

See Me! Hear Me! Know Who I Am!

By Bonnie Genevay

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This piece originally ran in the Spring 1997 edition of Generations. The Editorial Advisory Board found it remains relevant to this day (if not more so) and pertinent to this issue on Mental Health, Aging, and Resilience. Bonnie was a beloved member of the American Society on Aging and the former ASA Mental Health and Aging Network (MHAN). She fell in love with the field of aging in middle-age and spent the rest of her life working as a gerontologist, publishing a variety of books related to countertransference and bereavement, teaching, and counseling older adults. Bonnie's words remind us of how important it is to take a holistic, person-centered approach when working with older adults.

Who is the person inside? She was 92 years old in 1985, and this was her last home—a nursing home. Her new physician came into her room and introduced himself. Although her confusion often hindered communication, this happened to be a “good day.” When he said, “I’m Dr. Brown,” her 80-some years of experience in social intercourse came into play. She smiled, held out her hand, and looked up at him out of the corner of her eyes—her “vamp” look from the 1920s.

He began immediately with the mental status exam, and she did all right until he asked, “And who is the president of the United States?” As soon as she paused and that lost look came into her eyes, I knew she couldn’t remember. I wanted to plead with Dr. Brown: Be slow, be gentle; enter her world—please don’t make her feel dumb. She’s had so many presidents from the 1890s until now!

But she rallied quickly. Her old charm came through as she replied, “Franklin Delano Roosevelt, of course!” then she laughed as if it were a joke, and looked in his eyes to see if he’d join in the humor. I could tell she was buying time—hoping the right president’s name would fall into her mind while the doctor observed the social niceties. She’d always been interested in politics—it was a point of pride with her. But Dr. Brown kept his perfectly impassive face, silently jotted a note on her chart (she flunked Current Events), and went on to the next question.

This woman was my mother. I still wish Dr. Brown could have spent even three or four more minutes in getting to know my mother, allowing her to feel a little more comfortable with him. And I wish he’d understood that this was not a neutral process but a social event for her! She’d always liked handsome young men, and this young gentleman had come to call on her. She expected him to laugh with her, for, as she’s always said, “A little humor never hurt anyone!”

Most of the people she'd known were dead, and Mom needed to be seen and heard in all the splendor of her lifelong identity—not as a label in a chart.

Assessment and the 'Assessee'

Although I was a family counselor with elderly people for many years, one of my primary roles the past few years has been that of consumer of aging services. I have become the "assessee" instead of the assessor, and I have learned a great deal I wish I'd known 25 years ago. I've found that some professionals don't seem to care about any other parts of me (my experience, my "smarts," my perception of my own functioning) except the slice of me they are currently assessing. What ever happened to the notion that the whole is the sum of its parts?

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I think of assessment as a measure of well-being of physical, mental, social, emotional, and spiritual functioning that goes far beyond *formal* assessment (as in "the following instruments were utilized in gerontological assessment of the 'subject' "). In fact, if you ever refer to me as a "subject," I'll refuse to be assessed! I learned this perspective over 20 years ago from a feisty 80-year-old who overheard me referring to her as "the client" during a phone call. When I got off the phone she said, "My name's JoAnne. Don't you ever call me 'the client' again or you can take your services and ...!" To me, assessment should include everything that happens in human interaction between me and my care providers that allows them to diagnose, treat, and care for me.

The Context: The Whole Person

The first orthopedic surgeon showed me two X-rays: my right hip and the right hip of an 85-year-old man. "Now you can see how *little* arthritis you have, compared to this man's," he said, pointing to the fuzzy white joint areas. "We only replaced his hip last year. I recommend that you go home, increase your dosage of anti-inflammatories, and come back next year. You're not ready for surgery yet."

I wondered how he could have failed to understand how much pain I experienced and how poorly I functioned. I'd certainly tried to tell him. I didn't care how great my X-ray looked! He was assessing me by my X-rays, and they were only a picture of one body part. I was taking too many pain killers in order to be able to work, and I spent the majority of my time at home shuffling from bed to toilet to couch with my walker.

Unable to cope, I sought a second orthopedic surgeon, who assessed me from an entirely different perspective. “Your X-ray doesn’t look too bad, but from the pain you’re describing I’m assuming you have a very inflammatory kind of arthritis in this joint. If you’re ready for a new hip, I am.” Relief flooded my pores! Here was someone who believed me when I said I couldn’t move without pain, I couldn’t sleep, and I could drive my car only with great difficulty. I was certainly seen and heard by this assessor of my functioning. He looked at the whole person.

Good Assessments I Have Known

One of the best assessments I have ever had came from a wonderful occupational therapist who prepared me to live at home after my hip replacement. She observed me so carefully that I implicitly trusted her assessment of my new capabilities, and as a result I risked behavior and activities I wouldn’t have tried without her. She demonstrated again and again with her own body how I should walk, how I should bend, and I felt we were a team in my learning to walk “right” again. She tested my potential daily but didn’t push me beyond my limits. Her assessment of my level of functioning—and my potential level—was almost mystical in its accuracy.

