

“God Is a Talking Horse”

Dementia and the Performance of Self

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Scholars and activists within the fields of disability and age studies have fought hard to have disabled individuals of all ages recognized as *people* with disabilities, rather than a class of the *disabled* or the *old*. These two broad categories are peopled with individuals with life experiences and opinions, not just needs demanding attention. To better understand the experience of disability, scholars and activists call for the voices of the disabled, for their stories to be told and heard. But such a call also presents us with several challenges. *How* can the voices of the disabled be heard—particularly the voices of people with cognitive impairments or severe physical impairments? In what forms can and do their voices have meaning? Might certain forms of narrative and modes of performance actually support ideals of independence and selfhood that fuel fears of disability in the first place? What can the stories of the disabled tell us about the very meaning of the “self”?¹

I want to address these questions by following *Time Slips*, a creative storytelling project with people with Alzheimer’s disease and related dementia (ADRD)² that began in 1998 in both Milwaukee, Wisconsin, and New York City. As director of the project, I organized 18 weeks of storytelling workshops in Milwaukee and 9 weeks in New York City. In the second phase of the project, we translated a handful of the nearly 100 stories into a professional play production, a Website, and an art installation in order to deepen public awareness of the creative potential and humanity of people with dementia.

Interviews with staff and family caregivers, student facilitators,³ and the storytellers themselves reveal that the storytelling was a surprisingly moving process. Certainly none of the students expected to be invigorated by an hour of storytelling each week with people with Alzheimer’s disease. How and why it worked, what form the stories took, and what the stories can tell us about the performance of selfhood are the questions that fuel the first part of this article. In the second, I look to the production of the *Time Slips* play in Milwaukee in May 2000, and how responses in post-show discussions revealed common fears and understandings of the self.

Between You and Me

It is the social process itself that is responsible for the appearance of the self; it is not there as a self apart from this type of experience. (Mead 1934:142)

[The] self itself does not derive from its possessor, but from the whole scene of his action. (Goffman 1959:252)

At the root of the *Time Slips* project was an effort to encourage creative expression among people with Alzheimer's in a form that could capture the complexity of their worlds and our relationship to them. The people with whom we worked were either living at home with family or in long-term care. All had some form of 24-hour care and nearly all had symptoms consistent with middle-stage Alzheimer's disease.⁴ People with ADRD lose the ability to comprehend the chronological time systems that orient so much of global culture that it is nearly impossible for them to function without someone who can translate that world for them. Severe short-term memory loss can bring disorientation and paranoia: Who is this person coming into my room? What is this room? Gradually, the forgetting of details grows into the loss of concepts. One does not just forget where one put the keys. One cannot comprehend the *meaning* of a key.

People with ADRD are an extreme example of a "self" that is relational, that is formed through interaction with others. On the other end of the spectrum, however, is not an "independent" self, but simply a less extreme example. For example, I am able to perform my daily activities largely by myself—cooking, cleaning, walking, and generally tending to my needs. But my selfhood is also created out of my relationships to other people and institutions.

How can we represent these two extremes? Autobiography might seem a natural choice. I could write an autobiography, logging and assembling the thrilling moments of my days until they fill a nice, fat volume, which I could submit to a publisher in a recognizable and marketable form. Memoir. Autobiography. But what about people with memory disorders? People in intense caregiving relationships? What forms are available for their stories?

If a person with ADRD writes a traditional autobiography, she will necessarily have to mask the intensity of her caregiving relationships.⁵ The writer might borrow the autobiographical form to strengthen a sense of self, but in the process overlook or misrepresent the relational quality of her selfhood. Paul Eakin (1999) suggests that relational identities can be found in autobiographies whose writers emphasize the relationships in their lives (Carolyn Steedman's *Landscape for a Good Woman: A Story of Two Lives* [1986] 1987, for example), but this doesn't eliminate a larger problem. As Lennard Davis points out, "by narrativizing an impairment, one tends to sentimentalize it, and link it to the bourgeois sensibility of individualism and the drama of the individual story" (1995:11). In general, I find that the history and context of the traditional autobiography, in which a consistent "I" tells a chronological tale of selfhood, make it inhospitable to representations of the extremes of relational identity.⁶

With the *Time Slips* project, we set out to encourage the performance of self that did not rely on memory. We sought to emphasize the relational quality of the self and to enhance the social identity of people with ADRD by giving them a meaningful role to play in their institutional setting. By releasing the pressure to remember their pasts, the creative storytelling workshops invited any and all forms of communication and allowed participants to hone what communication skills they retained. By creating a valued, social role for

people with Alzheimer's (that of storyteller), caregiving staff were able to engage with them as functional people rather than simply bodies in need.⁷

The theoretical model of the relational self has ties to postmodern concepts of selfhood, which, over the past decade, critical theorists have described in terms very similar to experiences of mental illness. The postmodern self is "saturated," disoriented, and paralyzed by too much information (Gergen 1991), or made up of unpredictable actions and tactics (de Certeau 1984). Or perhaps the self is a shadow of something that doesn't exist at all (Baudrillard 1988). Deleuze and Guattari even borrow the term "schizophrenia" to describe how it feels to live in postmodern technoculture (1987).

