling proud of writing, focusing on reading comprehension, wanting to write, writing for self, experiencing cognitive difficulty, and adapting new reading practice. To stay close to the data, I also coded using "in vivo codes"—using the language or terms generated by participants. In Chapter 3 and Chapter 5, the participant Sandy's statement that "so many processes are involved with writing" was one in vivo code that led to the building of theories about "materials as prosthetic" to literacy and the "body as a technology" of literacy. Importantly, I coded both language and multimodal aspects—particularly gestures—featured in my data. For example, I coded gesturing, leading me to the codes "gesturing as a symbolic process" and "gesturing as an inventive process"—two of the practices that built to a theory of literate access-in-the-moment in Chapter 5.

Following open coding, I used focused coding to organize line-by-line and open codes into larger categories that acted as umbrellas to begin sorting and organizing patterns in the data

and thereby moving toward analysis. For instance, I created an "adapting with the body" focused code, which served as an umbrella category organize codes including "covering text with fingers while reading" and "visualizing words while writing." In the final stage of coding—theoretical coding—I worked to build theories by finding relationships between focused code categories. For example, the theory of "literate misfitting" from Chapter 2 arose from focused codes "experiencing literate difficulty," "adapting with the body," and "adapting with materials."

*Simultaneous Data Collection & Analysis*

Another major tenet of grounded theory advises researchers to conduct analysis as they are still interviewing or collecting data and to revise their interview protocol accordingly. For instance, I made one amendment to my interview protocol after my first interview. I realized the use of "tools" was confusing to an audience unfamiliar with the term from literacy theory: "What tools or technologies did you use to read or write (pre-aphasia)?" I rephrased to ask, "What kinds of reading or writing materials or kinds of technology did you use to read or write (pre-aphasia)?"

I also changed this question: "What is one word to describe how it feels to have aphasia?" to "Describe how it feels to have aphasia." I found the constraint for "one word" was not useful, and in fact it actually put undue pressure on individuals with aphasia who often have word-finding issues. And upon having a number of interesting conversations with people about "communication" more broadly, I added a question "After aphasia, what have you learned about communication?" These in-progress changes allowed me to refine my questions to improve the content of my data, but also to meet participants' communicative needs.

*Memoing*

My coding process and analysis was propelled by the grounded theory practice of

memoing. I composed memos, or largely unstructured pieces of writing (from a few sentences to several paragraphs) throughout data collection and analysis. Charmaz explains that memos "catch your thoughts, capture the comparisons and connections you make, and crystallize questions and directions for you to pursue" (*Constructing*, 72). For instance, I composed a memo "The Physical Act of Writing" as I coded the statement in Jean's transcript: "I liked the feel of actually writing." In the memo, I made connections to a number of other participants and codes, linking this "feel" to many participants' interest in "practicing writing" and to other participants' affective connections to various products, processes, and materials of writing (including handwriting). This memo led to the concept of "literate attachment" in Chapter 3. In addition to helping build theoretical codes, I found that memoing served as a "pivotal intermediate step between data collection and writing drafts of papers" (Charmaz 72). For example, I also composed a memo for each participant's interview transcript. Focusing on individual transcripts encouraged me to pay particular attention to individuals' literacy histories, which became the frame for Chapter 3.

**Participants with Aphasia: Backgrounds**

While aphasia more commonly affects people in middle- to upper-adulthood, my participants range in age from 24 to 82. The Telling Life Stories multimodal memoir group included 4 men and 6 women. Life history interviewees were similarly split across gender: 6 men and 11 women. All participants are predominantly white monolingual English speakers. One interviewee, Andrea, who immigrated to the U.S. from Peru in childhood, is bilingual in Spanish. About half of the participants come from rural backgrounds, and most participants have middle to working class roots. It is important to note that many live below the poverty line after aphasia and other physical disabilities arising from stroke or brain injuries have made holding jobs more

difficult. Participants have also been living with aphasia for a varying number of years: from one year to 15 years.

The following tables provide a range of demographic information about participants involved in both Phase One—Multimodal Memoir Group and Phase Two—Life History Interviewing:

**Figure 1: Multimodal Group Participants**

| Name | Gender | Age | Family Status | Highest Degree Attained | Occupation | Hobbies Pre Aphasia | Hobbies Post Aphasia |
|---|---|---|---|---|---|---|---|
| *Andrea | F | 52 | Divorced | All but dissertation of PhD | Family therapist/counselor | | Writing |
| *Bill | M | 55 | Married (second marriage) | BA | Former pilot | Homebrewing; canoe-building; home renovations | Family genealogy; interest in hummingbirds |
| Darla | F | 47 | Partnered | High School | Former cook | | |
| Frank | M | 82 | Divorced | High School | Musician / former military officer | Music | Music |
| Hugh | M | 76 | Married | PhD | Former chemistry professor | | |
| James | M | 47 | Married | BA | Former insurance salesperson | Fishing / outdoors | Painting and drawing |
| *Jean | F | 55 | Divorced; Currently in domestic partnership | 2 MAs | Former special education teacher | | |
| *Judy | F | 60 | Single / Divorced | BA | Former high school English and alternative education teacher | | |
| *Margie | F | 66 | Single | High School | Theatre usher / former data processing specialist | Reading | Reading |
| *Rose | F | | Single | BA | Current Tai Chi / Yoga instructor; | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | Former computer programmer and chef | | |
| * indicates individual was also a participant in Life History Interviews (see Figure 2) | | | | | | | |

**Figure 2: Life History Interview Participants**

| Name | Gender | Age | Family Status | Specified Communication Partner | Highest Degree Attained | Occupation | Hobbies Pre-Aphasia | Hobbies Post Aphasia |
|---|---|---|---|---|---|---|---|---|
| *Andrea | F | 52 | Divorced | None | All but dissertation of PhD | Family therapist/counselor | | Writing |
| Beth | F | 26 | Single | None | MA / Enrolled in PhD | PhD Student | | |
| *Bill | M | 55 | Married (second marriage) | Wife (Rita) | BA | Former pilot | Homebrewing; canoe-building; home renovations | Family genealogy; interest in humming birds |
| Bob | M | 65 | Married | Wife (Pam) | High School | Former grocery store regional manager | | Aphasia advocate / speaker |
| Gary | M | 55 | Married | Wife (Terry) | High School | Former bowling alley manager / current restaurant co-owner | | |
| *Jean | F | 55 | Divorced Currently in domestic partnership | | 2 MAs | Former special education teacher | | |
| *John | M | 47 | Single | None | BA | Former marine / | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | security officer | | |
| *Judy | F | 60 | Single / Divorced | | BA | Former high school English and alternative education teacher | | |
| Julie | F | 51 | Married | None | High School | Office manager | | |
| Laura | F | 24 | Single | Mother (Lucinda) | Some college | Former student | | |
| *Margie | F | 66 | Single | | High School | Theatre usher / former data processing specialist | Reading | Reading |
| Melissa | F | 38 | Single | Mother (Marilyn) | BA | Former Police officer / prison guard | | |
| Noreen | F | 45 | Single | Sister (Sheila) | BA | Former Chef | | |
| Rob | M | 61 | Married | Wife (Patty) | Doctorate in Pharmacy | Former Pharmacist | | |
| Ross | M | 81 | Divorced | None | High School | Former accountant | | |
| *Rose | F | | Single | | BA | Current Tai Chi / Yoga instructor; Former computer programmer and chef | | |
| Sandy | F | 64 | Single | None | BA | Former first grade teacher | | |
| * indicates individual was also a participant in the Multimodal Memoir Group (see Figure 1) | | | | | | | | |

**Accessible Research Design**

The field of disability studies has challenged researchers in Writing Studies to account for notions of "normalcy" and "ability," particularly in definitions of rhetorical agency (Lewiecki-Wilson and Dolmage; Brueggemann, *Lend*; Prendergast, "On the Rhetorics"). Less understood is how disability challenges the norms, practices, and values inherent in conducting qualitative research, particularly qualitative literacy research. While some studies embrace digital and multimodal components (Selfe and Hawisher), many Writing Studies methods rely on language: particularly through interviews, consent acquired through speech and text, and the analyzable products of relatively standard alphabetic literacy (Bazerman and Prior; Nickoson and Sheridan).

Despite these language barriers, I argue that qualitative research methods, particularly in-depth life-history interviews, are especially apt ways to work toward accounting for the perspectives of persons with language disability (O'Day & Killeen; Lloyd et al). A commitment to these perspectives, I suggest, takes seriously the disability rights maxim "nothing about us without us." With many scholars in communicative disorders and health communication research, I reject a view of language barriers as "insurmountable" (Lloyd et al 1399), the labeling of persons "with communication impairments […] impossible to interview," and the selection of "only participants who are articulate, reflective, and expressive in their communication" such as caretakers, family members, or those with very mild aphasia (Carlsson et al. 1362). My study asks, instead, not what barriers are presented by participants, *but by the methods used* (Carlsson et al.).

With Price (*Disability Studies*), I call for more attention to the implications of disability for our research methods, and my data collection methods are designed with accessibility as a

priority. Influenced by qualitative research practices from feminist and disability lenses in Writing Studies (Mortensen & Kirsch; Price, *Disability Studies*), I am committed to fairly representing the expressions and experiences of persons with aphasia. Further, with Price and Kerschbaum, I argue for the value of "centering disability," a process that moves "beyond compensation or inclusion, and requires consideration of the ways that disability unsettles assumptions about qualitative research itself."

Below, I present two specific efforts to collect and analyze data through accessible practices, reviewing two challenges and two corresponding tools to address those challenges: 1) gaining ethical consent and 2) conducting accessible interviews.

**Challenge #1: Ethical Consent**

The first challenge to completing ethical qualitative literacy research with persons with aphasia became clear to me when I decided to seek IRB approval to collect data and conduct interviews. I realized that, to account for persons' with aphasia's complicated relationship to language, I would do more harm than good by presenting participants with blocks of written text in a standard consent form. Simply stated, the standard consent form, though it is intended to be written for a "general audience" by avoiding jargon, is designed for a "normal" reader, writer, and language-user. Consent, itself, presumes a literate subject and—moreover—an autonomous individual agent able to freely reject or assent to participation. People with aphasia, however, often have an "unreliable yes/no," use the wrong word at the wrong time, or cannot understand spoken or written language—particularly at a fast pace.

**Tool #1: Image-based Consent Forms**

Drawing from Kagan, Winckel, and Shumay's *Pictographic Communication Resources* (1996), published by the Aphasia Centre, I designed an illustrated consent form for each phase of

my data collection (See Appendix B). I sought to minimize the amount of written text and to employ images ranging from stop signs supporting the message that "It's okay to quit the group at any time" to a padlock to emphasize confidentiality. In the terms of communicative disorders, I created a document to facilitate supported communication. "Supported communication" refers to the use of communicative modes and methods in addition to written and spoken language. In my case, the illustrated consent form provided communicative resources in addition to language, and I was able to point to images as I asked for consent. Unfortunately, my consent form expanded from a couple of pages to 11 (a length issue that caused many participants to rush me along as I turned through all of the pages)—and an issue that I want to explore the consequences of in further research.

Still, my move to illustrated consent forms follows disability and composition and rhetoric scholar Margaret Price's assertion that "Qualitative researchers are accustomed to thinking of our participants as people whose knowledge may be tapped through speaking, listening, or writing (to take a few examples), but if we re-examine our methods through a DS [Disability Studies] lens, we may notice that they are inaccessible to many" (*Disability*,166). As Price asserts, as researchers, it is essential that we interrogate "What kinds of participants" we are "imagining as we design our studies" and, accordingly, "how well" "our methods reflect our participants' strengths and abilities" (166).

**Challenge #2: Language-based Interviewing**

The second and most salient challenge I've faced in collecting data with persons with aphasia emerges from interviewing. While I am committed to "hearing," and "valuing" the perspectives and stories of persons with aphasia, the heavily language-based methods of qualitative research have made data collection a challenging process. One early interview stands

out as ineffective and indicative of the limits—and even barriers—of language in our communication. I offer some of the transcript and reflections from my research memos:

I interviewed James, whose aphasia allows him access to only a small range of words, typically one-word sentences, and a frequently unreliable use of "yes" and "no" about his experience with the life stories group and with creating a life book. James is also an accomplished, and constantly developing artist who puts tremendous detail into his paintings and drawings reflecting his love of wildlife and of the outdoors.

I began the interview by asking James to answer in any way he wished, inviting him to "answer this any way you want to, with words, drawing, whatever—how your experience has been with this group." James responds with silence, frowns, and (as I may have predicted) one-word answers.

I wait. I try to look calm while considering how much guidance is too much—how many questions to ask, how many options to give. I don't want to lead too much, to make someone's answers less than their own. But, still, James shrugs and his eyes water as he searches for a direction to take, stares into my eyes, and then looks to his left at Sara, one of the graduate students in our group who meets one-to-one every Friday with James.

"Is there anything you've especially liked about the group?" I ask again, struggling with how I can make my questions more accessible.

"Draw," he says, finally. "Draw." He lifts his left hand into the air, sketching with an invisible pencil.

"Drawing, yes," I respond, pleased that he has found an entry point into our conversation, and willing to follow wherever he wants to go.

Adding sound effects simulating the swoosh of a brush, James traces the frame of a large picture in the air and points to its center: “Fish,” he adds. “Draw.”

“Yes, you like to draw, and you’ve been sharing your art with the group,” I respond.

“Yeah,” he nods. “Yeah.”

I give him time to add anything else he would like, but he has reached the end of his words and stops, shrugging again as if resigned to waiting for the next question.

Later, watching the tape of our conversation, I think about asking him what his artwork means to him, what it means to share that artwork, and having him show me some of his artwork in the book he’s creating, but in the moment I think only of the next question on my list.

“Okay, so I, um, want to ask you another question: What were you hoping to get out of this group when you joined it? What were your reasons for joining it? And have you gotten what you want to out of it?”

“Oh,” he says. He brings his left hand to the side of his head, cocks his index finger into the barrel of a gun, “Boom,” he simulates the sound of a bullet as he pulls the trigger. He nods.

“Oh, well, tell me about that,” I say, surprised, concerned that it’s my own questions, in part, causing him pain.

His eyes water. “Hard,” he says. He opens his mouth and puts his hand up to it, waving as if words will tumble downward but only finding silence. “Hard,” he says again finally.

“Hard to speak—obviously,” I half-stutter.

“Yeah,” he says with a sigh and raised eyebrows.

“Hard to find the words,” I answer.

“Yeah,” he nods, falling again into a silence.

I end the interview after just 5 minutes, shutting off the camera, concerned that I've done little more than draw James's attention to his difficulty in answering my questions: failing to provide and encourage using ways of communicating beyond language. Though I have invited James to use any modes he wants to communicate, I have not used those modes myself, normalized drawing or using images as I communicate, even inviting him to show his life book. I have highlighted his difference, his "deficit." Rather than supporting my questions with other modes, I asked still more questions.

In addition to putting James in a frustrating communication situation, I also left the interview with much less information than I could have by more fully supporting James's multimodal communication. Fearing that I would interfere with James's responses, influencing him to answer in certain ways or even answering for him, I effectively did a disservice to James and to the other persons with aphasia who I interviewed by failing to provide other communicative means: written choices, access to artifacts or other symbols, or more time for processing. Notably, interview subjects appear to be deferring to a talk-centered interview, choose largely not to communicate with writing or other modes – and struggling, like James, to answer in speech. One interviewee, Bill, though he frequently uses writing in conversation, does not initiate writing to respond in our interview. I suggest that the accepted understanding of interviews as oral conversation demands that interviewers purposefully make their interviews multimodal.

**Tool #2: Accessible Interviewing**

From the lessons of the brief interviews that I conducted in my first phase of data collection and building from work in disability and qualitative research with language complications (Egan et al.) I developed a second set of life history interviews with accessibility

as a central concern. The interviews took place in a few stages. First, two weeks prior to the interview, I provided participants with paper and electronic copies of an aphasia-friendly interview protocol, listing the questions in clear, direct sentences (Egan et al.; Kagan et al.). I invited participants to prepare for the interview in any way they would like: by looking over the questions but not recording any responses in advance, by writing answers to the questions, by gathering writing or reading materials from their past or current literacy practices to use as helpful artifacts to answer questions, by recording responses on audio, by drawing in responses, etc. We then met for an in-person interview at a location in which the participant feels most comfortable or to which he or she has convenient access: a private meeting room at a local library or in the participant's home.

To aid in our communication, I invited participants to bring any answers they prepared for the interview questions and any artifacts of literacy—any reading or writing tools or examples that they used before and after acquiring aphasia so that we can talk about them during the interview. These artifacts could be writing they've done before and after aphasia or a laptop, I-Pad, or Kindle, etc. If we meet at individuals' homes, they may also choose to show me literate spaces including office areas where they often read and write.

Participants could also choose to bring a close communication partner (a friend, family member, caretaker whom they communicate with on a regular basis) to the interview. That person would be present to help support communication, mitigate communication breakdowns, and otherwise make the participant comfortable, but not to answer questions *for* the participant. I have chosen to make the presence of a communication partner an option, not a requirement, because—while a close communication partner may be an integral part of a person with aphasia's communication practices and support system—I wish to respect the independence of

the persons with aphasia. Having a close communication partner present will be an option to improve accessibility, but not a limiting—or potentially demeaning—requirement (Egan et al.).

Other disability-aware methods speak to a need for flexibility. "Crip time," in particular, acknowledges the various needs of disabled individuals who deal with chronic pain and fatigue (Price, *Mad*). People with aphasia who have survived strokes and other brain injuries often experience fatigue from lengthy conversations. To address that complication, I emphasized to participants that they could choose to take a break at any point or to stop the interview and pick up at another time. I also informed participants they may skip any question that they would like to, and that they should feel free to take their time to answer or even return to a question later.

After the initial interview, I provided participants with a transcript of their responses, and they may choose to add to, redact, or otherwise change their responses in a two-week time period. After their review, we will meet for a follow-up interview for participants to explain anything they revised and to ask me any questions that came up for them in reviewing their answers. I will also ask any questions that came up for me while transcribing and, finally, will ask for input from participants on the interviewing process itself. Following Paterson & Scott-Findlay, Egan et al., and Parr et al. (*Talking*), I believe that persons with language disability should have a say in effective, accessible research design.

**Successes and Complications of Working toward Accessible Research Design**

The interviews I conducted with Bill, a former commercial pilot, highlight several successes. In 6 hours' worth of two interviews with Bill, he offered rich responses as performances/gestures explaining a childhood avoiding reading and writing, including the humiliation of standing in front of his class during a spelling bee. He showed me documents, including maps tracing his family genealogy. He also showed me his computer, taking me

through examples of internet browsing he does, especially related to hummingbirds, on which he has compiled 6 large binders of images and research. These were especially rich interviews drawing on numerous artifacts. Bill also drew various images, including an airplane, and he wrote down words and numbers, including his SAT scores as he explained his life-long aversion to English.

What's complicated here is that this process takes time—6 hours for these interviews, including a little over 90 minutes of sitting alongside Bill at his computer. It also takes trial-and-error to work out communication preferences and most useful modes. I had the luxury of knowing Bill from a previous memoir group, so I knew a great deal about his communication preferences and needs. I also had a chance to interview him briefly in relation to the multimodal memoir group before our longer life-history interviews. In that earlier, briefer interview, I learned that, though he frequently writes in conversation, he did not initiate writing to respond in our interview conversation—suggesting a need to challenge oral interview conventions, inviting and normalizing the use of multiple modes of communication.

I also interviewed Julie—a former medical secretary, whom I met for the first time at our interview. That discussion benefitted from Julie's iPad, examples of Powerpoint slides she had been putting together telling about her life experiences and life goals in an aphasia support group. Julie also frequently wrote down words in a flip book that she carries with her in her purse at all times. I, too, wrote words to communicate and clarify my ideas. Admittedly, because I was only meeting Julie for the first time at our interview—and because we faced substantial communication barriers (particularly because I knew little about Julie's communication style before we met), I had significantly less information about her life history than some of the other participants.

It's clear to me that resources such as documents, artifacts, and materials related to the research topic are all helpful. Also, creating shared resources together in conversation—drawing, writing down words or numbers, and gesturing—are all important parts of communication for both interviewees and interviewers. Understanding the interviewer's role, too, as not transparent, but as a key part of making meaning together is an essential acknowledgment for qualitative research—and vital in foregrounding access for participants. The resource of time is also invaluable—though sometimes a great deal to ask for from participants. Finally, including communication partners may be an especially useful resource, but below I offer an extended discussion on how that practice should be conducted sparingly, with clear guidelines for all participants, and by taking into consideration their effects.

***Communication Partners: Supports and Interference***

Seven of the seventeen interview participants involved in this study chose to bring a communication partner to their interviews: spouses, mothers, and a sister. For many, the communication partner acted as an emotional and communicative support. "[P]arents, advocates, and/or committed caregivers who know the disabled person well," argues Cynthia Lewiecki-Wilson, may be understood to be co-participants in co-constructing communication or "rhetoricity"—the capacity to be understood as capable of being persuasive (161; Price, *Mad*; Prendergast, "On the Rhetorics"; Owens, "Confronting"). In her framing, when disabled individuals "do not speak or communicate through alternative technologies, 'listening' could be understood as thoughtful attention to the disabled person's sounds, habits, moods, gestures, likes, and dislikes" (161). My desire to give people with aphasia the option to bring a communication partner to interviews stemmed from this perspective. Intimate communication partners may be a resource for people with aphasia to get their ideas across, making gestures, sounds, and other

communication patterns understandable to me as the interviewer (who is simply not as familiar with their unique forms of communication).

People with aphasia often directed their partners to share relevant information, adding a word, accessing photographs, and more. Throughout her interview, Noreen writes and shows words to her sister Sheila who Skypes with us during her interview, encouraging Sheila to say the words aloud and sometimes elaborate on them. For instance, discussing what their parents did for a living, Noreen writes down "Wolf" and shows it to Sheila, who shares "Wolf. That's part of the name" of their father's company, and then goes on to share that full name as Noreen nods. Together, the two co-construct meaning about their family's history. Similarly, Gary directs his wife as a communicative resource, saying "Show her the picture" to have his wife, Terry, show me a picture of their grandchildren in response to one of my questions—a move that takes ownership over the direction of our conversation.

In addition to offering a resource to co-construct meaning, communication partners helped to support communicative confidence—as partners acted as advocates for people with aphasia's communicative needs and for the sharing of significant histories and strengths. Bill's wife, Rita, for instance, supported Bill's confidence. Prior to our interview, she encouraged Bill to get out his work on family genealogy and hummingbirds to share. Including communication partners like Rita also offered a great deal to the study, simply encouraging a number of people to participate who would not have come into a room alone with me to discuss their histories with reading and writing. Gary's spouse, Terry, also provided emotional support that helped in the stresses of the communication necessary in the interview. "I had a [sigh] I don't know what to do. I've lost it again," Gary answers in frustration to one of the interview questions. Terry,

supporting Gary, both reassures him and brings up other communicative modes: “That’s okay. Do you want to write it?”

A particularly interesting version of this kind of communicative support occurred in communication partners acting in the role of interviewer, rephrasing questions to make them more understandable or to encourage their partners to share. One example occurs here, in a conversation with Gary and Terry:

E: So, now I guess, after the stroke, is there a time when it's easier to read? [pause] Even a time of day or a certain, like I said if text is big. Does anything make reading easier?

Gary: [sighs] I don't know. [pause]

Terry: So, if you were going to do the receipts. I'll ask this question, if you were going to do the receipts, doing them in the morning or the afternoon would be easier? Right when you wake up?

G: [gestures pointing downward] This one. The day.

T: Right when you wake up?

G: Yeah.

Terry’s questions hone in on a particular kind of reading that Gary does. Drawing on her knowledge of Gary’s literate practices related to the restaurant they co-run together (and which came up only very briefly in our previous question), Terry narrows the question. She also further refines the question of time of day to the more concrete “morning or afternoon,” which Gary is able to pick up on with a pointing gesture that she then confirms as “morning.” The communication partner’s shared life experience and context brings additional resources to the interviews—not for speaking for or attaining “more accurate” responses—but as a

communicative resource, much in the same way as other communicative modes outside of speaking may become useful in interviews.

Still, while they are often emotionally and communicatively supportive, partners, however (often with the best intentions to help their loved ones), did engage in answering *for*. They privileged language, interrupted silences to offer a quick response, or spoke over their aphasic loved one. For example, Bob—a former grocery store manager who lives with aphasia after a brain tumor—is often interrupted by his wife, Pam during our interview. At one point, Bob loses his train of thought as Pam speaks: "I don't remember. I was going to say something, and I lost it." "I'm sorry. I kind of rushed him along," Pam responds. Patty, the wife of Robert—a former pharmacist whose stroke caused aphasia two years before our interview—is very quick to interrupt silences to add a word, response.

**Conclusion: Implications for Embodied and Accessible Research Design**

I had one primary aim in designing this study: doing research that accounts for complexly embodied communication and literate action performed by people with diverse bodies and minds. To reach that objective, I created an "Embodied" and "Accessible" research design. The embodied portion ensured that, to fully assess how individuals develop literacy across the lifespan and practice it in-the-moment, multiple methods were necessary contributors to this study. The second portion—accessible methods and methodology—served as the backdrop of this research, reflecting its spirit of access and co-production (discussed further in Chapter 5). Although illustrated consent forms, multimodal forms of communication during interviews, and communication partners did not provide perfect conduits for accessible participation for every person with aphasia in this study, these practices reflect the work of access that is necessary for

truly inclusive research. That access work in research is an obligation and that our research designs are not neutral are primary findings and contributions of this study.

# Chapter 3

## Literate Misfitting: Disability Theory and a Sociomaterial Approach to Literacy

"I opened the book and started to read…I COULD NOT READ. It was like my eyes would not cooperate….Allthewordsrantogether. I was so scared that I said, 'Oh my God, I can't read.' I must have said it louder than I thought because my waiting was over." Jean—a special education teacher for over 25 years supporting students with reading and writing and an avid reader and writer herself—writes these words four years after a stroke sent her to the emergency room and she found her "normal" literate practices completely overturned. Jean's memory marks her first realization that she had acquired aphasia, a disability affecting the production and comprehension of language, caused by stroke or other brain injury and creating a variety of challenges in speaking, writing, and reading.[3] Although Jean received the medical attention she needed in these alarming moments, she found that her literacy practices had been permanently changed. While by force of habit she expected it to, her body—her eyes—could no longer make sense of the book, a material of literacy used by Jean throughout her life and career. Aphasia presented to Jean what I am calling a "literate misfit"—a conflict between her body, mind and the materials of literacy. In this chapter, I show how that conflict sheds light on how the relationship between the embodied, material, and social aspects of literacy operate on all writers, disabled and normatively abled.

To make this argument, I draw from my life history interviews with people with aphasia, focusing in on the accounts of eight participants in particular. Like Jean, others also experienced losing control over body, mind, and materials. After aphasia, everyday literate practices that seemed "just normal" or automatic, such as reading a book in a waiting room, are uncomfortably

[3] Aphasia advocates importantly distinguish between "intelligence" and "language." That is, language causes barriers, but individuals' ability to think, process ideas, and indeed communicate in a range of non-verbal modes, remains intact. See Parr, Byng, and Gilpin; Shadden, "Aphasia as Identity".

disrupted. Dense newspaper text runs together, obscuring words and meaning; handwriting no longer looks like the writer's own; ideas feel "squashed"; reading requires re-reading. And individuals' sense of their literate identities alters as well. "I did, I tried to, [mimes reading] I can't do it. I can't read it," former pharmacist Bob explains. "Frustrating. Absolutely, positively frustrating," says former grocery store manager Robert of reading and writing after aphasia. "I don't have a flair to do it," former high school English teacher Judy says of writing after aphasia—explaining that she has "left the writing behind." What does this misfit between body, materials, and social expectations around literacy mean for the writing of people with aphasia? And what does it mean for understandings of literacy more broadly?

