“Common courtesy works because it’s common; it’s something every human being gets just because they’re human. Things like saying “excuse me” when you reach over someone to reach for a piece of paper, like saying “God bless you” when someone sneezes, things like asking you if you’d like some water when you get up to get some for yourself. It’s basic, but it means so much to someone who’s been treated like an un-human for decades. It’s basic, and it may seem trivial to you, but to people like me, it’s water to a dying parched husk of a person. Interactions like the[se] ... have more positive impact on the consumer than any elaborate treatment plan ever could.”

The statement above was made by one of us (Amy Johnson) to the other (Larry Davidson) in her efforts to explain how important seemingly trivial experiences, the so-called “little things” in life, are to persons early in recovery from a serious mental illness like schizophrenia. Based on both Amy’s own experiences of recovery and those described by other people with serious mental illnesses in a series of qualitative studies that we have conducted over the previous two decades (Davidson 2003; Davidson, Shahar, Staeheli, Sells, & Tondora 2006), this paper will examine examples of such everyday experiences as going to the movies, eating meals with friends, being respected by strangers, and having money in one’s pocket in the effort to reveal the ways in which such seemingly mundane experiences serve as building blocks in the recovery process.

Our hypothesis in this regard has been that these experiences, in addition to whatever other effects they may have, play a crucial role in the person’s efforts to rebuild a coherent and enduring sense of self as an effective social agent; a sense of agency that we have proposed constitutes a kind of Archimedean point in the overall recovery process (Davidson & Strauss 1992, 1995). In addition to the qualitative research on which this proposal was based, there is an increasing body of neuro-scientific and quantitative research as well that confirms and expands upon the long-standing clinical observation that persons with schizophrenia lack a coherent and functional sense of agency (e.g., Bayne & Pacherie 2007; Frith & Allen 1983; Frith & Done 1986, 1989; Synofzik, Thier, Leube,
Schlotterbeck, Lindner 2010; Voss, Moore, Hauser, Gallinat, Heinz, Haggard 2010). Frith (1987), for example, argues that many symptoms of schizophrenia can be attributed to ‘a failure to recognize the self in action’, resulting in the person attributing his or her own thoughts and actions to others. Based on a recent review of this growing body of literature, Jeannerod (2009) similarly concluded that the sense of agency is “deeply impaired” in persons with schizophrenia, with “first rank symptoms, which represent one of the major features of the disease, testify[ing] to the loss of the[ir] ability … to attribute their own thoughts, internal speech, covert or overt actions to themselves.”

These neuroscientific data regarding a loss of a sense of self are complemented by a recent empirical study by Chiu and colleagues (2013), which used structural equation models to show that the incorporation of a self-agency construct vastly improved the modeling of the adverse effect of stigma on the quality of life of persons with serious mental illnesses. In these, and other, ways, neuroscience, quantitative, and qualitative research all suggest that persons with serious mental illnesses may lack a sense of self-agency and that the regaining of such a sense of agency may be a first, important step in recovery. So it is this process that we will primarily be concerned in following.

But how does a person rebuild or regain a sense of his or her own agency? What Amy suggests, and others have consistently said as well, is that this process is often—perhaps always—mediated by the presence, responses, attitudes, and actions of others. As Amy writes:

[Having] schizophrenia means you must invite me to my own party because I don’t know to bring myself. [You must use] nice language to describe this stranger who’s coming to the party (i.e., me), [make her] sound like a nice person, [so that] I’d like to meet her when she arrives.

In less poetic terms, what Amy is arguing is that, just as we only come to know who and what we are for the first time through how we are treated by the caring (or uncaring) people around us during infancy, a person with a serious mental illness can only come to know who and what he or she is through how other people treat him or her as an adult. It is through social interactions that we rebuild a sense of ourselves as social agents, and it is only to the degree that these interactions are positive or successful that we come to see ourselves as effective social agents. Thus the simple “God bless you” or “excuse me” mentioned in the opening quote become important as they provide some proof that I am not invisible, unreal, or alien, but that I am indeed a person among other people.