Like Tony Kubiak (1998) and Anne Fleche (1997), I am concerned with the use of mental illnesses (multiple personality disorder for Kubiak, autism for Fleche) as illustrations of postmodern theories of fragmented selfhood. As Kubiak suggests, people with mental illnesses lead fragmented lives and are often deprived of even the simplest tools of self-expression. To reduce risks that they might hurt themselves and to enable the efficiency of caregiving routines, the institutions in which people with severe mental illnesses live limit tools for the performance of self and the social roles they can play. Institutional activities tend to keep clients busy and distracted rather than offering them genuine avenues for meaning-making.

Defining the "normal" postmodern self in terms of mental illness might eventually go a long way toward reducing the gap between people categorized as mentally ill and those who are not. As Herman Coenen suggests, "that which is so easily taken as a sharp unbroken borderline between two noninterchangeable worlds is regularly crossed from both sides" (1991:32). But in reducing this gap, one also risks ignoring differences between the lived experience of people with mental disabilities (and their caregivers) and the theoretical idealizations of their states of mind. I find the model of the relational self to be a more elastic model, adaptable to the practical realities and extremes of disability—the extremes of mythic independence and near-complete dependency.

The Method

Time Slips storytelling workshops make a clear and simple distinction: rather than focusing on who people with Alzheimer's disease *were*, we are interested in who they *are now*, complete with missing words, repeated sounds, and hazy memories. We stretch the boundaries of traditional reminiscence activities—common and effective tools for exercising memory—by telling participants that we are not interested in their memories. Rather than rehearse their pasts, together our storytelling groups make up *new* stories.

We held our original storytelling sessions for one hour once a week at two adult day centers in Milwaukee (1998–1999) and two in New York (1999). The four centers were all quite distinct, and each in turn had a diverse group of clients. To unify the storytelling process, we created a five-phase ritual that we repeated each week at each center; the greeting, the retelling of the story from last week, this week's story, the final retelling, and the farewell.

We began each session by inviting participants to sit in a circle of chairs away from other activities that might be happening at the same time. This separate circle helped give the sessions a "special event" status by freeing us from the long tables around which most activities take place in day- and long-term care centers. We welcomed the storytellers into the circle and greeted them by name. To eliminate confusion or guesswork on the part of the storytellers, facilitators wore name tags and introduced themselves each week.

After the greeting phase, a facilitator read back one of the stories from the previous week. The retelling reminded the group that the stories were cre-



1. Storytelling groups followed a clear, ritualized structure. Each session began by gathering the storytellers into a loosely formed circle. Here project associate Nichole Griffiths (seated on the floor) leads a Milwaukee group. (Photo by Dick Blau)

ative tales with no right or wrong answers. This can be a surprising message for those fresh from daily orientation exercises in which they are commonly asked to name the day, date, season, or the current President.

Before the group began telling a new story, student facilitators asked the storytellers to help them pick out an image for the week. The images we used shared two qualities: they were large enough to see without straining and they suggested a fantastical story. If the images appeared too realistic, or featured recognizable people, participants assumed there was a “real” story that they had forgotten and were reluctant to make up new stories, but staged, somewhat surreal images invited creative expression. Our favorite images were taken from greeting cards and magazine advertisements: three women playing accordions, a woman riding an ostrich, and a man sitting underwater in deep contemplation, menaced by fish.

The storytelling itself began with students distributing copies of the image around the circle. One student served as “the writer,” and sat in the center of the circle with the large sketchpad and a box of brightly colored markers. Other students sat around the circle among the storytellers and posed questions like, “What should we call her?” “Where should we say they are?” Questions focused on the sensory (“What does the farm smell like?”) and included the world outside the picture as well (“Does the woman riding the ostrich have a family?”). The storytelling became improvisational at this point. Storytellers’ answers carried the facilitators’ questions in new directions, and in turn our questions carried the storytellers deeper into the world of the story.

All answers were folded into the story. One storyteller, whose language was limited to sounds, offered “Bababababa.” It became part of nearly every story we told. If more than one name was provided for a character, we would hyphenate it. Often the storytellers themselves interpreted each other’s answers (“He meant this...”) or countered the direction the story was taking if they didn’t like it (“She isn’t jumping off the building, she’s jumping to the next building to see her friend”).