In addressing these questions, this chapter, and my dissertation more broadly, contributes to a recent move in Writing Studies to bring the social and material aspects of literacy into closer conversation. A social understanding of literacy foregrounds how within economic systems, power relations, and everyday experience literacies are valued or devalued and how literate subjects are differentially able to acquire, use, and mobilize those literacies (Street; Heath; Gee). Material approaches to literacy direct attention to how literacy is facilitated by tools or technologies such as pencils, paper, keyboards (Haas; Baron; Syverson; Prior & Shipka; Pahl), and, as I will underscore, the body (Haas & Witte; Fleckenstein; Purcell-Gates; Lindgren; Owens & Ittersum). Literacy activity theory, particularly as developed by Prior and Shipka, aptly encapsulates this materiality as "the dispersed, fluid chains of place, time, people, and artifacts that come to be tied together in trajectories of literate action" (180).

Theorizing literacy as "socio-material" exposes how social values, expectations, and trends are "imbricated" in the very materials of literacy and how the two "interanimate each other" (Vieira, "Writing"). The "familiarity of 'the social'" in Writing Studies has often

prevented researchers from articulating how the social nature of writing is, in fact, deeply material, argues Laura Micciche in a recent issue of *College English* on "Reimagining the Social" in composition studies (498). Failing to account for how writing is enabled by a range of material realities keeps us from fully articulating the social nature of literacy (Micciche 498; See also Brandt & Clinton; Prior; Shipka; Syverson). Of course, the materials of literacy are themselves socially constructed, weighted with "assumptions" about texts and the tools necessary to produce them (Haas 229). The social and material aspects of literacy are inseparable.

The crucial takeaway for my purposes here is that while the social and material aspects of literacy come together to facilitate literate practice, learning, and identity, they just as often exclude, hinder, and block. For instance, scholars studying the radically different contexts of the colony (Canagarajah, *A Geopolitics*) or the slave quarters (Cornelius) illustrate the uneven allocation of material resources, including papers, pens, light, and time. Without paying attention to the socio-material dynamics of literacy, we, too, are less able to account for differential consequences and benefits—why some individuals are able to gain economic and physical mobility, why some are able to claim a literate identity, and why others cannot (Vieira, "American"; Cornelius; Brandt, *Literacy*). To account for the social dynamics and consequences of literacy, we must attend to the material.

I contribute to this discussion of literacy as socio-material the concept of literate misfitting—or the conflicts readers and writers encounter when their bodies and minds do not fit with the materials and expectations of "normal" literate practice. Misfitting, explains disability theorist Rosemarie Garland-Thomson, "occurs when the environment does not sustain the shape and function of the body that enters it" ("Misfits," 594). For persons with disabilities, these

moments of misfitting occur when their bodies and minds conflict with materials built for the "able-bodied." I contend that disability studies, with its commitment to articulating the interdependence of the social and the material aspects of lived experience, helps Writing Studies to sharpen its understanding of how writers' bodies matter (Haas & Witte; Owens & Ittersum) specifically by drawing our attention to embodied experience as a way of knowing—as theory in and of itself (Siebers 14). Disabled writers, in particular, through embodied literate practices, "challeng[e] our assumptions about literacy and cal[l] attention to the physicality of literate acts" (Lindgren 99).

In this chapter, I draw from literacy history interviews I conducted with persons with aphasia to show how, in everyday literate activities, persons with aphasia 1) draw on the materials of literacy to take on various uses or aspects of their bodies and minds,[4] and 2) use their bodies and minds to take on various uses and aspects of the materials of literacy. For Writing Studies, these strategies deepen our understanding of the integral role of the body in the practice of reading and writing—pointing to the body itself as a technology of literacy. These strategies reveal an overlap between bodies and materials of literacy as the two share work and supplement one another in literate practice. However, I also show how, despite these productive strategies to read and write in the face of literate misfitting, social pressures from what individuals understand as "real" reading and writing push back on and sometimes limit individuals' new strategies and, in turn, their literate potential. The accounts of literate misfitting and the innovative strategies of persons with aphasia to address that exclusion show how the

[4] Throughout, when I use the term "body," I refer to the inextricable workings of body and mind, which are "not two distinct substances but somewhere in between those alternatives" (Grosz xii). In Writing Studies, I follow Haas and Witte's assertion that, when discussing the practices of literacy, "the distinction between the body and mind is a specious one" (416). In this way, my use of "bodies and minds" and "bodies" is consistent with Margaret Price's term "bodymind," which reflects "how mental and physical processes not only affect each other but also give rise to each other," how they "act as one" ("The Bodymind," 2).

imbrication of the social and the material aspects of literacy both enable and constrain literate practices and identities. Literate misfitting, then, reveals both how persons with disabilities are often excluded from normative conceptions of literacy and how their experiences adapting and innovating in the face of literate misfits offer vital insights into the social and material aspects of literacy.

**Studying the Social and Material in the Literate Practices of People with Aphasia**

The argument I present in this chapter is based on an analysis of the 17 in-depth literacy history interviews I conducted with persons with aphasia. The individuals I discuss in this chapter are a focal group of eight interviewees who elaborated on strategies for reading and writing after aphasia at length. All of these individuals experienced strokes, aneurysms, brain tumors, or other traumatic brain injuries that caused aphasia and, for some, weakness on the right side of the body. Among them, Jean, Sandy, and Judy are former teachers responsible for instructing about aspects of reading and writing. Jean was a special education teacher for over 25 years in elementary to middle school. Sandy taught first grade for over 25 years, and Judy taught high school English for 25 years and then worked as an alternative education instructor. Margie was a keypunch operator and data specialist at a manufacturing plant until the 1990s, then retired and now works part-time as a theatre usher. She is a voracious reader. Rose's career path shifted from computer programmer to chef to, after her stroke, tai chi and yoga instructor for senior citizens and stroke survivors. Robert worked up from grocery bagger to regional supermarket manager and now offers presentations encouraging aphasia awareness around the region. Bob was a pharmacist. John became a marine, worked overseas interpreting Morse code

transmissions of international intelligence—then worked domestically to manage security needs for a couple of corporations.

In order to understand how aphasia affects everyday reading and writing practices on material, embodied, and social levels, I asked participants to describe reading and writing before aphasia, soon after acquiring aphasia, and at the time of their interviews. Participants recounted childhood reading and writing struggles and successes. They recalled the role of reading and writing in their work and in hobbies. They also explained differences in reading and writing after aphasia, what makes reading and writing more or less difficult, and bodily and material strategies for navigating challenges and changes with reading and writing post-aphasia.

In this chapter, life history interviewing offers a window into under-acknowledged perspectives about post-aphasia writing and reading practices, matching my research goal to explore how the social, material, and embodied components of literacy intertwine and conflict in everyday literacy practices for people with aphasia (Brandt, *The Rise*; Duffy). Using grounded theory to analyze these interviews, I coded for practices; tools, materials, and resources; and motivations (Charmaz, *Constructing*). Through several rounds of coding, myriad themes emerged, one of which I will discuss in this chapter: persons with aphasia experience a conflict between their bodies, minds, and the normative materials and expectations of literacy—or literate misfitting.

## Literate Misfitting: A Disability Theory for Writing Studies

As I discussed briefly in Chapter 1, one of the primary contributions of disability studies has been to advance a social model of disability, revealing how disability is not a matter of individual impairment but is caused by environments built for “able” or “normal” bodies. The

very existence of stairs, for instance, assume, by their very design, bodies that can climb them and excludes people in wheelchairs from entering various spaces. Many disability scholars have argued, however, that the social model "erases the lived realities of impairment" and, therefore, disregards the embodied experiences of people with disabilities (Kafer 7; See also Shakespeare; Davis; Siebers; Snyder & Mitchell; Wendell, "Unhealthy"). The disability studies concept of "misfit" or "misfitting" responds to those critiques by foregrounding the body as a simultaneously social and material source of meaning-making. It is the *fit* or *misfit* between bodies and materials that highlights how both are weighted with expectations. A misfit, says Garland-Thomson, is "an incongruent relationship between two things: a square peg in a round hole. The problem with a misfit, then, inheres not in either of the two things but rather in their juxtaposition, the awkward attempt to fit them together" (592-93). Bodies and materials, that are both socially constructed and material, affect that fit or misfit.

I draw upon this work to offer the concept of literate misfitting, which makes two primary contributions to a socio-material perspective of literacy. First, it reveals that, due to ideologies about able bodies built into the technologies of composing, the very materials of reading and writing may misfit with and, therefore, exclude individuals with various kinds of bodies and minds. Unequal access to literate practices and identities, thus, is perpetuated by "material configurations misfitting with bodies" (Garland-Thomson 602). For instance, the material design of keyboards assumes hands and fingers that type; pens and pencils presume a grasping hand; the printed page aligns with eyes that take in the visual, brains that process and produce language—without pain, without delay. In the terms of a socio-material perspective of literacy, literate misfitting makes clear how assumptions about "normal" bodies and minds inhere in the very materials of literacy, sometimes constraining individuals' literate practice. This

relationship between "body and world" (Garland-Thomson 594) can be understood as a dynamic "choreography" as bodies and materials "come together in time and space" alternately fitting and misfitting, enabling and constraining literate action and identity (Garland-Thomson 595).

Second, literate misfitting develops embodied situated knowledge for individuals who experience it—vital perspectives that can inform literacy studies. The "productive power of misfitting" arises from what Jay Dolmage terms "metis"—a distinctly bodily intelligence" (233) and its ability to "yield innovative perspectives" about bodies, materials, and the ideologies that suffuse and constrain them (Garland-Thomson 604). In this way, the embodied experience of disability produces "theory" by exposing the "dominant ideologies of society," rendering them "open to criticism" (Siebers 14), and pushing toward more just "politics and praxis" (Garland-Thomson 597). By studying how individuals experience, respond to, and develop new strategies from literate misfitting—such as the persons with aphasia in this essay—Writing Studies stands to gain new perspectives regarding how the embodied, material, and social intertwine and come into conflict for readers and writers of all abilities. Specifically, we see how individuals draw on the materials of literacy function as a prosthetic for the body and on their bodies themselves as technologies of literacy. While social conceptions about "normal" literacy often keep individuals from valuing the new literate practices they have developed, the experience of literate misfitting also sometimes incites individuals to critique and revise normative practices and expectations of literacy.

**Literate Misfitting: Negotiating Materials and Bodies**

In this section, I analyze the experiences of literate misfitting that arise for readers and writers with aphasia in everyday literate practices as the needs of their bodies clash with the

affordances of the materials/technologies of literacy they encounter. I track both the exclusionary nature of these embodied and material conflicts and the knowledges, insights, and new perspectives persons with aphasia develop as they address literate misfitting. I am especially interested in the many creative strategies readers and writers use after aphasia to comport their bodies and materials/technologies beyond their "normal" uses. In each strategy, the enmeshment between bodies and material/technology is apparent as individuals alternately attempt to adapt the materials of literacy and their bodies to take up various functions of one another. That is, in individuals' strategies, the body takes on various uses or aspects of the materials of literacy, and the materials/technologies of literacy take on various uses or aspects of the body. These strategies are adaptive and inventive, emphasizing the interdependence of body and literate materials/technologies. In what follows, I examine the exclusionary experience of literate misfitting and its productive insights for persons with aphasia in two sections: *the materials of literacy as prosthetic*[5] and *the body as a technology of literacy*.

***1) Materials as Prosthetic***

After aphasia, in response to literate misfitting, individuals draw on various technologies or materials of literacy to suit the needs of their bodies and minds. In this way, materials of literacy serve as prosthetics, or supplements, to individuals' bodies. Analyzing these responses to literate misfitting reveals how intertwined technologies of literacy are with individuals' bodies: how, socio-materially, the body—as material with particular affordances and as socially constructed—inheres in the design and use of the materials of literacy. I detail, then, various uses of materials to take on functions of what the body can no longer do, including using writing itself as a material technology to aid in other literate practice.

Adapting with Materials

[5] See also Jay Dolmage's discussion in *Disability Rhetoric* of rhetoric as prosthetic.

Persons with aphasia draw on adaptable materials of literacy—including electronic books and readers—to meet their bodies' needs. Jean explains that, after aphasia, a misfit occurs between densely printed text and her body and mind's ability to separate words and decode language. "I can't separate the letters from one letter to letter," she says. To mitigate the misfit, Jean uses literate materials as prosthetics for her bodily needs. Using a Kindle or an iPad, she meets the needs of her body: "I have to have it big. I have to have it bold." Having text read aloud to her by her iPad also enables Jean to meet the needs of her body. "I'm really bad at nonfiction like an article or something," Jean explains, "and I was doing some research this week, and I read it and I was like, 'Okay, my brain didn't understand it, so I highlighted it and it read it to me and I was like 'Ah, now I get it!'" In this scenario, Jean identifies the material realities of her body ("my brain didn't understand it" from reading with her eyes) while welcoming, making use of, and negotiating technologies that provide access to an otherwise inaccessible reading experience. These material strategies help Jean manage literate misfitting and reflect her acknowledgment of her agency around own literate practice. "I don't get as many words on a page, but who cares," Jean says, noting, but rejecting social norms built into the materials of texts.

Electronic tools also help individuals address certain physical needs. Margie explains, "I use my Nook now. I like it. I can put it on top of a little pillow and I put it on my knee. I don't have to hold it. Because my hands sometimes, especially now that I'm getting arthritis in my hand, it's hard to hold a book for very long. So I find it's easier to do that. And I can adjust the print. I can make it bigger if I need […] and put more space between the lines." Indeed, the design of books assumes much about what a reading body can and should do: they must be held open to particular pages, pages that must be turned; un-adjustable print must be held at a certain

distance from one's eyes. An e-reader enables Margie to more closely fit her body's needs. These strategies for altering the materials of literacy to fit the needs of bodies and minds should remind literacy scholars and everyday readers and writers that no materials of literacy are neutral; built into all materials are expectations for what bodies and minds should do.

Using materials prosthetically to meet her body and mind's needs has caused Judy—a former English teacher—to completely rework her understanding of what embodied and material practices are involved in reading. Describing a "year and a half crying" after her stroke, Judy recalls "trying to read" and finding "it wasn't favor." The "unfavorableness" that Judy describes regarding her reading practices soon after aphasia stems from the misfit between normative materials of literacy and the needs of her body after aphasia. She recounts the "the real small writing" of the novels she attempted to read. They were "very tiny, and I couldn't remember, you know," she says of encountering small text and having difficulty comprehending the words. That experience of literate misfitting caused Judy to stop "reading at all." It was not until 10 years after her stroke that Judy found technology to make reading possible again. She heard about the Kindle Fire electronic book reader. "It's got words and [points to eyes and ears, respectively] words and listening. And that's very good. Very good," she explains. Judy uses the feature that highlights words as it reads aloud and slows the speed of the read-aloud feature. "Listening [points to ear] and reading [points to mouth]. Oh boy. I love that book," Judy says. By offering multiple modes to the process of reading, the technology of Judy's Kindle reader acts prosthetically to fit her body's needs—in this case, as Judy points out, both her eyes and ears, combining listening and reading. When asked "what is different about reading after aphasia?" Judy answers with her Kindle reading practices thoroughly assimilated into her "normal" reading. "I have to make the printing big. I can listen, and I can read, and um, [shrugs] you

know." Judy's matter-of-fact response is telling: the practice of reading/listening using her Kindle is a quotidian one after four years of using the technology. The materials of reading have been reorganized here to include orality and, moreover, to fit Judy's body and also her definition of being a literate, reading person.

Reorganizing materials of literacy to adapt materials/technologies to bodies was Jean's full-time job as a special education teacher for almost 30 years. When asked about teaching strategies she used for supporting students with reading, Jean responds by grabbing a piece of paper and using it to cover up the text and reveal one line at a time: "We take a little thing about the size of a book and put it on there [all but one line at a time], and they could read one sentence and then cover the top and do one sentence at a time." The materials of literacy, indeed, simply do not always fit for individuals' bodies and minds. As Jean recounts, sometimes viewing multiple lines of text on a page simultaneously or working to comprehend lines of text printed close to one another can overwhelm or confuse readers. Jean as a special education teacher explains modifying the materials of literacy to fit the needs of students' bodies and minds. She explains that these strategies vary based on the students' needs—ranging from using colored paper to recognizing that "some people read better with different lights." Ultimately, says, Jean, "you do everything you can." In the dynamic "choreography" of misfitting (Garland-Thomson 595), material strategies operate as prostheses for the body in literate practice—varying depending on individuals' needs and on the particular affordances of the material technologies.

And as Jean's work with colored paper and blocking off text demonstrates, adapting materials to meet the needs of individuals' bodies in reading needn't draw on digital or electronic technologies. Instead, adaptation calls most fundamentally for careful attention and openness, doing everything you can—or "attuning" oneself to the particular needs of the situation (Lorimer

Leonard). Rose, for instance, is attuned to even the minutest of details about the technologies of writing instruments and how they fit or misfit with her body.[6] When asked what makes writing harder or easier, she answers, "The pen makes a big difference. To have a good grip on it." Out of a container full of dozens of pens, she points to one with a "nice grip," "nice fine point on it," and "good weight at the top." While she says she has always been aware of these details in writing implements, Rose says she is even more attentive after aphasia "because if I'm going to writing something out, I want to be able to read it. That's an issue." This "issue" of understanding, getting meaning across to self or others, motivates Rose, Judy, and other aphasic individuals drawing on technologies of literacy to address the needs of their bodies and minds in literate practice.

This commitment to fitting the needs of bodies and minds by adapting materials/technologies continues for Jean after aphasia as she designs an "aphasia-friendly" website featuring resources to support aphasic individuals. Jean is inspired to create this website from a particularly vivid experience of literate misfitting that occurs for her when she tries to find information about aphasia online. Jean soon realizes that most online texts about aphasia are inaccessible, or no longer fit the needs of her body and mind after aphasia: they are full of dense blocks of text and complex sentences. "I went on the website to the National Aphasia Association," Jean says. "I couldn't read it. There's no cues—nothing to tell me. So I went through some others. Nothing. […] And so after all I went through, I couldn't find anybody to help me." The material design of the website, then, misfits with Jean's body and mind, and excludes Jean and other persons with aphasia from accessing the information most relevant to

[6] See Lorimer Leonard's concept of "attunement" for a related take on writers navigating and rhetorically deploying their language repertoires, and see Prior & Shipka's ESSPs (environment selecting and structuring practices) for parallel perspective on how writers navigate within, and adapt to, their environments.

their experience. Expectations about how individuals' bodies process language are built into the website's design, ironically and painfully, in a way that misfits with the bodies and minds of Jean and other people with aphasia.

Such misfits, stemming from the materiality of a website designed for individuals with certain kinds of bodies and minds, have tangible social consequences that exclude and isolate individuals. As a result, Jean feels not only frustrated, alone, and excluded, but also feels compelled to critique the theory of an autonomous literate person inherent in the website's material design:

> There's nothing that a person that has aphasia can read. You're supposed to have a caretaker; well my caretaker was very busy […] I had to do it myself, and there's many people like me. What if I was single and had a stroke and no one was around, you know?

Jean's experience of misfit offers insight into the normative assumptions about literacy built into this particular website: that a reader is autonomously decoding language or has the support of an autonomous, able-bodied reader. And access to literate support, Jean observes, is disproportionately available. Jean's partner works full-time on a dairy farm and is not available to care for her full-time. What's more, before aphasia Jean supports her partner, who has dyslexia, in his own literacy. Such a diversity of bodies, minds, and their literate needs misfits with the material design of the website. This experience of literate misfitting stimulated Jean's "awareness of social injustice" as Garland-Thomson suggests (597). Responding to the exclusion of persons with aphasia from online information regarding their own experiences, Jean co-designed her own "aphasia-friendly" website. "I wanted to do my thing so that anybody could read it," Jean explains. Together with a Masters student in communicative disorders who works

with a stroke support group Jean attends, Jean created content in short sentences, recorded and accessible aurally. Jean's experience of being excluded from accessing information online developed her situated knowledge about creating accessible websites for people with aphasia, and she turned that knowledge into action by designing her own site.

Adapting with Writing as a Technology

The potential of writing as a technology to move language and meaning across time and space is well established (Olson 137). Although social practice theories of literacy rightly check claims for writing as a technology that increases intelligence and builds complex societies, writing indeed technologizes language, making it material, and often aiding memory through listing and recording (Goody, "What's in a List?"). That use for writing spans across most participants in this study: making grocery lists, planning for complex tasks, or simply trying not to forget ideas. Robert's speech therapist convinces him to "write down the day's activities" to "help me with my memory." And John uses a binder with a day planner, address book, and space for notes. He calls this resource his "auxiliary brain," an external kind of "brain" composed of literate acts and materials to support all daily activities.

Writing, though, for people with aphasia, acts as a technology to more than memory; it also operates as a technology to help support additional literate tasks. In addition to using various materials and technologies—from electronic readers to colored paper to block out sentences—individuals with aphasia also take up writing itself, whether it's a few letters, words, sentences, or more, as a technology. Almost all of the individuals in this study use writing as a way of working through ideas or as a preliminary draft for other writing—from using text as a template to re-copy to drafting in handwriting. Some engage in a process of copying or transcribing writing from example texts. Bob explains that he sometimes copies thank-you notes that his wife

Patty has originally written into his own handwriting: “word by word. Copy, copy, copy. Even I don’t read it.” The social practice of writing thank you notes, says Patty, is a “tradition” in her family and one that both want to fully participate in. Others write out rough drafts. Jean describes always writing before typing because she “like[s] the feel of actually writing. It’s more calming.” Also, she hand-writes preliminary drafts because she doesn’t “want to commit it to my laptop until I’ve got it what I want to say.” Writing on a computer seems to have a sense of permanence for Jean, and certainly the idea that there is a distinct “feel” to writing by hand shows the close ties between bodily, social, and material practices of handwriting and literacy broadly.

In the same way that Jean likes to work out drafts of her sentences in handwriting before transferring them to her computer, Judy explains that she always hand-writes (rather than going directly to typing). Before aphasia, she would often type first, but now handwriting allows Judy to work through many of the sentence-level concerns that arise in writing. Handwriting acts as a kind of technology for literacy, much like a pen holds ink and supports inscription. Judy offers an example of this process, explaining that she will write down, for instance, a series of sentences: "I play the games. uhm. I will play the games. uhm. I played the games." Judy changes tense and pronouns in this process—or identifies missing words. "Tense is the most common," she explains, "played or play or played you know... I cannot remember that, you know?" Judy also talks and reads aloud while writing down and changing the sentence. Even with these strategies, Judy says she doesn't always catch errors. This process is a long, laborious one. Like Jean explains, writing simply takes more time, but writing itself aids writing.

Whether using a sheet of paper to block out all the lines of text but one, having a Kindle read aloud, or using the very materiality of written text to develop more writing, persons with aphasia address literate misfitting by adapting the materials of literacy to the needs of their

bodies. These overlaps between bodies and materials point to the interconnection between, and, constant need for negotiation of, the varied aspects of literacy.

***2) The Body as a Technology of Literacy***

Developing New Practices

While people with aphasia address literate misfits by using materials prosthetically to take on roles of the body, they also use their bodies to take on the role often fulfilled by material technologies of literacy. Individuals use their bodies in new and innovative ways to make the materials of literacy work for them. As Owens notes in a discussion of the affordances and constraints of writing with voice recognition, or speech-to-text, software, "Any type of writing, regardless of the technology through which it is mediated, requires the body" ("Look Ma"). I argue that the embodied literate practices of persons with aphasia go one step further: the body acts as a technology, performing the functions of materials and taking a central role in literate practice. In this section, I track instances of literate misfitting that reveal the clash between people with aphasia's bodies and the "normal" practice and expectations of literacy. The socio-material concept of the body as a technology of literacy arises from the situated knowledge of literate misfitting and informs literacy theory of both how bodies and technologies overlap and how bodies are central in all literate action.

An avid life-long reader, Margie explains, "I loved reading and I still love reading. I read everyday." While reading after aphasia, however, Margie finds that the literate materials and technologies she previously used are now built for bodies and minds other than her own. She explains a vivid memory of reading soon after acquiring aphasia that highlights the misfit between her body and mind and materials of literacy:

> I remember trying to read like a TV Guide or a TV listing in the paper. I couldn't understand what it was saying. […] And then I realized that they wrote the words together. That they didn't leave spaces between the words because they didn't have enough room or something. And then, when I realized that, I put my finger on the words, and each one separate, and I could read it [demonstrates].

The reading material Margie encounters is clearly designed for a body and mind to visually and cognitively separate words out of tightly spaced lines of text, creating a misfit for Margie and preventing her from accessing the information she seeks. As Margie ruminates on the newspaper designers' desire to save space, it is clear that the assumptions of a "fit" or "normal" body and mind are also bound up with economic interests and built into the materials of literacy.[7] Newspaper producers minimize resources, keeping costs down and pushing on individuals' bodies to bear the labor of literacy. One of the greatest challenges in reading and writing that individuals encounter after aphasia is the need for more time to do the encoding and decoding work of reading and writing. That need slams against the fundamental expectations of neoliberal literate subjects: that they quickly and efficiently do the work of reading and writing. Conflicting economic interests and ableist views of the body are imbricated in the very materials of literacy—an insight offered by literate misfitting.

In response to the layout of the text, Margie uses her body to take on or interact with the material of the text. She puts a finger on each word to help her navigate it. In this way, Margie addresses the misfit between her body and the materials of literacy by employing her body in atypical but effective ways to navigate the newspaper. More than just using her finger to guide herself through the text, Margie uses her body to temporarily alter the material characteristics of

[7] See Prendergast; Prendergast & Licko; Mortensen; and Canagarajah, *A Geopolitics* for more on links between the materials of literacy and economic constraints.

the text, creating more spacing by covering the words with her finger. In this way, the body takes on a technological role. Even these relatively everyday moments of literate practice importantly remind literacy theorists and teachers that materials of literacy are not ideologically neutral, but are designed for certain kinds of bodies and minds under economic constraints and interests. And those social structures push back on the individuals who use them, necessitating Margie's bodily action.

Jean's use of her body to help her read after aphasia further clarifies the role of the body itself as a tool or technology of literacy. After her stroke, Jean feels "really bothered" by the changes in her ability to decode language and symbols. In response, she describes taking control of her own re-learning of reading: "So once I got home [from the hospital], I started reading word by word, pointing to it, and I couldn't get most of it, but I kept reading, and so, it wasn't until the fifth or sixth book that I started [to say] 'Oh my God, I'm reading!'" In this scene of reading "word by word," Jean draws her body further into the act of reading than she had prior to her stroke, pointing to each word as she moves her eyes across it. She explains the practice as coming both from her experience teaching students with diverse learning needs in special education programs and from her role as a parent reading with her young daughter, who insisted that Jean, "Follow the words!" with her finger. Rather than being bothered by the relationship between this bodily practice of pointing and its association with childhood literacy learning, Jean focuses on the necessity of engaging with the text through both her eyes and her fingers. In the first several months following her stroke, Jean fits this bodily reading practice between bouts of overwhelming fatigue. "I had about a 15-minute span when I could do anything. Then I went back to sleep, and then I would try again, but I couldn't push myself past my point [of fatigue] because otherwise I couldn't follow my finger," says Jean. Jean characterizes the movement of

her finger as essential to the act of reading; following her finger and following the ideas become inextricably bound. The practice of simultaneously putting her eyes on and physically pointing to words was necessary literate work for Jean. Using her finger to point to the words *is* reading. Jean's body acts as a technology, linking her—with eyes, brain, and fingertips—to the material text.