In the quotation above, Amy argues that these experiences are especially important for people who have been treated as “unhuman for decades.” That is, these experiences provide counter-evidence to the kind of dehumanizing treatment many people have suffered both from the mental health system and from their families/communities. But in another passage, Amy also argues that the importance of these experiences emerges in response to some of the intrinsic features of the illness itself. As she writes:

Folks living with schizophrenia, they have a defective self-scanning machine. The
thing that reaffirms them as “human” is faulty, and their sense of being real is constantly challenged. This throws you off balance. You have to be real first, before you can do the tasks of any job, before you can take a shower you have to know that your armpits need cleaning; you have to acknowledge your armpits!! Speaking from personal experience, I struggle with this human question. It is most bothersome, it is like, I type up a 25-page report, spell check and all, and it’s perfect, and then I hit the wrong button on my computer and poof! My entire perfect presentation is gone. I work so hard to re-create the structure of reality, the thing that reality hangs on, only to lose it in an instant of fear or pain. Begrudgingly, I have to start my document all over again…

A sense of self is the basic. No self means nothing to defend, nothing to fight for, nothing to fight with… Now, I have a very fleeting, very fragile sense of self. I am thwarted by visual disturbances, auditory hallucinations, tactile flashbacks, waves of intense emotion, and paranoia. I get caught up in me easily, where I literally can’t see what’s in front of me. A sense of self gives one the right to speak, it fuels the indignation required to speak. Without a self, you can’t be selfish. You can’t find a boundary. A sense of self makes all other behaviors possible; without a self, nothing can happen. This is why schizophrenia is so debilitating.

For both of these reasons—i.e., that the loss of self intrinsic to the illness is further compounded by how the mental health system and society at large has treated people with serious mental illnesses as other or less than human (Davidson 1997)—how other people react to, and interact with, a person with schizophrenia can either further exacerbate the illness or provide a foundation for the person’s efforts to rebuild a self and a life. Such a foundation is built on experiences of feeling respected and, we will go so far as to argue, feeling loved by others. “I can come to recognize that ‘I am a human being’,” Amy writes, “because I found someone who can identify me as one.” She continues:

Respect is dynamic. Modeling self-respect and how to respect others involves active listening and improv; you must be ready at any moment to demonstrate respect. Little moments pop up … where the consumer’s weakness in self-esteem become apparent, and your job as a clinician is to pay attention to those maybe quiet holes and fill them. Self-esteem doesn’t point out where it’s been hurt, and that’s why listening is so important. You have to listen for the holes in self-esteem. Each person has a personality, and each person has a history, so the remedy for each hole may be a bit different, so you’ll have to think quickly on your feet and sort of craft a makeshift self-esteem for your client. It’s not dissimilar to a crisis triage in that you are working quickly and efficiently to save a person’s life. Self-esteem is critical to an individual’s sense of self, to an individual’s sense of efficacy, to a person’s recovery. I didn’t enter recovery until someone else thought I was worth recovery, until someone else loved me. I didn’t think I was worth recovery until someone else did.

Such experiences certainly can come from caring people in the person’s life who are outside of the mental health system, and they may even be more powerful when they
do; that is, when they do not come from people who are paid to care, like mental health providers. Examples of such experiences that we have cited in previous articles include the woman who described the difference between eating a McDonalds’ hamburger alone and with a friend (“when you go out [and] you’re not alone, you’re able to eat talking to somebody ... that can of beans could have been in a gold bowl instead of just a plain, cold tin can”; quoted in Davidson, Stayner, Nickou, Stryon, Rowe, & Chinman 2001); the man who described enjoying fried clams and “bottomless” iced tea with a friend as an antidote to suicide (Davidson, Stayner, Nickou et al. 2001), the young woman who discovered that “life isn’t one big horror” after going out to a movie with a friend (Davidson, Haglund, Stayner, et al. 2001), and, finally, the man who described “the best anti-depressant” he could take as being a $28 monthly stipend that he was given to go out and have fun because it allowed him to go out and spend more time with his friends. Not feeling like he was “on poverty row anymore,” this small amount of money allowed him, in his words, “to have a social life again” (Davidson, Haglund, Stayner, et al. 2001).

Especially for those people who are the most seriously disabled by these disorders—people for whom social relationships are the most difficult and problematic—however, the kinds of experiences we are describing may need to come, at least at first, from caring people inside of the mental health system, people who are paid to care. As perhaps early pioneers in the psycho-therapy of schizophrenia such as Harry Stack Sullivan and Frieda Fromm Reichmann learned, therapeutic work with persons with the most severe psychotic disorders requires an engaged, compassionate, and deeply respectful stance to their nascent personhood; a stance that we have taken the risk to describe as one of “love” (Davidson 2011; McCarthy-Jones & Davidson 2013). Granted, this form of love may be best described as “moderated” (to use a term suggested by Campbell [1984] to characterize the helping professions from a theological perspective) to distinguish it from other forms of love that are characterized by mutuality (i.e., love between lovers, family members, or friends), but it may be important to retain the word “love” since it seems to convey the deeply personal nature of this relationship better than more technical terms.