If storytellers got lost in the story, student and staff facilitators could call for a “retell,” and the “writer” would read back all the answers up to that point. Retelling the story—interpreting a random list of sensible and nonsensical answers into a “story”—demanded a certain theatrical flair. It also demanded that

2. Anne Basting serves as the "writer" in a Milwaukee storytelling circle.
(Photo by Dick Blau)



staff and student facilitators let go of their own reliance on linear narrative. Once they released their desire to guide the story in a particular direction, facilitators were able to elicit more responses from people who did not usually speak and to fold all the answers into the open narrative with greater ease.

The workshops quickly developed their own momentum. One story could go on for nearly an hour. Most often, we told two stories each week. At the end of each session, the writer would do one last retelling of the story and remind storytellers who had supplied which answers. Finally, the students said goodbye to each member of the group, individually thanking them for sharing in the storytelling process. For men and women with Alzheimer's, to leap into creative verbal expression is to risk revealing the stigmatized effects of the disease. Their efforts were no small gift, and the weekly "thank yous" were an important acknowledgement of the courage, energy, and trust it took to play their role.

From week to week, the storytellers would not remember our names. But the circle, the greeting, and the story images became familiar to them, and with these rituals they quickly associated trust, play, and the freedom to speak. For the staff, the storytelling ritual created a separate space in which they could, at least partially, let go of their authoritative roles. In this circle, they did not have to orient or correct the storytellers. Facilitating the storytelling allowed them to play with clients on the equal ground of the imagination. Freed from right or wrong answers, staff began to relax into the stories, to laugh, and to sing along with the group. Said one staff member in New York:

I can't even describe it. By doing the storytelling, it's like they are telling their own life story. They are putting it together and they are loving it. They are living what they are doing. And it makes us feel good! Because I really can get into the storytelling.

For me, the sessions became a way to fully access the present moment. My questions always began somewhat stiffly, with logical questions about names, weather, and geographic locales. But as the answers accumulated, the storytellers ushered us away from the logic of the outside world and into a realm between imagination and memory—ours and theirs. Storytelling became an

incantation that temporarily suspended the usual rules of time and authority that guide the institution and our lives outside it.

Certainly lines of power and authority still circumscribed the storytelling. If anyone became aggressive or “inappropriate,” they were removed from the group. But the lines were also blurred by the fact that staff and facilitators were no longer looking for symptoms of the disease in the spoken word. Language was suddenly free to carry emotional, rather than literal, meaning.

For example, one storyteller who had almost no language left would sing nonsense songs as her way of adding to the story. Facilitators would echo the song back to her, capturing the words, the tune, and the emotion as best they could, and then ask her if they had gotten it right. She would nod, her face beaming. With each retelling, the facilitators would begin the song and ask her to help them complete it. And with each retelling, the connection between them, and her joy, were fresh. Staff, volunteers, and storytellers—we all seemed to be under the spell of the present moment and our ability to communicate in it, occasionally in what seemed complete verbal nonsense. For me, storytelling was a time when fragments of memory could launch us all into new worlds that we built together rather than lock us into prefabricated labels of loss or badges of control.

After several weeks of workshops, it was clear that storytellers were not only aware of their new roles, but were developing those roles beyond my expectations. With a photographer (Dick Blau) and a videographer (Xavier LePlae) at nearly every storytelling session, the storytellers not only grew accustomed to the cameras, but also learned that their workshops were special—something worth documenting. One group not only played the roles of storytellers, but also commonly added their own names as characters in the stories. Their roles doubled as they played both storytellers and, for example, a famous, traveling blues guitarist or a bear who dances the cha-cha. Beth Meyer Arnold, the director of Luther Manor Day Center in Wisconsin told me she found it difficult to describe the storytelling process to peers and asked if she could invite people to watch. I was hesitant, concerned that an audience might shut down the creative process, but I trusted her judgment. One or two onlookers began to watch from outside the story circle each week, without adverse effects on the

3. Minerva, a Milwaukee storyteller, adds a song to the story “Tiny Bubbles,” whose main character, Gisacho Gusto, later found an alternate love interest in the Milwaukee Time Slips play. (Photo by Dick Blau)



process. One day, after a mix-up in RSVPs, 15 people arrived to watch the storytelling. My project associate who ran the session noted in her journal that the storytellers seemed to come out of their skins. They were performing for the crowd—projecting their voices, singing, and laughing much more than usual. Their answers seemed sharper and their story, about nine Italian women from Ireland fighting for independence, more vibrant.

The stories share common themes that are also reflected in this sample. They tell of longings for freedom (Ethel Rebecca), acceptance (Grandfather the elephant), and intimacy with family (the accordion-playing sisters) or lovers (Tom and God).

The storytellers clearly felt they played a special role in their day centers. In all four day centers, we created books that contained each group's stories and the images that prompted them. In a final celebration, we gave each storyteller, staff member, and student volunteer a copy of the book. At Luther Manor, where staff was the most involved with the storytelling process, the administration invited family members to a final celebration complete with food, a slide show, and the presentation of the books to the families. Roger, a man who had particularly flowered as a storyteller, stopped me at the celebration and grasped my hand. "You know why this is so great?" he asked. "You know why? It ain't cheap. You know what I mean?" Across the divide of communication, I took his meaning. The storytelling project and the Luther Manor staff valued the storytellers' words and shared that value with their families and extended communities. Roger felt valued.