Embodied knowledge about the body as a technology of literacy similarly arises from the strategies Sandy develops to address literate misfitting after aphasia. A former first-grade teacher intimately familiar with reading and writing development in children, Sandy describes her experience of those processes after aphasia. She reflects that "so many processes are involved with writing." The processes—word retrieval, spelling, inscription of letters on the page, and more—that Sandy describes are understood in cognitive psychology to be natural or normal for bodies and minds. Reading and writing is linked to development and acquisition of discrete, increasingly complex skills over time, leading to independent and relatively effortless encoding and decoding of written language, or "automaticity" (Purcell-Gates et al.). In this perspective, there is no literate misfitting—just learners with deficient bodies and minds who fail to master the discrete, "increasingly complex subskills" (Kliewer and Biklen 1) that form a "literacy ladder" (Kliewer, Biklen, and Kasa-Hendrickson 175). The socio-material idea of literate misfitting contests this perspective.

Far from deficient, Sandy's experience of literate misfitting generates an embodied knowledge of language, literacy, and materiality. Sandy exposes the role of the body as a technology of literacy as she describes the misfit between bodies and minds and the very materiality of language. The supposed "naturalness" of language and the processes of writing are denaturalized. Word retrieval is difficult; then pronunciation presents challenges—especially

with multisyllabic words. Writing barriers, Sandy describes, arise at various points in the process. Specifically, she explains the value and challenge of creating a "mental picture" of words—the process of imagining the appearance or image of a word. However, many words are simply difficult to "picture." She explains, "when you have to find the word, sometimes you can't even picture [it]." And different parts of speech may be themselves more or less difficult to picture. She notes the challenge of picturing verbs, particularly "be" and "have," for instance. Or picturing prepositions—how do you picture "after," she asks? For the task of writing, Sandy explains, "You have to retrieve the word, then you had to if you can't picture it, then you have to […] spell it, then you had to remember how the letters."

The role of mental visualization of words themselves is a key step to writing for Sandy. She describes using her body and mind to create an internal image of an object (what we might think of as technologizing an idea, or rendering it material). Pictures—or mental images—of words are part of the process of retrieving words and letters to put those words together. This strategy of mental visualization is central to reading and writing, and she consciously fosters this process to make writing work for the needs of her own body and mind, developing a rich sense of what kinds of words lend—and don't lend—themselves to visualization. For this reason, Sandy explains much of her own post-aphasia writing as primarily composed of nouns: "I didn't have a lot of verbs. So I couldn't refer them. And then prepositions. Oh my God, even the a, of, over, it was like, oh my God. Just one sentence would take a long time." And she explains that she needed to work through each sentence completely and slowly: "I had to go one at a time. One word at a time."

Through these steps of visualizing words and grappling with parts of speech, Sandy develops not only new practices, but a deepened relationship to language and writing. Her body,

mind, and the materials of literacy blur together. Each word requires mental operations that make the language itself accessible and available for writing. Sandy draws on processes of visualizing, or making an image in her mind, as a kind of technology to make writing possible—a cognitive visualization strategy that operates in much in the way a material thesaurus might assist an individual in coming up with additional words.

Many other readers and writers explain how they address the mismatch between body/mind and materials by tuning the needs of their body/minds to those of particular literate tasks That is, readers and writers with aphasia explain assessing their available mental energy and engaging in various literate tasks accordingly—all as a way of considering and mitigating problems with fatigue. After aphasia, many people consider time of day to navigate their reading and writing tasks. John explains that he writes emails "pretty much every day," but specifically in the morning because, later on, especially in the evening, "I know my brain's not working good." Andrea—a former full-time psychotherapist recently returning to part-time counseling for women and children—carefully structures literate tasks across the day: writing in the morning; reading complex texts, such as journal articles from her field of psychotherapy; leisure reading like mystery novels in the afternoons. Bill—a former pilot used to overnight flights and reading on layovers—conversely finds himself more alert in the evening, at which time he does much of his internet research and reading on his family genealogy or his interest in hummingbirds.

Taken together, Sandy, Jean, Margie, and other people with aphasia all recount how they have extended, repurposed, or reimagined technological uses for their bodies and minds to adapt the materials of literacy that they find no longer fitting their needs.

Retraining Existing Bodily Practices

While the strategies above feature individuals developing new or adaptive ways of using their body/minds to navigate materials of reading and writing designed for "normal" body/minds, individuals also describe working to retrain their body/minds to do some of the work of literacy. Almost all of the interview participants, to some extent, referred to handwriting as a central practice of literacy—and one that requires retraining or strengthening of the brain and body.

Strokes or other brain injuries that cause aphasia commonly affect movement on the right side of the body, including the right arm and hand. Weakness or paralysis in the right hand may interfere with handwriting and typing. Many people report this physical change causing major differences in their post-aphasia literate practice. When asked to explain what stops her from making lists after aphasia, former high school English teacher Judy answers, "My right hand would stop me." While some stop writing altogether rather than learning to handwrite with their left hand, many—like Rose— discuss a complex and focused process of re-learning to write with their right hand or learning to write for the first time with their left hand.

Rose, a former computer programmer who later transitioned into a career as a chef, is concerned after her stroke at age 50, with training her left hand to pick up on the writing needs her weakened right hand can no longer accomplish and, then, strengthening her right hand to return to writing. After her stroke, Rose's long-time hobbies and interests—yoga, Pilates, and especially tai chi—have turned into a primary interest and career, teaching tai chi classes to stroke survivors and senior citizens. These commitments to mind-body connections, exercise generally, and the importance of strengthening the body and mind, inform much of Rose's outlook on life, including her post-stroke goals and her literacy practices.

For Rose, this retraining of handwriting ability happens against the backdrop of a continual need for exercise: the body and mind must be exercised in order to build up the skills

and muscles necessary for reading and writing. “Yeah, I've always felt like I've been a child since the stroke,” Rose explains. “And basically we're talking about skills. Skills of reading, skills of writing. And, you know, I am you know always aware that this, these are skills and they can be built up.” One way she builds these skills is through reading aloud, which “keeps my voice good because speaking is so much—practical with the muscles and such that it really is like anything else, it's a skill that you have to continue to build.”

The literate practice of handwriting must be built up. Describing a vivid memory of writing right or soon after aphasia, Rose explains, “I couldn’t write with my right hand, so I sort of picked up that old fun habit that I had learned to write with my left hand.” As a child, Rose worked to emulate her grandmother’s left-handedness, trying out handwriting with her non-dominant hand. But after the stroke she “had to do it for real. And yeah, I didn't like that. Because now, in addition to being not my own handwriting, it made me seem like I was a third grader because of my skill of writing.”

It wasn’t until “three short years” after Rose’s stroke that she decided she wanted to change the look of her handwriting, to “get writing again.” “Part of it is getting back the strength,” she explains. Over time and with repeated Pilates, yoga, and tai chi exercises, Rose describes building physical strength into her right hand, enabling her to exercise the muscles necessary for handwriting. Part of that exercise included practicing letter by letter with handwriting practice workbooks designed for children.

“You gotta practice,” Rose says, applying the advice of the yoga books she reads to her handwriting practice. “If I don’t practice, it won’t ever get better, and so that’s what I need to do.” As a developing tai chi instructor for other stroke survivors, Rose is especially disturbed by the decisions of others to give up on that practice. She speaks of one client who has recently had

Botox injected into her weak right hand to stop problems with tremors. Rose worries on behalf of her client: “how can I grip a pen when that’s been inserted in my hand?” For Rose, exercise, again, is essential to literacy. Literacy requires muscles, and they: “have to keep moving or they're never going to start moving.”

Practice and retraining of handwriting is central, too, to Andrea, who describes the emotional experience of writing for the first time after her stroke in her speech pathologist’s office. “I started with hieroglyphics,” she says of her handwriting, but her committed practice improved the quality of her handwriting. Expressing that she had long “admired a girl that drew block letters really fast,” Andrea explains that she began to “practice, practice a bunch.” Like Rose, Andrea purchased workbooks designed for children, filling up dozens of pages practicing the strokes of each letter of the alphabet again and again, “everyday, everyday.” Looking at the pages during our conversation, Andrea says she feels a sense of accomplishment regarding that work.

Practice for Andrea moved from repeated inscription of each letter of the alphabet to quickly inscribing full words and sentences. She began taking a series of notes at the continuing education seminars she was attending at a local university. “I took notes on the things that I learned”—and, through that process, Andrea describes greatly improving her handwriting. “I got good at it. Yeah, I got good at it.” For Andrea, every piece of writing offers an important opportunity to practice her handwriting. Post-stroke, she has begun getting up every day around 5:00 or 5:30 am to write in a journal on topics large and small, meditative writing about daily life, religious faith, and whatever strikes her. When asked if she prefers to write or type that writing, she explains, “No, I write first. I always write first. Block letters, yeah.” This is another vital opportunity for handwriting practice: “I like to practice my lettering,” she explains. “If I

don't practice, why could I get better at it?" As Andrea suggests, any and all writing needs are vital opportunities for practicing, refining, and improving handwriting.

**Literate Habits and Ideals: The Social Pushes Back**

As we have seen, the material and embodied strategies individuals with aphasia employ to address literate misfitting are inventive and very often quite effective. Bodies act as technologies; materials act prosthetically: the body is imbricated in the materials of literacy, and vice versa. As they work through literate misfits, individuals develop and share insights about the material and mental "processes" of writing; they rework literacy to include listening or pointing with the body. However, in spite of these insights and individuals' effectiveness, many persons with aphasia compare themselves to various ideals of literacy. That is, they often see themselves as irrevocably unable to read or write in the *right* way. I show in this final section that the weight and influence of the social aspect of literacy inheres in the materials and bodies of literacy, often creating a condition of literate misfitting that threatens to constrain the embodied and material strategies they are willing to develop and use.[8] That is, nearly all of the people with aphasia I interviewed in this study describe a number of ideological attachments to literacy that push back on what they are willing to adapt or not adapt—or what they are willing to call reading and writing at all. And many of those attachments have to do with particular or routine ways of using their bodies to produce what they describe as standard or correct literate products. As Haas observes, as an embodied practice, writing "is habitual": "bodily movements and interactions in which writers engage are repeated by individuals and across individuals over time; a habit is a

[8] It is worth noting that these perspectives about bodily and material practices that do and do not "count" as literacy persist for some writers despite the proliferation of new media technologies mediating individuals' literacy experiences. See Sarah J. Sloane's insightful essay, "The Haunting Story of J: Genealogy As a Critical Category in Understanding How a Writer Composes" for more on how communication practices and habits from older technologies "haunt" newer forms.

kind of remembering in and by the body" (228). In this way, literate habits, felt and perpetuated through the body, are often sites for literate misfitting, contributing to conceptions of what it means to do the work of literacy and to be literate and constraining individuals' literate potential. In other words, despite myriad effective, innovative strategies of bodies and materials, the social pushes back, sometimes limiting individuals' literate potential.

The ideals of writing come through in individuals' descriptions of reading and, especially, writing failures. Writing presents a particularly knotty problem for many persons with aphasia. Individuals understand writing as typed or hand-written language in correct, complete sentences for accepted, formal genres like letters or poetry. Handwriting, in particular, is weighted with heavy social values. Strokes or other brain injuries that cause aphasia commonly affect movement on the right side of the body, including the arm and hand, which may interfere with handwriting and typing. Many people report this physical change causing major differences in their post-aphasia literate practice, creating a painful instance of literate misfit between their bodies, minds, and the material practice and social values of handwriting. When asked to explain what stops her from making lists after aphasia, Judy answers, "My right hand would stop me." Some stop writing altogether rather than learning to handwrite with their left hand, but others—like Rose—discuss a complex and focused process of re-learning to write with their right hand or learning to write for the first time with their left hand. Others remark that their handwriting no longer looks like their own, transformed to "hieroglyphics" or a child's scrawl. "Now my writing looks like a third-grader's," says Rose. Such comments reveal how handwriting is viewed as a skill to be mastered and committed to habit in childhood. Another man describes the smallness of his writing. "Look at my signature," he says pointing to his consent form with a look of disgust. "Little." "I hated my writing," Jean similarly explains. "I mean it was different. It was small. I

couldn't read it most of the time, so I tried not to do it, you know. I made my lists and I guessed at them at the grocery store, and so all I did was like write lists." The very loss of that habitual embodied skill and reliable product of script disgusts individuals and sometimes keeps them from writing.

For Judy, a literate misfit arises as the changes to her body after aphasia cause her to feel "panic" at the idea of writing because, she says, she has lost her "flair" for writing. As a result, she writes very little, explaining that she "didn't keep any of the things I remember" and saying that, after her stroke, "I left the writing behind." Judy finds herself unable to address the misfit between her body and writing. Though she writes short emails to her brother and others, Judy sees herself as unable to attain the literate achievements she had prior to aphasia. She explains her ideas are "squashed" and cites problems with spelling, word endings, and grammar as ongoing barriers. The social perception of writers having "flair," ease, and talent pushes on and misfits with Judy's post-aphasia writing. Her literate misfitting is deeply social in nature as she interprets her body and mind as failing to meet the standards of literate practice and identity, causing her to leave "the writing behind."

Leaving struggling students behind was unthinkable for Jean as a special education teacher. But even though in her teaching Jean was committed to addressing literate misfitting with her students and to creating accessible reading materials—including her website—for aphasic persons, her perceptions of her own literate practice reveal how the social pressures on literate practice both undermine her identity as a literate person and limit her practice. Most tellingly, Jean distinguishes between the changes to materials and technologies that she is willing and unwilling to make. Changing the size and spacing of text is essential to Jean's reading practices, and she welcomes and appreciates those ways of adapting the materials of literacy to

fit the needs of her body and mind. She also uses her iPad's talk-aloud feature to help decode difficult words in non-fiction articles. Jean is quick, however, to dispel the assumption that she uses the read-aloud feature consistently on her Kindle as she reads fiction on an almost daily basis. When asked if she uses a Kindle, she responds: "Yes, but I don't use the [read-aloud feature]. I only use that if I don't understand, so if there's a like, it's a complicated thing sometimes like Ted Dekker [an author she reads]. He writes weird stuff, and sometimes I can't imagine it, so I go back, and they have to read it to me. So, yeah, I don't usually use that because I'm too damn stubborn."

While Jean happily changes the size and spacing of the text, she insists on decoding—or reading—the words "herself." That independent decoding using her eyes and mind—not listening to the words—constitutes "real" reading for Jean. Writing, similarly, has clear boundaries for Jean. She expresses dissatisfaction regarding her participation in a multimodal memoir group not focused solely on writing in alphabetic text, but on composing in photographs, drawings, and more: "It [the multimodal group] wasn't what I wanted," she explains. "I wanted to *write* write," she says pointing to written text. To write is heavily weighted with expectations for bodies, minds, and materials. Further, to write and read independently, smoothly, relatively easily is an implicit goal, and for some individuals like Jean in this instance, there is no substitute for the alphabetic text encoded or decoded by a solitary individual visually and cognitively. In other words, the social values around what normal bodies and minds should do in reading and writing perpetuate literate misfitting and threaten to limit individuals' literate potential. Literate misfitting, then, is as much about the social construction—or the expectations—of materiality and embodiment as about the physical or cognitive characteristics of readers and writers.

**Conclusion: How Bodies Matter**

As Jean first encounters sitting in the emergency room taking out a book "just like normal" and experiencing the words running together, literacy requires a negotiation, or fitting, between bodies and materials. Embodied change, brought on by aphasia, brings that negotiation into bright relief. As Garland-Thomson notes, "When we fit harmoniously and properly into the world, we forget the truth of contingency because the world sustains us. When we experience misfitting and recognize that disjunction for its political potential, we expose the relational component and the fragility of fitting. Any of us can fit here today and misfit there tomorrow" (597). The fact is that bodily needs and abilities change over the lifespan—hands stiffen with arthritis, eyesight weakens, memory and access to language alters. Those changes inform our understanding of how literacy works across the lifespan, revealing in particular just how integral the body is in reading and writing. As bodies and minds change across the lifespan, literate fitting and misfitting, then, are essential lenses from which writing studies researchers and teachers can 1) better theorize the socio-material nature of literacy, in its embodied, material, and social complexity, and 2) following that understanding, more effectively support literacy learners of all abilities.

For literacy theory, the insights of people with aphasia experiencing literate misfitting reveal the deeply embodied nature of literacy. Bodies and materials are intertwined in literate practice, and the concept of literate misfitting helps to sharpen our field's understanding of some of the ways *how* bodies matter for writers. What this concept reveals is not just *that* bodies matter for literacy, not just that bodies are a part of the ecology of literacy, but that bodies change and vary and come into conflict with the stuff of reading and writing. There is no one kind of body with one set of needs. And diverse experiences of embodiment, as we have learned

with literate misfitting, create new and vital knowledges about the social and material realities of the world and ways to make those realities more just. The concept of literate misfitting, then, exposes normative assumptions about bodies, minds, and materials. Above all, however, literate misfitting reveals the inevitable conflicts that occur between the varied aspects of literacy—embodied, material, *and* social. As I show above, the social pushes back. Deeply held values around what bodies and minds and materials should do, look like, accomplish, or mean may limit individuals' literate practices.

For literacy educators, literate misfitting points to myriad opportunities to make literacy education more accessible. To design accessible literacy education, we must begin with, and proceed from, the recognition that bodies and minds are diverse. We must reject and denaturalize the idea of a neutral or normal literate practice, a neutral or normal body. Alternate, or non-normative, ways of writing and reading, such as collaborating with communicative partners on compositions; using speech-to-text software; or reading aided by large-print, or by audio from a tablet, must be introduced, supported, and normalized. But as my analysis of the literate experiences of persons with aphasia reveals, it is not enough to develop new practices. Educators must also address learners' relationship to the social value of literacy. Together, learners and educators must explore and address pressure, pain, and shame around what it means to be literate in the right or wrong way.

That process is not easy or simple. But the embodied knowledges of individuals with disabilities like individuals with aphasia featured here are essential to this process. As Garland-Thomson asserts, "Acquiring or being born with the traits we call disabilities fosters an adaptability and resourcefulness that often is underdeveloped in those whose bodies fit smoothly into the prevailing, sustaining environment" (18). Those perspectives and "resourcefulness" are

vital sources for people of all abilities to learn from. Interrogating the experience of literate misfitting and the innovative strategies of readers and writers with diverse bodies is an essential step toward mitigating that social stigma. Jean gestures to an alternative conception of literacy that stems from—even values—literate misfitting. Describing what it's like to write after aphasia, she explains:

> It's a new normal because it's not as easy. […] You have to find ways around it, or you know, just go through it and make mistakes. So yeah, I think that would be helpful to anybody who has aphasia because you know you can hide and lots of people do. Or you can say, 'Okay, I'm aphasic, and I have a right to live' and go out, and that's what I'm trying to do, to set an example.

Jean's "new normal" for literacy rejects stigma, opens up our expectations about correctness or "right" ways of being literate and doing literacy. Her "new normal" values alternate paths, accounts for complexity, and insists that the situated knowledge of literate misfitting be owned, shared, and exemplary in its own right.

# Chapter 4

## Negotiating Literate Identity after Aphasia: Normativity, Flexibility, and Relating to/Reworking Literacy Ideology

We saw in Chapter 3 that even with the inventive strategies that individuals develop to read and write after aphasia—adapting their bodies and the materials of literacy in new and creative ways—they often feel as if they are not literate in the *right* ways. In this chapter, I further interrogate where these social or ideological pressures around literacy come from and how they affect literate practice and identity after aphasia. Specifically, I am interested in what values around literacy allow people to cope or adapt to their changed bodies and minds after aphasia. What is it that keeps some individuals from adapting new practices or continuing to write? What social values around, or beliefs about, literate practice and identity enable other people with aphasia to respond so differently—to expand their composing, to read more, to adapt new and innovative ways of reading and writing? In this way, my larger theoretical question for this chapter is "What is the relationship between the social and embodied aspects of literacy?"

Literacy history interviews are helpful in answering these questions because they offer a window into how people experience the effects of acquired disability on their writing and reading lives. What is unique about aphasia is that it is an *acquired* disability affecting literacy. People remember what it was like to write and read differently before aphasia, often with more ease. They recall habits, preferences, and skills related to reading and writing across several decades and life experiences. They have developed beliefs about the value (or sometimes the lack of value) of literacy.

In this chapter, I build off of Lauren Marshall Bowen's claim that a "backward glance," or focus on literacy history reveals "how embodied, affective sources of motivation endure and

support literacy practices across the life course" (590). Bowen finds that some individuals develop across their lifespans a "literacy affinity"—"a significant affective disposition toward literacy in general" (591). This disposition is an "enduring attraction toward literacy, expressed and reinforced by affective and bodily experience" (592). Like Bowen, I find that some individuals with aphasia have developed a literacy affinity—a disposition toward, interest in, and engagement with literacy—before aphasia. However, the literate experiences of people with aphasia reveal that this "literacy affinity" or connection to literacy is not always a source of motivation persisting across the lifespan to "support" literacy practices. I find, rather, that normative standards delineating what it means to be literate and do literacy may limit individuals as they have experienced bodily change.

Beyond an "affinity for" literacy, some individuals develop an attachment to a *normative literacy identity*. That is, individuals are often not just attracted *to* literacy, but to a particular kind of literacy defined by expectations for bodies, minds, materials, processes, and products of literate action. To be attached to a normative literacy identity is to desire more than literacy. It is to be attached to the expectation of engaging in particular embodied practices and processes; to evince writerly talent, creative genius, and autonomous thinking. In this chapter, I'll show how these attachments to developing and maintaining a normative literacy identity grow over time—across affective and embodied experience—stemming from school-based contexts, gendered expectations, and—as aphasia makes especially clear—requiring a "normal" body and mind.

Specifically, in this chapter, I draw on six literacy-history profiles of people with aphasia to argue that ideologies of literacy—what people believe or value about literacy—develop into literate identities that endure across the lifespan. The experience of aphasia exposes how, although bodies change, literate expectations do not. This finding reveals how social or

ideological aspects of literacy are always in dialogue and tension with individuals' bodies—a condition of literacy highlighted by bodily change. I argue, then, that individuals attached to a "normative literate identity" find that, as they adapt to their changed bodies, values for what literacy practice and identity should look like push back on and limit their literate potential. Many of the standards for literate success, I show, rely on a "normal" body and mind, doing a disservice to readers and writers with all kinds of bodies and minds. I then show how individuals who developed literate identity outside of these norms are often able to adapt more effectively after aphasia—with less emotional strife, with greater flexibility for reading and writing differently. I explore this "flexible literate identity" as way of not only exposing literate norms, but also reworking them. First, I situate this chapter's analysis in scholarship on literacy ideology, bodies, and disability. I then establish "literacy identity" as an internalized theory of literacy ideology.

**Ideologies of Literacy: Marking Bodies and Disability**

New Literacy Studies (NLS) importantly exposes the ideological nature of literacy: that literacy is not a discrete set of skills, but rather weighted, "freighted," with value (Brandt, *Literacy* 4). Several decades since Brian Street called for literacy to be examined as a social practice rather than a discrete skill, NLS has made the social basis of literacy commonplace. Rather than just an individual cognitive skill, literacy "allow[s] people to do certain things (and not others), to mean certain things (and not others), and to be certain kinds of people (and not others)" (Gee, Foreword iii).

Because the benefits of literacy are not universal, but socially contextual, ideologies of literacy may in fact do significant harm. In particular, NLS has asserted and tracked how access to literacy is facilitated and denied based on identities marked on the body, such as, race, class,

gender, and disability. For instance, economic interests and classist values underpinning literacy and literacy instruction perpetuate inequality (Stuckey). Class, literacy, and intelligence become bound up, curtailing educational access for working class students, tracking them in remedial educational programming (Rose). And the tacit assumption of literacy as a white property right permeates our education system, its policies, and daily practices, doing racial violence (Prendergast, *Literacy*). In these ways, the ideological weight of literacy's value—who should have access to it and for what reasons—significantly complicates the doing, meaning, and being through literacy that Gee invokes. Indeed, "where 'a literacy' is identified, those with an interest in finding the corresponding illiterates are never far behind" (Street & Kress vii).

Illiteracy has often been bound up with ideologies marking able and disabled bodies. Ableist conceptions of literacy have permeated the policies of schools and various institutions that track, label, and limit the literacy practices and identities of individuals with disabilities, reading disabled bodies as "defective." Peter Mortensen, Brenda Brueggemann, Jay Dolmage, Margaret Price, and other composition and rhetoric scholars expose how individuals with disabilities chafe against "normal" standards of literacy. Mortensen shows how certain bodies are excluded from standard literacy, uncovering how class and disability were used to mark rural citizens' bodies in the late 19th and early 20th century as "feeble-minded," "illiterate," and even too defective to attain literacy. Such incompatibility between non-normative bodies and successful literate practice is similarly apparent with bodies marked as "disabled." Brenda Brueggemann finds that illiteracy "is often equated with deafness" (*Lend* 28). Illiteracy, or "literacy invisibility"—the exclusion from being considered capable of reading and writing at all—is often associated with students with cognitive and learning disabilities, in particular (Kliewer et al 175). The bottom line: the literacy practices of people with disabilities are often

perceived by educators, health professionals, and other authorities as problems of illiteracy and, thus, "something to fix" (Dolmage, "Mapping" 19).

**Literate Identity: Ideology Internalized and Theorized**

This chapter locates discourses, values, norms, expectations, and assumptions—that is, ideology—around bodies and disability in the everyday literate experiences (the practices and perceptions of those practices) of people with aphasia. Specifically, I explore how individuals relate to and grapple with ideologies of literacy to negotiate a new sense of literate identity after aphasia. I define "literate identity" as individuals' theories around the value of literacy, their roles as writers or not, their definitions for what literacy is and can do. Literate identity, then, offers a window into how individuals internalize, and theorize about, literacy ideology. If identity is "an epistemological construction that contains a broad array of theories about navigating social environments" (Siebers 15), "literate identity" offers theories about navigating literate practices, resources, events, and a literate culture broadly. Literate identity reveals how a person "identifies and becomes identified with a set of social narratives, ideas, myths, values, and types of knowledge" about literacy (Siebers 15). A "literate identity" offers theories about the values of literacy: about what literacy may do, who should do it, and how it should be done.

By studying how people grapple with literate identity after aphasia, I foreground how disability exposes norms and values. When individuals' bodies and minds change, so does their relationship to their environments and to the norms of how they are expected to act in those environments. These new embodied experiences and identities "conflict with society"—conflict with literacy—and, thus, "have the ability to expose its norms" (Siebers 21).

**Method: Tracking Literate Identity across the Lifespan & through Attachments**

In this chapter, I use literacy history interviews to show how individuals develop and become attached to particular literate identities—or internalized theories about literacy—across the lifespan and through embodied and affective experience. That is, over time, individuals engage with objects and practices of literacy as they develop feelings and values around it. I track those connections or "attachments" to literacy throughout individuals' literate histories as I examine how values around literacy affect adaptation across bodily change.

*Across the Lifespan*

Sociohistoric studies of literacy take the lifespan as their unit of analysis – how the social meanings of literacy develop over time, marked off in the lifespan where we can see historical changes in the meanings and values of literacy. A great deal of work in literacy studies gets at how the need and use of literacies changes over individuals' lifespans, propelling some with valued skills forward and leaving others behind. Brandt describes how these meanings and values "accumulate"—or "pile up" "as materials and practices from earlier times often linger at the scenes of contemporary literacy learning" (652). Such "residues" of literacy are both a "hindrance and a help to learning to read and write" (51, *Literacy*). Brandt argues that "the history of literacy at any moment is always carrying along a complex, sometimes cacophonous mix of fading and ascending materials, practices, and ideologies. Literacy is always in flux" (51, *Literacy*).

My exploration of the literate identities and experiences of people with aphasia performs a similar task across individuals' lifespans, tracking their development as writers and readers. I am interested in how the body and mind operate within that matrix of shifting values of literacy. What lingers, builds up, hinders, helps literacy practices after a significant change to the body and mind?