Assessment Determines Treatment and Services

I feel great ambivalence about assessment interviews like the ones I received before I left the hospital after surgery. They had much more to do with diagnosis-related groups, money, arbitrary categories, and staffing problems than they did with my capacity to live alone at home after surgery. I felt panic at not being told until the last minute whether I would receive rehabilitation in a rehab unit (daily) or at home (much less frequently). I didn’t yet have the confidence to survive on my own, yet I wanted to be as independent and undemanding as possible. In order to be deemed eligible for the rehab I felt I needed, I would have to demonstrate considerable deficits in functioning. This situation proved to be demeaning to me—I had to be an actress to get what I believed I needed and deserved. I was reminded that “Mrs. Jones, who is older than you, went straight home with her new hip last week.”

My fears strongly affected by assessment interview with the hospital discharge planner. I felt manipulative and two-faced as I tried to present myself as just dysfunctional enough to need nursing home rehabilitation, but not so dysfunctional that I appeared to be a “baby” or a hypochondriac. I didn’t believe that my perception of my own functioning would count for anything in this assessment. The issue was whether I could cook and go to the bathroom at home alone the fourth day after surgery, not how terrified I was. It was never clear from the discharge planning assessment what the parameters were. Each person (doctor, planner, occupational therapist, physical therapist, social worker) disclaimed power in the evaluation and decision making. I felt utterly powerless.

Power and Empowerment

There's no question about it. The assessor has the power. Our diagnosis, treatment, and services as patients and clients depend on assessment. In 1994 I experienced extreme gastrointestinal distress while working in Florida. I thought it was from some gulf shrimp I'd eaten. After I flew home and the pain continued, I was hospitalized for a week. The medical team couldn't diagnose the problem. The attending physician, a gastroenterologist, and the nursing staff were wonderful, however, in terms of letting me in on the assessment process! I was subjected to scans, ultrasounds, endoscopies, and many other tests and interviews that can leave one feeling like a guinea pig. But the medical team kept me informed of what they knew and what they didn't know, and I felt included in the process. When the pain gradually dissipated at the end of the week, I went home.

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What sticks with me is not the pain or the fact that they couldn't diagnose my problem, but the way each professional acknowledged uncertainty responded to my questions thoughtfully—with and without answers, and told me the truth. I felt honored as a person. They asked for my input frequently, as if I might actually know something! (I did. It was my body and my pain.)

The process of being assessed by people who saw me as a whole human being with intelligence was affirming and empowering. I know what being valued as an old person feels like and I will continue to ask for that kind of treatment the rest of my life. If I'm too frail or demented to demand such respect, I pray some enlightened helper will provide it.

Assessment and Assertiveness

Because I am vocal and assertive enough to make my voice heard, I do not allow people assessing me to ignore my contribution. I take more of their time because my answers aren't always one-word responses. But it empowers me immensely! Being this assertive is not always possible for frail elders who do not speak English or who are depressed, submissive, or confused, and they need advocates in the assessment process. But many quite old people do very well at being heard!

When my mother was 90, and weighed about 90 pounds, she greatly frustrated a professional caregiver in her small town because she wanted him to speak to *her* about her condition—not to her middle-aged daughter. He ignored Mom, looked at me, and spoke about her in her presence as if she weren't in the room: "Your mother appears to ..." and "What she needs is ..." This fierce little "client" (my mom) shouted at him, "Look at me! Talk to *me*! Don't tell *her* what I should do." (I've never been more proud of my mother. She may possibly have taught that

professional the critical lesson of seeing, hearing, and learning to know old people and paying attention to their own understanding of their problems.)

There's No Magic Formula for Assessment

What is assessment from the older persons' perspective? Many different things. I've only given you one old person's perspective—mine. There's no magic formula for assessment—we're all so different. We are more individual and different from others when we grow old than at any other time of our lives. My desire to be involved in the assessment process may be very different from the wishes of the older person who has willingly given away body, mind, and emotions to others to diagnose and treat. A friend my age described it this way: "I want the professionals to tell me what's wrong and what they're going to do about it; I want no part of it. Then if they make mistakes, it's their fault and I can blame them!"

My values and my experience tell me that the primary job of the one who assesses old people is to see us, hear us, and know who we are—in all our complexity, competence, and need for autonomy. Our many enmeshed mental, emotional, social, physical, and spiritual symptoms make it very difficult to assess us at times. I, for one, do not expect you to "cure" me of all the problems I have accumulated in my lifetime. But I do hope you will be able to be with me as I struggle with the end results of my heredity, my environment, and my life choices. And maybe—just maybe—I'll be able to contribute to the very challenging and difficult task of assessment. If you want my contribution, all you have to do is ask!

Bonnie Genevay, MSW, was a writer and trainer and consultant in gerontology and bereavement, based in Seattle, WA. She died in 2011 at age 83.