The Stories

The five stories I include here contain the common themes that emerged in nearly every story.

THAT'S A BIG BODY...

(In response to an image of an elephant and a little girl.)

We are deep in the heart of Austin, Texas.

Grandfather the elephant lives at the zoo and does tricks in the circus.

But he's not allowed to sing there.

One day, while walking down the street, he meets Amy, a 10-year-old girl.

Now, most people would run away when they meet an elephant on the street, but Amy has no fear.

They become friends.

One day, Grandfather takes his car and drives from the zoo to the church, where Amy is at a wedding.

He waits for her outside, because he's too big for the church.

If he went in, he'd break it down.

While Grandfather waits, he hears "Abide with Me" coming from the church. (*Group sings "Abide with Me."*)

He likes it because he's not allowed to sing at the circus.

Amy comes out to meet him and feeds Grandfather corn and hay and grass, because grass is good.

Grandfather has floppy ears.

He's a very good person, he's comfortable and happy.



4. Milwaukee storytellers Vera (left) and Mary hold the image of "Ethel Rebecca," the main character in "Filling In As She Goes Along." (Photo by Dick Blau)

Amy falls asleep on Grandfather, and he waits for her to wake, then gets back in his car and drives back to the zoo.

1998, Milwaukee

FILLING IN AS SHE GOES ALONG

(In response to an image of an elderly woman sitting in the cockpit of an old plane.)

Ethel Rebecca may be old, but she's full of vim and vigor.
She knows how to fly, and flying makes her happy.
She's flying over Chicago on her way to work.
Ethel's got a perfect record—no crashes—because she's a very determined pilot.

She's not flying alone—Dizzy Gillespie is in the back seat playing the clarinet.
After Chicago, they'll fly to Seattle to visit her granddaughter Dorothy.
Ethel has three children, Hilda, ABCDEFG, and Grizelda Mary.
She has a husband—she better!—named James who drives a bus.
He's only 70...Ethel's a bit of a cradle robber!

People tell her to keep good sense and keep her feet on the ground.
Her family worries themselves sick about her.
But Ethel flies because it makes her feel free, and because her family doesn't pay her enough attention.

One day, when Dorothy reaches the flying age of 16, Ethel will teach her granddaughter how to fly too.

All the way to Seattle, the weather is clear, Dizzy plays his clarinet, Ethel sings an Italian song (*group sings "Cera Luna Mezza Mara, Mama Mia, Ma Mari Dari"*), and she remembers the farm her father Lee Hugh built up and his big red horse.

But that's all gone now.

1998, Milwaukee

LOOK AT THOSE EYES!

(In response to an image of three women playing the accordion.)

Persephone, Mary, and Rosemary are accordion-playing sisters in a group called the 3 Musketeers.

It is also known widely as the Triple Group.

Their eyes are talking, saying, "listen to me."

Right now they are in a studio playing accordions (partly because they don't know how to play anything else...).

They are loud and happy. You can tell because their mouths are wide open in big smiles.

They usually play for free, but they are especially happy today because they're about to become rich and famous.

Donald Trump has invited them to play for a party for 500 in New York City, a party in celebration of...himself!

They'll play the "Too Fat Polka" (*group sings "Too Fat Polka"*), and the "Beer Barrel Polka" (*group sings "Beer Barrel Polka"*), and of course, requests.

They'll eat anything that tastes good, but not too much or they won't be able to play.

There'll be cheese, ham, buns, wine, fruit cocktail, chitlins, and, of course, beer.

Mary is the oldest, and Persephone is the youngest.

Their mother died when they were young.

The three sisters grew up fixing each other's hair, teaching themselves the accordion, and Mary made all their fancy clothes.

They are smiling and happy.

1998, Milwaukee

A HORSE IS A HORSE OF COURSE OF COURSE

(In response to an antique advertisement of a cowboy and his horse.)

He is a handsome man.

The man and the handsome horse are making love.

A horse! My my my.

No...they aren't making love, they are too much in the open.

He is serenading the horse, singing a cowboy song.

(Sing) "Get along, get along, get along..."

They live in the west country.

They keep moving.

5. Student facilitators asked open-ended questions of storytellers to guide them deeper into their imaginations. Here Kim (right) asks Equary questions about the image that inspired the story "A Horse Is a Horse of Course of Course," about Tom the cowboy and his talking horse God. (Photo by Dick Blau)



The cowboy is a married man, but he's very available.
 He is attracted to beautiful women like us.
 He is whatever age we want him to be.
 He's probably around 28.
 The horse thinks he's a good guitar player.
 He's not riding the horse right now, but he does sometimes.
 The horse's name is Godfrey, woops, Godfreya.
 The man's name is Thomas Rex.
 They go by Tom and God.
 Tom and God are inseparable. They are buddies. They even sleep together,
 in the barn of course—it's much roomier.
 The cowboy is also singing "Daisy, Daisy, give me your answer do..."
 God is a talking horse.
 He's been trained.