*Embodied and Affective Attachments*

What lingers, I find, is the embodied and affective attachments individuals have to ideologies of literacy. Bodily change brought on by aphasia makes apparent what Prendergast calls "the most deeply held assumptions about literacy, the most deeply felt attachments that develop through literacy" (10). These "attachments" are "bound up with how" individuals "perceive their own identity, and the identity of others" (10). For instance, in a study of a high-achieving undergraduate student who acquires severe carpal tunnel syndrome that affects her ability to write, Mahiri and Godley find that, as the student's "physical ability to write" changed, so did her sense of identity—as a productive and intelligent student, daughter, and community member. What's more, even though she was able to adapt new practices to make up for what she could no longer do through writing, "she was not able to change the values she had come to attach to her abilities to write" (430).

That inability to adjust occurs because literate identities are tightly bound up with bodies and perceptions about what they should do in reading and writing. Similarly, Bowen's "literacy affinity" is developed, "expressed and reinforced by affective and bodily experience" such as typing training that, later in life, dictates a straight-backed computer chair and reinforces a sense of correctness in literate practice (590). Embodied engagement with cultural artifacts—from the material, possessing books; to the abstract, attaining labels like "good student"—enables individuals to develop literate identities as they strive to both "seem" and "feel" literate (Bartlett). And the very "lure of feeling literate" is an affective, embodied draw to literacy underpinning and sustaining individuals' literate identities (Strickland 47). Indeed, literate identities are not just individual or idiosyncratic. They play out within larger cultural systems and can be traced across time and through embodied and affective attachments to literacy.

Feelings and values around literacy, as I show in this chapter, "allow literacy studies to focus simultaneously on the individual and the cultural work of that individual's orientation toward literacy" (Strickland 48). These attachments allow me to identify "normative" and "flexible" literacy identities in what follows.

**Literate Identity Across the Lifespan: Profiles of Six People with Aphasia**

I now turn to analyze six literacy-history profiles of people with aphasia. I selected these six individuals as representative of particular literacy identities in two contrasting categories: normative and flexible. To establish a sense of "normative literacy identity" and its effects on literate practice before and after aphasia, I profile Judy, Jean, and Beth in the first section. Judy is a 64-year-old former high school English teacher who explains that she "leaves the writing behind" after aphasia. Beth, a high-achieving 26-year-old PhD student who has thrived as a reader and writer, struggles to adapt after aphasia. And Jean, a 61-year-old former special education teacher, experiences a fraught relationship to literacy before and after aphasia.

I then turn to three individuals with very different literacy experiences and identities. Andrea, Sandy, and Bob help me establish a sense of "flexible literate identity" that offers room for individuals to adapt new practices post-aphasia. Andrea, a multilingual speaker and writer struggled with literacy before aphasia but expands after. Sandy, a former first-grade teacher who develops an "integrative" approach to literacy that serves her well after aphasia. And Bob, a 68-year-old former grocery store regional manager who "didn't have much interest" in reading and writing before aphasia but who demonstrates remarkable flexibility in literate practice after.

**Normative Literacy Identity**

In this section, I analyze the literacy histories of three women who I show are attached to a normative literacy identity: Judy, Beth, and Jean. All three are, or have been, dedicated

students and teachers. They are literacy experts, wielding language, supporting others in literacy learning. All three also found, at various points before aphasia, success with literacy and placed a great deal of value upon being and seeming literate, and doing literate work. Their literacy identities are based in ideologies that attach literacy to autonomy, adulthood, talent, and intelligence. Essentially, their pre-aphasia identities conformed to normative literacy standards, or expectations about the processes and products of literacy based on able bodies and minds. I argue that their pre-aphasia normative literacy identities make it more difficult for people with aphasia to develop adaptive strategies and, moreover, to understand themselves as literate after changes to their bodies and minds.

It is perhaps not surprising that individuals feel the loss of something they valued, something that helped to constitute their identities as people, students, and teachers. My main point here, though, is that when individuals have developed a normative literacy identity, this identity depends upon actions, practices, processes, and products matched to normal bodies and minds. These standards around what it means to read and write in the "right" ways endure and put pressure on individuals after bodily change. These responses occur not just because individuals experience a sense of illiteracy or stupidity, but moreover, because they perceive (and lament the loss of, struggle to deal with, etc.) certain ways of being literate that show up in process, product, and practice, and their very bodies.

This finding indicates that a successful literate identity is based in part on tacit expectations for what bodies should do in reading and writing. From bodily actions—holding a pen, inscribing clear letters, typing with ten fingers. To cognitive processes: coming up with ideas quickly and autonomously. To characteristics of the writing products themselves: error-free, elegant prose. As Kim Hensley Owens notes, "Any type of writing […] requires the body"

("Look Ma"). But what writers with aphasia come up against is a number of internalized and externalized expectations for how bodies should operate as they write: smoothly, even (as Disability theory has critiqued), invisibly, without pain, without delay.

***Judy: "I don't have a flair to do it"***

Judy was always a successful student who then went on to become a high school English teacher. Before aphasia, her process of reading and writing was easy and simple. Reading and writing was something that made sense to Judy and something that benefitted her as a professional and as a person. Aphasia, however, turns her unmarked literacy practices and identity to something marked by loss and difficulty. Specifically, she explains that weakness in her hand affecting her handwriting and a sense that her ideas are "squashed" prevents her from writing. These experiences reveal a clear literate attachment: a belief that writing requires aptitude, natural talent, or—as Judy calls it—"flair." As her body and mind changed after aphasia, so did her access to that "flair." Judy's attachment to literacy as proceeding from ease and talent relies on a particular kind of body and mind, creating negative feelings, or "panic," about her writing after the bodily changes of aphasia, and ultimately prevents her from being able to maintain a positive literate identity post-aphasia.

Judy's attachment to literacy as flair grew from childhood. Learning to read and write was easy, she recalls. She loved reading as a young child, growing up on a hobby farm near a mid-size metropolitan area, playing "teacher" with her sister, instructing her animals as her pupils. And an interest in and skill for literacy ran in her family. Judy's father was a linotype machine operator at a local newspaper and a "very good speller." She proudly shows a black-and-white framed photo of him sitting at the machine, setting the lines of text.

As a young woman, Judy's literate identity strengthened as she became known and recognized as a strong writer in school and in her community. When she went on a European tour with a group of other recent high school graduates and good friends, the editor of her local paper asked her to write up the story. Headed to college at a regional state university near her family's home, she didn't initially plan to major in English, but data processing. But books like *Catcher in the Rye* surprised and won her over. She found the focus on English to be a fit, realizing "the whole spectrum of writing and reading is what I wanted to do," so she majored in English education, training to be a teacher.

As a high school teacher, Judy's knack for reading and writing continued to serve her well. Judy read and wrote "constantly," composing lesson plans, and writing comments on students' papers. Though she was almost always reading and writing for work, she still filled her spare time with reading for pleasure: "Every night, every morning, I read and read"—including books about spirituality and *Chicken Soup for the Soul*. Reading was an easy, relaxing escape for Judy. And she describes instilling in her own children a similar interest in reading and writing, proudly describing that her youngest of two sons shares that propensity for and interest in the written word: "He's a reader, you know?" For Judy, aptitude makes readers and writers.

While Judy has clearly benefitted from what Bowen calls a "literacy affinity" tying her to a love of reading and writing and even leading to a career teaching English, her rigid sense of what makes a "reader" and, more significantly, "a writer," constrains her relationship to literacy after aphasia. After aphasia, Judy finds that she no longer fits what her attachment to literacy required: ease in reading and writing. She explains that the weakness on the right side of her body and changes to her language caused by her stroke force her to leave teaching, giving up her role of literacy expert. Her emotions, too, she says, kept her from reading soon after her stroke,

as she "spent a year and a half crying." It wasn't until almost ten years after her stroke that Judy acquired a Kindle electronic book reader to regain access to the daily reading that gave her so much joy prior to her stroke (See Chapter 3 for more on Judy's reading practices after aphasia).

However, Judy finds no similarly palatable solution for writing. She identifies both physical and cognitive changes as intractable problems with her post-aphasia writing. Though Judy adapts to writing with her left, non-dominant hand, the task still tires and irritates her. Likewise, one-handed typing slows her process. For instance, explaining why she no longer writes lists, Judy grabs her weak right hand with her left hand, saying, "my right hand would stop me." The difficulty of these physical changes keeps her from wanting to write. They make writing more laborious and, notably, mark her writing as non-expert.

Changes to her ability to do the manual and mental work of literacy reveal to Judy that she has lost her "flair to do it." When asked, "What's different about writing after aphasia," Judy answers:

> J: "Writing is sign… um the ah [shakes head]. Panic. Panic."
> E: Panic?
> J: Mmm hmm. Yeah.
> E: So like panic in the moment?
> J: No [gestures hand forward]
> E: Getting it out?
> J: Yeah, getting it out. Getting it out. [gestures hand forward]
> E: So when you think of writing, do you think of panic?
> J: Yes, I think of panic. Yeah.
> E: What makes you most panicked about writing?
> J: Because I don't have a flair to do it, you know. I just ugh [sighs]. I don't know. I don't know [shaking head].

"Flair" denotes a kind of talent, skill, or ease. That ease is gone for Judy, causing panic, anxiety, and a sense of loss. This new frustration and difficulty causes Judy to no longer think of the writing she does as "writing." The attachment to writing as flair, ease, and talent itself is attached to various bodily practices and characteristics of literate products that Judy can no longer create.

Judy further asserts that writing is out of her reach. “I left the writing behind,” she responds when I ask what writing she has done that she feels good about or proud of after aphasia. Judy’s statement spurs an extended discussion about what she’s left behind--and why:

> E: That's really interesting. So you left it behind after leaving the [writing] class or after the stroke, or?
> J: No, uhm... Hmmm. I don't know. After the strokes, yeah. [nodding]
> E: How do you feel about not writing?
> J: Well, I write um... [points to computer]. Ah, um. I write, but I don't write for the [writing] class. [Shakes head. Sighs] hmm...
> E: So okay what I'm hearing is writing before the strokes is one thing.
> J: Yes, Writing. Exactly. But after the strokes, I don't know, I don't know. [shakes head with concern]
> E: Well, I think it's interesting that you said, "I left writing behind." It sounds like certain parts of the way you used to write you didn't take or keep or whatever.
> J: Right, I didn't keep any of the things that I remember. Yeah.
> E: And I know that's the hard part to answer is like what didn't you keep, but what do you think it is? What didn't you keep?
> J: Ah, aphasia, yeah. Oh yeah. um, and writing [lifts right hand] you know? And I my ideas were just squashed [gestures hand in front of face]. Right. Coming up with ideas. Oh jeez.

Judy distinguishes between the writing she does on a daily basis (pointing to the computer) and the kind of "writing" that she "left behind." According to her, the writing she has access to after aphasia is rudimentary, brief, basic. Writing with “flair”—with ease, with complex ideas, with her arm and hand not getting in the way—is no longer available to her. It is the writing of her past. The ideological weight of literacy and writing as flair is heavy here for Judy: writing as a product and process should look a certain way. Flair is marked on and carried out by a normal body and mind. When her stroke affected her ability to use her right arm and to—she says—come up with ideas, Judy says she simply lost that flair and necessarily left behind writing. In this way, her changed literate practices sever her relationship with writing and what it means to be a writer. A writer has “flair” that is both cognitive and physical—an openness, an ease, in the thinking and doing of writing. But Judy perceives her literate ability as

"squashed"—an evocative image suggesting uncomfortable constriction and the shutting down or narrowing of the mind she gestures to.

Still, though she doesn't count it as "writing," Judy does write after her stroke. She joined a multimodal memoir group at a local speech and hearing clinic 12 years after her stroke, and during that semester-long group, she composed a life story book, full of old photos she captioned with hand-inscribed Post-It notes labeling those life-events. She then joined a semester-long text-based writing group that developed out of the multimodal group, composing a few short poems, parts of the story of her stroke, and a few other short pieces. Yet, she expressed in interviews regarding the group that she had simply lost the ability to write. Though Judy explains that she "did enjoy the writing" she completed in that group, she perceives her lack of flair as preventing that writing from taking on the standards of texts and text production that she previously easily held. Upon follow-up questions, Judy concedes that she writes, "but not anything." For example, she composes emails her brother and sister—"It's just ah one line or maybe two," saying things like, "Thanks – I had a very nice time." Likewise, she writes down—but does not share—questions to ask the building coordinator at her senior living complex about taxes, retirement, and other logistical concerns. But these texts are rudimentary, according to Judy. As Mahiri and Godley note, even though Judy is able to write and to come up with adaptive ways to write, the values around what writing is and how an individual should accomplish that writing cannot be accommodated. That is, the attachment of a writer's talent and ease, built from her history of unmarked, easy literate practice makes her post-aphasia literate practice impossible.

***Beth: "I had a whole system"***

Before aphasia, Beth's literacy history reads like a textbook literate success story: accomplished student and voracious reader and writer, with a privileged educational background.

Literacy always fit Beth's needs and served her well. And since early childhood, Beth developed routines, performances, processes, and standards for the products literacy that sustain that identity as a good writer and good student. I show how those "systems," as she calls them, help Beth to cultivate an attachment to literacy as providing a sense of independence and intelligence. This literate attachment was threatened, however, when Beth was struck by a drunk driver, causing a brain injury and aphasia, just three days after she submitted her Masters thesis in theatre and drama. Beth explains how, after aphasia, nearly every aspect of her writing—including the products and the processes of her writing—signal the embodied changes that she has sustained. While literacy before aphasia provided Beth with a sense of autonomy and intelligence, after aphasia, Beth interprets her literacy as deficient because she sees her system of processes and standard products as damaged. Her embodied change marks and alters the literate "system" she has developed, threatening her literate attachment to independence, control, and intelligence. Even though at the time of our interview Beth reads and writes extensively and successfully in the first year of a PhD program in theatre and drama, I show how her literate attachment of control has been disrupted on every level. As a result, she both quits various practices she had previously valued and struggles with her writing process.

Beth developed literate systems early on, reinforcing and reinforced by a literate attachment to reading and writing as ways to gain and evince control, independence, and intelligence. Her family was full of literate role models, individuals Beth observed wielding independent control over literacy. Both her mother and father were professors of economics who always wrote at home and work: editing an academic journal, writing grants, grading papers. Christmas presents from Beth's grandparents "were always books," and her aunt was a published author of young adult fiction. Inspired by these family members, Beth wrote "almost

compulsively" as a child—a diary, short stories, and poems. She read constantly as well, convincing her parents that she was afraid of the dark so they'd "leave the overhead light on just a little bit." She sped through the popular childhood books like Harry Potter and then, in the fourth grade, refined a more acute sense for the proper way to develop her literacy, turning to the literary classics. "I decided to be…I was very I can't remember what the word is…pompous…maybe," she explains. "I decided I was smart enough for classics." Beth's reading and writing goals clarify her ideological attachments to literacy as a self-directed avenue to build intelligence and cultural capital: devouring dense texts by lamplight, both developing and marking her as an educated person.

Beth harnessed literacy to mark her intellectual independence outside of the home, developing many additional practices and standards for her literacy. School bored Beth, but she could stretch and refine advanced reading and writing habits in extracurricular activities, especially National History Day (NHD). Throughout middle and high school in NHD, Beth set high (and particular) standards, feeling "inadequate if I had less than 50 sources, 20 of which had to be primary." She even opted out of family sightseeing in London to pour over old manuscripts and microfiche in basement of the Imperial War Museum. Beth explains that this self-initiated and self-guided learning (not to mention class-privileged—a middle-schooler accessing centuries-old primary historical documents in a world-renowned archive) motivated her and made her feel a sense of control and intelligence: "I think I liked that it wasn't for anyone but me, so I could do it whatever way I wanted and I didn't have to sort of conform. But, also I think it's just I really like knowing everything about something." Advanced, specialized literacy practices lend Beth a sense of independence, intelligence, and control of knowledge. Such ideological attachments, carried out by specific processes and practices, simply feel good to Beth.

As a college student before her injury, Beth similarly developed careful processes around drafting papers. She finished her composing well ahead of deadline to make time to share multiple drafts of her writing with peers and her parents for feedback—designating peer readers first, then her mother, and then her father for a final reading. Her peer readers consisted of a small group of high school friends who exchanged writing throughout college. The group came up with a complex "system" of commenting that doesn't "make sense to anyone but" them, using Word software to add comment bubbles, writing in red, indicating "you can accept or reject," a "2-page critical response at the end of the paper," and an additional note in the body of their email correspondence. This process, which Beth calls, "intense" is central to her literate practices—and generative for her self-identity. Beth describes the commenting she did on peers' papers as a kind of "life force"—an exciting process of seeing what's possible in writing.

After aphasia, Beth's formerly well-ordered process became "chaotic." She explains how her reading and writing became slow and frustrating. Her handwriting and spelling were not like her own. These embodied signals of change and deficit led Beth to quit, reject, and change many of the writing practices that had been familiar and comfortable prior to her accident. Note-taking and journaling, two daily and central writing practices to Beth, become tiring and taxing due to the changes in her body and mind. But moreover, the appearance and "feel" of Beth's handwriting and her spelling especially changed after her accident, causing Beth to compare and judge her body and mind against a pre-aphasic ideal—and to give up those practices. Though she has kept a daily journal since childhood, Beth explains that—after aphasia—she gave it up, finding it "too frustrating." "I didn't want to deal with it," she says. "It was I think also knowing that something that had been so routine was then really difficult."

Before aphasia, Beth also took copious notes as a student. “I used to be, almost, a transcript writer,” she says. “In classes, to pay attention, I’d have to write down everything the teacher was saying as they were saying it.” Handwriting, in particular, activated that memory for Beth. Now, after aphasia, handwriting is slower, full of spelling errors that disrupt her attention. But while handwriting no longer fits the needs of her body and mind, she can find no substitute to address the values she held about handwriting. She tries to type, but she describes that practice as an ineffectual substitute and a distraction. “I hated it. I don't think I'm ever going to do it again,” she says. “I don't have any memory of it. I don't remember the class because I don't have that sort of memory of the note taking.” In these ways, changes to her body, mind, and especially to Beth’s perception of herself as failing to meet normative literacy standards constrains how she chooses to write.

In addition to changing the way she chooses to write, after aphasia, Beth fears that the very products of her writing signal the changes to her body and mind, revealing her lack of literate control. In response, she doubts her own ability and stops sharing her writing altogether. Beth is fearful that her writing in and of itself reveals the changes to her body and mind, marking her as “brain injured.” She “worries” that her post-aphasia writing is now “as incoherent as sort of my own thoughts sort of have become” and now has a “harder time understanding whether or not it's actually cohesive, if there's any flow to the argument, if there's even an argument. Most of the time I don't even know what the argument is. So, I feel embarrassed showing it to other people.” In Bartlett’s terms, Beth is afraid that the errors in her writing keep her from “seeming” literate to other people. That fear keeps Beth from what she called her “life force”—the sharing of writing with others.

In addition to stopping sharing her writing, Beth alters and struggles with her own writing process as her embodied changes and the ways they fail to align with her literate attachment to independent, well-ordered composing also keep her from "feeling" literate. She describes feeling "disappointed all the time" at the difficulties she has coming up with ideas and words while writing. In response, she alters her writing process to keep herself from noticing these changes. Specifically, she uses extreme procrastination "to block everything else out." For Beth, procrastination and panic distract her from "having a brain injury, or not being good enough, or not knowing what I'm talking about." She "uses" panic and procrastination to suppress that changed and unsettling identity, forcing herself to "write it how it comes out."

While after aphasia Beth does compose written papers and presentations that adhere to rigorous standards for academic writing in a competitive PhD program, her attachments to literacy make her process painful and fraught. Her extreme procrastination causes significant anxiety. She describes a writing process punctuated by "running around the room crying" and "dance parties to force myself to stop panicking." And, in turn, she is ashamed of this adaptive procrastination. She feels shame and frustration at not being able to go about literate practices in the *right* way. When asked about writing she feels good about or proud of post-aphasia, Beth explains that even though she is proud of some of her ideas and writing, she cannot "feel good about it." She feels "guilty" for taking so long to write, for waiting until the last minute, for not including more time to revise. "So it's kind of a combination of good but not proud," she explains. "I feel like I can only be proud of things that I know I spent the appropriate time on."

The feelings of "guilt" and sense of not "earning" through her literate practices the right to be proud are telling. Literate standards, for Beth, are moral, are focused in diligence and work. Beth's distinction between feeling "good" about versus "proud" of her post-aphasia writing

further reveals how she continues to judge her literate practices based on her expectations for a "normal" body and mind.

***Jean: "It's like your whole life is gone"***

Over Jean's lifespan, she has developed an ideological attachment to literacy equating reading and writing with adulthood—autonomy, intelligence, and maturity. Jean struggled with literacy as a child, being labeled as learning disabled and tracked in a remedial reading group. As a high school student, she experiences literate success and support, feeling "smart" and respected. That association with intelligence and independence and writing grows throughout college and a career as a special education teacher supporting diverse students in reading, writing, and learning. When aphasia disrupts Jean's role as literacy expert, her attachment to literacy signaling adulthood and intelligence becomes clear. And the affective, embodied attachments to that ideology become apparent as Jean struggles to adapt to her changed body and mind after aphasia.

Jean grew up in a rural area on a hobby farm with a stay-at-home mom raising six children and a father who worked as an electrician. Her rural background and tomboy attitude was not a fit with the demands of school-based literacy. Being a good student was about bodily performance of docility, looking straight ahead, sitting still, and that performance was distinctly middle-class and suburban, whereas Jean bore the marks of a rural and working class background. A positive literate identity—or literacy affinity—was hard fought for Jean: from grade school, she found herself marked as learning disabled and tracked in a remedial reading group. "Positive or negative?" she first responds when I ask her to recount early memories of reading and writing. She decides to begin with the negative "to get through that" first—a still-painful experience of remembering her outsider status.

In elementary school, Jean was placed in a remedial reading group. “If you were a bad reader, you were in the blackbird group. If you were a good reader, you were in the robin group. And that was just totally devastating," Jean reflects. For Jean, the label of "bad" reader and student became bound up with "disabled," or the more common label of the 1960s: "mental retardation." Jean explains that her fifth grade teacher (whom she later recounts as mocking another student's speech disability) "told my parents I was retarded and I wouldn't graduate high school." Jean explains that the policies of labeling and tracking students by ability level and the pain she felt from it first-hand encouraged her to become a special education teacher. Becoming a teacher, her own experience bore heavily on her teaching practices as she “swore” she “would never do that to anybody.” The affective experience of being on the outside of literacy achievement encouraged Jean to pursue a role as very much inside it, as a literacy expert helping those on the outside—students in special education.

In addition to outright labeling of literacy deficit, Jean also reflects, as a child, that she found much of the literacy instruction in school to be boring, unrelated to her, and even infantilizing. She perceived workbooks focused on reading comprehension and “stupid story starters” to be unrelated to her or her learning to read or write. For this required work, she wrote briefly (“Why waste your time?” she asks) and begrudgingly. For instance, when she was assigned the very same “story starter” writing assignment as her mother (“something about a woodcutter”), Jean decided to turn in her mother’s writing instead. Reading became engaging for her when Jean could imagine herself in it and engage with the ideas. Despite her lack of interest in—and effort for—school-based literacy, Jean read voraciously at home, scraping together money to buy Nancy Drew and Trixie Beldon novels. “First, I’d save my money up and get candy,” Jean explains, “but now I just wanted a book [laughing].” Around 4$^{th}$ grade, she recalls

getting into these stories, getting "lost in them," picturing herself in Nancy Drew's sleuth pursuits, at the wheel of her blue convertible, "driving the car and swerving in and out and all kinds of stuff, and it was just really cool."

Seeing herself in school-based literacy related to school did not occur until high school, when Jean received support from teachers in subjects that interested her when she gained respect and support from teachers. In her junior and senior years of high school, Jean enrolled in independent studies in special education. In this context, "not a wimpy course—you really had to read it, and you really had to understand it," Jean began to establish a sense of positive literate identity, based on independence and intelligence. Jean explains that for the first time, she "really felt that you know that people getting… you know giving me things and trusting me and that I felt like I could…I was smart." Literacy became attached to "being smart," to gaining access to expressing one's intelligence. It meant acting as a role model—as she started volunteering to work with students in special education classes in her lunch hours, after school, and at a summer camp. It meant writing papers throughout college and graduate programs in special education and educational —administration—some of which were recognized as excellent and recommended for publication by her professors.

From here, reading and writing suffused and sustained nearly all of Jean's adult roles. At home, she drew on her own father's literacy practice of poetry writing, by penning rhyming poems turning her reluctant young daughters' morning routines getting ready for school into a scavenger hunt directed by poems; composing poems for family members' homemade cards. She served the adult role of reading to her daughters, taking them to the library every week, and then to her grandchildren. At work, as a special education teacher for twenty five years, Jean read "all the time," getting to know each and every book her upper-elementary and middle-school students

would be covering across the curriculum. Drafting countless daily lesson plans and rhetorically savvy individual education plans (IEPs) to provide the greatest access and flexibility for her special education students also kept Jean writing all of the time. In her "spare" time Jean wrote dozens of papers for two Masters degrees: one in special education and one in educational administration. What's more, as a special education teacher, Jean *taught* reading and writing, directing students to new strategies for covering up all but one line of text, reading alongside books on tape, changing the lighting, reading outside, reading with others. But most important, Jean says, is helping students to "understand that their words are important." That goal, again, underscores her belief in literacy as a road to independence, maturity, and intelligence.

After aphasia, Jean finds the adult roles that she has developed and sustained with reading and writing significantly altered. She perceives the changes caused by aphasia to her ability to read and write as directly damaging her adult roles: "I think it's not being able to do it. You know, it's like your whole life is gone, especially being a teacher. I mean, I couldn't do what I could do before." And on a personal level, she found that she could not write the meaningful "notes or poems" to family members going through a difficult time, particularly her mother dealing with her father's death.

After aphasia, the changes to Jean's body and mind threaten her literate attachment to adulthood, independence, and intelligence. When Jean's doctors recommend that she begin reading children's books after her stroke, her sense of literate competence is threatened. "I didn't go back to baby books," she explains:

> They told me to go back to like a third grade level. Well, they're not funny. They're not interesting, you know, and so I read my regular books, so I think it was something about tropical island and a murder and, you know. Anyway, so I

> read that because I started, um, the same book. I don't know how it ended. Well, I went back and read it now [laughing] because I can read it better, but yeah.

The suggestion to read easier children's books conflicts with and threatens Jean's sense of literacy as tied to intelligence and adulthood, and she rejects it with a commitment to practicing and rebuilding her "adult" reading practices. "You have to work, you have to really, really work," Jean describes her commitment to practicing her reading immediately after her stroke. "I did it every day. I did it every night […] I had about a 15-minute span when I could do anything. Then I went back to sleep, and then I would try it again." Practice, here, is a strategy for re-asserting Jean's adulthood and independence.

Jean's writing after aphasia, however, is challenged in a way that cuts closer to the quick of her literate attachment around adulthood and maturity. One particularly painful experience challenged and damages her belief in her ability to write to adult" standards. About a month after acquiring aphasia, Jean was volunteering in a kitchen at an "aphasia camp" she was attending for people with aphasia and their families. She noticed that:

> They weren't putting the things in the dish room properly, so I wrote a nice note um to say 'Please put things where they belong.' Well, I got the wrong… I didn't write it right, and so then they went and fixed all my errors, and I was so embarrassed because these were kids, you know, and, oh man, that was the worst thing.