How can people who are severely disabled by schizophrenia know when they are being respected and loved in this way? By feeling listened to, taken seriously, and treated as a fellow human being. By having someone else see them and view them as persons even when they may not yet view themselves that way. Writes Amy:

> It is what Amy prayed for all these years – not to be laughed at, not to be dismissed, to be listened to and taken seriously. I can’t believe it. There are people on this planet that will listen to Amy. Wow. It makes me cry. It makes me cry. I cry because I waited a long time for this. I waited alone. I waited just me, cheering me on, saying, “Hold on Amy, hold on. One day somebody will see you.” And then here is it. Here you are... It was well worth waiting for, at the end of the rainbow sits a pot of gold, more like, the end of the garbage heap, the end of the sewage
plant sits a pot of gold. I feel like my soul is sputtering, is gasping, because it’s been not breathing for a long, long time, and you ... are performing CPR, or blowing air into lungs long dead, lungs long dead that are only now gasping for air because I believed, because though I was dead, my mind stayed alive, and I sat up in there alone, like a magician, I believed, I turned coal into gold, told myself it felt good to be dead, it felt good to be lonely. It did not. I only lied to keep hope alive, so that if anyone ever came along and noticed I needed oxygen, they would blow some into my lungs so I could breathe again on my own.

An initial result of these kinds of experiences of affirmation is to drive a wedge in between the person and the illness he or she is suffering from, to open up some room for the person to separate him or herself from the disorder. Pat Deegan described the devastating impact that results when the person and the illness have become one when she wrote:

Once a person comes to believe that he or she is an illness, there is no one left inside to take a stand toward the illness. Once you and the illness become one, then there is no one left inside of you to take on the work of recovering, of healing, of rebuilding the life you want to live (1993, p. 9).

What Amy describes is how engaged compassion, or love, is required to reverse this process of identification, to convince the person that he or she is not an illness but rather has remained a person who has an illness. She writes:

I tried to think ... about ... why personhood [is] so important ... You separate the forest from the trees. I can't always separate the forest from the trees. If I am my illness, instead of I am a person who an illness happens to, then I can never get better. Because I can't pull the illness off of me if I am the illness. If the illness and I are the same thing, then there ain't nothin' I can do. I can't change me, I can't... The forest and the tree become the same thing. But if you separate the two, suddenly I find strength. I ask myself: Where? Why do you find it? I find it in the separation. If we are not the same thing, if I am not the illness, then I can beat it, I can trick it, I can outmaneuver it, I can go to the library and read about how to navigate around it. If I am not the illness, then I can learn how to navigate around it... If I am not the illness, then the hope that I can maybe beat it springs forth... hope then, comes from splitting off the illness from the person.

Unfortunately, once the person succeeds in separating him or herself from the illness, there may not be much of a “self” remaining. The identification of the person with the illness may have been so complete, or may have persisted over such a long period of time, that the person may have lost touch with who he or she had been prior to the onset of the illness. One core aspect of the work of recovery then becomes rebuilding that self, again, in part, through the relationships one develops with others. For these relationships to contribute positively to the re-building of the self, more is required from others than respect and active listening, though. What is required comes to be considered “love” because it also requires a personal investment, enough of an investment to do the hard work of looking for, detecting, and eventually coming to a mutual
understanding with this person whose experiences will have been drastically different from one’s own. Writes Amy:

Self-esteem is tricky for me because I don’t show up in pictures. I’m like a vampire. I can’t see myself when I look. No carbon footprint … I need to have compassionate people because the way I’ve been forced to alter the consensual reality means others can’t ever understand me, and all they’ve got to get close to me and save me from the death of alienation, is compassion. They must be super compassionate, trying to imagine all the time what it must be like for me, and, willing to sit down with me and give me lots of their time, as we struggle to understand each other, as we map out a common language that is translatable in both my native tongue and theirs.

Coming to a mutual understanding of the person’s anomalous experiences then lays the groundwork for another step in the self rebuilding process, which we, based on Vygotsky’s work (Bruner, Goodnow, & Austin 1956), liken to “scaffolding.” Upon the foundation of respect and acceptance offered by this loving relationship, the person can be encouraged to reconnect with who he or she used to be and/or explore who he or she would like to become. Through participating in meaningful or pleasurable activities, both alone and with others, the person comes to see him or herself as a friend, a student, a musician, a horse lover, or a mechanic, gradually constructing a stable edifice to withstand the onslaught, and provide shelter from, the ravages of the illness. While each step in this process may appear to be based on “little things” that might easily be overlooked, their sum total is an ordinary, everyday life of one’s choosing, which, in reality, is all that any of us can ask for, with or without a serious mental illness.

References