1999, New York

UNCONSCIOUSLY MAKING THINGS TOO SMALL

(In response to the same image that prompted "That's a Big Body...")

This is a story about Anna.
 Anna is friendly with everybody.
 It's medium outside, a medium summertime day.
 Anna's friend is an animal, an elephant to be specific.
 God knows where they met.
 Together they have a home, but we're not sure where.
 It's their own business what they do.
 There are too many answers—everybody has different answers.
 There's a chicken and a little tree in the background.
 The story is much bigger than the elephant.
 It's so big, you can't go oversimplifying it.
 You cannot put things like that.
 Unconsciously we try to make things too small.
 Every person has a story.
 There's not a human being that doesn't have a story.
 But making it mish-mosh is bad.
 It's like a bomb.
 This is a story about Anna.
 Anna is sitting on a pail.
 Anna is friendly with everybody.
 Anna's friend is an elephant.
 Leave Anna alone!
 It's too much of a story to be a story.
 Writing has its limits.
 It can't be blown up like a balloon.
 Anna is listening to the elephant's heartbeat.
 Her hand looks like a chicken's foot.
 Anna and the elephant are waiting for a ride.
 But it's stupid to have a car in the background.
 They are not iron and nails!
 Anna and the elephant are singing a song. We knew the song, but we sold it.
 There are prettier things to look at than an animal's whatchamacallit.
 You can't go making things—leave Anna alone.
 They are a family.
 They've got the whole world in their hands...

1999, New York

The first four stories—deliberately funny, sometimes outrageous—are typical of most of the stories that emerged in the workshops. As trust grew, the storytellers played off of each other as well as with facilitators. Answers were designed to provoke and/or please tellers and facilitators alike. Only the second story contains a nonsensical answer—which was much more common than this sampling suggests. Nonsensical answers fell into two camps: answers that challenged the process and answers that came from the illness. “ABCDEFG” was a “challenge answer.” When we asked a storyteller what we should call Ethel Rebecca’s daughters, her reply was (very typically), “I don’t know.” The facilitator reassured her (also very typically) by saying, “You can say anything you like.” As if to say “oh yeah?” the storyteller smugly responded, “ABCDEFG.” Recording challenge answers was a vital part of the process. By our willingness to weave challenge answers into the story, storytellers were assured that our promise to accept any answer was sincere. For those with deep rifts in their ability to speak and formulate thoughts, this proved comforting. They could contribute answers without fearing the pressure to “make sense.”

Nearly all the stories from the workshops in both Milwaukee and New York share common themes that are also reflected in this sample. They tell of longings for freedom (Ethel Rebecca), acceptance (Grandfather the elephant), and intimacy with family (the accordion-playing sisters) or lovers (Tom and God). These themes appear in nearly every story, and understandably so. The storytellers are under the watchful eyes of 24-hour caregivers—some family members, some paid attendants. Some storytellers are removed from their families, or cannot remember them. They know they had intimacy in their lives (and continue to long for it), but often cannot remember with whom. For those who feel simultaneously isolated and fully dependent, dreams of freedom and intimacy are hardly surprising.

The structure of these five sample stories is also typical. Each week, my project associate, Nichole Griffith, and I translated the stories from sketchpad to computer. Our aim was to capture them as closely as possible, without succumbing to urges to clean them up or craft them into well-made tales. In the beginning of the project, this was difficult. I had an almost overwhelming desire to make sense of the stories, to draw out and polish the rich metaphors and symbols that lay like geodes in the riverbed of the tales. Early reactions to the stories, however, helped me resist the temptation. When I gave copies of the first few stories to outside readers, they skeptically asked whether I’d actually written them. “Cleaning up” the stories did not present the disease or the storytellers in a better light. It only robbed them of their authenticity. The value of the stories clearly rested in their raw form. So the stories remain in the random, list-like format in which they were initially written down.

The fifth story is unique. It sprang from what was for me the most difficult of storytelling days. A very poetic storyteller was upset that day. New medication made it difficult for her to handle more than one person talking at a time, and she was overstimulated by the storytelling. The group as a whole was excited by the image and eager to weave together a story. But this participant stood up and insisted emphatically that our story was pointless, if not damaging. I struggled to decide what to do. Should I honor her dissent and stop the process? Day center staff continued to assist in the storytelling and I followed their lead. When I translated the story to the written page, I included her dissent as another contribution to the story, and now find it to be the most powerful example of all the *Time Slips* stories of the strength of character of people with Alzheimer’s disease. It serves as a valuable reminder that some experiences of dementia are beyond words.