This first experience sharing her writing publicly exposed Jean to damaging critique. Again, her sense of identity as a competent, independent literate person was threatened, and her shame regarding her writing—as one might expect—increased drastically. For Jean, this event revealed that she was making mistakes—a mark on her literate ability, and a mark made all the more

painful by the fact that the “kids” working in the kitchen found and exposed those mistakes. Jean’s role was reversed. She was used to being the teacher and to helping kids with literacy, not being judged for her own errors—particularly by “kids,” or those she assumes to be much less experienced with reading and writing.

With her literate attachment to adulthood and maturity severely challenged, Jean quit writing altogether: "After that I didn't write anymore because that was just devastating," she says. In fact, she stopped writing for three years until she joined a multimodal memoir composing group at a local speech and hearing clinic. During those three years, she thought of writing as “something I can do without,” writing only lists to herself for the grocery store. And Jean’s attachment to various processes and practices of literacy remind her of her loss of adult reading and writing ability. Her handwriting in those grocery lists reminded her of her aphasia and inability to retain and discouraged her from writing more: “Ah, writing was -- I hated my writing. I mean it was different. It was small. I couldn't read it most of the time, so I tried not to do it, you know. I made my lists and I guessed at them at the grocery store.” As mentioned in the closing of Chapter 3, Jean’s affective attachments to literacy cluster around her embodied writing practices and processes. She willingly increases the size of print on her iPad, but she refuses to have her iPad read aloud to her (unless it’s especially confusing). Decoding with the “normal” senses of literacy—sight and cognition of language—makes for “real” reading that she accomplishes as an adult.

As she joins a writing group for people with aphasia, Jean grapples with her literate attachment to doing things on her own, as an adult, in the normal processes of literacy and the idea of a “new normal” that loosens those literate attachments and works for more flexible ones. Describing her discomfort with being vulnerable or showing mistakes in her writing, Jean

acknowledges that she's "always tried" to make her "reading and writing and all that kind of stuff" perfect. "I want everything I write to be perfect," she explains. "I don't want to be laughed at." That fear of being marked and ridiculed as "less than" adult, mature, or able resonates through Jean's literate history, through affective and embodied attachments. She has been laughed at as a child because of perceived literate deficiency because of how she didn't quite fit with the docile literacy learning of the classroom. And she was marked (literally) again after aphasia as a deficient reader and writer: encouraged to read kids' books, corrected by the kids who marked her sign, and pushed out of a mature role of literate competence.

Despite those painful experiences, Jean purposefully challenges the attachment to literacy as a sign of adulthood—through rethinking autonomy and many of the mundane practices of literacy. She seeks a "new normal" for literacy, which she sketches out in a poem she wrote for an aphasia writers' group 4 years after her stroke.

My New Normal

I wish that I could be back to normal,
where I could:
Read anything
and understand deeply
Write a letter
or beautiful poetry
Talk smoothly
without thinking about it
Figure out math
in my head
Remember thing, like events,
or where I put the key....

My new normal teaches patience,
I can:
Read and understand deeply,
it just takes time
Write a letter or beautiful poetry,
it just takes practice
Talk smoothly,

but I have to think about the words
Figure out math in my head,
but check it with a calculator
Remember things,
if I write them down and keep organized.
Be patient,
it is a new gift from God.

Judy, Beth, and Jean all, to some extent and to varied results, developed attachments to a normative literacy identity prior to acquiring aphasia. These attachments endure across the bodily changes stimulated by aphasia. And those changes bring to light the rigidities and restrictions of a normative literacy identity. Signs of their losses and deficiencies mark these writer's processes and the products of their writing. The loss of flair, ease, creative genius, systems of reading and writing, quickness in doing literate work and thinking are all altered. A normative literacy identity, then, puts expectations on bodies that suffuse every material, embodied, and social value tied to literate practice and identity. Because those literacy successes or failures are, in turn, attached to qualities of intelligence, adulthood, creativity, and flair, these embodied markers on process and product all cut at the quick of literate identity. What's more, as bodies change, those attachments stick and endure, preventing people from adapting comfortably to new practices and new identities. Though normative literate identity may serve some individuals who fit it, bodily change severs that comfort and ultimately damages literate practice—doing a disservice to all readers and writers.

## Flexible Literate Identity

Jean's literate experiences have alternately positioned her on the inside and outside of a normative literacy identity. Her call to critique and rework the norms of literacy—away from

autonomy to collaboration, away from correctness to flexibility—links her literacy identity with Andrea, Sandy, and Bob featured in this section. As Jean's struggle with literacy has produced a range of knowledge about literacy, so do the experiences of Andrea, Sandy, and Bob.

In these three literacy history profiles, I show how individuals used to struggling with, or disconnected from, a normative literacy identity before aphasia often find themselves better able to adapt to bodily changes after aphasia. Though they were sometimes less successful at reaching many of the school-based standards of literacy before aphasia, these individuals are often able to adapt more effectively. Their literate actions offer an under-articulated facility and adaptability in the literate experiences of individuals sometimes considered to be on the outskirts of literate success. Indeed, an outsider identity to literacy creates knowledge about literacy, its norms, and the underacknowledged ways literacy may be "complexly embodied" (Siebers; see Chap. 1).

Drawing on the literate experiences of three individuals—a multilingual counselor, a first-grade teacher, and a grocery store manager—I sketch out ways an openness to understanding literacy as outside of norms for the body and individual production can be instructive for how educators may better prepare learners for literacy across the lifespan. Finding themselves constrained by (or, in Bob's case, disinterested in) the norms of literacy, these individuals encounter the fact that "normativity is comfortable for those who can inhabit it" (Ahmed 155). Early on in their literate histories, these individuals who have developed flexible literate identities each work to "inhabi[t] norms differently" (Ahmed 155). In doing so, they generate knowledge of the constraints norms place on bodies—memorization, correctness, physical inaction, autonomy. And they rework those norms, involving others in their reading and writing practices, focusing on creating meaning and expressing the self—beyond correctness, and cultivating an integrative understanding of literate practice and identity. These flexible

literate identities, then, generate knowledge about literacy that proves to be indispensable after aphasia.

***Andrea: "I wanted to write about myself"***

After aphasia, Andrea explains that she is writing more and better than ever before. That experience is surprising given the changes that aphasia brings on, but it is more understandable in the context of Andrea's life-long relationship to literacy. Literacy, for Andrea, has always been tied to an expression of selfhood. Her interest in and engagement with literacy—her attachment—came from her desire to express herself. That attachment developed across childhood and persisted through the challenges of being a multilingual writer and reader pursuing and doing advanced writing in post-secondary education and graduate work in a second language. And that ideological attachment to literacy as self-expression endures across aphasia, mitigating self-censoring. Further, affective and embodied attachments to literacy as self-expression developed across the lifespan and surprisingly enable Andrea to strengthen her literate identity as she writes extensively after aphasia.

Born and raised in Peru, Andrea moved to the Midwestern United States for college. Her experience as a multilingual speaker, reader, and writer has instilled in her a belief in the power of literacy as essential to economic and intellectual mobility. Andrea's mother stayed at home with her and her three older siblings, but she managed the household accounts as Andrea's father went to work as an accountant for a private college. The upper-middle class status of her family afforded Andrea the opportunity to attend bilingual schools throughout her primary and secondary education. And literacy acquisition in Spanish and English was a marker for family, friends, and neighbors who praised Andrea and her siblings' progress and lauded their "good futures."

Writing was something Andrea felt connected to from the age of three or four. “Yeah, I love it. I love it,” Andrea answers when asked how she felt about writing as a child. Her first memories of literacy are of writing her name, sitting alongside her older siblings doing their homework at the kitchen table. She vividly recalls, “trying to write, but I have no memories, no memories of trying to read, just memories of trying to write. And I would write my name and that’s it.” It was her mother’s “beautiful writing”—“her writing was like a work of art”—that, Andrea says, made her want to write. Unlike writing, Andrea found reading to be disconnected from herself and thus less enjoyable. Of reading as a child, Andrea explains, “I didn't care for it. Maybe it was. I didn't care for it at all, yeah." “Maybe I had to sit and wait for the lettering to get into my brain,” she recalls. “I’d rather be out playing or something like that, yeah. [laughing].” Andrea describes reading as physically and conceptually outside of the self—only made internal through cognitive work and a delay as meaning from “lettering” gets into the brain. In this way, Andrea felt reading to be frustratingly sedentary, mediated by potentially interfering materials and, most saliently, apart from the self.

When she moved to the US to attend college at a public regional university in the Midwest, Andrea describes a similar feeling of delay, distance, and disembodiment between reading, writing, and understanding as she experienced difficulty understanding English. “At first, when I go to the U.S.,” Andrea recalls, “I didn’t understand what people were saying to me. I didn’t know the idiom.” In daily communication, she felt a constant desire to say to people, “stop right there because I didn’t understand that!” In reading, she felt a similar gap or delay in understanding. “I remember reading, ah training to read as I could. Because I didn’t understand what the reading was about,” Andrea says. She recalls reading next to a dictionary but having to look up so many words that she “lost the ideas.” Andrea constantly dreaded writing for classes

and "was thankful for the exams that were bubbles only. [laughing] I didn't have to write at all! Yeah [laughing]." Frustrated by the painful and distancing experiences of reading, writing, and speaking in English, Andrea transferred to another university, then dropped out after a semester to work full-time at a restaurant.

Outside of school and work, however, writing served as an important mode of self-expression. Writing in Spanish afforded Andrea an outlet for her ideas and emotions, enabling her to express herself and her experience. Andrea wrote "about my life" in order "to get my feelings on paper. I didn't have anybody to tell." Writing became a place she could escape from that isolation by expressing and asserting herself—a conduit through which she could reconnect with her sense of self.

After having three children, Andrea returns to pursue additional education in psychology as a single parent at the age of 32, citing a desire "to care for my children" and "to become better than I was." Completing an Associates degree, a Bachelors, a Masters, and all but the dissertation of a PhD in family therapy, she finds that writing in academic genres in English further creates a sense of disembodiment from her writing and ideas. Feedback from professors on her writing especially challenged Andrea's self confidence. She recalls a few particularly painful experiences of feeling hurt and threatened by the harsh feedback she received from professors on her writing: "I got them back with all red marks around it. Oh, yeah, and I wanted to die. Yeah. And I wanted to die. Instead of learning about it, I felt hurt. I felt hurt because of my low self-esteem, yeah. I should have wanted to learn, but I didn't." Andrea, like many or most students, responds to criticism of her writing as criticism of her self. In hindsight, Andrea interprets those feelings as misplaced: she felt hurt, rather than focusing on learning. This shame and stress around writing ultimately dissuaded Andrea from completing a dissertation. "I thought

how could I write a dissertation when I am getting so many mistakes on it [writing]," she says. "How could I?" Reflecting back now, Andrea ultimately regrets her decision not to write the dissertation. "I should've written it. Again and again and again," she says.

The school writing she had been doing and the writing she went on to do for her job as a family therapist—writing notes about patients, summaries of cases, assessments—all eliminated time Andrea had to write the self-focused kind of writing she so valued when she first moved to the U.S. Ten years after starting her career, Andrea became severely ill and suffered a sudden series of strokes. Her experience with literacy after these strokes and the aphasia they caused draws on her attachment to literacy in relation to self expression. The desire to write about the self pervades her motivation to write again and propels her to do much more self-sponsored, creative, and self-focused reading and writing after aphasia. Practically speaking, after aphasia, Andrea is also aided by time and by freedom from writing in constraining/heavily critiqued contexts to broad ones, ones based in sharing, in expression. Literacy, for Andrea, has always been tied to an expression of selfhood. But academic genres and the requirements for correctness of language kept her from feeling at home in literate practice or from developing a positive literate identity.

Immediately after her strokes, Andrea explains, both grave illness and weakness in her right hand kept her from reading and writing. She becomes emotional as she recalls having lost the ability to read on her own: "I remember my sister reading to me [Crying… long pause]. And feeling so sad because I couldn't read at all. [Crying]." Her strongest desire, though, was to write again. About 9 months after her stroke, Andrea first tried to write in her speech therapist's office. Her first memory of writing after aphasia bears striking resemblance to her first memories of writing as a child. She recalls writing her name again for the first time after aphasia: "I wrote my

name and I wrote my address, and I wish I could find the pieces of paper. I wrote very making mistakes and I wrote. Unbelievable. Unbelievable. They seem not letters. It looks like hieroglyphics." But her response to her first writing is not disdain, but awe and excitement at attaining something she so desired.

When asked how she responded to this first writing, she describes an intense desire to write: "I was crying, and I was. I wanted to write. I wanted to write so bad I could taste it. I wrote [Laughing] very, very carefully and very slowly I wrote the letters "Andrea." I wrote a round "A" [laughing] and an "n" a funky looking "d" an "r" and a scribble for an "e" [and "a"] [laughing]." Here, in these memories of writing soon after aphasia, we find striking parallels to the experience of writing as a child, as a three-year old, chasing the beautiful writing of her mother's – like a work of art – as she penned her name for the first time. The embodied experience of writing is a pleasurable one. She explains this desire to write coming from "My self-conscious. I wanted to write about myself because I felt deep inside—my willingness to write. I don't now. Deep inside I feel I have so much to say, and the only way I can tell people is to write." Writing and self are thoroughly meshed in Andrea's experience. She writes her name and, in doing so pursues—and seems to attain—self-expression. Experiencing a wanting, a willingness, a deep feeling of having something to say as a person, Andrea identifies writing as the "only way" to accomplish that expression.

Being freed up from constant demands to write in professional and academic genres gives Andrea time to pursue this self-expression through writing after aphasia. School kept her from self-sponsored writing before her stroke. Instead of papers, Andrea "wanted to write more about myself. And I couldn't. I had to write my school papers, yeah." And also freed from genre constraints that impose external assessment, Andrea values her writing and, through it, herself. In

these loosened constraints around literacy, Andrea observes, “I’m able to express myself better.” She attributes that improvement to “my paying attention to what I write” and a “willingness to do it.” Freed up from rigid requirements, Andrea now pays more attention to “Verbs, tenses, adjectives” and the affordance of language. Of adjectives, for one, she ruminates: “they explained so many things about people, animals, and things that you never think about.” In this way, an attachment to literacy based in finding room for self-expression, combined with the resources to accomplish it (including time) enables Andrea’s literate practices to grow despite the challenges to language and physical writing post-aphasia.

In fact, the bodily practice of teaching herself to write with her left hand offer Andrea a focus and a productive goal. As she loved to inscribe words as a child, she teaches herself to write in increasingly refined “block letters” through dedicated practice. She handwrites every day: using children’s letter practice books every day, taking notes from continuing education classes in block letters, and always handwriting in block letters prior to typing. Unlike Jean, Judy, or Beth, these literate practices and the changed appearance of her handwriting do not challenge her sense of self. Instead, she is constantly forward-looking, focused on self-development and expression. When asked to describe a time after aphasia she has used reading or writing she feels good about or proud of, Andrea describes her current morning writing ritual. “I wake up at 5:30 in the morning, and I use the time to concentrate on myself, to meditate, and I write freely,” she details. “I write freely on what I need to write. I don’t know what it is, but it is wonderful to me. Yeah. I treasure that time.” When I ask her if that writing has parallels to the reflective writing she did in the past, in Spanish, when she first got to the U.S. “Then it was all sad,” she reflects. “And now it is more hopeful, yeah. Then it was all about my past. Now it is about my future.”

***Sandy: "you could integrate all of those things"***

Like Jean and Andrea, Sandy's literacy learning has not always been smooth. Sandy's literacy history is marked by fraught early connections to an ideology of literacy as independent and correct, much like Jean, Beth, and Judy's ideological attachments. Sandy struggled as she failed to fit those ideals. She recalls her first literacy learning in elementary school as being all about skills, including memorization and phonics, designed to lead to smooth, automatic decoding and encoding of language. But, for Sandy, those experiences were anything but smooth or automatic. She felt slow, deficient, and simply "not good" when it came to reading. Sandy felt stifled by the constraints of sitting still and "memorizing" words to succeed at school-based literacy. It was not until she became a first-grade teacher that Sandy could counter these ideologies of independence and correctness, developing instead an attachment to literacy as an integrative process that can be explored and taught through multiple means—kinesthetic, spatial, collaborative, and more. This attachment to literacy as integrative developed before aphasia and enables Sandy to develop and adapt new practices after acquiring aphasia.

Sandy grew up in a working-class household. Sandy's mother was born in a Bohemian community, and her first language was not English. She completed only an 8$^{th}$ grade education, was a stay-at-home parent for Sandy and her cognitively disabled brother, and then worked on an assembly line after divorcing Sandy's father. Sandy's father ran a root-beer stand, and Sandy never saw either parent reading or writing at home. When I ask if she ever helped her brother with reading or writing, Sandy answers no, "But then I didn't have a role model for that." Sandy explains that much of her mother's attention went to her brother's learning needs and that, being a woman growing up in the 1940s and 50s, Sandy's looks were what her mother hoped would gain her attention. But there was also an "assumption" that Sandy would work to "be very good

at school and become a teacher." Sandy recalls that she would line "up all of my dolls on the swing and would teach them." And, she observes, gender constrained her career options: "In that generation," she explains, "if you want to go to school and become something, it would be a teacher or a nurse." Indeed, Sandy was one of the first in her family to go to college and, for that, is still a "maverick" on her mother's side.

All the way from grade school to completing a college degree to become an elementary school teacher and a certification to work with students with cognitive disabilities, Sandy experiences persistent discomfort with reading and writing focused on correctness, memorization, time limits, and other rigid standards—skills and requirements she feared she always failed to reach. As early as first grade, she recalls feeling that her reading marked her as slow, deficient, and "at the bottom of the class." Timed writing and testing in her sixth grade classroom caused her to "panic." College entrance exams caused similar feelings: "I was panicked to read all of those words," Sandy says, "And then I would just guess." While Judy, Beth, and Jean identify embodied and affective attachments that link them to particular ideologies of literacy, Sandy finds that the ways bodies and minds are expected to act in literacy (under time constraints, memorizing, etc.) detach her from literacy.

But at the same time, Sandy's literacy history shows how she develops different bodily and affective attachments—one's links to a more open and integrative ideology of literacy. Namely, she describes her spatial, kinesthetic, and physical literacy practices. While she had difficulty memorizing words, Sandy details her almost "photographic" memory for pages of books and the ideas they contain—a result, she suggests, of her slow reading pace combined with her proclivity to the spatial and kinesthetic. Similarly, the process of learning Latin challenged Sandy's ability to "learn all of those words," but she "knew all about how to place the words,"

the grammatical "structure" of the sentences. It worked well to partner with friends who could memorize well, Sandy explains, "because they had the words, and I knew the structure." In this way, spatial components of literacy turn attention to the materials and processes of literacy – rather than the value of correctness.

This awareness of the bodily, kinesthetic, spatial components of literacy comes to full fruition for Sandy when she becomes a first-grade teacher. "I know I became a very good reader when I started to teach reading to first graders. And I could see how to integrate all of the different skills." In the first-grade classroom, Sandy found room to put together not only phonics and word knowledge, but her own insights as a "physical, kinesthetic learner." Unlike her experience of being forced to sit rigidly in a desk, Sandy engages students in movement and multiple modes as they learn. She describes one such activity, learning how to use vowels by including students in a skit in which a "magic fairy"—acted out by a student with a magic wand—sprinkles fairy dust on one of the vowels, "gives his power and gets very quiet" to demonstrate the rule of "two vowels sandwiched together in the middle are short." Students remember these concepts from movement and active engagement. Sandy, likewise, draws on her mother's experience learning English with nursery rhymes, writing songs and rhymes to teach science and other subjects.

This integrative style of teaching literacy improves Sandy's own reading, she reflects: "when I made all of those connections with the language and the phonics and the writing my reading improved and I found, like I said, the joy of reading a lot a lot a lot." She attributes this expanded sense of joy and improvement in reading to finding "patterns" in words in addition to fully engaging multiple ways of learning, beyond rote memorization. Reading, after this integrative style of teaching and learning becomes "part of my life," Sandy reflects.

After aphasia, it's this attachment to literacy as integrative process that sustains Sandy's new practices as she is able to grow and adapt new post-aphasia literate practices. She interprets her growth after aphasia through her expertise as a teacher: "most of my recovery on my own is related to my experiences with teaching. You know? I and I just, I can spot some of the students', developmental markers you see in kids in my speech." Indeed, without judging these practices as too infantile or challenging her sense of maturity, Sandy's integrative attachment to literacy facilitates her openness to reading children's books to practice her reading post-aphasia. Immediately after her stroke, Sandy reflected that she was at a first-grade reading level. She began, then, by reading from that level: "Little Bear Books." When she left rehab, moved to Owl at Home and Frog and Toad. She read Pee Wee Scouts and then Beverly Cleary. She even read them aloud for the first few months to practice both reading and speaking. Reading children's books has no stigma for Sandy; instead, it offers another way to support her development as a reader.

Writing post-aphasia similarly challenged literate attachments based in independence or adulthood. Sandy describes relying on others and various resources to compose post-aphasia. To fill out her students' report cards while she was still in the hospital, Sandy draws on the help of a fellow teacher and friend, who writes down numbers and has Sandy point to them to facilitate the process. Sandy requests that another friend bring a dictionary to help her write and pay bills related to her mother's recent move into an assisted living facility. Sandy first finds that a "real small, thick" dictionary is impossible to read and seeks other resources: a primary dictionary, for first-grade with pictures and text. Sandy's practices here are integrative and open, flexibly drawing on other people and a range of materials (even children's books) to adapt new practices after aphasia. Her attachment to literacy as integrative facilitates those practices.

***Bob: "It was too boring" to "a weight off the shoulders"***

Bob, a manager at supermarkets and warehouses for over 30 years had a brain tumor that caused aphasia and led to him leave his work. In the ten years since his tumor and surgery, Bob makes presentations to local groups—at churches and clubs—about aphasia. From childhood, reading and writing always struck Bob as "too boring." Bob grew up in the rural Midwest, the fifth of seven children in a working class family. His mother worked as a nurse and his father as a factory worker at a local plant that manufactured pressure cookers. Money was tight and so was his parents' time. Bob doesn't recall being read to at home, and he describes avoiding reading and writing, "unless I had to for schoolwork." "I was just an average student," he says. Instead of sitting and reading or writing, Bob explains, "I'm a hands-on type of guy." Literacy, instead, was a task that could be delegated to others. As a high school student, he even avoided book report writing, having his then-girlfriend, now-wife of over 40 years, write them for him. Eventually, writing did become something he had to do on the job as matter-of-fact, hands-on composing. As he advanced to store and regional management positions, he explains, "We had to write, take inventories, that was part of my job."

In these ways, Bob's neutrality and frequent detachment from literacy can be contrasted with Beth, Judy, and Jean's strong attachment. What is most significant for my purposes, however, is the way Bob's detachment from literacy surprisingly facilitates his success navigating and adapting literate practices after aphasia. While Beth, Judy, and Jean's sense of changed embodiment causes them to quit particular literate practices altogether, Bob's literacy expands outward. I'll discuss how he involves others and moves to new mediums and focuses on meaning. In not being attached to normative expectations around literacy—certain processes and products, created autonomously—Bob is, to some extent, freed up from pressures around what

literacy should look like and, in turn, actually adapts, expands, and grows as a reader and writer post-aphasia.

While Beth isolates herself, Bob actively involves others to aid in his literacy after aphasia. He does so in ways that range from everyday reading and writing to larger-scale projects that push at the bounds of authorship. An example of Bob involving others to read for functional purposes occurred five years after acquiring aphasia. Bob took a day-long course at a local community center to make snowshoes. There, he found that he could not read the instructions for the project. “I couldn’t make heads or tails of those instructions. I couldn’t follow instructions at all,” he matter-of-factly explains. So, he advocated for his needs, having the course instructor read out, explain, and show him the instructions. “Show me and I’ll get it,” he asserts. Bob is less concerned here with his process of reading, than with getting the meaning and getting the job done.

Similarly, when Bob wants to seek funding to support the informational talks he gives about aphasia, he involves others. He works with a speech language pathologist who facilitates a support group he is involved with the co-write a grant proposal. Bob mentions this grant as writing he’s done after aphasia that he is proud of and feels good about. Only after I ask more about his writing process does he tell me that he co-wrote the piece, dictating much of the composing to his co-writer. Dictation and input are integral parts of writing and forms of authorship for Bob.

Secondly, in addition to involving others, Bob also moves across modes and various technologies to compose—concerned, mostly, with getting the meaning out. Bob, who never used a computer to write before aphasia, has found after aphasia that his iPad is “the best thing since canned beer.” He notes “the availability” it offers “to store thoughts.” He writes down

reminders to himself and ideas and notes for his aphasia presentations. He also collects inspirational quotes from Facebook and integrates them into his presentations. While Beth's practices contract in the face of powerful normative literacy standards—giving up journaling (which is, for her, dependent on handwriting that, in turn, reminds her of her bodily failings), Bob's expand. He tries out new technologies and media for his daily needs and new advocacy role.

More than adhering to particular literate processes and products, Bob is concerned with meaning and getting his point across. And using his literacy skills has helped him to do that after aphasia and in his new role as an aphasia advocate. He created and constantly modifies PowerPoint slides and a script for his presentation. "Different groups. Different mind sets. Different surroundings," he explains of the churches, civic groups, and community organizations he visits to present. These are important literate and rhetorical skills, but the meaning is what is most important to Bob. "It helps me," he explains. "This is my therapy." For Bob, sharing about aphasia is a "relief," "a load off the shoulders." He notes "the feeling" he gets "when people are really interested in" his "message" as the impetus for why he gives the talks in the first place. Bob is less interested in the form of his literate action—or even that it is writing or reading at all—but feels compelled to share and connect with others. While Beth describes her post-aphasia literacy in terms of guilt, embarrassment, panic, and blockage and Judy in terms of loss, Bob describes his literate actions lightening his load. Literacy, unweighted by normative standards or attachments to process, practice, or body, offers a great deal to Bob as he makes meaning for himself and others. What is significant for Bob, however, is that factors like gender and class that distance him from developing a normative sense of literacy, and indeed make that identity unattractive and unnecessary, actually encourage him to develop pre- and post-aphasia literate

flexibility. This is not an endorsement of often damaging gender roles, but an observation of these intersectional factors on literate identity.

Andrea, Sandy, and Bob all demonstrate flexibility in relation to their literate identities before and after aphasia. Both Andrea and Sandy experienced difficulty "fitting" with literacy throughout their pre-aphasia literate experiences. Andrea found herself attached to the idea of expressing herself through writing, but always put off by reading: the idea of getting ideas in was less interesting to her than producing her own ideas in writing. Getting ideas in through literacy in a second language—and having to get them out in constrained, high stakes academic and professional documents—further distanced Andrea from an engagement with literacy. But post aphasia she feels freed up, finds room and time to express herself in genres of her choosing. Time and requirements for correctness also distance Sandy from literacy before aphasia. It's not until she becomes a first grade teacher instructing students in integrative approaches to literacy that she feels attached to reading and writing. Those flexible, integrative processes and perspectives on literacy serve her well as she adapts whatever processes and practices she finds useful post-aphasia. Bob, too, is flexible—before and after aphasia, he is unattached to particular literate ideals, norms, or values. He involves others, wants to compose for meaning, and ultimately grows into new genres after aphasia. These flexible perspectives and practices pre- and post-aphasia enable individuals to re-work literate norms, freeing them up to practice literacy with others, and with their bodies in a variety of ways.

**Conclusion**

This chapter has drawn on literacy history interviews and profiles to establish the enduring links between social values around literacy and the body. I forward a conception of both "normative literate identity" and "flexible literate identity" to show how the social and embodied aspects of literacy are in tension and dialogue across individuals' lifespans—and exposed by the bodily change of aphasia. These identities form in relation to embodied and affective attachments to literacy that, particularly for normative literacy identity, put particular kinds of pressure on bodies, processes, practices, and products of literacy. Individuals who have separated from those normative senses of literacy are able to adapt more freely to literacy after their bodies and minds have changed after aphasia. What this chapter exposes is, in Mary Jo Deegan's words, how "physical limits" around disability and bodily difference may often be "integrated into everyday life, but social limits are the most untenable, potentially humiliating, and dangerous factors emerging from physical limitations" (45). This chapter traces those strong, durable, and damaging social attachments to literacy and finds how they linger and put pressure on people's bodies as they read and write.