For those of us without cognitive disorders, the stories provided a rare window into the world of dementia. They gave the storytellers’ families a way to

interact with each other—to acknowledge the loss the disease incurs, yet also to recognize the creativity and humanity of their loved ones. Several family caregivers told us that they copied the final book of stories and sent it to relatives or read the stories to grandchildren. The open, poetic quality of the stories enabled families to connect, at least psychologically, with each other and with the storytellers.

People with ADRD lose the ability to weave a narrative of selfhood from memory. But given a valued social role, these storytellers retained and sharpened their abilities to respond as a group and to shape a story with fragments of memory—with answers born of illness, and answers born of creativity. Nuances of individual personalities were clear in the group. One woman loved to make up quirky names. Always with a wry smile, one man consistently gave the stories an adulterous plot twist. But the emphasis in the story circles was on group participation. The stories are composites of the voices of all participants—the facilitators and the storytellers. The stories do not tell the narrative of one independent self, but of relational selves. They help us hear the experience of dementia without mistakenly falling back on a mythic construction of the independent self.

The Milwaukee Arts Events⁸

As the storytelling workshops took shape, I assembled a team of artists to collaborate with storytellers and each other to translate the stories into a series of public arts events. Our aim was to captivate Milwaukee audiences through the enchanting and poignant stories that came from people with Alzheimer's disease. We wanted to demonstrate the creative potential of people others thought incapable of creativity. We also aimed to echo the relational quality of selfhood in the workshops through a collaborative process of artistic creation as well as the artistic products themselves.

The artistic team, which met once a month over the course of a year to design the arts events, included a photographer, a videographer, a Web designer, a book designer, a playwright (me), and my project associate. Dick Blau photographed nearly every storytelling workshop in Milwaukee. He truly became an integral member of the storytelling circle. Blau played with the storytellers and they often added his name to stories. He was respectful of those who shied away from the camera, and let those who were fascinated with its mechanics hold it while he explained how it worked. Xavier LePlae, who had been teaching inner-city school kids how to make their own videos, became our videographer. About every other week, he set up his camera in the storytelling circle and captured the process for a training video. Chad Anderson was the original designer of the *Time Slips* Website. Because the Website would feature Blau's photographs and possibly LePlae's video, the monthly design meetings were crucial to the Web design. Beth Thielen, a California-based book artist, came out to Milwaukee to participate in several storytelling sessions and design meetings. Thielen crafted two handmade books—filled with images of the sessions and the storytellers, and the stories themselves—that would become part of the *Time Slips* art installation.

The monthly meetings of the *Time Slips* artistic team culminated in the launch of our Website in April 1999. After that point, the collaborative efforts shifted to the advisory board—made up of local and regional specialists in education, dementia care, dementia research, and the arts—who crafted an out-

6. Storytellers like Ed in Milwaukee (left) developed a special relationship with videographer Xavier LePlae (right) and photographer Dick Blau, which enhanced their roles as performers and storytellers. (Photo by Dick Blau)



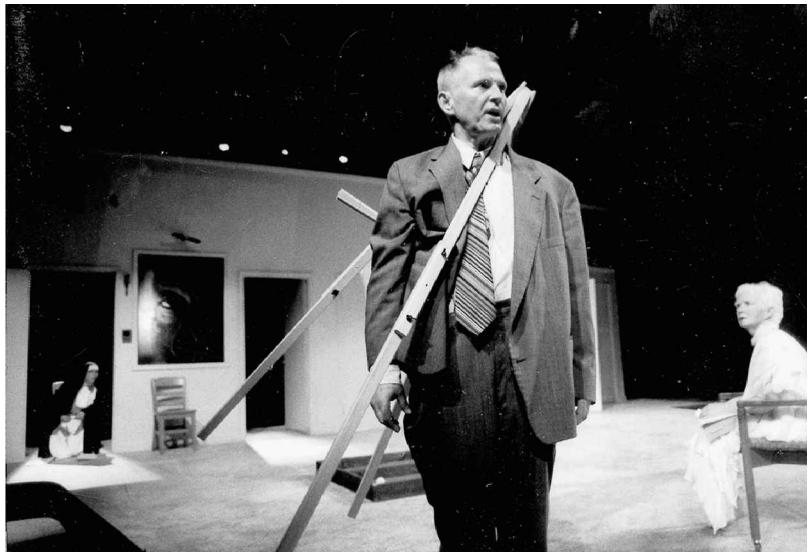
reach plan for the arts events. The collaborative model was also taken up by the team of artists creating the *Time Slips* play.

The Play

In May 2000, the *Time Slips* project produced a play inspired by six of the stories told in Milwaukee. Performed by a largely professional, intergenerational cast on the University of Wisconsin-Milwaukee's large thrust stage, the *Time Slips* play combined the stories and characters with the plot of the disease.⁷ In the first scene, all nine characters are introduced and each defines his or her unique vocabulary of movement, text, props, sound, and song. The characters are clearly outrageous. Ethel Rebecca and Grandfather the Elephant were both featured in the play. Ethel "flies" onto the thrust stage by running up a steep ramp built out over the audience, holding a small, battery-controlled fan as a propeller. She wears an old-fashioned aviator jacket and hat and sings "Cera Luna Mezza Mara." Grandfather the Elephant, played by a middle-aged man in a gray suit five sizes too large for him, lurches onstage waving a small American flag. He lifts a foot as if doing a circus trick. Gisacho Gusto is a man who lives underwater in a pond where his father lived as well. Tormented by fish that nibble at him all day, he dreams of returning to Ondiamo, a woman he left on the surface. Two nuns, Sister Edista and Sister Sixtus, move from fishing hole to fishing hole, patiently waiting to land a prize-winning walleye. An artist named Hanover paints his model, Ericka, who dreams of fame. Running Jumping Woman is addicted to the feeling of falling. Throughout the play, she rushes onstage, finds precipices small and large, and leaps off of them in an exaggerated fall. And finally, a nursing assistant named Polly quickly marches across the stage as if to organize the characters' worlds with the pattern of her pacing.

After these characters are defined in the first scene, the entire scene repeats almost exactly. Slowly, as this second scene progresses, several props and costume pieces begin to circulate from one character to another. The characters do not acknowledge the change, but the audience now reads two layers of meaning for the objects that transform as they change hands. In the third scene, the initial scene repeats again, but this time, props and costume pieces circulate rapidly, characters lose language, and slide projections of sentences fracture into single words or letters. The characters react with a growing sense

7. *Time Slips* (2000), by Anne Basting, directed by Gülgün Kayim at the University of Wisconsin-Milwaukee Center for the Arts. In scene three of *Time Slips*, props identified with particular characters circulated freely among them. Here, Grandfather the Elephant (John Kishline) wears an easel belonging to Hanover, a painter. (Photo by Dick Blau)





*8. Time Slips began with fragmented, projected images and ended with full portraits of the storytellers.
(Photo by Dick Blau)*

of frustration, but not confusion. Their actions are still clear to them. It is their surroundings that seem to betray them.

In the fourth and final scene, the characters have very limited means of expression. Simple gestures are arduous and language is fragmented at best, garbled at worst. The characters must rely on each other to resolve their stories. Running Jumping Woman helps the grounded pilot climb a wall for a final flight. Grandfather the Elephant sings "Abide with Me" with a choir made up of his fellow characters. Gisacho Gusto finally swims to the surface of the pond, only to find Ericka (the artist's model) in place of his beloved Ondiamo. Ericka had hopes of becoming famous, but accepts the warmth of Gisacho's embrace instead. The nuns finally reel in their prize catch in spite of the fact that one of the sisters has lost language entirely. Hanover began painting a small canvas, but ends using his arm as a brush, as his painting appears, animated, on the large back wall of the set.

In the play, each character, born of the creativity of people with Alzheimer's disease, endures or overcomes the challenges of the disease through creative and communal effort. There is a clear and deliberate parallel here to the storytelling workshops themselves, where people with ADRD faced broken language and disorientation and constructed a sense of selfhood through communal creative expression.

The play ran for five performances. Our outreach efforts targeted schools, the arts community, healthcare workers, and those concerned with Alzheimer's and dementia, from churches to support groups. As a result, audiences were largely a blend of these populations. Extensive local media coverage ensured that nearly everyone in the audience knew a bit about how the play had evolved, but some audience members came with no knowledge of the storytelling project at all.

Post-show discussions (which followed each of the 70-minute performances) revealed that there was some confusion over whether the actors were portraying imaginary characters or people with Alzheimer's disease. Certainly there was a deliberate attempt on our part to overlap the characters and the storytellers. We had put the characters into the plot of the disease—they appeared to be suffering it themselves. The characters successfully drew the audience into the experience of repetition, disorientation, and the unreliability of objects, language, and memory. But too much confusion meant that audiences might have missed the most important point of the play: that these tales of loss and transcendence had been forged in a collaboration between facilitators and people with Alzheimer's disease themselves.

Assessing audience reaction is always a slippery endeavor. But after reviewing notes from post-show discussions, I believe the audience reactions point to two things. First, the structure of the play and pre-show materials did overly cloud the distinction between the characters in the creative stories and the storytellers with Alzheimer's disease. As playwright and project director, I had been concerned that too much information about the origin of the play would either repel potential audience members or inhibit them from seeing the play as an "artistic" experience. Promotional materials (posters, postcards, press releases) emphasized that the play was "an original, multimedia, poetic journey in one act," and only secondarily mentioned that it was inspired by creative stories *told by* people with Alzheimer's disease. The program materials alluded to the storytelling workshops, but included no more than a paragraph on them. The loose description of the storytelling process in the promotional materials left holes large enough for audience members to misinterpret the play's characters as actual people suffering from dementia, rather than as creations by people with dementia.