# Chapter 5

## Beyond Misfit and Retrofit: Enacting Literate Access in a Multimodal Memoir Group

The previous two chapters explore how the social, material, and embodied aspects of literacy intersect and come into conflict for people with aphasia. As we have seen, aphasia exposes norms around literacy that are attached to able bodies and minds. I've shown how the experience of literate misfitting occurs between bodies, minds, materials, and the expectations about what each aspect *should* do in reading and writing for individuals with aphasia. Embodied change affects individuals' literate identities differently based on their pre-aphasia attachments to literacy. In this chapter, I turn our attention to what we—writing studies scholars and literacy educators—stand to learn about literacy from an environment in which no one fits a literate norm—an environment in which misfitting is the fit, in which people with aphasia actively re-fit communication and literacy to new norms and new practices. I ask, how can we understand literacy differently from the insights of people with aphasia communicating and composing in a multimodal memoir group?

The "Telling Life Stories" multimodal memoir group stemmed from a collaboration across disciplines between me, a graduate student in English—Rhetoric and Composition, and a speech language pathologist and clinical professor, funded by a university center for the humanities for community programming. As facilitators, we consciously worked from the perspective of universal design—making as many resources available as possible for multimodal storytelling (Dolmage, "Mapping"). But we found that, much more than our efforts as facilitators at creating an accessible environment, one of the most generative parts of this group resulted from the way people with and without aphasia created their own literate access in the moment:

with other people and modes, with their bodies, as they challenged norms and practiced an ethic of care for one another's access to expression.

In this chapter, I explore how in this multimodal memoir group aphasia and disability were far from problems to be fixed or rehabilitated. On the contrary, I argue that the inventive composing of participants with aphasia offers insight into what *literate access* looks like and its implications for understanding communication and literacy outside of standards for "normal" bodies and minds. By "access," I mean "the ability to use, enjoy, perform, work on, avail of, and participate in a resource, technology, activity, opportunity, or product at an equal or comparable level with others" (Oswal). Rather than a checklist of rigid requirements, a commitment to access is an ethical orientation: in Jay Dolmage's framing, access is "a way to move," "a form of hope, a manner of trying" ("Mapping"). In this chapter, then, I refer to *literate access* to denote the ability to engage in literate actions and practices, to take on a literate identity for oneself, and to be acknowledged as literate by others[9].

In what follows, I analyze select examples from videotaped group interaction from our multimodal composing group to show how people with aphasia, often denied literate access, cultivated and experienced it in this group. Acting as exceedingly adept, responsive, and flexible composers, people with aphasia expanded the boundaries of how we understand design, access, multimodal composition, communication, and literacy by reworking a number of literate norms. Ultimately, the composing and communicating practices of participants in the Telling Life Stories group turn our attention to how communicative and literate access is enabled not only by materials that can be used by individuals with all kinds of bodies and minds—making multimodal composing resources available, from digital tools to manual instruments of

[9] Literate access counters "literate invisibility," in Kliewer, Biklen, and Kasa-Hendrickson's terms. It is a way of refiguring literacy as potential, partial, collaborative, embodied, and in flux.

composition like pens and paper—but also and importantly by the ways that people with aphasia create, co-create, and rework their own norms around literacy in moments of composing.

Accordingly, this chapter takes a close look at how literate action and access occurs so creatively and effectively, often with little access to language. Rather than deficiency in literate skills or knowledge, people with aphasia and their communication partners enact a deep and extensive knowledge about and facility with literacy. I show how the context of aphasia in fact encourages a kind of attunement to the many ways of communicating, listening, composing, and doing literate work: people with aphasia are poised between modes, between language and bodies, between self and other, between the message and the many paths to it. They are particularly attentive listeners—listening not only to speech, but also to gestures, facial expressions, drawings, written words, objects surrounding them, and more. They wait, clarify, let some confusion go, re-route, give others time, allow people room to invent before they express, and draw on all the resources available to make and receive meaning.

To show how people with aphasia enact and establish literate access in-the-moment, I analyze observations from a semester-long multimodal memoir group for people with aphasia. This examination of the communication and composing in-the-moment of people with aphasia follows ethnomethodological and phenomenological methodologies that emphasize how "social actors construct categories and orders in every day interaction" (Prior, "Combining" 169). Such an approach is essential for accounting for how the participants in this group construct their own norms for communication and literacy. From this analysis, I find that (as Suresh Canagarajah traces with multilingual speakers and writers) people with aphasia "co-construct" their own, in-the-moment "norms and conventions" to do literate work, ("Multilingual Stratgies" 20). In what follows in this chapter, I show how people with aphasia and their communication partners create

literate access in-the-moment by reworking key norms around literacy and communication and co-constructing their own: 1) decentering language, 2) using the body as a technology of literacy, 3) blending orality and literacy, 4) practicing dispersed authorship, 5) and practicing an ethic of care.

First, I offer background about the structure and rationale for the multimodal memoir group for people with aphasia. Then I detail key issues in "access"—arguing for a move from retrofitting or retroactively redesigning environments and practices to an approach to ongoing participatory design. I apply that logic to related work on access and communicative disorders and then move into an analysis of how people with aphasia enact literate access in the multimodal memoir group.

**Background and Structure of the Multimodal Memoir Group**

The Telling Life Stories multimodal memoir group for people with aphasia that I began co-facilitating in Spring 2012 developed out of a commitment to rethinking communicative access in the design of a "writing" or memoir group. The group stemmed from a collaboration across disciplines between me, a graduate student in English—Rhetoric and Composition, and a speech language pathologist and clinical professor, funded by a university center for the humanities for developing community programming.

We began with the premise that—of course—individuals with aphasia have a wealth of stories to tell and vital experiences and insights to share. As we designed the group, we were informed both by communicative sciences and disorders research tracing how the disruption to language caused by aphasia commonly unsettles how individuals create a sense of identity through communicating with others and the notion, from Rhetoric and Composition, that writing and storytelling are powerful sites for expressing self-identity. Groups that bring people together

to meet, compose, and share writing are often considered to be places to express a sense of self-identity, to adapt to life challenges, and to identify strengths. Drawing on these potentially empowering notions of writing groups and the opportunity they offer for self-narration, we developed a semester-long life-story composing group designed for participants to create multimodal texts. In these scrapbook-like life-stories, participants used drawings; words; and personal artifacts, including maps, family trees, old ticket stubs, photographs, even locks of hair to reflect on and express aspects of their life experiences (See Appendix C for images of multimodal memoirs).

Ten people with aphasia participated in our group, meeting for thirteen weeks over the course of a semester at a speech and hearing clinic at a large public university. I videotaped one-to-one and group interaction during these sessions and to interview group participants to find out more about their experiences in the group. During weekly 90-minute meetings of the group, aphasic people worked one-on-one with graduate student clinicians enrolled in a Masters program in communicative sciences and disorders to create their life-story projects. Participants used laptop computers and tablets to compose various pieces of their life-stories: they spent time online, using search engines to find related images and information, to jog memories, and to aid in communication breakdowns. Using gestures, speech, their life-story projects, and various materials, they also brainstormed and shared their compositions with other participants, creating an experience similar to those in text-focused writer's groups.

While the group was funded by a humanities program and explicitly designed *not* to be therapy, at the beginning of our group, clinicians—who are training to become speech therapists and need practice in the work of their field—gave participants a brief diagnostic test to gain a

sense of how much language they tend to use (primarily showing participants cards with pictures and asking them to respond). Participants could choose to opt out of this testing.

In total, I videotaped nearly 140 hours of group interaction and 10 hours of interviews over the course of the term. I also collected hundreds of images of life-story compositions. In this chapter, I present the results of my grounded theory analysis of 52 hours of that video, coding for communicative and literate practices—drawing, gesturing, performing a scene, speaking, writing and communication breakdowns, developing strategies to mitigate confusion, and more.

**Access: From Retrofit to Co-Production**

"Access" is a central term, concept, and commitment in disability studies. Disability scholars and activists expose the fact that all of the phenomena we engage with—from buildings to learning environments to technologies—both physical and social, are built with the intent of having certain kinds of individuals move, participate, and gain access to resources within them. To misfit, as we have seen in Chapter 3, is to be denied access, to find that environments have not been built for your body, mind, and being. In this way, misfitting brings to light "the false value-neutrality of inaccessible environments," tools, and experiences (Hamraie).

One "solution" to the exclusion caused by such value-laden designs is to "retrofit" or add components to existing environments or materials to fit the needs of disabled individuals. As disability scholars and activists commonly note, however, retrofitting marks disability as an "afterthought" (Dolmage, "Mapping" 21), disabled people as "other," and often an "individual" problem. A common example of a retrofit is the construction of ramps, often winding around the sides of buildings that previously only housed stairs. Such retrofits demand that individuals "access spaces differently" and usually in secondary or decentered ways, observes Allison Hitt: "Rarely do we see ramps at the entrances of buildings; rather they are on the side or in back."

"Accommodation"—a common term in disability services—also stems from a retrofit logic. Accommodation "in all of its reasonableness, is a bandaid," explains Melanie Yergeau: "It implies that there exists a nature or reasonable system, and that our minds and our bodies are somehow lacking because we cannot fit into this natural system." The logic of retrofitting and accommodating, then, upholds norms and perpetuates the exclusion of those who fail to fit those norms. As we see also see in the previous two chapters, this exclusion causes deep affective consequences as accommodation and retrofitting "reinforce" a "sense of shame" (Yergeau).

Given its afterthought logic, retrofitting simply does not secure access for disabled individuals. Nor does adhering to a checklist of requirements that cannot possibly meet the full range of individuals' needs. Instead, creating accessible environments requires a commitment to working toward access on an ongoing basis, to treating access as an ethical orientation: "a way to move," "a form of hope, a manner of trying" (Dolmage, "From"). For Tonya Titchkosky, similarly, "access is a questioning orientation, an important way to perceive, speak of, and take action on the relations between bodies and social space" (x).

Universal Design (UD) and Universal Design for Learning (UDL) offer approaches to rethinking access to social and physical spaces. Initially a spatial theory forwarded by architect Robert Mace in 1988, Universal Design advocates for the design of spaces, from the beginning, to provide the greatest access to the greatest number of individuals. The UDL approach, developed by the Center for Applied Special Technology (CAST) in 1994, followed suit, applying UD principles to pedagogy and pedagogical spaces, striving to develop universally accessible learning environments.

Dolmage, however, warns against understanding UD and UDL as a panacea, as a "a kind of rocketship or an alternative to the science of evolution" ("From" 7). He cautions that the

“universal” approach can be taken up as a neoliberal commodity reinscribing new—but still exclusionary—universals. Instead, Dolmage emphasizes the value of the “design” part of UD and UDL. Creating accessible environments is an ongoing process. Therefore, “UD should be registered as action — a patterning of engagement and effort. The push towards 'the Universal' is a push towards seeing space as multiple and in-process. The emphasis on 'design' allows us to recognize that we are all involved in the continued production of space” (Dolmage, “From”). And specifically, in the classroom, “students should be agents in this negotiation.” In this way spaces, learning, and access to them are accomplished through “co-production” or “participatory design” that has the potential to overturn after-the-fact retrofitting or accommodation.

**Aphasia, Communication, and Literacy: From Ramps to Participatory Design**

This chapter explores how literate access may be established through ongoing negotiation of norms around communication and literacy. The concepts of retrofit, Universal Design, and co-production are important interventions into discussions of how individuals with language disability may gain literate and communicative access.

Within the field of communication sciences and disorders, Aura Kagan’s ideas about “supported communication” have gone a long way to train speech language practitioners and to inform individuals more broadly about aphasia not being about intelligence, but about communication barriers. Kagan advocates for a supported communication approach grounded in “the idea that people with aphasia have a right to communicative access” (818). This model of communication is focused not so much on people with aphasia going through drill-based language therapy with the ultimate goal of communicating independently, but on what a “dyad” of communicators—most often a person with aphasia and a trained speech language professional—“achieves interdependently” (818).

Notably, she calls for the importance of clinicians and non-aphasic individuals providing a "communication ramp" for people with aphasia. That ramp in communication has a "direct parallel," says Kagan, to "the area of physical disabilities where people have a right to on-going physical access in the form of aids such as walkers, wheelchairs and wheelchair ramps, when therapy cannot restore normal function" (818). For Kagan, communication ramps "give" people with aphasia chances to engage in casual interaction to vital discussions about medical care and other key life decisions (818). And skilled communication partners provide that ramp and, in turn, help to "reveal" the aphasic person's "competence."

I mention "communication ramps" not to critique these moves in communicative sciences and disorders scholarship and practice. On the contrary, these are important developments—seeing meaning as co-created between, or interdependently, with people with aphasia and others. But I also wish to push even further, beyond ramps. This chapter focuses not so much on what therapists or non-aphasic partners can do to "help," to "give" opportunities, but *more on what people with aphasia do*, how they accomplish access in the moment both as they communicate and as they rework literate norms. In doing so, I follow Margaret Price's important critique that disabled people "do not need *help* participating. We need ethical infrastructures" ("Space").

Further, putting the emphasis on a "ramp" risks continuing to naturalize a "normal" form of communication: that is, this form of communication, requiring ramps, only exists, as Kagan puts it, "when therapy cannot restore normal function" (10). Failing to question "communication" as natural or normal perpetuates an ableist logic that, in turn, reifies the medical model of impairment housed only in an individual and normalizes the lack of access disabled individuals encounter. As a result, "the lack of access for disabled people (and thus our absence) is naturalized to such an extent that even when barriers and processes of exclusion are

noticed they are still conceived as somehow natural, reasonable, sensible, and even seemingly justifiable" (Titchkosky xi).

Communication and literacy, as this dissertation shows, certainly run the risk of appearing unquestionably natural. It is difficult, Parr, Duchan, and Pound argue, to move beyond an understanding of aphasia from an "impairment perspective," or "a difficulty the person has with language" to a "disability perspective as a poverty of ways that those interacting with people have in supporting their expression" (5). To adhere too closely to "ramps," and the idea of aphasic individuals compensating for a language deficiency, is to overlook what people with aphasia create in their communication and literate action: in-person, through speech, drawing, drawing on space and gesture, writing, and much more. This chapter asks, how can we conceive of a literate environment—of communication, literacy, writing—that builds literate access from the ground up? That eschews circuitous ramps and embodies an ethic of co-production. In what follows, I show that people with aphasia, in fact, create that literate access in-the-moment.

**Reworking Literate Norms: Enacting Literate Access**

I turn for the rest of this chapter to an analysis of how individuals in the multimodal memoir group enact literate access. They do so by breaking down, re-working, and co-constructing norms of literate action in-the-moment. I'm helped in this analysis by scholarship across the field of literacy and writing studies that examines the systems of "literate activity" and the ways individuals work within them to compose and communicate. Specifically, I observe individuals developing and enacting literate access within "the dispersed, fluid chains of places, times, people, and artifacts that come to be tied together in trajectories of literate action" (Prior & Shipka 180). Enacting access in these dispersed networks requires writers to "tune" themselves

to their surroundings—working across multiple communicative modes, drawing on their bodies inventively, coming up with strategies "on the fly" (Lorimer Leonard 228).

In particular, observing the composing, literate, and communicating practices of people with aphasia in these groups, I follow Canagarajah's move to trace the "conversational encounters" of multilinguals to gain an "emic perspective" to "help explain why multilinguals adopt the forms and conventions they do in their writing" ("Multilingual"17). Very importantly, Canagarajah refigures deficit as insight. He does not consider the "ramps" multilinguals are offered or given in communication, but the "unique strategies" they "employ" (17). Multilingual speakers "stick to their linguistic peculiarities and negotiate intelligibility through their difference" (18). They reject the notion of error in favor of "co-constructing" their own, in-the-moment "norms and conventions" to reach mutual understanding. They supportively move through confusing vocabulary and syntax, working collaboratively toward meaning and draw on their surroundings to communicate, including "the physical environment, social context, gestures, and multimodal resources" (20).

In what follows, I make a similar move: I detail how people with aphasia in this multimodal memoir group enact literate access in five categories, reworking and refitting literate norms: 1) decentering language and drawing on multiple modes and other people as they compose and communicate; 2) employing the body as a technology of literacy—for inventing, developing, and composing in literate practice; 3) blurring the lines between orality and literacy by writing in oral communication; 4) refiguring the role of the autonomous writer into a practice of disperse authorship; and 5) sustaining this literate and communicative access through an ethic of care, listening across failure.

**1) Decentering Language: Drawing on Other People and Modes**

The first literate norm that people with aphasia rework in the multimodal memoir group is that literacy and communication is exclusively language-based. An environment that enables literate access accounts for the fact that alphabetic language is not always the first, best, and never the only mode for making meaning. I show how people with aphasia make meaning by using the body, space, objects, modes, and digital technology in the multimodal memoir group.

With the Body

In the multimodal group, people with aphasia rework the means by which communication and literacy happen. Many make creative and compelling use of their bodies to express themselves and make themselves understood to others. Gesturing and performing in the moment are both key uses of their bodies. Examples of this bodily communication appear right away in the brief, optional diagnostic testing at the beginning of the group. The clinician Sarah shows James, one of the participants, a series of cards and asks him to say the name of the object on each card. Even while it was optional, this testing in and of itself marks—and measures—deficit or otherness. The task could easily and understandably be construed as insulting or upsetting. James, however, responds to Sarah in inventive and complex gestures and performance, employing his body to re-represent or re-embody the objects. In this way, James demonstrates intelligence, insight, and humor as he enacts access to meaning in his multimodal responses. As Julie Hengst argues, in spite of problems with language, people with aphasia continue to *communicate* effectively and compellingly: individuals with aphasia are "able to *communicate* better than they *talk*, that is… their "communicative competence is better than, though masked by disruptions in, their language abilities" (109).

James moves far beyond language, creatively employing his body, gestures, and performance to make meaning. The object pictures include a pair of glasses, a computer, a tire

jack, and a thermometer. With the glasses card, James places the picture card in front of his eyes like an actual pair of glasses, comically lifting it above his eyes while raising his eyebrows and pursing his lips in a serious pose, lowering the card/glasses beneath his eyes as if peering over a pair of reading glasses. As Sarah writes down his response, James comes up with another expression, cupping his one functioning left hand into a circle around his eye in the form of one lens, forming another embodied portrayal of glasses. Responding to the picture of the computer, James borrows, in the same way as with the glasses, on the bodily functionality of a computer, gesturing a typing motion with his fingers tapping alternately and hands moving side-to-side on the tabletop. Identifying the tire jack, James, similarly gestures the cranking of a handle, moves his hand, palm down, up in a few incremental movements, demonstrating the lifting of the jack, all while making a clicking noise simulating the sound of the lifting jack.

While not expressed through language, James's gestures in fact carry a great deal of layered meaning: certainly, James retains all the system and procedural knowledge about a thermometer. The only missing piece of information is its nomenclature. His facial expressions with the glasses offer a laughable pretentiousness to the glasses or their imagined owner—perhaps representable in language as "spectacles." Indeed, Sarah frequently chuckles in response to James's gestural identifications, expressing her appreciation of his creativity and the obvious ways that he accesses and conveys the meaning of the objects.

With Space

Similarly, aphasic persons in the multimodal group often use space and surrounding resources to communicate. Several small instances serve as examples, including Fred telling a story about his former work as a maintenance person "here" pointing downward to which Mariah answers, "At the university"? James, too, through a gestural representation, demonstrates that

time passed between his multiple moves across the United States. He creates a timeline through the movement of his left hand, palm to the right and moving incrementally to the right to show stages on the timeline. Bill also shows the order of his siblings—whose names he has written down—by pointing to each respective name and moving his hand farther up in the air to show heights or ages. In explaining their frustration about aphasia, Bill, Harold, and James all use remarkably similar gestures: they draw on the space immediately in front of their mouths, putting their hand into this space and moving their fingers or full hands in a circular motion seemingly mimicking words tumbling out, but remaining open-mouthed, silent. All of these bodily movements demonstrate the powerful ways aphasic people draw on their bodies as a kind of technology to convey meaning and create communicative access.

With Objects and Modes

Intertwined in the foregoing descriptions of bodily and gestural communication are many objects individuals draw on to create meaning and access. Objects like maps and photographs, as well as personal artifacts like wedding napkins, old resumes, ticket stubs, and many others aid substantially in communication. Maps are very prevalent conduits for communication in these groups, and are acknowledged in Rhetoric and Composition as powerful ways to construct and convey one's reality—whether they are printed in Bill's case or online for James, Hugh, Frank, Maggie, and others (Reynolds). For Bill, maps allow for the extension and concretization of his textual family history. In another instance, he writes names of family members and points to locations where they live on a map. James and his clinician Sarah use maps to trace the contours of James's childhood into adulthood as he moved from Florida to Arizona to Illinois to Wisconsin. Taking advantage of questions from Sarah, pointing to various locations on the map, occasionally writing down an age or word, answering only through "yes" and "no," and

employing some drawing, James expresses a chain of complex reasons for moving and conveys the timeline of his life. These objects serve as ways through which individuals create and convey meaning. The co-creation of meaning happens across objects, modes, and people as individuals enact communication access.

One five-minute interaction between Bill and his clinician Laura aptly demonstrates that collaborative communicative process. Bill and Laura have been discussing their fondness for cats, and Laura explains that her cat is "very active…like a dog almost. She climbs trees [gesturing climbing trees] and gets birds and things." Both respond with laughter, and Bill is moved to share information about his own cat. The two go on to draw on gestures, objects, and multiple modes to navigate toward understanding.

After a slight waving of his hand indicating that he has something to share, Bill begins drawing a picture of a house. When Laura recognizes his drawing as a house, she asks, "In the house" and Bill reinforces "Ah, very good" and then begins to act out a search for his cat, "Simon? Simon?" he calls out while gesturing with his hand above his eyes as if searching into the distance. Incorrectly hearing Bill's speech, Laura says, "Diamond [laughing]. You call for a diamond?" Bill accesses his cat's name, written down as "Simon" on a notepad near them to clear up this confusion. Here the notepad and the writing on it become technological objects, tools in the basic sense of technology, enacting communicative access. With the scene established as Bill searching for and calling for his cat, Simon, Laura then contributes her own language and guiding questions, asking, "And she comes back when you call her?"

Seeking to push the conversation in a different direction, Bill uses gesture and language, shrugging and saying "yeah," to which Laura adds more language resources by asking more questions: "Did she come back because she hears [points to ear] you calling or because of food?"

"Ah, no. [laughing, shaking head] no," Bill answers and returns to his gesturing/performing: "Um, ah. Simon? Simon?" and turning back to drawing to offer more information. Laura recognizes his drawing, calling out, "Oh, the mouse!"

Their conversation proceeds through Bill's use of multiple modes, including gesturing, drawing, and language. Both Bill and Laura explicitly pick up on and make use of the communicative resources that the other offers to co-create meaning. This process is anything but linear, but frequently recursive, moving through mis-communication to generate more communicative pieces to elucidate additional meaning. Slightly later in their conversation, Laura picks up Bill's speech, believing she hears "proud" when he has said "bird"—as in his cat also hunts birds. Laura responds, "Yeah, she's very proud, right. She's like wow, I got the mouse" and gestures a proud, prancing movement. Bill laughing, does not explicitly negate or correct Laura's statement. However, he clarifies and adds, "Bird."

Sometimes, however, meaning is made through elimination or rejection of options. Later, believing that Bill has said "door," Laura responds, "So there's a little cat door." Bill uses gesture to thoroughly eliminate this option. He seems to pause the entire conversation by repeating "No" while making an "x" motion in the air and then holding up his hand as if to make a complete break from and resetting the direction of the conversation. Even in this brief exchange, it is clear that gestures, language, objects, and multiple modes all work as kinds of assistive technology enacting Bill's communicative access.

With Digital Technology

Computer and digital technology, likewise, offer access to not only maps, but also a range of images and other media that serve as inventive and communicative resources. Many participants are introduced by their clinicians to Google Maps and to images of their childhood

homes or old neighborhoods. These experiences prove affectively evocative for many individuals who had not been exposed to this online resource, and the images generate much additional conversation, ideas, and writing for their life-books. Having the resource of digital technology in the group offers many people with aphasia welcome communication aids. Several aphasic individuals point to or request that a clinician look up a topic during their individual meetings when a communication breakdown occurs. Fred suggests they look up the name of an amusement park he can't quite remember. Bill, a former pilot, wants to look up images of the kind of plane they've been discussing so he can show his clinician Laura that she has printed the wrong image of a plane for his life-book. Digital resources, in these interactions, provide essential resources to create in-the-moment access to communication, helping work through communication breakdowns.

Privileging a range of communicative modes enacts literate access for people with aphasia in these multimodal memoir groups. An exclusive focus on language perpetuates an ableist and exclusionary conception of communication and even humanness. Many scholars in disability studies have commented on the limitations of privileging alphabetic expressions of written and spoken language at the expense of other ways—or modes—of knowing (Davis, "The End"; Lewiecki-Wilson; Dolmage; Price, Siebers; Brueggemann). Lennard Davis confronts "one of the foundational ableist myths of our culture: that the norm for humans is to speak and hear, to engage in communication through speaking and hearing" (*Enforcing* 15). Reliance upon speech and hearing, he says, is culturally conditioned—not "natural" to human beings. This normalization of oral/aural communication reflects an Enlightenment belief in the human voice and speech itself as "the vessel and content of Reason" (Brueggemann, *Lend* 11).

As the focus on the "language" part of literacy has been critiqued as exclusionary, many have called for openness to multiple modes in literacy and writing studies. Disturbed by a "link" between "lack of language skills, lack of intelligence—or even lack of humanness" (*Talking* 21), Patricia Dunn urges writing teachers to use "multiple literacies" to help writers with varied learning styles, strengths, and weaknesses to integrate the "visual, aural, spatial, emotional, and kinesthetic, or social ways of knowing, or unique combinations of them" into their writing.

Certainly, the composing and communicating of people with aphasia in the multimodal memoir group embraces how meaning is always made multimodally. Even a "standard," "text-based (word-processed) and printed" document without "an online, audio, or visual component," Jody Shipka contends, "may have emerged from a thoroughly multimodal composing process" (52). A multimodal text, and process, therefore may result from frequently unaccounted-for processes like "doodling, sketching out one's ideas, listening to music, reading the text aloud, discussing one's ideas with others, blogging one's ideas, or exchanging drafts of the text online" (52). People with aphasia expose those often invisible multimodal composing processes and, most importantly, help to better account for the ways we make meaning as we invent, compose, and write. Indeed, people with aphasia enact literate access through these multiple modes. To ignore these modes is to ignore, reject, and limit their literate potential.

**2) Inventing with the Body: The Body as a Technology of Literacy**

While the body is a mode for expression—one of the multimodal resources useful in communication—the actions of participants in this multimodal composing group reveal another role for the body as a technology of literacy: invention. One of the primary ways individuals with aphasia develop and enact literate access in the multimodal memoir group is by employing various bodily resources (speaking while writing; gesturing while speaking, etc.) as they work

through thought and language. Such uses of the body are apparent throughout interaction of aphasic and non-aphasic persons, pointing to a deep relationship between thought, language, and the body (McNeill). Recent work in writing studies seeks to find links between gestures and writing, pointing to potential for "embodied invention" (Haas et al.). The body as an inventive resource is clear in the frequent hand gestures that punctuate the often halting production of spoken language. In Kirsh's words, embodied action "bootstraps," supports, or helps to generate thought—and in the context of aphasia—language. The role of the body in thinking and producing language is clear as aphasic people use multiple, embodied strategies to produce writing, including speaking aloud while writing, spelling aloud while writing or gesturing writing, gesturing and/or speaking while writing, or reading aloud while reading. In this section, I both define the term "the body as a technology of literacy" and show how the phenomenon helps individuals with aphasia to enact literate access.