My other reading of the audience reaction to the Milwaukee *Time Slips* production is fairly simple. Alzheimer's disease can be a horrifying experience for those who suffer it directly, as well as for those who watch the memory (and some believe the personality) of their loved one evaporate. Caring for a person with Alzheimer's disease is an exceedingly challenging task. There is little hope for people embroiled in the world of the disease—little hope for medical solutions, economic relief, or cultural understanding. In a country that declared its "independence" and that prides itself on its bootstrap success stories and its rugged individualism, Alzheimer's disease is the ultimate nightmare. We long to find reasons for it, to make sense of a disease that seems to strike regardless of gender, class, race, or education. With both eyes on the losses they and their loved ones have suffered, it can be understandably difficult for people directly engaged with the disease to find meaning in the fantastical tales told by people with Alzheimer's disease.

And yet, the majority of audience members that spoke at post-show discussions clearly "got it."¹⁰ I believe the poetic imagery of the stories and the staging of the play will linger for those who didn't. Seeing the humor and power in the stories can only come when people are ready for it—when fear and anger and grief subside enough (perhaps only momentarily) to allow room for humor, to allow room to hear the voices of people with Alzheimer's themselves.

Notes

1. Thank you to the students, the members of the *Time Slips* artistic team, the storytellers and their caregivers (family and staff) for making this project possible. The *Time Slips* project received generous support from the Helen Bader Foundation, Inc., the Brookdale Foundation, Luther Manor Day Center, Alterra Healthcare Corp., The Extendicare Foundation, Blue Cross and Blue Shield, and, most importantly, from Kathleen Woodward and the Center for Twentieth Century Studies at the University of

Wisconsin-Milwaukee. The New York arts events are being hosted by the Brookdale Center on Aging at Hunter College. Watch our Website <<http://www.timeslips.org>> for news of the New York *Time Slips* play, scheduled to run from 30 October to 18 November 2001 at HERE Arts Center. The *Time Slips* art installation will appear in the lobby of the Empire State Building from 1 October to 15 November.

2. Alzheimer's disease is the most common form of dementia. Dementia is an umbrella term for a variety of conditions that are marked by various cognitive disorders, including disorientation, memory loss, and paranoia.
3. Undergraduate student facilitators were drawn from multiple disciplines. In Milwaukee, students came from the University of Wisconsin-Milwaukee and Mount Mary College, from the fields of education, studio art, art therapy, theatre, nursing, and creative writing. In New York, the project drew undergraduate theatre students from Hunter College, Empire State College, and New York University.
4. There were three exceptions. One participant suffered oxygen deprivation to the brain during a heart attack. One was the victim of a stroke that inhibited most of her speech. And finally, one had short-term memory loss and conceptual difficulties, but had not received a diagnosis.
5. There are several examples of autobiographies written by people with ADRD, including Diana Friel McGowin's *Living in the Labyrinth* (1993), Robert Davis's *My Journey into Alzheimer's Disease* (1989), and Cary Henderson's *Partial View* (1998). For an extended critique of these autobiographies see my essay, "Looking Back From Loss: Views of Self in Alzheimer's Disease" (2000).
6. In their introduction to *The Body and Physical Difference: Discourses of Disability*, David Mitchell and Sharon Snyder state clearly that, "first person narratives cannot singularly provide the interpretive paradigms needed to revise cultural understandings of disability" (1997:11).
7. Hava Golander and Aviad Raz's study (1996) suggests that caregivers work best with people who have an identity—whether fictitious or "real."
8. A similar series of public arts events will be produced in New York City in October and November 2001. See the *Time Slips* Website <<http://www.timeslips.org>> for more information.
9. Gülgün Kayim directed the play, which featured John Kishline (Grandfather the Elephant), Rebecca Myers (Sister Sixtus), Margot Fuchs (Sister Edista), Beverly Karpfinger (Ericka), Jeana Stillman (Polly), Sarah Wilbur Price (Running Jumping Woman), Mondy Carter (Hanover), Gisacho Gusto (Bo Johnson), and Adekola Adedapo (Ethel Rebecca). The play followed on the heels of an art installation at the Charles Allis Museum in Milwaukee in March 2000, which featured 10 larger-than-life portraits of storytellers, two handmade "pop-up" books that capture the storytelling process, a computer displaying the project's Website, and two of the stories writ large on enormous posters.
10. The husband of one of the storytellers came to two performances. When I interviewed him later, he said that he had heard someone say that there was no plot to the play. "But I saw nine plots," he said, and proceeded to describe each character's evolution. "But I don't go to the theatre, so maybe I'm wrong." I assured him he wasn't.

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