Exploring the literate practices of people with aphasia critically highlights the integral role of the body in writing and reading. When I say that the body is a technology of literacy, I mean not merely that the body is a tool for literate action, but that the body operates as an important—but to this point, largely invisible—part of the systems that make literacy happen: the literate production, reception, and recognition of literacy.

By calling the body a "technology of literacy" I link up with a long-standing discussion about the definition and use of literacy broadly. New Literacy Studies has grappled with issues of literacy as a technology of the intellect (Goody & Watt), for generating abstract thought (Ong), and for thereby advancing society. Ong, for one, argues that writing is a technology, "because it requires tools—instruments for recording and disseminating," "it manipulates and transforms nature," and it "allows us to interpret nature on our terms instead of on its terms by wresting

language out of oral, real-world contexts and making it a tool for contemplation of alternate worlds" (Brandt, *Literacy as Involvement* 18). Troubling the notion of literacy as a uniformly productive "technology," New Literacy Studies has theorized the role of *various* technologies that people use in literate practice, from pencils to the printing press to computers and the Internet (Baron).

The definition of "technology" I draw on, however, pushes beyond a conception of technology as totalizing or autonomous, or as a tool to be simply employed in literate production, to a view of technology as a systemic, networked process. My definition comes from Christina Haas, Deborah Brandt and Katie Clinton, and more recent work from Jack Goody. Haas explains that a technology is "a complex of objects, actions, people, motives, and uses [...] not an object, but rather a vital system that is bound to the world of time and space" and steeped in historical and cultural context (xii). Similarly, Goody revises his earlier claim for "writing as a technology of the intellect" as more than "pen and paper, stylus and tablet," to include "the training required, the acquisition of new motor skills, and the different uses of eyesight, as well as to the products themselves, the books that are stacked on library shelves, objects that one consults and from which one learns" (qtd. in Collins and Blot 169). Technology, then, is a system of objects, including—and interacting with—the body as one of those objects. And as we have already seen in Chapter 3, the body and materials of literacy act interdependently in literate production—a phenomenon that reveals even more clearly how the body itself acts as a technology of literacy.

In the multimodal memoir group, the body is a central inventive technology for literacy. As Dunn acknowledges, "writing involves many complex intellectual processes that can be stimulated through activities beyond the act of physically writing" ("Reversing"). In the multimodal group, often, speech is not directed toward an audience, but a method of self-speech

that assists in the writing process itself. When Jean is handwriting about her childhood experiences camping and fishing with her father, she mouths and speaks words aloud as she writes. She asks the question "would you call that…a blue gill?" Though it is a question, when her clinician, Leigh, takes it up asking "a what?" Jean appears distracted, answering Leigh only through minimal words. Leigh, on the other hand, appears to take the speech as an invitation to converse, recounting her "only experience with that" as a child fishing with a Donald Duck fishing pole. Jean's minimal responses, looking down, only occasionally offering a half-smile or nod, make clear that her speech was not intended to open up a dialogue, but to help her work through her own writing. In an interview with me, Jean explains that she learned to write again after aphasia by talking aloud, saying, "It's the only way I could do it." The combination of speaking and writing was necessary for Jean to reinforce both modes, deepening concentration and even stimulating recall of language.

Spelling aloud also appears in the writing processes of many people with aphasia. Fred helps his clinician Lola to spell his hometown and home state "Chattanooga" and "Tennessee," saying the letters for her as she writes them. Andrea often spells aloud as she re-reads writing she has just written or that she is proofreading later on. She spells aloud both to herself and to Jill, her clinician. Both women catch errors, and Andrea uses whiteout and pen to go over those errors. Spelling, word ordering, and other grammatical concerns like subject-verb agreement are typical problems for writers with aphasia. And facing those challenges—getting the spelling right, in particular—is a concern for people with aphasia.

People with aphasia also frequently spell or form words in conversation by using their hands or fingers to trace out words or letters in the air or on a surface. People (whether they can write relatively fluently or not) use their bodies to gesture writing, tracing out letters or numbers.

This movement seems to happen to help get at language—using the body's movement to form letters themselves as a way of finding the words. In James's case, he traces an "M" on the table to begin answering a question about the location where a past event occurred. The city he was looking to identify, indeed, began with "M," and the clinician, Sarah, was able to narrow in by asking about the city he was currently living in. Likewise, in another session, he traces out numbers in the air to answer the number of years he had been a part of a particular friendship. Judy also traces out the letters of a childhood friend's uncommon name as she explains the name to her clinician Taylor. Andrea and Bill, too, express the number of years for their education by writing numbers in the air.

These movements of the body, uses of speech and text, are not standard parts of acknowledged literate practice. But they draw on the body as a technology of literacy to enact literate access. Certainly, they provide a specific example relevant to people with aphasia, but these practices for the body are useful for thinking about writing pedagogy broadly. As Dunn argues, "we need to think of writing not only as a product and process, but as a broad set of invention activities." To help enact literate access, writing educators should draw on the body as a technology of literacy, refiguring "writing" as a process of drawing on "whatever activities we and our students can think of to stimulate ideas, frame concepts, make connections, formulate critiques" ("Reversing").

**2) Upending Orality and Literacy: Writing in Conversation**

In addition to exposing the role of the body as a technology of literacy, key in literate production and invention, the literate and communicative practices of people with aphasia blur the lines of another central category in literacy studies: orality and literacy. Writing is a key way to communicate in the context of aphasia—and writing in the moment is an important way of

sustaining communicative and literate access. Writing is a first option for many (even before speaking) and a back-up option—one that they seldom or never choose—for others. The use of writing for in-the-moment communication in the context of aphasia blends very apparently between orality and literacy. Frequently, people with aphasia and their communication partners write to communicate, and writing interestingly takes on an important role in supporting orality. Writing—whether it's a word or two, a few sentences, or more—is commonly used by people with aphasia and their communication partners to help clarify, work through a communication breakdown in speech, and get a message across to another person. Many people write in response to questions, to make or expand on a point, or to verify an idea. While orality has often been viewed as a comparatively simple, preliminary move toward literacy (Ong) here *literacy* clearly helps accomplish the in-the-moment communicative function commonly ascribed to orality.

Bill, for instance, writes in response to nearly every question. He most often writes down one- or a few-word answers (seldom complete sentences) to questions or conversations that have clear, concrete answers: a time, place, duration, or specific fact. Bill responds to questions about his education by writing out a timeline from being a senior in high school to attending college to completing a masters degree in aeronautical engineering (training as a pilot). Answering questions about his former occupation, Bill writes the name of the airline where he worked as a pilot and writes a list of types of planes—727, 737, 767, and more—that he flew in the past. "Wow, the list goes on!" his clinician Laura responds, "That is pretty cool. I'll have to ask you a lot more questions about that." Writing sustains conversation for Bill and Laura, allowing Bill to offer details about his life that Laura, in turn, asks him to expand upon further. When Laura gives Bill the "Living with Aphasia" diagnostic test to assess his experiences coping with aphasia, Bill writes almost all of his responses: his birthdate, address, name of his wife, and more. Writing—

like the gesturing that James engages in above—allows Bill to express his competence in ways that are simply not accessible for him through spoken language.

In these ways, writing supports orality for Bill and for other aphasic persons, including James and Darla, two individuals with aphasia even more severe than Bill's. Both James and Darla have much less access to language, speech and writing, but they both write occasional words in response to questions. Darla writes her brother's name to clarify which of her several brothers is featured in a photograph she is including in her book. James, too, writes his daughter's name when describing a photograph. In these situations, we see that familiar words or names are often more likely to remain accessible after aphasia, and multiple modes and communicative supports can help individuals to access and write those words. For Bill, James, and Darla, looking at photographs, maps, or other images related to the words they seek to find helps them to think of and to write those very words (or related ones, like names of other family members, even though they might not be pictured in Darla and Bill's cases).

In addition to people with aphasia, the clinicians involved in the multimodal memoir group also do a great deal of writing. Clinicians often act as scribes, writing down what they understand from the spoken language, gestures, other writing, drawing, or other expressions of people with aphasia. Clinicians sometimes take notes on the expressions of aphasic persons and run that writing by them immediately to verify clarity or accuracy. In these cases, literacy serves to verify orality. When Bill and Laura discuss his family history, Laura records in her own writing what Bill has expressed multimodally, in the words he jots down, through gestures, and through references he makes to family genealogy books. She writes down this information on a pad of paper located on the table between them, and Bill—reading Laura's responses—then makes additions or corrections through speech, gesture, and writing. The clinician's inscription

becomes a way to get ideas in one place and to confirm, reject, and modify these ideas. In other cases, clinicians essentially take on an interviewer role, asking questions to gather information, including memories from childhood or adolescence such as schools they've attended or their first cars. These "interview notes" become a shared text that serves as the base for ideas for life book compositions or as the very text of the book itself.

These myriad uses for writing-in-the-moment in the multimodal memoir groups create communicative and literate access. They also unsettle what we mean by "literacy" and "orality." In this way, written communication in the conversation of people with aphasia contributes to discussions about orality, literacy, and disability. Following Ong's definition of orality as grounded in immediate interaction without a mode of inscription (Brueggemann, *Lend* 186), American Sign Language, for instance, has been restricted to "orality." Bauman and Murray, however, argue that the increasing prevalence of video technologies that record, or inscribe ASL, operate as a kind of writing. Academic journals recorded in ASL available online (249) along with recordings of poems, fiction, and other literary works (Brueggemann, *Lend* 201) challenge us to rethink what we mean by "writing" or "inscription." Resonating with autonomous theories of literacy, Brueggemann claims that "[w]riting removes us from the present. Writing disembodies. Writing provides a synonym for literacy. Orality does not; sign language does not" (*Lend* 186). I argue, however, that the experiences of writing-in-the-moment in the multimodal memoir groups counter this clean distinction. Above all, writing in the moment challenges norms of both literate and communicative practice, but ultimately enact access for people with aphasia.

**4) Dispersed Authorship**

Another challenge that writing in the multimodal memoir groups makes is to authorship: the writing that happens in this group expands our understanding of an author as autonomous.

Authorship, here, is concretely transformed from an individual accomplishment to a dispersed, embodied, and material practice occurring between people and objects. As literacy serves orality; as both aphasic persons and their communication partners write in the composing process; as their gestures explicitly augment, inform, and transform language, conceptions of authorship become more complicated.

The composing processes of people with aphasia and their communication partners help us to see authorship on a more complex kind of spectrum—from solitary author, apart from others and other technologies (and even one's own body) to authorship wholly dispersed across people, bodies, and objects. Viewed through the solitary end of the spectrum, people with aphasia can be understood as having experienced a break in the encoding/decoding process—a fissure that occurs around language. James, for instance, can be seen as experiencing such a fissure in language when his clinician Sarah asserts that he "knows all" the images she asks him to identify, but just cannot express them in language. Indeed, his gestures *replace* language.

In such a model, authorship requires a ramp to accommodate this language deficiency, causing people with aphasia to engage with other people to try to get those communication partners to understand the word or concept they have in mind and to translate that concept into language. In this way, other bodies/people serve a prosthetic function. Other people (and very materially their brains, mouths, vocal cords, hands to write, etc.) become a prosthetic (or a technology) for orality and literacy for people with aphasia. These practices are real, powerful, and empowering methods of authorship, but I want to push the conception of authorship in this group even further—further than figuring people with aphasia as seeking other people and modes to simply compensate for a lack of language.

Concerns over "ownership" of writing and ideas recur in the multimodal memoir group. Clinicians often, and understandably, express that aphasic individuals' ideas are their own, repeating the mantra "it's your book—you can put whatever you want to into it." Taylor tells Judy, for instance, "You're the lead author. I just help you," and Lola, pointing to the text she has written, tells Fred, "Those are your words. I just write them down." Such remarks, while they come from a genuine desire to empower people with aphasia, retain a norm of solitary authorship and of the tie between language and that pure ownership and authorship.

It is indeed the literate practices of people with aphasia, in their embodied, in-the-moment, negotiated contexts that may help to deepen an understanding of how a dispersed sense of authorship may ultimately prove more (or equally) generative and empowering—how dispersed authorship may help to enact literate access. Such "dispersed authorship" is well illustrated in the shared composing process of Andrea and her clinician, Jill. Andrea and Jill frequently return to the notes that Jill has written from oral discussions (essentially interviewing Andrea about her experiences growing up in Peru, immigrating to the US, attending college, and getting married and divorced) to revise and develop ideas. Both Andrea and Jill alternately read the writing aloud, and Andrea takes a lead in writing down more ideas and crossing out extraneous or inaccurate statements. The two also often catch errors like missing words or grammatical problems as they read the text aloud. In these collaborative writing sessions, both Andrea and Jill pass one pen between them as they write. In the give-and-take of gestures that happen between people with aphasia and communication partners; in transcription of words, erasure or rejection of those words; in the addition of drawings and many more multimodal interactions between people, we find many useful perspectives on what writing looks like for

people with aphasia, and for writers more broadly. Writing looks embodied, negotiated, dynamic, and dispersed across people.

This dispersed approach to authorship—and to enacting literate access—does not rely on a retrofit or on a ramp. It relies on co-constructing norms for literate production (passing a pen back and forth, for instance) and identity (collaborator, for instance). This approach mitigates misfitting, avoids retrofitting, and moves toward a kind of re-fitting for literate norms. Andrea's responses to the group make clear that she values this mode of dispersed authorship. She expresses appreciation for how everyone involved with the group—other people with aphasia and clinicians—"get to know me better by questioning me" and that she especially appreciates the "practice" that the group provides. "The practice is very beautiful," she says, "and the place is very gorgeous, and the people are very magnetizing." When I ask her to expand on what she means by "magnetizing," Andrea answers that "they attract themselves...they make you feel... ah, no... like are… in control... yeah, and that makes it all special, all special."

Andrea's astute reflection points not just to the respectful interest of clinicians in people with aphasia, but also to the dispersed practice of enacting literate access. The experience is based in mutual engagement. And that experience is clearly a powerful and affective one—characterized by beautiful, gorgeous, and magnetizing, all adjectives conjuring a rich sensory experience. And the juxtaposition of the boots-on-the-ground and ordinary, even tedious, "practice" with "beautiful" evokes a truly grand image. Certainly, the "place" of the groups—an old residential dormitory transformed into a clinic building still outfitted with orange and yellow 1970s décor—strikes few as "gorgeous." It is the experience of enacting literate access captivates Andrea. Andrea offers a nuanced sense of "control" not as control over another, but control or empowerment accomplished collaboratively, built and sustained across bodies and people.

**5) An Ethic of Care—Listening across the Senses and beyond Failure**

As Andrea's experience composing in the multimodal memoir group reveals, care is a key piece of the group's success. Care, engagement, and support is central in making literate access happen in this group. Access always requires an ongoing ethical commitment, and misfitting and retrofitting have damaging affective consequences (Dolmage; Yergeau; Hamraie). In this final section, I show how an ethic of care is necessary for developing and sustaining literate access. This orientation is especially important in light of often challenging acquired communication impairment.

As we saw in Bill and Laura's conversation above, misunderstanding and confusion frequently does arise in the context of communication and composing with aphasia. Indeed, many people with aphasia explain failure and loss as part of their perspectives about living with aphasia broadly and regarding communication and literacy after aphasia, specifically. When I ask James why he joined the group, he brings his left hand to the side of his head, cocks his index finger into the barrel of a gun, "Boom," he simulates the sound of a bullet as he pulls the trigger. Harold, a former chemistry professor, also frequently expresses intense frustration. He had a severe stroke just one year before the multimodal group and lives with Wernicke's aphasia, which causes fluid production of language—but very often the *wrong* language. "It's not there. It's not there. It's horrible. Horrible," he answers to various questions. "Everything here is gone," he says to his clinician Mariah as they look through his old photographs. "Taught for 25 years, and *poof*, it's all gone." He often becomes emotional, apologizes, or chooses to end an exchange, saying, "Forget it."

Communicating, reading, or writing for people with aphasia is often not easy or smooth. However, a commitment to understanding, to listening across the senses and multiple modes, and

to working through and with confusion and failure, is key to enacting communicative and literate access. That commitment to listening and collaboratively approaching understanding is apparent between participants in the multimodal memoir group. “I love hearing and sharing,” the participant Jean says of the group. “And everybody’s so proud of themselves, you know, it’s a wonderful […] they get to share, and it’s so nice, you know?” With her own proud, encouraging smile, Jean reflects on the power of both sharing her own experiences in the group and hearing those of others.

The collaborative, open nature of the group and the commitment to genuinely listening to and getting a sense of what others want to share is especially clear in the participant Rose’s reflections about the common experience of inaccessible communication. She shares in a large group discussion: “The problem is that people get tired of waiting, and they want to finish your sentences for you. But then you forget what you wanted to say. And then you want to just give up trying to talk.” Earlier, in our interview, she explained to me that the group offers a welcome alternative to that problem. “When we’re talking in the group,” Rose observes, “I’ve noticed that people are really good at listening. Sometimes you want people to fill in the words for you, but other times I’m totally going in a different train of thought and somebody fills in the word and it’s like my whole thought is lost. So that’s why it’s really important to listen.” Group members are “really good at listening,” and that skill for listening is based in patience, giving others time to express themselves, and not taking over their ideas.

But the powerful listening happening in this multimodal group goes beyond all participants allowing one another time to think, to access language, and to express that language. As Bill and Laura’s conversation discussed above demonstrates, both aphasic and non-aphasic communicators listen across the senses. Listening isn’t just about hearing spoken language. It

emerges from a true commitment to understanding what another person has to say and then engaging multiple modes and senses to reach that understanding. After expressing her appreciation for getting to know other group members and never feeling intimidated or "scared by anybody," Rose comments on the unique forms of listening happening in the group: "It's kind of neat actually. I want to say I hear what the people have to say, but some of them don't ever speak, and I feel that's good. […] I feel I can know what they're talking about when they're going yeah, yeah [and nodding or gesturing]." Rose's observation importantly gestures to "hearing" or "listening" that goes far beyond the ears. Listening across the senses calls on individuals to create meaning and enact access using their bodies as a whole—not just through language or speech, to watch gestures, to read writing, to make a gesture oneself, to move across modes in a collaborative project that proceeds toward understanding. Such a method of listening across the senses highlights the active, embodied nature of listening and contributes to discussions of listening as productive and multimodal (Ceraso; Ratcliffe).

Further, such a commitment to listening across the modes or senses and beyond failure can be understood as the practice of a kind of "care"—acknowledging the shared humanity, intelligence, competence, and capacity of others. This "ethics of care," says philosopher Eva Feder Kittay, challenges a liberal notion of personhood—one predicated upon autonomy and independence. An ethics of care assumes that all humans are vulnerable, require assistance at various times, and in this way are inevitably interdependent beings. The connection and need for others should be framed, says Kittay, as a "resource," instructing us in the nature of human experience and sustaining more just relations between people (56). Similarly, in her analysis of "rhetoricity"—or the potential for individuals to be seen as capable rhetors, persuaders, and communicators—and individuals with cognitive disability, Cynthia Lewiecki-Wilson draws on

such an ethics to argue for a move away from alphabetic language (in speech and writing) as markers of rhetoricity or humanness. For Lewiecki-Wilson, an ethics of care in communication and disability calls for "an expanded understanding of rhetoricity as a potential," as co-constructed between people, and as including "the performative rhetoric of bodies that 'speak' with/out language" (157).

Participants in the "Telling Life Stories" multimodal memoir group put into practice an ethics of care based in listening attentively across the senses. That listening and openness to understanding begins with acknowledging the shared humanness of others, proceeds patiently, and values a range of communicative modes. To decide, for instance, to listen only to James's spoken identification of objects on the cards discussed above would be to devalue his creative, evocative gesturing, rejecting and erasing not only what he has to communicate, but his very "rhetoricity"—or capacity to be seen as being capable of meaningful communication. In this way, the multimodal memoir group gave speech therapists in-training who buddied up with people with aphasia vital experience in practicing an ethics of care in interacting with and listening across modes to people with aphasia. Rather than seeing their role as one of assessment or rehabilitation, clinicians came to see respect, care, and collaboration as central to interaction with persons with communicative disorders.

As a researcher, practicing an ethics of care meant committing myself to communicative access, patience, and respect. I created illustrated consent forms with minimal language composed in direct, concise sentences. I also drew on multiple communicative modes in our interviews—encouraging participants to use whatever mode of communication they preferred, from gesturing to drawing, to writing, to pointing to objects and artifacts (particularly the life-story books they were composing in the group). I, too, wrote, drew, and worked to listen across

modes. Such an ethics of care in research and interviewing draws on multimodality, expands what we mean by listening. It is a method of research that rejects positivist fictions of objective truths gathered from purely autonomous individuals. It values potential, co-creation of meaning, and the justness of caring for and attending to the input and experiences of people who are often deemed unable to speak for themselves.

The ethic of care and listening emerging from the groups can be understood as not only a necessary component of developing literate and communicative access, but also as a sign of what disability activist Mia Mingus calls "access intimacy." Mingus describes access intimacy as "that elusive, hard to describe feeling when someone else 'gets' your access needs." What she calls "eerie comfort" resonates with Andrea's words about the "gorgeous" environment of the groups and "magnetizing" nature of the people who make her feel empowered. Such an experience of transcendent shared understanding aligns, too, with Rose's sense of knowing what people mean without language and in the safety of the group space itself. This environment as a whole—resources available, social values and norms around literacy held at bay and reworked by participants with aphasia—makes room for access and the access intimacy that comes with it. "Instantly," Mingus observes, access intimacy creates a sense of "steel vulnerability" as individuals together "can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety, and pain of access." The multimodal memoir group offers a place where individuals may enact literate access. Finding themselves freed up (to some extent, and for a while—while in the groups) of communicative and literate norms, they co-construct new ones. The weight around literacy's value, as we see is so heavy in Chapter 4, is lifted a bit here as individuals have room, time, space, and freedom to reinvent and enact access.

**Conclusion**

The various scenes of people with aphasia enacting access in the Telling Life Stories multimodal composing group discussed here reveal much more than communication made accessible by the facilitators' multimodal group design or of multimodal texts being created. Instead, people with aphasia create access in-the-moment: they act as inventive, attentive, and ethical communicators, drawing on the technological resources of their own bodies, objects, modes, and digital tools to make meaning. In this way, for teachers and scholars interested in access, disability, technology, multimodality, and pedagogical design, the communicative work of people with aphasia in the Telling Life Stories memoir group has much to tell us about how the body may itself function as a technology in concert with objects, modes, and digital tools. It reminds us as instructors, facilitators, co-authors, and co-creators that not all students bring rhetorical tools cut from the same communicational cloth, and it asks us to realize that not all means of communication and persuasion might have been exhausted in the current pedagogies. In addition to the inventive work of people with aphasia drawing on various technologies to communicate, the group emphasizes how much of access—and in this case literate access—rests on an ethical commitment to listening and understanding across the senses and beyond misunderstanding and failure. The people with aphasia in this group listen across the senses and across misunderstanding, providing on-the-ground support for the disability studies conception of access as an ethical orientation or a "way to move" (Dolmage, "Mapping" 24).

The enacting of communicative access through the resource of the body and through listening across the senses makes clear that multimodal composing benefits from much more than multimodal resources being made available. Instead, designers of accessible multimodal groups have much to learn from in-the-moment multimodal communication, particularly the

bodily and the gestural. For multimodal composing, this study points to the centrality of the body and of gesture as key, underexplored facets of multimodality, learning, and access. And the availability of various communicative modes and openness to those modes can be, as we see from this group, a part of facilitating ethical communication and composition.

Even as this chapter provides a glimpse into the literate practices of people with aphasia, often associated with illiteracy or literate deficit, it is not enough to show how aphasic individuals practice literacy differently. As Kliewer and Biklen note, countering the association of disability with illiteracy is not a matter of "accumulation of opposing evidence" (186). Rather, the "denial of literacy is insidious, as is racism, and is nearly impervious to conflicting evidence"—a more pervasive, "hegemonic" association (186). In this chapter and throughout, then, I have sought to recount not just "local, situated, and often marginalized literacy practices and their cultural distinction from mainstream literacy practices" (Prendergast, *Literacy* 10). But, rather, I identify the norms behind mainstream practices and the knowledge produced by the individuals who rework them through lived, in-the-moment practices.

# Chapter 6

## Conclusion: Toward an Embodied Theory of Literacy

To close this dissertation, I summarize my chapters and main findings. I then review the contributions for those findings to several fields, research, pedagogy, and aphasia advocacy. I spend the bulk of this chapter discussing directions for future research and ways to expand this study.

### An Embodied Theory of Literacy: Primary Findings

Together, this dissertation's chapters draw on the experiences of people with aphasia as they work to read and write. From those experiences, I establish an embodied theory of literacy. Each chapter focuses on a different facet of how bodily change affects literate practice and identity—and how individuals negotiate that change. Chapter 3 explores the relationship between bodies and materials. Chapter 4 shows the enduring pressure of social values on bodies, and Chapter 5 features how people with aphasia rework social norms around literacy to support the needs of their bodies.

As a whole, across the chapters, this dissertation forwards an embodied theory of literacy characterized, again, by the following principles:

An embodied theory of literacy:

- reveals the integral role of the body as people read and write in everyday life—how their bodies fit or misfit with materials of literacy, how they work and rework their bodies as technologies of literacy in and of themselves, how they grapple with values and expectations around bodies in literacy, and how they work and rework those values to support the needs of their bodies

- makes the body apparent, accounting for the fact that all bodies are different, bodies are fallible and changeable across the lifespan and across ability/disability. Bodies are not

neutral or "normal"

    - reveals the body itself as a technology of literacy (interacting closely with and taking on aspects of the materials of literacy [See Chapter 3] and acting as a tool for invention [See Chapter 5])

- exposes how materials of literacy, too, are not neutral or normal. They are designed to fit certain kinds of bodies—keyboards for ten fingers, dense newspaper text for eyes and a brain that processes language quickly

- emphasizes literacy is always valued in certain ways. What the experiences of people with aphasia add to that is how much social values around what bodies should do and be figure into individuals' understanding of themselves as literate or not literate

- above all, reveals how—in order to read and write—people with aphasia (and all readers and writers) must negotiate bodies, the available materials of literacy, and the social expectations for what it means to be literate and to practice literacy

***Chapter Summary / Key Findings***

In "Chapter 2—"Embodied and Accessible Research Design: Exploring the Literate Practices of People with Aphasia," I make a methodological contribution to literacy studies by sketching out a framework for researching embodied experiences of literacy in-the-moment and across the lifespan. My second major implication is for accessibility: qualitative research is often exclusively language-based, which is not always accessible for participants. In turn, I reviewed the challenges this focus on language created—particularly with attaining consent and conducting interviews. I then offered two corresponding tools for working toward accessibility: an illustrated consent form and efforts to make interviewing accessible. I close by reviewing some of the challenges of that I encountered in working toward accessibility, particularly with communication partners attending interviews.

Chapter 3 "Literate Misfitting: Disability Theory and a Sociomaterial Approach to Literacy" builds on the experiences of people with aphasia and on disability theory to offer the concept of "literate misfitting." Literate misfitting highlights some of the conflicts that arise

between bodies, materials, and social values around literacy when people experience bodily change. This finding reveals that no aspect of literacy is neutral as materials are designed to fit certain kinds of bodies and minds, and individuals' bodies are suffused with social values around what they *should* do in reading and writing.

Chapter 4 "Negotiating Literate Identity after Aphasia: Normativity, Flexibility, and Relating to/Reworking Literacy Ideology" further explores the social values around literacy by tracing how people's pre-aphasia literate identities affect their literate identities and practices after acquiring aphasia. I find that individuals who have developed an affective and embodied attachment to "normative literate identity" before aphasia—defining literacy around successful processes and products of literacy that adhere to a normal body—have a very difficult time adapting after aphasia. Those who have more "flexible literate identity" before aphasia—experiencing difficulty with literacy, finding themselves not very interested in it, or defining literacy in a flexible manner—tend to grow, thrive, and adapt as readers and writers after aphasia. This chapter emphasizes the tension between social norms around literacy and the body.

People rework literate norms in the environment of a multimodal memoir group for people with aphasia in Chapter 5 "Beyond Misfit and Retrofit: Enacting Literate Access in a Multimodal Memoir Group." I find that "literate access"—or the ability to access reading and writing practices and to develop literate identity—emerges through the actions of people with aphasia composing multimodal memoirs. By analyzing video data from this composing group, I show how people with aphasia rework social norms around literacy to fit the needs of their bodies, enacting literate access in-the-moment. I draw disability studies scholarship to show how people with aphasia themselves design and enact literate access through their actions and orientation to one another and values around literacy.

## Contributions

This dissertation grew first not from a research interest, but from my engagement designing and facilitating a multimodal memoir group and subsequent text-based writing groups for people with aphasia. I did not begin with questions of research, but questions of access for people with aphasia. In that same vein, I hope that this dissertation marks the beginning of a research trajectory with contributions reaching across fields, research, pedagogy, and activism. In what follows, I outline contributions for those areas.

### *Literacy Theory and Writing Studies*

First, for literacy theory, the insights and experiences of people with aphasia reveal the deeply embodied nature of literacy, leading to my embodied theory of literacy. Embodied change, brought on by aphasia, brings the influence of the body in literate practice and identity into bright relief.

An embodied theory of literacy has much to say to literacy studies broadly, including making conflicts and tensions paramount, challenging current discussions of literacy's "withness" (Micciche) and fluidity (Prior). In this way, I join and contribute to current discussions of literacy as sociomaterial (Vieira, *American*). The body is, indeed, particularly as I have shown through insights from disability studies, complexly social and material. An embodied theory of literacy makes the body apparent as both weighted with social values and material in and of its own right. I develop the idea of the body as a technology of literacy, for instance, to forward that connection between social and material.

The conflicts between body, social, and material aspects of literacy are not just a theoretical insight, but have practical implications for understanding what norms around bodies

suffuse and enable or limit readers and writers with particular kinds of bodies and minds—or, as in the case of people with aphasia, in the even of bodily change.

Lifespan research with persons with aphasia in particular reveals not just that bodies matter for the on-the-ground accomplishment of reading and writing, such as using hands to write or fingers to type, but also normative standards—ideologies, values, or expectations around what bodies and minds should do in reading and writing. In this way, this study extends lifespan research that focuses on changes in technology and the economy to include changes to the body. While Brandt, Selfe & Hawisher, and others look at how changes in technology and economy alter the value of literacy, I analyze how changes in the body reveal normative values around what everyday readers and writers believe it means to be literate.

Many of those values are invisible or tacit before an acquired disability, but as the experiences of the participants in this study reveal—they are present to varying degrees in readers and writers, at varying times in their lives. In my participant Beth's case, for instance, her literate practices and identity before aphasia served her very well. Before aphasia these values and practices made her successful: writing independently and quickly, journaling daily, sharing her writing with others, revising ahead of time, and more. But after aphasia, they serve as painful reminders of loss and change. The social values around the body put pressure on and limit post-aphasia literate practice and identity.

***Disability Studies***

This study is thoroughly indebted to disability studies activism and theory. My concept of literate misfitting in Chapter 2 draws on the feminist materialist conception of misfitting from disability theorist Rosemarie Garland Thomson. My theorizing of identity as embodied in Chapter 4 is similarly linked to another disability theorist, Tobin Siebers. Likewise, Chapter 5

works with disability theory and activism—access, retrofitting, universal design, and access intimacy all come from those discussions. Disability's take on embodiment and reality as grounded simultaneously in the material and the social, access as about co-production, and much more bring essential theoretical interventions to literacy and writing studies.

What I contribute to disability studies is a fine-grained, empirical take on many of these key theoretical concepts, including an extended and expanded treatment of misfitting in chapter 2. My analysis of people with aphasia creating and enacting literate access in-the-moment also provides a rich case study of what co-produced access looks and feels like in a composing context.

***Communicative Sciences and Disorders***

This dissertation also contributes to theoretical discussions and practical interventions in the field of Communication Sciences and Disorders (CSD). I am indebted to CSD's focus on supported communication approaches, communicating interdependently and through multiple modes.

Focusing on the literate practices and identities of people with aphasia as I do in this study stands to contribute to CSD in terms of therapy and theory. Over the past couple of decades, CSD has expanded its "life participation" approach to therapy, emphasizing just that: instead of drills to practice language out of context, the life participation approach puts individuals into social contexts, using authentic communication methods (Kagan). The multimodal memoir group fulfills the goals of this approach and opens up various ways of thinking about communication in context: across speaking, gesturing, writing, reading, drawing, and much more. The concepts of literate and communicative access developed in Chapter 5 are useful to this approach as well, centering not on creating communicative ramps, but enacting

access in-the-moment. Such an approach aligns with a theory of "adaptive leadership" used to train clinicians in CSD to support the knowledge and expertise of clients.

Likewise, a focus on literacy as social, embodied, and material has much to say to CSD. Hengst and Johnson suggest that CSD has overlooked "social" research, focusing more on skills-based approaches (480). This dissertation contributes to their call for focusing on reading and writing in real-life contexts for people with communicative disorders—as a way to develop more relevant, useful theory and therapy for clients.

***Research***

I discuss contributions for research in much greater depth in Chapter 2, but here I will briefly say my study contributes theories, critiques, and strategies for working toward embodied, accessible methods and methodologies for qualitative literacy research. Specifically, the use of both in-the-moment observation and life-history interviewing contributed important insights into how people enact literate access in-the-moment and how they cultivate attachments to certain literate identities and practices through affective and embodied actions across the lifespan.

A focus on accessibility is the key contribution of this dissertation. I critique norms around qualitative research, particularly through a focus on language. And then I offer concrete strategies for addressing those barriers, including an illustrated consent form and reworking interviewing conventions to support diverse participants.

***Literacy Education/Educators***

For educators, then, the findings from this dissertation point to myriad opportunities to make literacy education more accessible: to both meet the needs of individuals with bodies and minds of all kinds, but also to prepare learners to thrive across life change. Aphasia reminds us of the reality that bodily needs and abilities change over the lifespan—hands stiffen with

arthritis, eyesight weakens, memory and access to language alters. If we as literacy educators are to support learners across the lifespan and prepare learners to thrive across life change, we must take bodily change and disability as central to our understanding of literacy across the life course, as social and embodied.

Here are two pedagogical imperatives arising from my research with implications for classroom teachers and program administrators: 1) challenging norms around literate practice and 2) creating a culture of access.

1) Challenging norms around literate practice/identity

To design accessible literacy education, we must begin with, and proceed from, the recognition that bodies and minds are diverse. We must reject and denaturalize the idea of a neutral or normal literate practice, a neutral or normal body. Alternate, or nonnormative, ways of writing and reading, such as Bob's flexibility and willingness to involve other people, work across modes and technologies, and focus on meaning, must be introduced, supported, and normalized. Assigning students to compose in unfamiliar modes—in handwriting, with speech-to-text software, with other people are ways to move toward that normalization.

But as my analysis of the literate experiences of persons with aphasia reveals, it is not enough just to develop new practices or to bring in new technologies. Educators must also address learners' relationship to the social value of literacy. Together, learners and educators must explore and address pressure, pain, and shame around what it means to be literate in the right or wrong way. That process is not easy or simple. But learning from people with disabilities like individuals with aphasia featured here are essential to this process.

I suggest and have had success in my writing classes by assigning literacy narrative assignments that ask students to interrogate their histories with literacy, how their beliefs have

developed. In this way, the literacy history interview protocol and format may be tremendously useful not only as a research instrument, but also as a pedagogical tool. In narratives students create about their histories, it is important to explicitly guide students to discuss literate attachments and detachments and to describe how those connections to literacy are tied to writers' bodies and normative expectations placed upon them. With students, we must work to unpack labels like "bad writer" and, perhaps even more importantly, "good writer." One way to complicate those identities is to work with students to understand what "good" really means when it comes to literacy. Rather than literacy just making better feel better about themselves, developing an "affinity" for literacy and a sense of cultural capital, being able to adapt creatively to changing economies, technologies, and—as my research reveals—bodies and minds defines successful literate individuals today.

2) Creating a culture of access

Second, I argue that we must work to create a culture of access in our classrooms, writing groups, and writing programs. Chapter 5 thoroughly discusses access as "the ability to use, enjoy, perform, work on, avail of, and participate in a resource, technology, activity, opportunity, or product at an equal or comparable level with others" (Oswal). Access is an ongoing orientation to producing spaces that meet learners' needs. Classroom and learning spaces should be seen as "multiple and in-process," and the experiences of people with aphasia misfitting and working to refit their needs as readers and writers reminding us that we—students and teachers—"are all involved in the continued production of space" (Dolmage) This method of "co-production" or participatory design foregrounds and truly values the diverse needs of learners. It starts with and constantly revised from the insights, strengths, and needs of individuals' diverse bodies and minds.

***For People with Aphasia / Aphasia Advocacy***

This research began with questions that arose in my teaching in a community-based multimodal memoir group for people with aphasia. In this cross-disciplinary, community-university space, I was not initially thinking of research at all (in fact, I very much did not want research to interfere with that memoir group), but of the opportunities available (or, more often, *not* available) for people with aphasia to engage in public spaces. This dissertation shows how, in relation to literacy or more generally, aphasia can be tremendously isolating. Isolation and lack of access is perpetuated, UK disability activist and scholar Sally French argues, by communication barriers that keep "people with aphasia from having a strong voice within the disabled people's movement and within research" (xi).

It is a primary goal of mine to have my research speak back to, engage with, and impact the practices and lived experiences of people with aphasia. In this way, one major contribution I hope to make through this study is to aphasia advocacy. A number of participants, including Marilyn (the mother of the participant and person with aphasia, Melissa) asked me throughout the research process how my research would "help." While I cannot answer that with a set of clear "techniques," as Marilyn requested, I can say that I can say that the insights I've gained in this research process—through observation and interviewing—and through my development of an embodied theory of literacy have influenced my teaching and my work with an aphasia writer's group.

I have a strong personal and professional commitment to people with language disability attaining access to educational and other resources. Though it affects nearly 1 million people and 100,000 more each year, aphasia is not well known. A great proportion of people with aphasia live in nursing homes without access to close communication partners and other resources to

enable communicative or literate access—or anything else beyond the basics of daily living. I continue to strive to have this research reach broad audiences

## Limitations

I consider this dissertation to be the beginning of a research trajectory focused on literacy, disability, embodiment, and access. As such, it is a first draft of findings, necessarily marked by a number of limitations. I will wrap a number of these limitations into my discussion of future directions for research (those directions are stimulated by a perceived gap and need), but I'll mention two related ones here:

### *Recruiting a diverse population of study participants*

Given the location of my research (upper Midwest, mid-size university town and surrounding rural area), my study population is not as diverse as I had hoped. My study consists of almost entirely white, monolingual speakers with not a great deal of class diversity. Not only location limited my study population. Frankly, it is difficult to recruit people with language disability. Often, they are isolated, have transportation barriers, or are unwilling to participate. The participants I did recruit tended to be well-linked with resources: enrolled in services already at a speech and hearing clinic, engaged with aphasia advocacy groups, and often well-supported by partners or family. That is a very important subset of individuals to learn from, but I also wish to include a broader sampling of experiences: particularly across race and socioeconomic status. For instance, rates of stroke and aphasia are highest in African American populations, but they are not represented in this study (National).

### *Developing relationships / collecting rich data from newer participants*

One other limitation in the current study's structure and current data is that, as much as I attempted to, if I had not met people before their interviews (and particularly if their aphasia was

quite severe), I encountered difficulty acquiring rich data. Communication partners assisted with this concern (as I show in Chapter 2), working collaboratively with people with aphasia to navigate communication breakdowns, convey preferences for communication, and more. In future research with people with aphasia, I would like to do more sustained interviewing and observing—as I did with Bill (who I met for 6 hours), meeting over a course of time, observing literate practices and spaces. The multimodal memoir group (and aphasia writing groups, not discussed in this dissertation) do provide me with that exposure to individuals over time and offer important sources of data.

## Future Directions for Research

As I close, I review just a few directions for future research as this project continues. My plan is to work to expand, refine, and transform this dissertation into a monograph. Below I review some of my goals for that task.

### *Further Develop the Idea of an Embodied Theory of Literacy*

Because research—and particularly grounded theory and coding—is an iterative process, I plan to further develop my theory of embodied literacy. This task will benefit from additional coding, particularly of the multimodal memoir group—focusing even more closely on additional hours of data. I will engage in follow-up interviews to track and develop my theories further.

As that coding proceeds, I'm interested in linking up even more thoroughly with body related scholarship, particularly focused on norms and ideologies. While I've done that work in disability studies, I am interested in expanding outward to body studies more broadly.

### *Compose Additional Chapters*

I also plan to further develop these theories through composing additional chapters. Here are a few I have in mind:

Aphasia Writer's Group:

The biggest addition to the study is drawing on data I've been collecting for the past four years: a group of six women with aphasia (all enrolled in other parts of this study – the multimodal memoir group and the life history interviews) have been meeting for a weekly writer's group. The group actually spun off of the multimodal memoir group when Jean and other participants expressed interest in doing more text-based writing. I've facilitated, participated in, and collected video data and hundreds of drafts of writing from that group over the last four years. I have roughly designed a rough outline of this chapter "Bodily Awareness and Writing as Craft: A Longitudinal Study of a Writing Group for Women with Aphasia." Roughly, I'd hope to cover something like this: Writing for people with aphasia is often physically and emotionally painful (Garcia Obregon, 2008; Hengst & Johnson, 2009). But under what conditions might writing serve a rehabilitative role for those who have experienced language loss? To answer this question, I draw on conducted a four-year longitudinal ethnographic study in a writers' group for six women with aphasia, collecting 59 hours of video-taped interaction and hundreds of drafts of writing. I coded the data, using grounded theory (Charmaz, 2006), for how emotional responses to writing practice and identity shifted over time. I find that in the early years of the study, participants developed an awareness of their bodies in writing, thereby expanding their sense of writing as a craft, the writer as craftsperson, and the body as a writing tool. Analysis of later years revealed that this bodily awareness contributed to a group environment wherein participants supported one another's bodily and emotional healing.

I'd also be interested in having women from the group contribute their writing and reflections about their experience as writers with aphasia to this chapter.

Handwriting:

Another chapter, or expanded focus to a current chapter (perhaps Chapter 2) would explore handwriting as a kind of template for an embodied theory of literacy. Handwriting brings together the concerns and conflicts of body, material, and social values. Nearly every participant reflected on concerns—material or value-based, usually both—about their handwriting. This topic also links up with recent cutting-edge scholarship by Christina Haas and Shirley Brice Heath about the hand in writing.

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# Appendix A: Large-Print Interview Questions for Phase 2 of Research—Life History Interviews

UNIVERSITY OF WISCONSIN-MADISON

**Title of the Study:** Literacy beyond Language: Studying the Reading and Writing of Persons with Aphasia

**Principal Investigator:** Kate Vieira (email: kevieira@wisc.edu)

**Student Researcher:** Elisabeth Miller (phone: 507-884-6634; email: elmiller5@wisc.edu)

INTERVIEW QUESTIONS

## Introduction:

My name is Elisabeth Miller. I'm a graduate student in English at the University of Wisconsin-Madison working on a project about aphasia and literacy. The interview questions will ask you about your reading and writing memories before and after aphasia and your current reading and writing practices.

The interview should take no more than 3 hours total.

When I analyze the data from the interview, I won't use your name, and I will eliminate any sensitive personal information. Thank you so much!

### Reading and Writing in Youth

- Describe one vivid memory you have of reading or writing when you were young.
- What kinds of things did you read and write in school? At home? Did your family read or write at home?
- What writing do you remember your parents or siblings doing?
- Describe any memories you have of people who helped you to learn to read or write.
- Do you remember teaching yourself to read or write?
- Do you have memories of being tested on your writing or reading?

Reading and Writing in Pre-Aphasia Adulthood

- When did you write or read for school (if post high-school) or for self-education?
- Describe how you used reading and writing for your job.
    - What did you write?
    - Who did you write for?
- Describe when you wrote at home. Who was this writing for?
- Describe when you read at home. What were you reading? Why?
- Did your family read or write at home? What were they reading or writing for?
- Describe a time when you used your writing skills to get something you needed.
- What was your writing “process” like? When did you write? What did you write with—a computer, a journal, etc.?
- What tools or technologies did you use to read or write (pre-aphasia)?
- Describe a time you have shared your writing with other people.
- Describe a time you have read with others.

Post-aphasia Reading and Writing

- Describe a vivid memory of reading right/soon after you acquired aphasia.
- Describe a vivid memory of writing right/soon after you acquired aphasia.
- Describe how it feels to have aphasia?
    - What do you mean by that?
- What’s different about reading after aphasia?
- What’s different about writing after aphasia?
- Describe a time you used reading or writing (after aphasia) that you feel good about or are proud of.
- Describe a time you wrote or read (after aphasia) when you felt disappointed or hurt.
- When do you write now? Who is it for? Why do you write?

- When do you read now? Why do you read?
- Describe a time you have shared your writing with other people.
- Describe a time you have read with others.
- What's your writing "process" like? When do you write? What do you write with—a computer, a journal, etc.?
- What tools or technologies do you use to read or write (post-aphasia)?
- When is writing easier for you? When is it harder?
- Describe a time (after aphasia) when you used your writing skills to get something you needed.

Looking at reading/writing samples or spaces

- Describe when you read/wrote this. Who was it for? Why did you read/write it? What was enjoyable or frustrating about reading/writing it?
- Describe how you use this to read/write [about technology]. Show me how it works. What features do you use?
- Tell me/show me around your space. Where do you read? Where do you write?

I may ask you for a brief, follow-up interview.

In that case, follow-up interview questions/topics will cover the same topics as those of the initial interview.

The questions will ask you to confirm or expand upon the questions listed here.

## Appendix B: Illustrated Consent form for Phase 2 of Research—Literacy History Interviews

INFORMED CONSENT
for
# RESEARCH

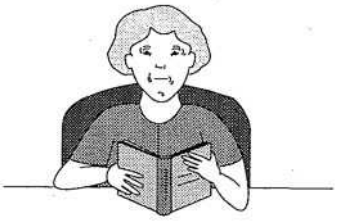

**Participant:** _____

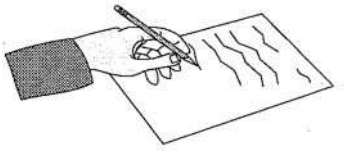
**Investigator:** Elisabeth Miller (507) 884---6634, elmiller5@wisc.edu ------Student Researcher
Kate Vieira, kevieira@wisc.edu ------Primary Investigator

**Project Title:** "Literacy beyond Language: Studying the Literate Practices of Persons with Aphasia"

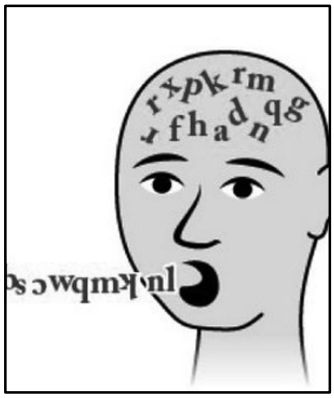
Adapted from Kagan A., Winckel, J., & Shumway E. *Pictographic Communication Resources*. Aphasia Centre—North York, 1996.

**Purpose:** To learn how people with aphasia **read** and **write**





**Before** and **after** acquiring aphasia



## Potential Benefits

✘ No personal benefits to you

✓✓ Helps with research in aphasia, literacy, and education

what ? can you expect?

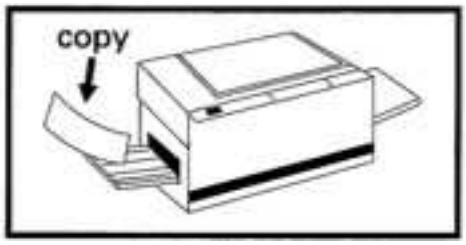
## **Video-taping** an interview

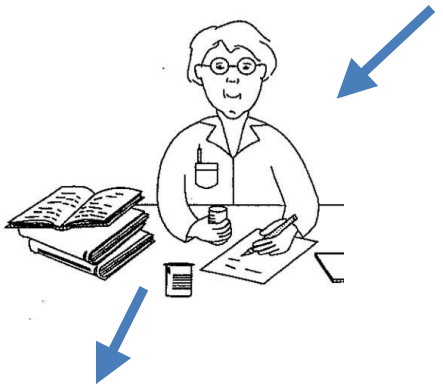

**Interview**

**how long?**

Less than 3 hours

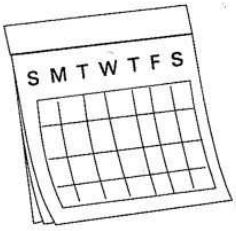
## Researcher **copying** and **looking at** your writing




## Potential **follow-up interview**

**when?**



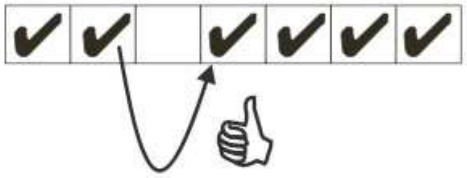

**to be arranged**

**how long?**

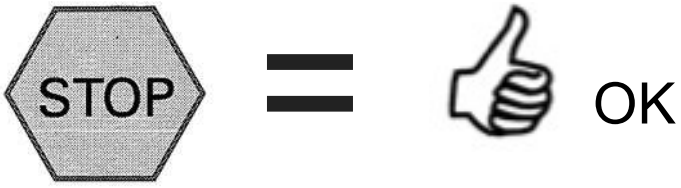
Less than 3 hours

## Your Rights

✓✓ You can skip a question



✓✓ You can stop the interview any time




✓✓ You can quit the study any time

## Potential Risks

Risks are **minimal**

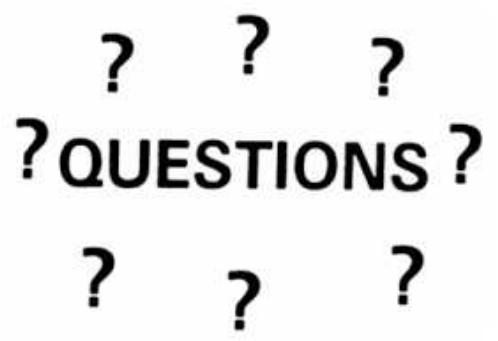
Some risk to confidentiality because of the **small** study and **personal** details


## Steps to Minimize Risk

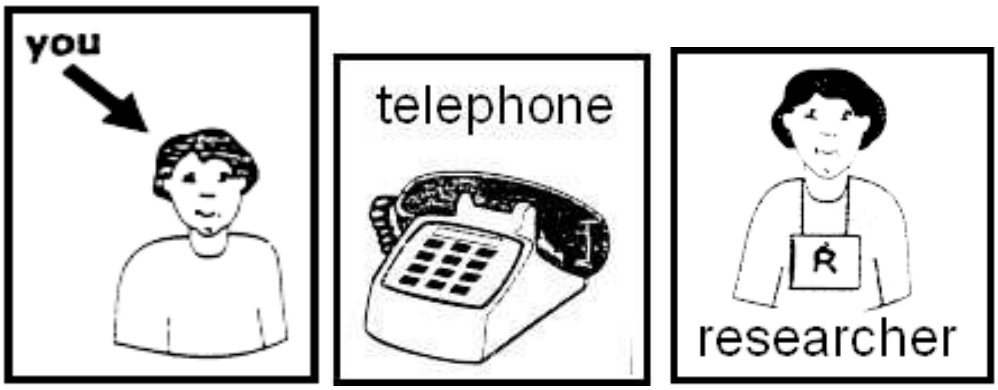
Videos and transcripts in locked cabinet.

You may view, remove, or change sections of audio and video-recording any time.

Your name will never be used in transcripts, research, publication, or presentations**.**




**You can call the researchers to ask questions.**




**Elisabeth Miller 507-884-6634**

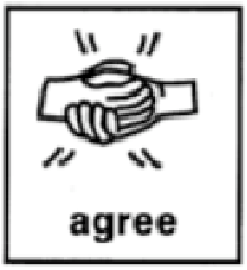
Or, for questions about your rights as a participant, call the Social & Behavioral Science IRB at 608-263-2320.

## Project Consent:

The information presented on the previous pages has been **explained** to me.

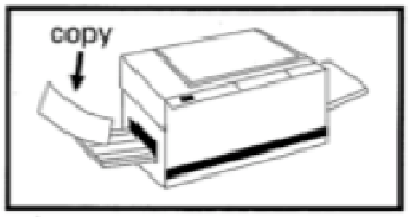
YES _____

I **agree** to participate in this research project.




YES _____ NO _____

I have been given a **copy** of this form.




YES _____ NO _____

I agree to be video-audio taped.

YES _____ NO _____

_____ _____

Signature of Participant Date

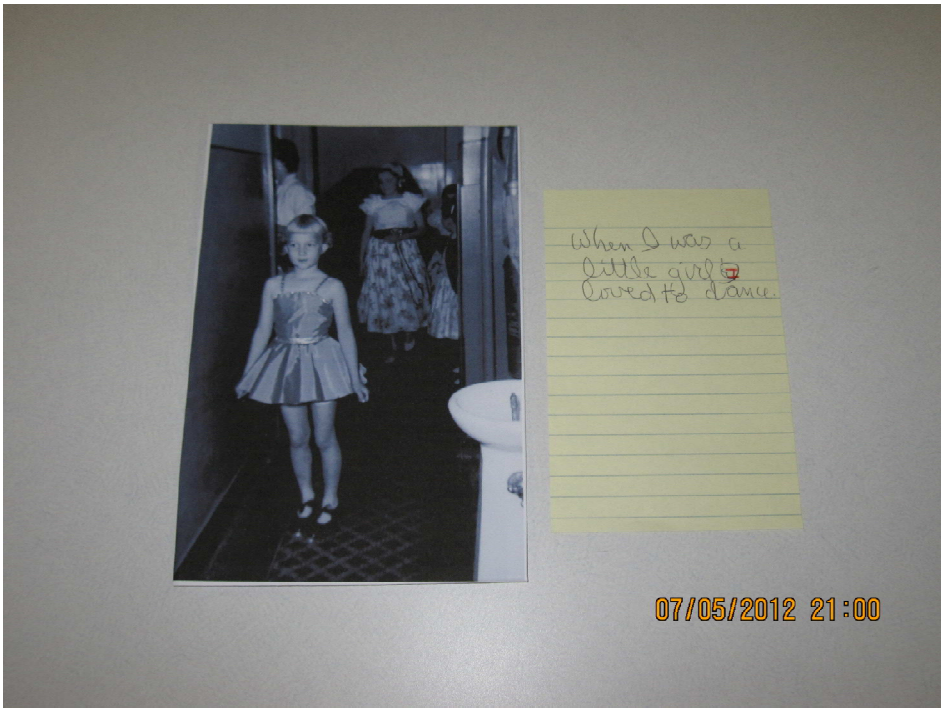
_____ _____

Signature of Witness Date

# Appendix C: Images from Multimodal Memoirs


A page from James's memoir


A page from Bill's memoir




A page from Judy's memoir